

THESIS

GROUP OCCUPATIONAL THERAPY AND YOGA: THE CAREGIVER EXPERIENCE

Submitted by

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## ABSTRACT

### GROUP OCCUPATIONAL THERAPY AND YOGA: THE CAREGIVER EXPERIENCE

The purpose of this qualitative study was to examine the experiences of caregivers of people with stroke after participating in a group occupational therapy and yoga intervention (MY-OT). Participants elected to either participate in the 8 week MY-OT intervention or to not attend. Participants completed the Zarit Burden Interview and Positive Aspects of Caring scale retrospectively after the MY-OT intervention. Caregivers also chose to participate in focus groups and individual interviews following the intervention. Qualitative data were analysed using an iterative, coding process to generate larger themes based on caregiver experience.

Caregivers who attended the MY-OT intervention saw a 47% decrease in caregiver burden and a 26% increase in positive aspects of caring. Those who did not attend saw a 2% decrease in caregiver burden and a 4% decrease in positive aspects of caring. Five themes were elicited from focus groups and interviews: 1) Changes in daily life; 2) Coping Mechanisms; 3) Learning through observation; 4) Sense of community and 5) Learning new information. Group occupational therapy, focused on self-management, and yoga are effective and beneficial interventions for the caregiver and care recipient together.

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## LIST OF KEYWORDS AND DEFINITIONS

### **Caregiver Burden**

Caregiver burden is a term used to describe the weight or load carried by caregivers as a result of adopting the caregiving role (Rigby, Gubitz, & Phillips, 2009).

### **Complementary and Integrative Health (CIH)**

A group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine. [previously known as CAM] (National Center for Complementary and Integrative Health, 2016).

### **Group Occupational Therapy**

The delivery of occupational therapy in a group setting in order to develop task-specific and interpersonal skills. Occupational therapy uses everyday life activities, or occupations, to enhance participation in various contexts (American Occupational Therapy Association, 2014).

### **Hatha Yoga**

The most common type of therapeutic yoga used in Western cultures is hatha yoga, which incorporates physical postures (asanas), breath (pranayama), and meditation (Collins, 1998).

### **Informal Caregiver**

Informal caregiving refers to the help and support that unpaid caregivers, usually family members and friends, provide to assist individuals who are unable to function independently (National Institute on Aging, 2016).

### **Yoga**

Yoga is the combination of breathing exercises, physical postures, and meditation to calm the nervous system and balance the body, mind, and spirit (Barnes, Bloom, & Nahin, 2008)

### **Positive Aspects of Caregiving**

Positive feelings and experiences that result from caring for another person (Cohen, Colantonio, & Vernich, 2002).

### **Stroke**

A stroke occurs when blood flow to the brain is disrupted when a blood vessel ruptures or is obstructed (Sacco et al., 2013).

## CHAPTER 1: INTRODUCTION

### 1.1 Purpose

The purpose of this qualitative study was to assess the impact of the Merging Yoga and Occupational Therapy (MY-OT) intervention on caregivers of people living with chronic stroke. While MY-OT was developed for people with stroke to improve balance and decrease fall risks, caregivers of participants were invited to attend and are the focus of this study. Specifically, this study looks at the experience of caregivers after choosing to participate in the MY-OT intervention or not. It also examines whether caregiver burden and positive aspects of caregiving changed after participating in MY-OT versus not attending.

### 1.2 Background and Statement of Problem

In the U.S., informal caregivers provide the equivalent of \$470 billion dollars of care annually, fulfilling an integral role within our healthcare system (Reinhard, Feinberg, Choula, & Houser, 2015). Informal caregivers are the unpaid helpers of those who are unable to fully care for themselves, usually individuals with complex medical needs and chronic conditions. Currently, 39.8 million Americans are informal caregivers, and of that 59% are caring for someone with a chronic condition (National Alliance for Caregiving, 2015). Stroke is a common chronic condition for which many people require caregiving (Mozaffarian et al., 2016). Stroke results from a disruption of blood flow to the brain that affects 6.6 million Americans (Mozaffarian et al., 2016) and leads to physical, cognitive, and functional deficits. Caregiving for people with stroke often requires providing assistance with daily living, self-care, medication management, community access, and socialization (National Alliance for Caregiving, 2015). The relationship between the caregiver and the care recipient, known as the caregiver dyad, is interconnected, where the outcomes for one person wholly effect the other. (Lyons, Zarit, Sayer, &



Whitlatch, 2002; National Alliance for Caregiving, 2015). For example, the care recipient's ability to engage in self-care affects how much care the caregiver provides each day.

Due to the intensity of the caregiving role, caregivers often experience negative effects, which is known as caregiver burden. Significant burden is experienced by 25-54% of informal caregivers (Rigby et al., 2009) and can result in: high levels of stress; emotional distress; restricted social participation; and increased risk for health conditions (Cameron, Cheung, Streiner, Coyte, & Stewart, 2011; Carretero, Garces, Rodenas, & Sanjose, 2009; Grigorovich et al., 2015). In contrast, Mackenzie and Greenwood (2012) found that positive aspects of caregiving exist and include: a sense of purpose; closer relationships; inner strength; and skill acquisition. Caregivers with higher levels of positive aspects of caregiving report greater life satisfaction despite higher levels of burden (Kruithof, Visser-Meily, & Post, 2012). As such, it is necessary to provide interventions for caregivers that increase these positive aspects of caregiving in order to mediate the burden and negative aspects of caregiving.

Current caregiver interventions for caregivers of people with chronic stroke fall into three different types of interventions: psychoeducational; support; and skill building (Bakas et al., 2014; White, Cantu, & Trevino, 2015). Interventions include caregiver mentoring; self-management; support groups; and respite (Garces, Carretero, Rodenas, & Aleman, 2010; Greenwood, Mackenzie, Cloud, & Wilson, 2009; Won Won, Fitts, Favaro, Olsen, & Phelan, 2008). However, there is a lack of evidence-based interventions for caregivers targeting support for managing daily life at home and within the dyad's community (Danzl et al., 2013; Rosalyn Carter Institute for Caregiving, 2010). Furthermore, there is a significant need for interventions that address the caregivers' physical, emotional, and cognitive health as a result of lifestyle changes within their caregiving role.

Yoga is an intervention that has been found to positively affect caregivers' physical, emotional, and cognitive health. Measured outcomes show reductions in stress, anxiety, and depressive symptoms as well as increased lower body strength, coping abilities, and quality of life (Danucalov et al., 2013; Umadevi, Ramachandra, Varambally, Philip, & Gangadhar, 2013; Van Puymbroeck, Payne, & Hsieh, 2007). However, yoga alone does not address ways in which the caregiver can manage their health effects and organize their daily lives to optimize positive health outcomes.

Similarly, occupational therapy (OT) considers each client holistically, working to address individual needs in multiple environments (American Occupational Therapy Association, 2014). OT has been shown to improve caregivers' management of their multiples roles and participation in valued activities (Bastawrous, Gignac, Kapral, & Cameron, 2015; Gibbons, Ross, & Bevans, 2014) through various avenues, including self-management and group therapy interventions (Valluzzi, 2014). Specifically, group OT provides group cohesiveness, instills hope, and promotes interpersonal learning (Cole, 2012; Falk-Kessler, Momich, & Perel, 1991). This group format has also been found to be effective for community dwelling older adults in addressing physical function, social function, role limitations, and general mental health (Clark et al., 1997).

To date, no research has been conducted examining yoga and group OT together as an intervention for caregivers of people who have had a stroke. However, results of studies with other populations are encouraging (Chugh-Gupta, Baldassare, & Vrkljan, 2013; Schmid, Van Puymbroeck, Portz, Adler, & Fruhauf, 2016). Yoga and group OT together could likely address multiple aspects of caregiver needs, including physical, psychological, social, and role management factors. This thesis specifically examines caregiver's experiences, which includes

changes in caregiver burden and positive aspects of caregiving, after self-selecting to participate in yoga and group OT.

### **1.3 Research Questions**

1. What is the experience of caregivers participating in group OT and yoga versus not attending?
2. Is there a decrease in caregiver burden for caregivers after participating in group OT and yoga versus not attending?
3. Is there an increase in the positive aspects of caregiving for caregivers after participating in group OT and yoga versus not attending?

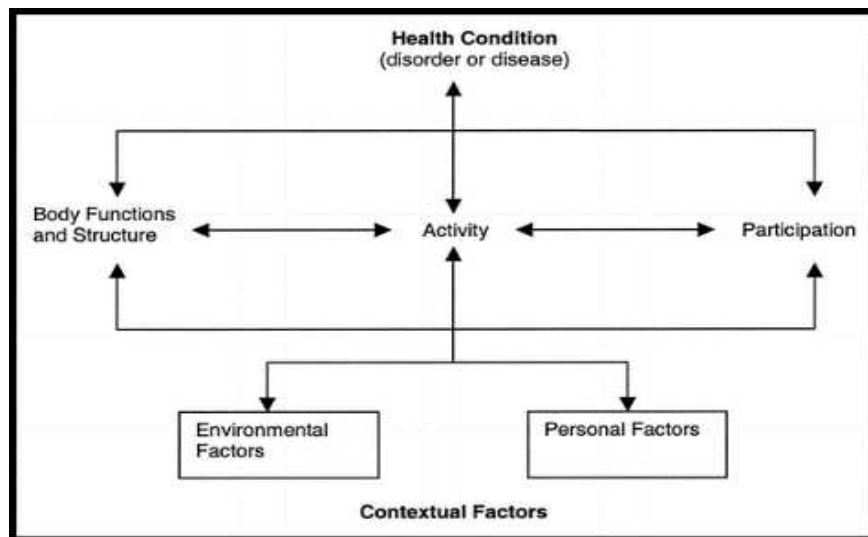
## CHAPTER 2: REVIEW OF THE LITERATURE

### 2.1 Introduction

This chapter focuses on a review of literature relating to caregiving for people with chronic stroke. To begin, I will introduce the conceptual framework which guides this work. I will then present the incidence and prevalence of both caregiving and stroke as well as definitions of main concepts within caregiving. Following that, I will examine current caregiving interventions for caregivers of people who have had a stroke. In this, I will identify gaps in research and provide support for yoga and occupational therapy as concurrent interventions that address this gap.

### 2.2 Conceptual Framework

The conceptual framework that guides this research is the International Classification on Functioning, Disability and Health (ICF). Figure 1 demonstrates the interactions between the main concepts and determinants of health: health condition, body function and structure, activity, participation, and contextual factors, which are separated into environmental factors and personal factors (World Health Organization, 2001).



**Figure 1: International Classification of Functioning, Disability and Health**

According to the ICF, a *health condition* is considered the “diseases, disorders and injuries” a person has. *Body function and structures* refer to each individual’s unique physiological make-up. *Activity* is considered the initiation of a task that an individual may engage in. *Participation* is defined by the ICF as “involvement in a life situation”. *Contextual factors* is separated into two categories, *environmental factors* and *personal factors*. *Environmental factors* are the influences outside of a person like social perceptions, architectural features, and culture. *Personal factors* are those that are internal to a person, such as age, education, and experience (World Health Organization, 2001).

The participants in this study are caregivers for people who have had a stroke. Caregivers often experience deficits at the level of participation and activity, as their caregiving role and associated activities interfere with engaging in activities of daily life, such as work or leisure. These factors are also influenced by environmental factors, like access to services within the community that address the caregiver and care recipient’s specific needs. Personal factors are seen through each caregiver’s unique demographics and experiences contributing to and limiting their ability to engage in their caregiving role.

The interventions in this study are yoga and group occupational therapy. In relation to the caregiver participants, yoga can address body function and structure to increase physical strength, increase health, and reduce stress levels. Yoga may also affect caregivers at the activity and participation levels through engagement in new, health-promoting activities. The group occupational therapy provides education and training for the care recipients which may, in turn, affect the caregiver at the activity, personal factors, and participation levels. If both the caregiver and the care recipient are better able to safely engage in daily activities through fall prevention

education and training, then the caregiver's participation in daily activities, including caregiving, may change as well.

## **2.3 Caregiving and Stroke**

### **Definition of Caregiving**

Caregiving is addressed throughout multiple disciplines including nursing, sociology, social work, psychology, education, and occupational therapy. Hermanns and Mastel-Smith (2012) conducted a multidisciplinary literature review in order to answer the question 'What is caregiving?'. After this review, they defined caregiving as:

The process of helping another person who is unable to do for themselves in a "holistic" (physically, mentally, emotionally, and socially) manner. Caregiving is facilitated by certain character traits, emotions, skills, knowledge, time, and an emotional connection with the care recipient. (p. 15)

An informal caregiver is a caregiver who is unpaid, typically has a previous relationship with the care recipient, and is often a family member (National Alliance for Caregiving, 2015).

### **Incidence and Prevalence of Caregiving and Stroke**

Currently, 39.8 million Americans are informal caregivers to adults and have been in their caregiving role on average for 4 years. Of those, 59% are providing care for a person with a long-term physical condition and spend an average of 24.4 hours per week providing care (National Alliance for Caregiving, 2015). An estimated 6.6 million Americans have sustained a stroke, a common chronic condition characterized by an injury to the central nervous system resulting from a disruption of blood flow to the brain (Mozaffarian et al., 2016). People who have had a stroke frequently require care due to a loss of physical and cognitive function. People who have had a stroke can experience physical, cognitive, emotional, and functional deficits.

Caregiving includes assisting with activities of daily living (ADLs) such as bathing, dressing, and eating as well as managing instrumental activities in daily living (IADLs) like community involvement, transportation, and work (National Alliance for Caregiving, 2015).

### **Caregiving and Stroke**

Caregiving for people who have had a stroke is unique due to the sudden nature of stroke, where unforeseen changes happen abruptly and are long lasting (Jaracz, Grabowska-Fudala, Gorna, & Kozubski, 2014). Caregivers experience a transition into the caregiving role without any preparation that can be characterized by shock, role ambiguity, social changes, and suffering (Camak, 2015; Gibbons et al., 2014). Immediately following the stroke, the care recipient requires more intensive care and rehabilitation. Following this acute phase, chronic stroke is characterized by less immediate and acute care needs, a return to the community, and adaptation of daily living to accommodate changes due to stroke (Cameron, Naglie, Silver, & Gignac, 2013). Thus, the caregiving role changes over time.

The relationship and partnership that develops over time is often referred to as the caregiver dyad as both caregiver and care recipient's needs and outcomes wholly influence the other (Lyons et al., 2002). This relationship is completely interrelated and extends beyond the individuality of the caregiver or the care recipient. Researchers are beginning to examine the outcomes of the dyad, as well as individual outcomes, in order to demonstrate how interconnected this relationship is (Savini et al., 2015). Thus, it is important to consider the dyad when creating interventions in order to address all needs wholly.

## **2.4 Caregiver Burden**

### **Definition of Caregiver Burden**

Caregiver burden results from the stress and strain of caring for another person. affects both the physical and psychological well-being of the caregiver, and can have a long term effect (Carretero et al., 2009; Hoffman & Mitchell, 1998; Pearlin, Mullan, Semple, & Skaff, 1990; Zarit, Reever, & Bach-Peterson, 1980). Caregiver burden is typically separated into objective and subjective indices where objective burden relates to caregiving tasks (bathing, dressing, transportation, decision making) and subjective burden relates to attitudes and feelings related to the caregiving role (stress, depression, grief) (Bastawrous, 2013; Montgomery, Gonyea, & Hooyman, 1985). Rigby et al. (2009) show that 25%-54% of caregiver's experience significant burden (both objective and subjective) when caring for another person. These high levels of burden in caregivers need to be addressed so that caregiver's may lead healthy and productive lives.

### **Caregiver Burden and Stroke**

Camak (2015) conducted a recent literature review of caregiver burden for caregivers of people with stroke and found that caregivers experience high levels of stress leaving them at risk for negative physical and psychological outcomes. Factors that are associated with increased caregiver burden are: lower incomes; higher levels of care; greater time spent caregiving; poor functional status in care-recipient; low levels of self-efficacy; coping skills; skill mastery; poor mental health of the caregiver; and poor physical health (Greenwood, Mackenzie, Cloud, & Wilson, 2015; Rigby et al., 2009; Schulz, Mittlelmark, Burton, Hirsch, & Jackson, 1997). Often, caregivers will reduce time spent in their valued activities (work, exercise, hobbies) to fulfill their caregiving responsibilities. This difficulty in balancing life roles leads to increased stress,



decreased time and energy for activities outside caregiving, and potential conflict within relationships (Bastawrous et al., 2015). Caregivers continue to experience high levels of burden many years after the stroke occurs, with only 13% of caregivers experiencing a reduction in burden after five years (Jaracz et al., 2015).

### **Risks associated with Caregiver Burden**

Due to these high rates of burden, caregivers are at risk for cardiovascular disorders, immunological disorders, depression, and anxiety which may lead to premature mortality (Carretero et al., 2009). Higher levels of stress and emotional distress are associated with the care recipient's lowered cognitive status, increased amount of care, increased dependency on caregiver, role strain, and psychological strain (Cameron et al., 2011; Jaracz et al., 2014; Pearlin et al., 1990). Participation in valued activities is more likely to be restricted when caregivers have multiple other roles (caring for other family members, work), when the care recipient has greater care needs, or higher rates of caregiver depression (Grigorovich et al., 2015). Caregivers report a decrease in quality of life after taking on the caregiving role for people with stroke at 1-2 years following the stroke (Jaracz et al., 2014). Similarly, caregiving dyads that reported combined lower levels of life satisfaction reported significantly higher levels of caregiver burden. Conversely, dyads that reported combined high levels of life satisfaction significantly reported lower levels of caregiver burden. Low levels of satisfaction were significantly correlated to impact of the stroke on daily life (Bergstrom, Eriksson, von Koch, & Tham, 2011).

## **2.5 Positive Aspects of Caregiving**

### **Definition of Positive Aspect of Caregiving**

Positive aspects of caregiving are the positive experiences and outcomes that result from caring for another person. Mackenzie and Greenwood (2012) conducted a systematic review of

positive experiences reported by caregivers which included: seeing positive changes in care recipient; improving relationships; feeling love and devotion; feeling appreciation; gaining a sense of meaning and purpose; appreciating life; gaining inner strength; overcoming difficulties; and learning new skills. Researchers have also found that effective coping skills are associated with positive aspects of caregiving which include problem-focused and emotion-focused coping strategies. These positive aspects of caregiving are often motivating for caregivers to continue providing care (Greenwood et al., 2009; Mackenzie & Greenwood, 2012; Pierce, Steiner, Govoni, Thompson, & Friedemann, 2007).

### **Positive Aspects of Caregiving after Stroke**

Positive aspects of caregiving in stroke include: more time spent with loved ones; a strengthening of the relationship between the caregiver and the care recipient; reciprocity; and life satisfaction (Ekstam, Johansson, Guidetti, Eriksson, & Ytterberg, 2015; Forsberg-Warleby, Moller, & Blomstrand, 2004; McPherson, Wilson, Chyurlia, & Leclerc, 2011). Interestingly, a buffer effect is seen for caregivers who have high levels of positive experiences, even with high levels of caregiver burden, leading to greater life satisfaction (Kruithof et al., 2012). Forsberg-Warleby et al. (2004) found that the following factors influence levels of life satisfaction: life as a whole; daily occupations; recreation; intimacy; relationship status; and social engagement.

Researchers have found that lower levels of depression and higher levels of cognition in the care recipient are correlated with higher levels of psychological well-being for the caregiver. Likewise, the following characteristics in caregivers are also associated with caregiver psychological well-being: higher levels of engagement in preferred activities; better physical health; personal gains related to providing care; higher levels of skill mastery; the quality of the premorbid relationship; and making sense of the illness (Cameron, Stewart, Streiner, Coyte, &

Cheung, 2014; Williams, Morrison, & Robinson, 2014). Furthermore, White, Lauzon, Yaffe, and Wood-Dauphinee (2004) created a quality of life model for family caregivers of people who have had a stroke and stated that mediating factors between burden and life satisfaction include the caregiving situation (physical disability of care recipient, functional status and relationship), caregiver factors (demographics and personal attributes), and environmental factors (finances, health-care, support system). Addressing these factors can aid in increasing positive aspects of caregiving and quality of life for caregivers and the caregiving dyad (Savini et al., 2015).

## **2.6 Interventions for Caregivers of People with Chronic Stroke**

### **Current Interventions**

General advisements for caregiver interventions are to focus on building coping skills, increasing social supports, and taking a family centered approach (Pearlin et al., 1990; Visser-Meily et al., 2006). Current interventions are often community based and include respite care, caregiver mentoring, and self-management training. (Garces et al., 2010; Greenwood & Habibi, 2014; Sundar, Fox, & Phillips, 2014; Won Won et al., 2008). The American Heart Association and the American Stroke Association conducted a review of current caregiving interventions and Bakas et al. (2014) found three general types of caregiver interventions: psychoeducational, support, and skill-building. Each of these have been shown to support caregiver and care recipient outcomes through meeting educational and psychosocial needs. However, a combination of approaches is recommended in order to meet caregiver's array of needs, as well as tailoring interventions to the needs of the dyad.

### **Gap in Interventions**

Generally, interventions for caregivers are still limited. Corry, While, Neenan, and Smith (2014) conducted a systematic review of systematic reviews for caregivers of people with

chronic illnesses. They found evidence for educational and supportive programs leading to an increase in quality of life, lower depression scores, and reduced caregiver burden. However, few interventions address the social needs of caregivers and evidence supporting psychosocial interventions is limited (Brereton, Carroll, & Barnston, 2007; Cheng, Chair, & Chau, 2014). Programs typically target one aspect of caregiving. For example, respite care allows the caregiver to increase time spent in activities outside of caregiving, but it does not address other aforementioned needs, such as psychosocial or physical needs.

Caregiver research continues to be inconsistent in regards to sampling, assessments used, and quality of research (Rigby et al., 2009) and few interventions address caregiver's physical, cognitive, and emotional factors together. Current interventions lack education, preparation for role change, consideration of the caregiver's schedule, self-care and social engagement. There is also a lack of caregiver perspectives in current research (Kerr & Smith, 2001). Researchers have found there is a need for interventions that: are client-centered; increase time spent in caregiver's valued activities; increase coping skills; reduce stress; meet educational needs; address the changing relationship dynamics within the caregiving dyad; address issues of transition; and increase healthcare coordination (Camak, 2015; Cameron et al., 2013; Haley, Roth, Hovater, & Clay, 2015; Jaracz et al., 2015; Lutz, 2010; White, Lambert, & Wood-Dauphinee, 2007). Thus, multimodal interventions, which may include physical activity such as yoga, which include caregiver perspective are necessary in order to address caregiver's multiple needs.

## **2.7 Yoga**

### **Definition of Yoga**

Yoga is one form of Complementary and Integrative Health (CIH – formerly Complementary and Alternative Medicine, CAM) that is frequently used to complement current

health care. Yoga means to ‘yoke’ or connect the mind and the body. It includes a series of seated, standing, and supine physical postures (asanas) in conjunction with breath work and meditation (Salmon, Lush, Jablonski, & Sephton, 2009). CIH is becoming increasingly more common, with approximately 10.1% of adults engaging in either yoga, tai chi, or qi gong, and has grown in use by 50% in the last four years in the US (Clarke, Black, Stussman, Barnes, & Nahin, 2015). It is becoming increasingly popular and accessible, with cost, convenience, and quality of instruction being the most influential factors in a person choosing to engage in yoga. The main reason people choose yoga is because of its positive impact on health and opportunities for stress relief (Ipsos Public Affairs, 2016). Yoga is an adaptable intervention that can be delivered in a group setting, addressing population based needs. It is a low-cost intervention that can be used to address mental and physical health care needs. Overall, yoga is a person-centered intervention that seeks to address body and mind together in a holistic manner, addresses the needs of the triple aim (improve health, reduce costs, and improve the patient care experience) and can be adapted for use within multiple populations (Berwick, Nolan, & Whittington, 2008; Weber & Sculthorp, 2016).

### **Yoga as an Intervention for Caregiving and Stroke**

Often, caregivers reduce their own self-care in order to complete their caregiving responsibilities. A review of studies looking at physical activity in informal caregivers found that caregivers are typically less physically active than non-caregivers (Burton, Newsom, Schulz, Hirsch, & German, 1997). However, those caregivers who do engage in physical activity have less depression, caregiver burden, stress, and anger. Caregivers also demonstrated improved self-efficacy, improved physical traits (balance, strength, and endurance), higher perceived rates of self-care, and perceived breaks from their caregiving role (Etkin, Prohaska, Connell, Edelman, &

Hughes, 2008; Hill, Smith, Fearn, Rydberg, & Oliphant, 2007; Loi et al., 2014). Yoga has been found to have perceived physical, mental, and social benefits for community dwelling, older adults (Nayak, Neela, Wood, Dufault, & Guidotti, 2014) as well as higher levels of quality of life (Oken et al., 2006). Danucalov et al. (2013) used a standardized hatha yoga protocol including physical postures, awareness and breath exercises, and a meditation program for caregivers of people with dementia and found a statistically significant ( $p < .001$ ) reduction in stress and anxiety scores as well as depressive symptoms. Waelde, Thompson, and Gallagher-Thompson (2004) also found increased self-efficacy and improvements in physical and emotional well-being for caregivers of people with dementia after engaging in hatha yoga which included physical postures, breathing, guided imagery, and mantra repetition exercises. Similar results were found for a one month yoga intervention in reducing stress and anxiety scores as well as increasing quality of life ( $p < .001$ ) for caregivers of people in inpatient facilities for neurological disorders, including stroke (Umadevi et al., 2013). Another study looking at yoga for informal caregivers also found that lower body strength improved significantly and coping abilities positively increased (Van Puymbroeck et al., 2007).

Perceived barriers to participating in yoga include a lack of time, classes are too long, and a belief that yoga will hurt or worsen health conditions (Nayak et al., 2014). Participants who dropped out of yoga interventions stated that it interfered with their caregiving duties and that their care recipients felt resentful (Hill et al., 2007). Further, attrition may be related to already having multiple commitments and role activities to fulfill (Van Puymbroeck et al., 2007). Suggestions for future studies with yoga and caregivers are to find ways to reduce time away from care recipient, which may include involving them in the physical activity (Hill et al., 2007; Van Puymbroeck et al., 2007).

## **2.8 Occupational Therapy**

### **Definition of Occupational Therapy**

Occupational therapy (OT) is “the therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of enhancing or enabling participation in roles, habits, and routines in home, school, workplace, community, and other settings” (American Occupational Therapy Association, 2014, p. 1). Occupational therapists (OTs) provide holistic care that seeks to increase engagement in meaningful activities. This meaning is derived from social engagement, belongingness, and engagement in preferred activities which contributes to health and well-being (Hammell, 2014).

### **Occupational Therapy as an Intervention for Caregiving and Stroke**

In a report on the state of caregiving in the U.S., the National Alliance for Caregiving (2015) reported that only 16% of caregivers recalled a healthcare provider asking about their needs. OTs are suited to address the needs related to the occupation of caregiving and the activities that comprise that role (Bastawrous et al., 2015). Researchers found that caregivers restructure their lives in order to accommodate their caregiving role. Dimensions of caregiver's lives that are affected by their caregiving role include: management of multiple roles; daily life; relationship with stroke survivor; future hopes and plans; and time for self (Bastawrous et al., 2015; Silva Smith, 2007). OT is uniquely suited to address these dimensions. Specifically for caregivers, OT's work in a variety of settings, including hospitals, rehabilitation facilities, and community centers and can assist with: stress management; adapting daily activities and routines to address caregiver burden; increasing coping skills; providing education and training; accessing resources; managing the role transition; and increasing participation in social activities (Ekstam et al., 2015; Gibbons et al., 2014; Gray, 2007; Moghimi, 2007). For example, caregivers who

choose to continue to work experience daily challenges, prioritize activities, and shape other roles in order to regain joy through working (Van Dongen, Josephsson, & Ekstam, 2014).

Gibbons et al. (2014) found that when caregivers adapt to these changes over time, they find meaning in new experiences, remain hopeful, keep a sense of humor, live in the now, and rely on spirituality. Moghimi (2007) found that caregivers find motivation through positive aspects of caregiving, and suggests that OTs leverage this motivation within therapeutic interventions for greater positive outcomes.

Both the caregiver and the care recipient, and the dyad together, experience restrictions in participation, as defined by the ICF (involvement in life situations) (World Health Organization, 2001). High levels of participation restriction are correlated with low levels of life satisfaction. This includes loss of time for both caregiver and care recipient in ADLS, leisure, social activities, and work-related activities, which has been found to be correlated with increased stress levels and caregiver burden (Bergstrom, von Koch, Andersson, Tham, & Eriksson, 2015; Kniepmann, 2014; Pellerin, Rochette, & Racine, 2011). However, in contrast, stroke survivors and close family members were found to engage in the recovery process together, engage in meaningful activities together as well as find balance in meaningful activities individually, despite the changes that occur as a result of the stroke (Arntzen & Hamran, 2016).

OTs can uniquely address the challenges of caregiving by choosing relevant performance and participation-based assessments and choosing appropriate interventions. Furthermore, therapists can empower the caregiving dyad to collaboratively problem solve and address needs using a family-centered approach to engage in meaningful activities (Arntzen & Hamran, 2016; Moghimi, 2007). Group OT is a unique method of delivering educational and therapeutic interventions where participants with similar needs are treated in a group setting. Specifically,



group-based occupational therapy has been found to be effective for community dwelling older adults in addressing physical function, social function, role limitations, and general mental health (Clark et al., 1997). OT groups have also been found to provide social cohesiveness, instill hope, create self-understanding, and improve interpersonal learning (Cole, 2012; Falk-Kessler et al., 1991).

## **Conclusion**

By examining the gaps in current caregiving and stroke literature, a sound case can be made for yoga and occupational therapy as direct interventions to support caregiver and caregiving dyad's need. AOTA indicates that OTs can use CIH practices within OT practice (American Occupational Therapy Association, 2011). Yoga can be adapted to help improve health, reduce stress, and improve coping skills, thus affecting factors associated with caregiver burden and improving positive aspects of care. Group occupational therapy can provide a socially supportive atmosphere that affects change through education, training, and problem solving relating to activities comprising the caregiving role. Together, yoga and group OT can be a powerful and effective intervention that addresses caregiving needs, provides an opportunity to address dyad needs, and fills a gap in current research.

## CHAPTER 3: METHODS

### **3.1 Design**

This is a qualitative study exploring the experience of informal caregivers after their care recipients with chronic stroke completed the Merging Yoga and Occupational Therapy (MY-OT) intervention (Schmid et al., 2016). Caregivers chose whether to complete the MY-OT intervention with their care recipients or to not attend. Additionally, we included two quantitative measures to support qualitative analyses assessing caregiver burden and positive aspects of caregiving. Individual interviews and focus groups were conducted with the caregivers after the 8 week MY-OT intervention. Changes in caregiver burden and positive aspects of caregiving were then used descriptively to support themes found through qualitative methods.

### **Researchers' Positions**

The research team for this study consisted of two professors of occupational therapy, one professor of Human Development and Family Studies and one graduate student completing her masters work in occupational therapy. During frequent discussions and personal reflection, we acknowledged how our backgrounds may influence our perspectives during the data analysis phase. However, through these discussions, we were able to meet consensus during the coding process which we felt limited individual bias.

### **3.2 Recruitment and Participants**

In order to participate in the MY-OT study, participants had to have a chronic stroke, fear of falling, and impaired balance (Schmid et al., 2016). Caregiver participants in these analyses were informal caregivers of people with stroke who were participants of the MY-OT study. Ten caregivers were invited to attend the MY-OT intervention and then self-selected between attending the MY-OT intervention with their care-recipient or not attending the intervention. All

caregivers were then asked to complete questionnaires and interviews after the eight-week intervention. All participants provided written consent prior to participating in the study.

### **3.3 Procedures**

Once caregivers consented to participate, they self-selected between attending the MY-OT sessions or to not attend the intervention. Following the 8-week intervention, caregivers then participated in focus groups, individual interviews, and completed quantitative assessments.

### **Quantitative Data**

Data were collected by a trained researcher using standardized assessments. This included basic caregiver demographics such as age, race, gender, education level, and time since the care recipient's stroke. Both pre- and post-assessments were administered retrospectively which has been shown to be an effective self-evaluation method (Farhan, Gottesman, de Grave, Steinert, & Winer, 2012). This method allows participants to effectively reflect on changes they have seen throughout the intervention. Variables of interest are caregiver burden (CGB) and positive aspects of caregiving (PAC). These were measured using the Zarit Burden Interview (ZBI) and the Positive Aspects of Caregiving (PAC) scale, respectively.

#### **Caregiver Burden.**

The ZBI is a 22 item questionnaire on which caregivers provide ratings (0-4, "never" to "almost always") about their perceptions of burden in their caregiving relationship. Scores range from 0-88, with 0-20 indicating little or no burden, 21-40 indicating mild to moderate burden, 41-60 indicating moderate to severe burden, and 61-88 indicating severe burden. Items generally address the ideas of personal strain and role strain related to the impact of caregiving in the caregiver's daily life (Zarit et al., 1980). Originally developed for use with caregivers for people with dementia, the ZBI has also been used for caregivers of people with Alzheimer's, stroke, and

traumatic brain injury (Bachner & O'Rourke, 2007). The ZBI has been found to be a valid and reliable measure for caregivers of people who have had a stroke (Bachner & O'Rourke, 2007).

### **Positive Aspects of Caregiving.**

The PAC is an 11 item questionnaire that uses a 1-5 rating scale (“I disagree a lot”, “I agree a lot”). Caregivers rate phrases that address their mental and emotional state in relation to their caregiving role which represent to two main constructs, ‘self-affirmation’ and ‘outlook on life’. These constructs are based on literature reviews of caregiver satisfaction within the caregiving relationship. Scores for the PAC range from 1-45 with higher scores indicating greater positive aspects of caregiving. This scale was originally developed for caregivers of people with dementia and has been found to be reliable and valid with that population (Tarlow et al., 2004). Psychometric properties have not been determined for caregivers of people who have had a stroke. However, the PAC’s development was based on the Caregiver Health Effects Study which looks at measures for caregivers of people with physical and cognitive impairments (Beach, Schulz, Yee, & Jackson, 2000).

### **Qualitative Data**

Focus group and individual interview questions were developed and conducted to assess the experience of caregivers after participating in the MY-OT intervention with their care-recipients or not. All caregiver participants were invited to participate in both types of interviews. This interview process allowed for further understanding and analysis of the caregiver’s experience (Seidman, 2013). Through interviewing the participants as a group and individually, nuanced elements of each caregiver’s experience were revealed. Focus group interviews were 45 minutes to one hour long after the last MY-OT intervention session. The focus group was led by a trained researcher to facilitate rich, group discussion (Morgan, 1996).

Individual interviews were scheduled within two weeks of the last intervention session and lasted between 30 minutes and one hour. Individual interviews were conducted in locations of the caregiver's choosing, which included the research lab, coffee shops, or their home. Two focus groups (8 caregivers total) and 7 individual interviews were conducted. A total of 9 different caregivers participated in any given combination of the assessments and interviews. Interview questions and probes focused on eliciting the experience of the caregivers after participating in MY-OT or not participating. Caregivers answered questions relating to perceived physical, emotional, and social changes for both caregiver and care-recipient as well as any impact these results may have had in their daily lives (See Appendices A & B).

### **3.4 Intervention**

The MY-OT intervention targets people who have had a stroke, have a fear of falling, and have impaired balance, during which their caregivers were invited to participate. The intervention was not initially developed to focus on the caregiver or their needs. The MY-OT intervention consisted of a one hour, biweekly group OT session focusing on managing fall risks and preventing falls which was led by a registered and licensed occupational therapist (OTR/L). In order to address post-stroke fall risk, the group OT addressed post-stroke fatigue, need for physical activity, fall risk factors, home modifications, self-advocacy, community access, and behaviors and attitudes (See Table 1). Following the group OT sessions, one hour of yoga, two times a week for 8 weeks, was led by a registered yoga teacher (RYT). The yoga protocol is a standardized progression of physical poses (seated, standing, and supine) and was developed to improve balance, strength, and range of motion in lower extremities for people who have had a stroke. The yoga intervention focused on increasing balance related to falls (see Table 2). Guided

relaxation was also completed each session and each participant received an audio recording of a guided relaxation to use at home.

**Table 1: Group OT Weekly Topics (Stroke)**

Week #	Session #	Weekly Topic
1	1	Introduction to falls
	2	Changing behaviors and attitudes
2	3	Analysis of a falls story and goal setting
	4	Stroke effects and fall risks
3	5	Managing your stroke effects: Medications and Alcohol
	6	Managing your stroke effects: Physical activity and mobility aids
4	7	Managing your stroke effects: Endurance and using a pedometer
	8	Managing your stroke effects: Fatigue and activity modification
5	9	Managing your stroke effects: Fatigue and activity modification; Floor
	10	Managing your stroke effects: Physical activity and strength
6	11	Managing the environment: Home, community, and goal planning
	12	Managing the environment: Managing falls
7	13	Managing the environment: Managing falls
	14	No group OT this session, yoga only
8	15	Program Summary
	16	Program Evaluation; Focus Group

**Table 2: Yoga Protocol (Stroke)**

Position	Description and Yoga Posture
<b>Seated Postures: Weeks 1-8</b>	Slow, deep and rhythmic breathing (Alternate Nostril Breathing and Lion's Breath)
	Horizontal, vertical and diagonal eye movements
	Neck and shoulder rotation, extension and flexion
	Scapular range of motion and arm movements (Receptive Movements)
	Finger movements (Mudras)
	Spinal extension, flexion, lateral flexion, and rotation, respectively (Cow, Cobra, Half Moon and Fish King)
	Hip rotation, ankle rotation, foot and toe stretching/movement (Pigeon Pose)
	Spinal twist with hand to opposite knee
<b>Standing Postures: Weeks 2-8</b>	Standing with support of chair (Mountain Pose, with and without cactus arms)
	Knees bent, squatting, seated position, up & down on toes (Chair Pose)
	Hip extension, alternating legs (Locust Pose)
	Lunges while standing with support of chair (Warrior I Pose)
<b>Supine Postures: Weeks 5-8</b>	Posterior leg stretch (Big Toe Pose)
	Supine extensions with pelvic lifts, tilts and rolls (Bridge Pose)
	Knees to chest, one at a time and then both (Energy Releasing Pose)
	Supine relaxation, legs extended or knees bent (Corpse Pose)
	Guided meditation and relaxation

### **3.5 Data Analysis**

#### **Quantitative Data**

Quantitative data were analysed using SPSS 22 software (SPSS Inc, Chicago, IL). Descriptive statistics using the mean, standard deviations, frequencies, and proportions were used to describe the sample. Due to the small sample size, percent change for each outcome score was calculated ( $\text{Time 1} - \text{Time 2} / \text{Time 1} \times 100$ ). Additionally, we examined the caregivers by groups, i.e. people who chose to attend the MY-OT intervention and people who chose to not attend.

#### **Qualitative Data**

All interviews and focus groups were audio recorded and transcribed by trained researchers. Each interview was then analysed and coded by at least two researchers using an inductive process occurring at two levels: “In vivo” identification of codes and the generation of larger themes that represent the caregiver’s experience. “In vivo” coding was completed using direct quotes from the participants to identify codes (Miles, Huberman, & Saldana, 2013). To do this, each researcher familiarized themselves with the interviews by thoroughly reading each transcript line-by-line, making notes of ‘chunks’ of meaning and generating tentative themes within interviews (open coding). Afterwards, the researchers met for multiple consensus meetings to compare codes and discuss emerging themes.

Following “In vivo” coding, the data was categorized into larger themes (Miles et al., 2013). To begin identifying larger themes, sub-themes were generated and organized across interviews. Themes were also compared between caregivers who attended the MY-OT intervention and those that elected to not attend. Researchers continued meeting to interpret findings, discuss potential final themes, and ensure themes are grounded in the data. Finally,

researchers collaborated until consensus was reached regarding final themes. Nvivo 11 software (QSR International, Melbourne, Australia) was used to support analyses.

Throughout this process, researchers noted any contradicting ideas in order to fully understand caregiver's experience. To ensure trustworthiness and credibility, further methods for rigor include research triangulation and researcher positioning. Throughout the analyzation process, an audit trail was recorded by each researcher (Creswell, 2013).



## CHAPTER 4: MANUSCRIPT

### 4.1 Introduction

In the United States, informal caregivers provide the equivalent of \$470 billion dollars of care annually, fulfilling an integral role within the healthcare system (Reinhard et al., 2015). Informal caregivers are the unpaid helpers of those who are unable to fully care for themselves, usually individuals with complex medical needs and chronic conditions. Currently, 39.8 million Americans are informal caregivers, and of that, 59% are caring for someone with a chronic condition (National Alliance for Caregiving, 2015). Stroke is a common chronic condition for which many people require caregiving (Mozaffarian et al., 2016). Stroke results from a disruption of blood flow to the brain that affects 6.6 million Americans (Mozaffarian et al., 2016) and leads to physical, cognitive, and functional deficits. Caregiving for people with stroke often requires providing assistance with daily living, self-care, medication management, community access, and socialization (National Alliance for Caregiving, 2015). The relationship between the caregiver and the care recipient, known as the caregiver dyad, is inter-connected, where the outcomes for one person wholly effect the other. (Lyons et al., 2002; National Alliance for Caregiving, 2015). For example, the care recipient's ability to engage in self-care affects how much care the caregiver provides each day.

Due to the intensity of the caregiving role, caregivers often experience negative effects, which is known as caregiver burden. Significant burden is experienced by 25-54% of informal caregivers (Rigby et al., 2009) and can result in: high levels of stress; emotional distress; restricted social participation; and increased risk for health conditions (Cameron et al., 2011; Carretero et al., 2009; Grigorovich et al., 2015). In contrast, Mackenzie and Greenwood (2012) found that positive aspects of caregiving also exist and include: a sense of purpose; closer

relationships; inner strength; and skill acquisition. Caregivers with higher levels of positive aspects of caregiving report greater life satisfaction despite higher levels of burden (Kruithof et al., 2012). As such, it is necessary to provide interventions for caregivers that increase these positive aspects of caregiving in order to mediate the burden and negative aspects of caregiving.

Current caregiver interventions for caregivers of people with chronic stroke fall into the following categories: psychoeducational; support; and skill building (Bakas et al., 2014; White et al., 2015). Interventions include caregiver mentoring; self-management; support groups; and respite (Garces et al., 2010; Greenwood et al., 2009; Won Won et al., 2008). However, there is a lack of evidence-based interventions for caregivers targeting support for managing daily life at home and within the dyad's community (Danzl et al., 2013; Rosalyn Carter Institute for Caregiving, 2010). Furthermore, there is a significant need for interventions that address the caregivers' physical, emotional, and cognitive health as a result of lifestyle changes within their caregiving role.

Yoga has been found to positively affect caregivers' physical, emotional, and cognitive health. Measured outcomes show reductions in stress, anxiety, and depressive symptoms as well as increased lower body strength, coping abilities, and quality of life (Crowe, Schmid, & Van Puymbroeck, In Press; Danucalov et al., 2013; Umadevi et al., 2013; Van Puymbroeck et al., 2007). However, yoga alone does not address ways in which the caregiver can manage their health effects and organize their daily lives to optimize positive health outcomes. Therefore, further education and training is necessary for caregivers.

Similarly, occupational therapy (OT) considers each client holistically, working to address individual needs in multiple environments (American Occupational Therapy Association, 2014). OT has been shown to improve caregivers' management of their multiples

roles and participation in valued activities (Bastawrous et al., 2015; Gibbons et al., 2014) through various avenues, including self-management and group therapy interventions (Valluzzi, 2014). In this way, OT can extend yoga's benefits to fully meet caregiver needs. Specifically, group OT provides group cohesiveness, instills hope, and promotes interpersonal learning (Cole, 2012; Falk-Kessler et al., 1991). This group format has also been found to be effective for community dwelling older adults in addressing physical function, social function, role limitations, and general mental health (Clark et al., 1997).

To date, no research has been conducted examining yoga and group OT together as an intervention for caregivers of people who have had a stroke. However, results of studies with other populations are encouraging (Chugh-Gupta et al., 2013; Schmid et al., 2016). Yoga and group OT together could likely address multiple aspects of caregiver needs, including physical, psychological, social, and role management factors. The purpose of this qualitative study was to assess the impact of the Merging Yoga and Occupational Therapy (MY-OT) intervention on caregivers of people living with chronic stroke. MY-OT was originally created as a fall prevention intervention for people who have had a stroke and their caregivers were invited to participate. Specifically, this study looks at the experience of caregivers, changes in caregiver burden, and changes in positive aspects of caring after participating in the MY-OT intervention versus not attending.

### **Research Questions**

1. What is the experience of caregivers participating in group OT and yoga versus not attending?
2. Is there a decrease in caregiver burden for caregivers after participating in group OT and yoga versus not attending?

3. Is there an increase in the positive aspects of caregiving for caregivers after participating in group OT and yoga versus not attending?

## **4.2 Materials and Methods**

### **Design**

This is a qualitative study exploring the experience of informal caregivers after their care recipients with chronic stroke completed the Merging Yoga and Occupational Therapy (MY-OT) intervention (Schmid et al., 2016). MY-OT was focused on fall prevention for the person with stroke. Caregivers chose whether to complete the MY-OT intervention with their care recipients or to not attend. Additionally, we included two quantitative measures to support qualitative analyses assessing caregiver burden and positive aspects of caregiving. Individual interviews and focus groups were conducted with the caregivers after the 8 week MY-OT intervention. Changes in caregiver burden and positive aspects of caregiving were then used descriptively to support themes found through qualitative methods.

### **Researchers' Positions**

The research team for this study consisted of two professors of occupational therapy, one professor of Human Development and Family Studies, and one graduate student completing her masters work in occupational therapy. During frequent discussions and personal reflection, we acknowledged how our backgrounds may influence our perspectives during the data analysis phase. However, through these discussions, we were able to meet consensus during the coding process which we felt limited individual bias.

### **Recruitment and Participants**

In order to participate in the MY-OT study, participants had to have a chronic stroke, fear of falling, and impaired balance (Schmid et al., 2016). Caregiver participants in this study were

informal caregivers of people with stroke who participated in the MY-OT study. Ten caregivers were invited to attend the MY-OT intervention and then self-selected between attending the MY-OT intervention with their care-recipient or not attending the intervention. All caregivers were then asked to complete questionnaires and interviews after the eight-week intervention. All participants provided written consent prior to participating in the study.

## **Intervention**

The MY-OT intervention targets people who have had a stroke, had a fall or a fear of falling, and had impaired balance. The intervention was not developed to focus on the caregiver or their needs, but instead on fall prevention for the person with stroke. The MY-OT intervention consisted of a one hour, biweekly group OT session focusing on managing fall risks and preventing falls and was led by a registered and licensed occupational therapist (OTR/L). Following the group OT sessions, one hour of modified hatha yoga was led by a registered yoga teacher (RYT). The yoga protocol is a standardized progression of physical poses (seated, standing, and supine) and was developed to improve balance, strength, and range of motion in lower extremities for people who have had a stroke. The yoga intervention focused on increasing balance related to falls. Guided relaxation was also completed each session and each participant received an audio recording of a guided relaxation to use at home. Additional intervention details were previously published (Schmid et al., 2016).

## **Procedures**

### **Quantitative Data Collection**

Data were collected by a trained researcher using standardized assessments. This included basic caregiver demographics such as age, race, gender, education level, and time since the care recipient's stroke. Both pre- and post-assessments were administered retrospectively,

which has been shown to be an effective self-evaluation method (Farhan et al., 2012; Sibthorp, Paisley, Gookin, & Ward, 2007). This method allows participants to effectively reflect on changes they have seen throughout the intervention. Variables of interest were caregiver burden (CGB) and positive aspects of caregiving (PAC). These were measured using the Zarit Burden Interview (ZBI) and the Positive Aspects of Caregiving (PAC) scale, respectively.

### ***Caregiver Burden***

The ZBI is a 22 item questionnaire on which caregivers provide ratings (0-4, “never” to “almost always”) about their perceptions of burden in their caregiving relationship. Scores range from 0-88, with the following ranges: little or no burden (0-20), mild to moderate burden (21-40), moderate to severe burden (41-60), severe burden (61-88). Items generally address the ideas of personal strain and role strain related to the impact of caregiving in the caregiver’s daily life (Zarit et al., 1980). The ZBI has been found to be a valid and reliable measure for caregivers of people who have had a stroke (Bachner & O’Rourke, 2007).

### ***Positive Aspects of Caregiving***

The PAC is an 11 item questionnaire that uses a 1-5 rating scale (“I disagree a lot”, “I agree a lot”) where scores range from 1-45, higher scores indicating greater PAC. Caregivers rate phrases that address their mental and emotional state in relation to their caregiving role which represent to two main constructs, ‘self-affirmation’ and ‘outlook on life’. These constructs are based on literature reviews of caregiver satisfaction within the caregiving relationship and has been shown to be valid and reliable for caregivers providing care for people with physical and cognitive impairments, such as stroke (Beach et al., 2000).

## **Qualitative Data Collection**

Focus group and individual interview questions were developed and conducted to assess the experience of caregivers after participating in the MY-OT intervention with their care-recipients or choosing to not attend. All caregiver participants were invited to participate in both types of interviews. This interview process allowed for further understanding and analysis of the caregiver's experience (Seidman, 2013). Through interviewing the participants as a group and individually, nuanced elements of each caregiver's experience were revealed.

Focus group interviews were 45 minutes to one hour long after the last MY-OT intervention session. The focus group was led by a trained researcher to facilitate rich, group discussion (Morgan, 1996). Individual interviews were scheduled within two weeks of the last intervention session and lasted between 30 minutes and one hour. Individual interviews were conducted in locations of the caregiver's choosing, which included the research lab, coffee shops, or their home. Two focus groups (8 caregivers total) and 7 individual interviews were conducted. A total of 9 different caregivers participated in any given combination of the assessments and interviews. Interview questions and probes focused on eliciting the experience of the caregivers after participating in MY-OT or not participating in the intervention. Caregivers answered questions relating to perceived physical, emotional, and social changes for both caregiver and care-recipient as well as any impact these results may have had in their daily lives (See table 3).

**Table 3: Sample Interview Questions**

<b>Focus Group Questions</b>	<b>Individual Interviews</b>
<ol style="list-style-type: none"><li>1. What changed over the last 8 weeks? Possible probes: physical, emotional, social, stress</li><li>2. Would you recommend this program to other people with stroke? Why?</li><li>3. Now that you have finished this study, describe how confident you are about your ability to do exercises?</li></ol>	<ol style="list-style-type: none"><li>1. What changed over the last 8 weeks? Possible probes: physical, emotional, social, stress</li><li>2. Has this study had any impact on your own activities or your shared activities?</li><li>3. Tell me about how this program has impacted your care recipient? And how has it impacted you?</li></ol>

## **Data Analysis**

### **Quantitative Data**

Quantitative data were analysed using SPSS 22 software (SPSS Inc, Chicago, IL).

Descriptive statistics using the mean, standard deviations, frequencies, and proportions were used to describe the sample. Due to the small sample size, percent change for each outcome score was calculated ( $\text{Time 1} - \text{Time 2} / \text{Time 1} \times 100$ ). Additionally, we examined the caregivers by groups, i.e. people who chose to attend the MY-OT intervention and people who chose to not attend.

### **Qualitative Data**

All interviews and focus groups were audio recorded and transcribed by trained researchers. Each interview was then analysed and coded by at least two researchers using an inductive process occurring at two levels: “In vivo” identification of codes and the generation of larger themes that represent the caregiver’s experience. “In vivo” coding was completed using direct quotes from the participants to identify codes (Miles et al., 2013). To do this, each researcher familiarized themselves with the interviews by thoroughly reading each transcript line-by-line, making notes of ‘chunks’ of meaning and generating tentative themes within



interviews (open coding). Afterwards, the researchers met for multiple consensus meetings to compare codes and discuss emerging themes.

Following “In vivo” coding, the data were categorized into larger themes (Miles et al., 2013). To begin identifying larger themes, sub-themes were generated and organized across interviews. Themes were also compared between caregivers who attended the MY-OT intervention and those who elected to not attend. Researchers continued meeting to interpret findings, discuss potential final themes, and ensure themes were grounded in the data. Finally, researchers collaborated until consensus was reached regarding final themes. Nvivo 11 software (QSR International, Melbourne, Australia) was used to support analyses.

Throughout this process, researchers noted any contradicting ideas in order to fully understand caregiver’s experience. To ensure trustworthiness and credibility, further methods for rigor include research triangulation and researcher positioning. Throughout the analyzation process, an audit trail was recorded by each researcher (Creswell, 2013).

### **4.3 Results**

#### **Findings**

Of the ten caregivers, one elected not to complete any assessments or interviews due to personal beliefs related to the spirituality of yoga. The average age of caregivers of the seven caregivers who completed the quantitative assessments was 64.86 and the majority of all caregivers were female (66 %). See table 4 for additional demographic data. All Caregivers were requested to attend the first and last class of the session. Three caregivers chose to not attend the intervention. The others attended approximately 75% of the sessions.

**Table 4: Caregiver Characteristics (n=9)**

Variable	Total
Age (mean (SD)) (n=7)*	64.86 (4.59)
Gender (female)	6 (66%)
Race (white)	9 (100%)
Married/Part of Couple	8 (89%)
Relationship to Care Recipient (spouse)	7 (78%)
Years Caregiving (greater than 5 years)	6 (66%)
Education ('some college' and above) (n=7)*	5 (71%)

\*Data unknown for two caregivers who did not complete quantitative assessments

For caregivers who attended the MY-OT sessions, caregiver burden decreased by 47% compared with those who used did not attend, whose caregiver burden decreased by 2%. Caregivers who attended MY-OT demonstrated an increase of 26% in positive aspects of caregiving while caregivers who did not attend saw a decrease of 4%. See table 5 for further descriptions.

**Table 5: Changes for CGB and PAC**

Variable	Pre: Mean (SD)	Post: Mean (SD)	Percent Change
CGB: MY-OT (n=7)	32.23 (18.75)	17.00 (12.49)	↓47%
CGB: Did not attend (n=7)	32.00 (12.36)	31.25 (12.31)	↓2%
PAC: MY-OT	28.33 (4.62)	35.67 (3.78)	↑26%
PAC: Did not attend	34.67 (7.10)	33.25 (6.34)	↓4%

CGB = Caregiver Burden; PAC = Positive Aspects of Caregiving

Five major themes emerged during the coding process regarding experiences of caregivers who either did not or did not complete the MY-OT intervention. Major themes included: (1) Changes in Daily Life; (2) Coping Mechanisms, (3) Learning Through Observation, (4) Sense of Community, and (5) Gaining Information. Within each major theme, secondary themes were identified to further describe caregiver experiences. Table 6 summarizes these themes.

## **Major Themes**

### ***Theme 1: Changes in Daily Life***

Caregivers noted multiple changes within their daily lives after participating in MY-OT. This included changes for themselves as well as changes for their care recipients. Several caregivers noted that when their care recipient initiated engaging in more activities or engaging independently, it influenced the caregiving relationship.

*Change in Relationship.* While caregivers who did not attend the MY-OT intervention noticed no specific changes in their relationship, those that attended MY-OT did. They found themselves feeling less stressed, laughing more, and spending greater quality time together. They found the dedicated time together each week provided them with shared, positive experiences. Several caregivers felt as if they were ‘nagging’ less because they did not have to provide as much one-on-one care during the intervention.

*“You know, yesterday we did my husband’s shower, which is, I have to help him, we have a tub in the shower and so he can’t get in and out. And usually it seems like that’s a chore. So I thought “Shower today...” But we had fun! I mean we talked and visited and laughed and he teases me and squirts me. I mean I realized, I said ‘This was fun!’. This is fun! He said, “Yeah!” [several laugh] He thought it was fun all along. But maybe, maybe that’s where that perspective came from because it never had occurred to me that that was fun before. It always was a chore. But it wasn’t. We did, we had a good time, like we usually do. So, that might have come from the yoga...introspection...I don’t know...”*

*Change in Activity Level.* Many caregivers noted that attending the intervention two times a week provided them with a new activity to engage in together. One participant said “It did change our activity level because we were kind of in a rut...” Frequently, the caregiver and care recipient would extend this time by going out to eat or running errands together afterwards. Caregivers that attended MY-OT also said that their care recipients would initiate more activities, such as taking walks or attending social events and that they felt inspired to try more new things (e.g. going on vacation, attending yoga in the community). Caregivers stated that this added a new, positive dimension to their daily life. One caregiver made the following statement:

*“So, that has added a real positive dimension to our relationship and in my life because I still have to drive her, I still have to do things, but you know, she does more on her own than she used to, so it’s not like I’ve gained 20% more free time. In fact, I drive her more places and you know, I have to do more things and the driving her around more is one of those physical time consuming things. In terms of my emotional state, I don’t think I have to worry about what is she thinking about today. And that gives, that does give me more mental free time to pursue some of the things that I want to do.”*

This did appear to increase the caregiver’s responsibility in some areas, such as driving. For example, caregivers who did not attend noted an increase in burden through driving their care recipient to the intervention which sometimes interfered with their own planned activities.

*Physical and Cognitive Changes.* While physical and cognitive changes were mainly seen in care recipients, this likely influenced the type and quality of care the caregivers provided outside of the intervention. Several caregivers reported seeing changes in balance, endurance, alertness, vision, and speech. Caregivers indicated that this allowed the care recipients to engage in more activities for longer periods of time, raising spirits, and providing the dyad with greater opportunities in the future. Several caregivers reported their care recipients being tired after the intervention, but felt that it was a natural consequence of exercise and mental engagement. One caregiver who attended MY-OT did report feeling less pain due to rheumatoid arthritis.

*“Well, I’ll start. Um, for my husband, it’s been amazing. I don’t know if you all have seen the difference in him but he is talking so much more so when people come to the house or when we’re out and about, he’s initiating conversation, which he hasn’t done very much because he’s so, feels so bad about not being able to access words. He’s embarrassed about it. But he’s, that has been a change. The other change in his language is that he’s using three and four words strung together now. Where up ‘til now, it’s pretty much been single words so that’s just been a huge change. The kids have noticed it. The grandkids have even noticed it. Um, he’s a lot stronger than he was when he started and he, um, is a lot more flexible. His balanced has changed. Before, just to get down to nitty-gritty, to flush the toilet was really difficult for him.”*

These quotes suggest that participating in group OT and yoga together allowed caregivers and care recipients to use strategies in their daily lives.

### ***Theme 2: Coping Mechanisms***

After attending MY-OT, caregivers reported multiple ways in which they garnered positive feelings and greater self-awareness. They report feeling hopeful about their current and future situation, feeling better physically and mentally, changing their perspective, and using breathing as a coping tool in everyday life. Caregivers who did not attend reported observing their care recipients having more self-confidence, but reported no personal changes related to this theme.

*Being Hopeful.* Caregivers reported feeling that participating in the study was a positive experience that led to the dyad engaging in more activities in their lives. They report feeling hopeful about the future and wanting to engage in more new activities.

*And so it’s like, yeah, I got a new camera and I’m going to be doing more stuff. And it will take more time because it’s always a balancing act and I can’t give up caregiving but I also know that I don’t have to devote mental energies to things that she’s doing and that I can go and do other things and not be worried about, you know, what she’s doing at this hour. So, that has been, it’s change and it’s a change that is kinda like the compass needle starts pointing in that direction, you know.*

*Staying Present.* Caregivers also report reduced stress levels, less worry, raised spirits, and enjoying having something new to do. This likely relates to participating in yoga which taught awareness of being in the present moment.

*“What I think is so miraculous is that when I get to participate in the yoga, I’m not thinking about her. I’m not wondering if she’s doing it or not. I’m wondering if I’m doing it or not and so I’m no longer reflecting about the future, because I can remember the fut-, er the past, I should say. Because I remember the past very, very well, probably more than she does... I’m not worried about the future so much as, you know well, what if, what if. I mean, I’m in the present, and isn’t that wonderful? To just be in the present, be grateful for where you are, grateful for what you have and not worry about either the past or the future. So, that’s been my experience, has just been absolutely fantastic.”*

*Change in Perspective.* Caregivers frequently mentioned seeing what they once thought of as negative as positive. One caregiver mentioned seeing her care recipient as strong instead of fragile and feeling more grateful for the gifts they have been given in life.

*“I mean it happened, and it’s like, ‘ok, we’ll roll with the punches’. So, we’ve had to change our routines and things that have happened in our lives. But this has added a dimension of hope and/or ‘ok, we’re not in a stasis’. My wife, I think, is realizing that yeah, things can change. And that she can, that it won’t happen without her effort. That, more than anything, you don’t have to sit and just wait to die.”*

Caregivers also reported that the confidence and motivation their care recipient’s gained positively influenced their interactions. Caregivers felt less likely to ‘nag’ and more willing to let their care recipients engage in activities independently.

*“Before, I was pushing, pushing, pushing all the time, I just felt like a Grinch, and now he’s just automatically does two or three walks down the hallway when he gets up, so that’s amazing. And um, he wants, he wants to go fishing now. Before we all said, “Don’t you want to go fishing?” It’s his favorite in the world! Now he wants to get his boat out, he wanted to know where his boat was, is his boat ok and um, he also was talking about getting out in the garden this summer. So, we’ll see but that’s really amazing because we’ve been asking him, “Don’t you want to do this? Don’t you want to do this?” But, now he’s, he’s initiating that too. So, this has been for us, an amazing, amazing thing.”*

After participating in the group OT and yoga, the dyad experienced changes in perspective which positively influenced the choices they make in their daily life.

*Breathing.* Caregivers repeatedly remarked about the benefits of breathing. They stated it helped them feel more calm and felt it was a free and easy tool the caregiver and care recipient could use anywhere throughout their days.

*“Oh, I think the one big that that my husband and I both carried, the breathing, the positive breathing. Because my husband has issues with the breathing anyway because of the brainstem damage from the stroke and that really, I mean seriously. And in fact, I’ve got our daughter, cuz she gets really stressed too, and it’s like “just try it”. It’s amazing! The effect that it has on your whole body. You know, your mental state, your emotional, physical, the whole nine yards.”*

### ***Theme 3: Learning through Observation***

For caregivers who attended MY-OT, observing interactions between the participants and between participants and staff was invaluable. Being able to ‘sit back’ and ‘give space’ appeared to be an important aspect of this theme. Caregivers learned more about their care recipients and new information by listening to their answers and observing them interact with other people.

*“I learned so much and my person opened up and answered questions that I never asked, or no one ever did ask her and she admitted to things or acknowledged things that I didn’t know about. So, by being an observer and having the interplay with the group, I learned so much that I, cuz I didn’t know. Because as a caregiver, you’re the last to know, you know? [laughs]”*

*“So, um, I really thought that the way it was handled, it was important for us to be an observer because we observed the interaction with the participants and it was almost like group therapy. And as an observer, you get probably...because you get a different perspective as an observer than if you do if you’re participating. Because you’re thinking about ‘Well, what am I going to say now?’ but if you don’t have to say anything and you observe all 8 people. And then you observe the lead OT and the interactions...and the questions she asks and encourages people, you get a tremendous amount of information that way.”*

Observing their care recipient interact with other people allowed the caregivers to see their care recipients in different ways, which then carried over into daily life.

*“Because initially, after her stroke, I looked at her as being so fragile. And um, I didn’t want to do anything that was going to tax her strength or anything like that. Well, as I’ve looked at the participants in this study, none of them are fragile. They wouldn’t be here today if they were fragile because they have strength, they have stamina, that have determination and they’re, um, they’re focused in how much energy into doing the simple things we take for granted and so I’ve been much more appreciative of knowing that she can take care of herself. You know, I’m a manager, I take control, manipulate, mother, all those little things that are really an unhealthy thing and I have found that simply the information, I am much more relaxed.”*

This information suggests that including caregivers in the intervention provides opportunities to learn new information about the care recipient through observation.

#### ***Theme 4: Sense of Community***

All caregivers in the study acknowledged the value of the social aspect of the intervention. Being able to interact with other people who understand the experience of living with stroke provided support and opportunities to meet new people.

*Social Interaction.* Caregivers who attended MY-OT reported feeling positive about the new relationships they built while participating in the intervention. Caregivers found support in each other and observed their care recipients forming new friendships as well.

*“Realizing that he’s not the only one, that there are other people out there like him. And I believe it just makes him so relaxed. And when he gets relaxed, you know, his speech comes out a lot better.”*

*“And so the right people came to that study and the people that needed to see each other came to that study and I think that we now have been given so many gifts as a result of that study. Not only individual and personal gifts but a networking...and knowing that we’re ok and knowing that we all are ok. You know, we have a sense of humor and our intelligence and we tell it as it is.”*

The social aspect provided an open and relaxed environment for caregivers and care recipients alike to grow personally and socially. Caregivers were able to ‘step back’, form relationships with each other and give their care recipients the space to do the same.



*Quality of Therapeutic Experience.* Caregivers who attended the MY-OT intervention were provided with materials, given coffee, and were invited to sit in the fall prevention OT group.

They report feeling welcome and included in the study.

*“I was delightfully surprised at how attractive you made the course. Um, it seemed attractive to me when we first heard about it and we wanted to join it. Uh, and I can’t remember exactly how you presented it but then we got goodies out of it!”*

*“From day one, the ambience and the people that were doing this, made me feel, and I’m, I think my wife’s also agreed with this, that this is, the people here that are a part of this study were made to feel like they were the focus. It’s all about them. It’s not about, you know, somebody getting another grant. This was for their benefit and all the efforts were for the benefit of the people here and that’s sets a positive tone that my wife was excited about coming here. You know this wasn’t, ‘Ok, let’s go, we’ve gotta show up, we’ve agreed to it’. She was excited about it.”*

They also stated that learning therapeutic information in a community setting provided a supportive learning environment.

*“It’s real because the lead researcher is a teacher. So, she wants to impart that information to you. When you go to a medical person, you have an exam and they tell you this and then it’s over. And I think to be able to have a teacher tell you all of these aspects and then of course you have wonderful helpers too, I think was just phenomenal! Because it’s not controversial, you’re not competing with another medical person over here, but you’re being told, for the very first time for me, that these things exist with stroke effects. I didn’t know that.”*

### ***Theme 5: Learning New Information***

Both caregivers who attended MY-OT and those who did not attend reported learning new information regarding fall prevention management. However, caregivers who did not attend learned the information second-hand through their care recipients. Caregivers who attended MY-OT reported more robust gains in knowledge, specifically about fall prevention, stroke and fatigue, and increasing awareness in daily activities. Caregivers also learned that physical change is possible even years after stroke and many commented that they were frustrated they had been

initially told that ‘what is gained after six months is all you can expect to gain’. By learning this new information, caregivers stated they felt relief at understanding the bigger picture of living with stroke.

*“I, for me, the discussion, around the table, was really good. And I think maybe that’s really why I am much easier with my husband, much less likely to get stressed. Just hearing everyone else’s comments and, the fatigue, for example, the doctors have acted like that’s unusual for so long, we need to change the medicine but everybody at that table talked about fatigue even years into stroke, so I don’t know why OTs know that and doctors don’t [I laughs] but um, so it was really beneficial for me to hear how people worked around those situations [uh huh] and how they’re stroke symptoms affected them because some of that stuff I was thinking, you know “What are we doing wrong? We should do something different”. [right] And probably not, probably it’s just normal trying to deal with it. So, I really got a lot out of the OT sessions.”*

Learning new information also included learning about the components of yoga and how to safely participate in yoga, which provided caregivers with a new coping tool.

*“Yeah, learning yoga is the biggest benefit for both of us.”*

*“Then we, I was particularly impressed with the yoga because of that fact that we participated and my experience with that was that when I was doing yoga, I was not thinking about her. I was just concentrating on what I was supposed to do. And so for an hour, my attention was directed toward myself rather than toward her or any of the other participants and so that was kind of a neat thing.”*

Learning new information, even years after the onset of stroke, was a valuable experience for caregivers. This allowed them to learn new strategies and o make sense of the ‘bigger picture’ of living with stroke.

#### **4.4 Discussion**

The aim of this study was to examine caregiver’s experiences after participating in the MY-OT intervention or not attending. By qualitatively examining caregiver’s experiences, we were able to show that, in this study, positive experiences for caregivers can be garnered through targeted interventions. The five main themes demonstrate that caregivers have a multitude of

needs that can be met through a multimodal intervention such as MY-OT. Like previous studies, our study found that the caregiving role leads to high levels of caregiver burden (Camak, 2015; Jaracz et al., 2015). Caregivers in our study also demonstrated strained relationships, decreased participation in valued activities and reduced physical activity (Bastawrous et al., 2015). However, our findings were also consistent with the Mackenzie and Greenwood (2012) systematic review of positive experiences of caregiving in stroke, where positive coping skills were linked to positive experiences in caregiving. We also found that changes in perspective were related to positive experiences, potentially leading to greater feelings of meaning and purpose in life. Our findings support recommendations for research on positive experiences following stroke (Lou, Carstensen, Jørgensen, & Nielsen, 2016). Consistent with a systematic review of interventions for caregivers of people with chronic conditions, our findings show that skill-building, education and training, and supportive social environments were of value to caregivers (Corry et al., 2014). Previously, researchers found that caregivers desire access to supportive, community programs, a collaborative health care team and positive lifestyle change, which also parallels our findings (White et al., 2007).

Multiple researchers recommend providing interventions for caregivers throughout the continuum of care (White et al., 2015) as needs change based on severity of the care recipients stroke symptoms and ability to engage in daily activities. Community based programs, such as OT led groups, are cost effective, provide social supports, provide access to health professionals and teach techniques for self-management (Rosalyn Carter Institute for Caregiving, 2010). Our study provides preliminary evidence that yoga merged with group OT may meet these goals and provides evidence for physical, emotional, and social change for both the caregiver and the care recipient many years after the stroke occurs.

Likewise, the yoga portion of the intervention works to meet the goals of the triple aim set out by the Institute for Healthcare Improvement (Berwick et al., 2008) to improve health, reduce costs, and improve the patient care experience (Weber & Sculthorp, 2016). Our findings show that this intervention meets each of the aims by simultaneously providing yoga to both caregivers and care recipients in a group setting run by licensed occupational therapists. The yoga protocol was standardized, yet individually adapted in meaningful and safe ways, as was recommended by Bayley-Veloso and Salmon (2016). After MY-OT, caregivers reported feeling less stress, more flexibility, and a shift in awareness, which is consistent with outcomes found in yoga research (Mehling et al., 2011; Nayak et al., 2014; Ross & Thomas, 2010). Using yoga in conjunction with OT led groups provides an opportunity to create positive experiences. These positive experiences may mitigate the effects of caregiver burden as well as provide opportunities for positive change in daily life, such as decreased stress, change in perspective and change in activity levels.

In 2014, the American Heart Association and American Stroke association reviewed current interventions for stroke caregivers and found 39 research studies examining 32 different interventions (Bakas et al., 2014). The main finding in this review was that interventions were not adapted to the individual needs of the caregiving dyad, which our study attempted to rectify by allowing caregivers a choice in participating. Interestingly, caregivers who did not attend saw little to no change in caregiver burden or positive aspects of caregiving. However, those who participated, saw a marked change in both areas. They also reported many positive changes related to information gathering, changes in daily life, a change in perspective, and coping skills (Crowe et al., In Press). While all caregivers reported learning new, pragmatic information, those who attended MY-OT reported experiencing more complex and robust modes of learning, such

as learning through observation or implementing what was learned at home, which likely impacted other areas of their lives. Caregivers also reported multiple advantages of sharing the experience with their care receiver, including increased quality of time together and observation of the care recipient in a new setting. This suggests that interventions targeting the caregiver dyad may provide an opportunity to meet multiple needs for both individuals across their continuum of care.

### **Limitations**

The main limitation in this study is that the intervention was initially created as a fall prevention program for people with stroke, and not their caregivers. However, data collection shows that involving caregivers in the intervention was still greatly beneficial. Future studies should focus on creating interventions targeting both the caregiver and the care recipient together. Another limitation is that we cannot say what specifically affected change in this study. Both the group OT and the yoga target different needs, and it is possible that their combination together provided greater opportunities for growth. However, we cannot isolate if one over the other affected greater change. Other limitations include a limited sample, homogeneity of race, education levels, and gender. A large limitation of yoga research is the over representation of females in studies, which also occurred in our study. Also, the study was conducted in a small, college town, which does not provide a representative sample of caregivers of people with stroke throughout the country.

### **Future Research**

As mentioned above, future studies should look at group OT and yoga for caregivers and care recipients together. This may allow for a wider range of assessments and data collection for both populations, as well as a greater focus on adapting the intervention to the needs of the

individuals. Likewise, a continued focus on community-based programs for caregiver dyads along the continuum are still needed (White et al., 2007). Caregivers and care recipients require different types of information and instruction beyond information provided in the acute phase of stroke. It's possible that OT led education and self-management groups combined with yoga may be beneficial following completion of stroke related outpatient therapies. It is also recommended that the caregiver and care recipient both participate in the study, as caregivers report learning through observation of their care recipients and participating in the yoga and group OT together. Future studies may want to provide opportunities for the caregivers to meet separately, as this would allow for further socialization, support and networking, as was suggested by caregivers in their interviews. Providing the dyad with this information sooner in their recovery process may prevent unwarranted difficulties later in the process.

### **Clinical Implications**

Therapists are advised to provide client- and family-centered interventions, involving the caregiver, so as to best address the needs of the dyad. Caregiver's needs are often overlooked, but if addressed, may allow the caregiver to provide better quality care to their care recipient. Also, professionals are advised to find provide interventions along the continuum of care, especially after the initial six months' post-stroke. Specifically, OT led groups and yoga together are a powerful tool for affecting positive physical and emotional change, providing stress relief, teaching management skills, and providing coping tools for the dyad.

### **4.5 Conclusion**

Researchers continue to recommend the creation of interventions that address both the caregiver and care recipient's needs. The experiences of caregivers after participating in MY-OT mirror outcomes found for care recipients in previous studies (Schmid et al., 2016). Thus,

merging group occupational therapy and yoga is a powerful, multimodal intervention that is capable of addressing a variety of needs for both individuals. Caregivers provide a great service within our healthcare system and are often overlooked. By providing targeted interventions, such as MY-OT, we can support our caregivers in living long and healthy lives while fulfilling their caregiving roles.

**Declaration of Interest**

No potential conflict of interest was reported by the authors.

## CHAPTER 5: CONCLUSION

While MY-OT was initially created to address the needs of people with stroke, it was found to also be a feasible intervention for their caregivers as well. Results show that caregivers who participated in MY-OT not only decreased caregiver burden and increased positive aspects of caregiving, but their educational, physical, emotional, and social needs were positively affected as well. Caregivers reported changes in perspectives that impacted their daily activities, interactions with their care recipient, and provided a positive outlook. The experiences of caregivers after participating in MY-OT mirror outcomes found for care recipients in the primary study. (Schmid et al., 2016). Thus, merging group occupational therapy and yoga may be a powerful, multimodal intervention that is capable of addressing a variety of needs for both individuals. MY-OT has the potential to be an effective, community-based intervention to address both the caregiver and care recipient's varying needs. Caregivers provide a great service within our healthcare service and are often overlooked. By providing targeted interventions, such as MY-OT, we can support our caregivers in living long and healthy lives while fulfilling their caregiving roles.



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## APPENDIX A

### Focus Group Questions

Thank you for being part of this study. We appreciate your time. We would like to spend a little time talking to all of you about the last 8 weeks of the study and about your role as a caregiver

Let's start by talking about your perspective as a caregiver.

1. Please tell me what you thought about this program.

#### **Probes**

- Liked – why?
  - Teacher
    - Were modifications helpful
    - Did the instructor recognize when you needed modifications?
  - Location
  - Parking
  - Favorite positions or times of the sessions
- Did not like – why?

2. What changed over the last 8 weeks? For yourself? For your care recipient?

#### **Probes**

- Physical changes
- General health
- Falls and fear of falling/worry about falls
- Visual
- Emotional / Attitude
- Social
- Confidence
- Change in other activities
- Driving
- Function
- ADL's/IADL's
- Stress
- Sleep

3. How did this program make you feel physically and emotionally?

- Confidence
- How did you feel about getting to the floor?
- Did you prefer floor, standing, sitting exercise?

4. Will continue with any of the exercises?

- Why or why not

5. How did you feel about the people and the number of people who were helping during the sessions?

6. Did your family and friends know that you were participating in this program? What were their perceptions about this?
7. Now that the exercise sessions are over, do you have any plans to
  - Continue seeing each other
  - Continue to exercise
  - Join a gym
  - Do other studies
8. Is there anything else you would like to tell us about the therapy program?



## APPENDIX B

### Individual Interview Questions

Thank you for being part of this study. We appreciate your time. We would like to spend a little time talking to all of you about the last 8 weeks of the study and about your role as a caregiver

Attended some of the MY-OT sessions ☐ Yes ☐ No

1. If yes, what were your favorite parts?
2. Would you recommend this program to others? ☐ Yes ☐ No
  - Tell me why?
3. We know that sometimes caregivers give up a lot of their own activities or activities that were once shared with your loved one. Has this study had any impact on your own activities or your shared activities?
4. If you didn't attend the sessions, may we ask how you used or enjoyed the hours when your loved one was with us?
5. If you did not address this in the focus group -what would you change to make this program better?

#### **Probes**

- Describe how this program can be improved
  - What would you change about this program?
  - Is it appropriate for people with stroke?
6. If we do a study like this in the future, do you think we should continue to have the caregivers be in the same program, or should we offer different programming?
  7. Tell me about how this program has impacted your care recipient? And how has it impacted you?
  8. Tell me about the changes that have occurred with this program?

#### **Probes**

- Physical
- General health
- Falls
- Visual
- Emotional/attitudes
- Social
- Confidence
- Change in other activities
- Driving
- Function
- ADL/IADL

- Stress
- Sleep
- Quality of life

9. Please tell me what you thought about this program (for yourself or your loved one).

**Probes**

- Liked – why?
- Did not like – why?
- What changed over the last 8 weeks?
- How did this program make you feel
- Confidence
- How did you feel about getting to the floor
- Did you prefer floor, standing, sitting exercise
- Will continue with any of the exercises?
- Why or why not
- How did you feel about the people and the number of people who were helping during the sessions
- Too many?
- Confusing?

10. How does this compare to rehab or other programs since your loved ones stroke.

11. Would you recommend this program to other people with stroke?

**Probes**

- Describe what you think about the idea of doing yoga.
- Do you think others like yourself would think about yoga exercise in the future?
- Describe how you would talk about yoga to other caregivers/people with stroke.
- What did you like the most about the yoga exercise?
- What did you like least about the yoga exercise?

## LIST OF ABBREVIATIONS

ADLs	Activities of Daily Living
AOTA	American Occupational Therapy Association
CIH	Complementary and Integrative Health
CGB	Caregiver Burden
IADLs	Instrumental Activities of Daily Living
ICF	International Classification of Functioning, Disability, and Health
MMSE	Mini Mental State Examination
MY-OT	Merging Yoga and Occupational Therapy
OT	Occupational Therapy
OTR/L	Registered and Licensed Occupational Therapist
PAC	Positive Aspects of Caregiving
RYT	Registered Yoga Therapist
SPSS	Statistical Package for the Social Sciences
ZBI	Zarit Burden Interview