

Research Article

## A Multi-modal Intervention after Stroke: The Caregiver Experience

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### Abstract:

**Background:** A fall prevention intervention was delivered to people with chronic stroke (Merged Yoga and Occupational Therapy intervention-MY-OT). All caregivers were invited to also attend the 8-week intervention and were included in these analyses.



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**Methods:** The aim of this study was to examine changes in caregiver burden, positive aspects of caring, and caregiver's experiences after participating in the MY-OT intervention. This was a secondary data analyses and the purpose of this mixed-methods study was to quantitatively assess changes in caregiver burden (Zarit Burden Interview) and positive aspects of caregiving (Positive Aspects of Caregiving scale) and qualitatively explore the experience of the caregivers who attended the intervention. Focus groups and individual interviews with the caregivers were completed, transcribed, and reviewed. Qualitative data were analysed to identify emergent themes that described the caregiver experience.

**Results:** The average age of nine caregivers was 64.86 years old and most caregivers were female (66%). Caregivers who attended the MY-OT intervention (n=6) demonstrated less caregiver burden (47% decrease) and more positive aspects of caregiving (26% increase) than those who did not attend (n=3). Four qualitative themes emerged and included: positive changes in daily life; being in the present; new learning opportunities for the dyad and individual; and building a sense of community.

**Conclusions:** In this small sample of caregivers, yoga and occupational therapy appeared helpful in reducing caregiver burden, increasing positive aspects of caregiving, and contributing to positive experiences over all. Future research studies should be developed to include the caregiver and address the caregiver dyad.

### **Keywords**

Caregiver; dyad; yoga; occupational therapy; self-management; stroke

## **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 [1]. 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 [2], such as stroke. Stroke results from a disruption of blood flow to the brain that affects 6.6 million Americans [3] and may lead to significant 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 [2].

Together, the caregiver and the care recipient become a caregiver dyad. This is a close, interconnected dyadic relationship where the outcomes of one person wholly affect the other [2, 4]. 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 [5] and can result in: decreased mental health including high levels of stress and emotional distress; restricted social participation; and increased risk for health conditions [6, 7]. In contrast, Mackenzie and Greenwood (8) found that positive aspects of caregiving also exist and may 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 [9]. 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 within one of three types: psychoeducational; creating support; and skill building [10]. Specific interventions for caregivers include mentoring; self-management; support groups; and respite [11, 12]. However, there are a lack of evidence-based interventions for caregivers that are multimodal or target the dyad together [13]. Furthermore, there is a significant need for interventions that address the caregivers' mental, physical, emotional, and cognitive health as a result of lifestyle changes within their caregiving role.

Considering this need, yoga has been found to positively affect caregivers' mental, physical, emotional, and cognitive health. Measured outcomes show yoga leads to improved: stress; anxiety; depression; lower body strength; coping abilities; and quality of life [14-16]. However, yoga alone may not be enough to address ways in which caregivers can manage their health effects and organize their daily lives to optimize positive health outcomes. Therefore, Lambert, Duncan (17) recommend taking a multi-modal approach and combining physical activity with self-management to holistically address caregiver's needs.

Self-management interventions build skills in individuals with chronic conditions to manage their health within their daily lives [18]. Preliminary research shows that within the caregiver dyad, self-management can contribute to both the caregiver and care recipient's sense of self-efficacy, improved quality of life, and engagement in daily activities [19, 20]. Occupational therapy (OT) has been shown to improve caregivers' management of their multiple roles and participation in valued activities [21, 22] through self-management and group therapy interventions across environments [23]. Specifically, an OT-led group format can provide group cohesiveness, instil hope, and promote interpersonal learning [24]. 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 [25]. Thus, combining yoga and group OT may be an effective way to address caregiver's psychosocial and physical needs.

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 using yoga and OT with other populations are encouraging [26, 27]. Yoga and group OT together could likely address multiple caregiver needs. The purpose of this multi-methods study was to assess the impact of the **M**erging **Y**oga and **O**ccupational **T**herapy (MY-OT) intervention on caregivers of people living with chronic stroke.

## **Ethics Statement**

Institutional Review Board approval was received for the full study. All caregiving participants provided written informed consent prior to participating in the study.

## **2. Materials and Methods**

### **2.1 Design**

This was a secondary data analysis, as the primary research intervention and questions were related to fall prevention in people with chronic stroke [27]. All caregivers were invited to also attend the MY-OT fall prevention intervention; this current study was a mixed-methods study exploring the experience of the informal caregivers who attended the intervention. We included two quantitative measures, assessing caregiver burden and positive aspects of caregiving, and completed focus groups or interviews after the intervention.

### **2.2 Recruitment and participants**

People with stroke were recruited to the study via local stroke support groups, flyers, and contact lists. Thirteen people with stroke participated in the MY-OT study, individuals had to be six months post stroke, have a fear of falling, and have impaired balance [27]. The majority of stroke survivors (77%) had the stroke more than five years ago. Nine study participants identified an informal caregiver; all nine caregivers were contacted to be recruited to attend the MY-OT intervention. Caregivers then self-selected between attending the MY-OT intervention with their care recipient (n=6) or not attending the intervention (n=3). Regardless of attending MY-OT, all nine caregivers were asked to engage in data collection; seven completed assessments, eight attended the focus group, and seven completed the interview, therefore each provided written informed consent prior to participating in the study.

### **2.3 Intervention**

The MY-OT intervention included yoga and group OT twice a week for eight weeks and was developed to address fall prevention for people with stroke. The intervention was not designed to address caregiver outcomes, however we invited caregivers to attend the intervention and complete caregiver related outcome assessments as there is evidence that including the caregiver may be beneficial to both members of the caregiving dyad [28, 29].

Hatha yoga was led by a registered yoga teacher (RYT). The yoga protocol was a standardized progression of physical poses (asana) in sitting, standing, and supine. The yoga protocol was developed to improve balance, strength, and range of motion in lower extremities for people who have had a stroke. Yoga also included breath work (pranayama) and mantras related to stroke recovery. Guided meditation (dhyana) with relaxation was also completed at the end of each yoga session. The OT sessions were approximately 45-50 minutes and consisted group OT focusing on managing fall risks and preventing falls. The OT was led by a registered and licensed occupational therapist (OTR/L). OT sessions included education, training, and self-management techniques to mitigate future fall risks for participants. Additional MY-OT intervention details were previously published [27].

### **2.4 Procedures**

All caregivers, regardless of attending MY-OT were asked to complete the quantitative assessments and qualitative data collection in focus groups and interviews.

### 2.4.1 Quantitative data collection

Data were collected by a trained researcher using standardized assessments. Caregiver demographics such as age, race, gender, education level, and time since the care recipient’s stroke were collected. Variables of interest were caregiver burden (CGB) and positive aspects of caregiving (PAoC). These were measured using the Zarit Burden Interview (ZBI) and the Positive Aspects of Caregiving (PAoC) 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. Total potential scores range from 0-88, with the following interpretations: 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 [30]. The ZBI has been found to be a valid and reliable measure for caregivers of people who have had a stroke [31].

*Positive Aspects of Caregiving.* The PAoC is an 11-item questionnaire that uses a 1-5 rating scale (“I disagree a lot” to “I agree a lot”) where potential scores range from 1-45, with higher scores indicating greater PAoC. Caregivers rate phrases that address their mental and emotional state in relation to their caregiving role. An example of one such question is: “Providing care for my care recipient makes me feel more valued”. The phrases are constructed to represent two main constructs, ‘self-affirmation’ and ‘outlook on life’.

### 2.4.2 Qualitative data collection

Focus group and individual interview questions were developed to explore the experience of caregivers after participating in the MY-OT intervention with their care recipients. All caregiver participants were invited to participate in both focus groups and individual interviews. This interview process allowed for further understanding of the caregiver’s experience [32]. Through interviewing the participants as a group and individually, nuanced elements of each caregiver’s experience were revealed. Caregivers answered questions relating to perceived mental, 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 1). Both focus groups and individual interviews were conducted to address group and individual dynamics resulting from the intervention.

**Table 1** Sample interview questions.

Focus Group Questions	Individual Interviews
1. What changed over the last 8 weeks? Possible probes: physical, emotional, social, stress 2. Would you recommend this program to other people with stroke? Why? 3. What are the benefits of participating in this intervention in a group setting?	1. Have you seen any changes in your relationships since participating in this study? 2. Has this study had any impact on your own activities or your shared activities? 3. Tell me about how this program has impacted your care recipient? And how has it impacted you?

Focus group interviews were approximately one hour and followed the final MY-OT intervention session. The focus group was led by a trained researcher to facilitate rich, group discussion and understand the group impact of the intervention [33]. Individual interviews were scheduled within two weeks of the last intervention session and lasted between 30 to 60 minutes. Questions focused on eliciting the experience of the caregivers after participating in MY-OT.

## **2.5 Data analysis**

### **2.5.1 Quantitative data**

Quantitative data were analyzed using SPSS 23 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 (Time 1-Time 2/Time 1x100). Additionally, we examined the caregivers by groups (i.e. people who chose to attend the MY-OT intervention and people who chose not to attend).

### **2.5.2 Qualitative data**

All interviews and focus groups were audio recorded and transcribed by trained researchers. Each interview was then analyzed 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 [34]. To do this, researchers 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 [34]. To begin identifying larger themes, sub-themes were generated and organized across interviews. Researchers continued meeting to interpret findings, discuss potential final themes, and ground themes in the data. Finally, researchers collaborated until consensus was reached regarding final themes. Nvivo 11 software (QSR International, Melbourne, Australia) was used to support qualitative analyses.

To provide trustworthiness and credibility, further methods for rigor include research triangulation and individual researcher positioning [35]. The method for triangulation occurred through individual coding, meetings to discuss the evolution of coding schemes, and the end-result of consensus regarding coding each unit of meaning. Throughout the analyzation process, an audit trail was recorded by each researcher.

## **3. Results**

### **3.1 Findings**

The average age of caregivers was 64.86 years old and most caregivers were female (66%). See Table 2 for additional demographic data. Three caregivers chose not to participate in the intervention for the following reasons: chose to use the time to run errands; chose to use the time to read or other leisure activity; and wanted the husband with stroke to have an independent

activity where she (caregiver) was not attending to him. On average, the remaining six caregivers attended 12±2.8 of the MY-OT sessions. All nine caregivers were invited to participate in data collection, eight caregivers participated in the focus group and 7 individual interviews were conducted.

**Table 2** Caregiver characteristics (n=9).

Variable	Total
Age (mean (SD)) (n=7)*	64.86 (4.59)
Gender (female)	6 (66%)
Race (Caucasian)	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%. In contrast, for those who did not attend, 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 3. Caregivers who did not attend MY-OT stated that they used the four hours a week for various activities, such as: shopping, reading, and running errands.

**Table 3** Change for CBG and PAoC.

Variable	Pre: Mean (SD)	Post: Mean (SD)	Percent Change
CGB: MY-OT (n=4)	32.23 (18.75)	17.00 (12.49)	↓47%
CGB: Respite (n=3)	32.00 (12.36)	31.25 (12.31)	↓2%
PAoC: MY-OT (n=4)	28.33 (4.62)	35.67 (3.78)	↑26%
PAoC: Respite (n=3)	34.67 (7.10)	33.25 (6.34)	↓4%

\*CGB = Caregiver Burden; PAoC = Positive Aspects of Caregiving

### 3.2 Major themes

#### 3.2.1 "A huge change"

Caregivers who did not attend MY-OT reflected no specific changes in their relationships. However, caregivers who did attend noted multiple changes within their daily lives, for both the caregiver and the care recipient. Caregivers who attended MY-OT found themselves feeling less stressed, laughing more, and spending greater quality time with their care recipient. They also found the dedicated time together contributed to 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 after the intervention. For example, a caregiver stated:

*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!" [laughs] 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...*

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 after the MY-OT intervention. Caregivers who attended MY-OT also said that their care recipients would initiate more activities, such as taking walks or attending social events and that the dyad felt inspired to try more new things (e.g. going on vacation, attending yoga in the community). Caregivers stated that these changes added a new, positive dimension to their daily life. Participating in the intervention did appear to increase the caregiver's responsibility in some areas, such as driving. For example, caregivers who chose not to participate in the intervention noted an increase in burden through driving their care recipient to the intervention which sometimes interfered with their own planned activities. Supporting this finding, a 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.*

While physical and cognitive changes were mainly seen in care recipients, these changes likely influenced the type and quality of care the caregivers provided outside of the intervention. Several caregivers reported observing care recipient improvements in balance, endurance, alertness, vision, and speech. Caregivers indicated that these changes allowed the care recipients to engage in more activities for longer periods of time, raised spirits, and provided the caregiving dyad with options to participate in activities in the future. One caregiver who attended MY-OT reported feeling less pain due to rheumatoid arthritis. These experiences suggest that participating in MY-OT contributed to changes that allowed caregivers and care recipients to participate more fully in their daily lives.

### **3.2.2 I'm in the present**

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

Caregivers also report their own reduced stress levels, less worry, raised spirits, and enjoyment in having something new to do. This likely relates to participating in yoga which taught awareness of being in the present moment. For example, one caregiver stated:

*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 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.*

Caregivers frequently mentioned seeing what they once thought of as negative experience as now 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. This was illustrated when she states:

*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 recipients' gained positively influenced their interactions with each other. After participating in the MY-OT intervention, the dyad experienced changes in perspective which positively influenced the choices they make in their daily life.

### **3.2.3 I learned so much**

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 the care recipients' perspective as well as new information by listening to the care recipients' answers and observing them interact with other people. This carried over into daily life as is illustrated by the following statement:

*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 ... 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 due to the information [OT], 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.

All caregivers reported learning new information regarding fall prevention management and how to engage in yoga. However, caregivers who did not attend the intervention 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. For example,

*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 it was really beneficial for me to hear how people worked around those situations [uh huh] and how they're stroke symptoms affected them...*

All 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'. Caregivers who attended MY-OT reported that by learning how to safely participate in yoga, they were given a new coping tool that they could integrate into the dyad's daily life. By learning this new information, caregivers stated they felt relief at understanding the bigger picture of living with stroke. Learning new information, even years after the onset of stroke, was a valuable experience for caregivers. For caregivers who attended the MY-OT intervention, they learned new strategies, how to apply those strategies, and were able to make sense of the 'bigger picture' of living with stroke.

#### **3.2.4 There are other people out there**

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. 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. For example, one caregiver stated:

*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.*

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.

Caregivers who attended the intervention reported that the supportive atmosphere and the experience of the professionals involved was very important. Those who attended were provided with materials, given coffee, and were invited to sit in the fall prevention OT group. They reported feeling welcome and included in the study. They also stated that learning therapeutic information in a community setting provided a supportive learning environment. This was discussed by a caregiver:

*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.*

Thus, by providing a supportive social environment, caregiver's reported greater feelings of well-being, social growth and opportunities for learning.

#### **4. Discussion**

The aim of this study was to examine changes in caregiver burden, positive aspects of caring, and caregiver's experiences after participating in the MY-OT intervention. Like in previous studies, we found that the caregiving role leads to high levels of caregiver burden [36, 37]. When reflecting on the time prior to the intervention, caregivers demonstrated strained relationships, decreased participation in valued activities and reduced physical activity [21]. Interestingly, caregivers who did not attend the MY-OT intervention saw little to no change in caregiver burden or positive aspects of caregiving. However, those who participated, saw a marked improvement in both areas. Our findings were consistent with the Mackenzie and Greenwood (8) systematic review of positive experiences of caregiving in stroke, where positive coping skills, in this case learned through yoga and self-management, were linked to increased positive experiences in caregiving. This suggests that multimodal interventions, such as MY-OT, can be used to target changes in caregiver burden and positive aspects of caring.

By qualitatively examining caregiver's experiences, we showed that positive experiences for caregivers can be garnered through specific interventions. After participating in MY-OT, caregivers reported many positive changes related to information gathering, a change in perspective, coping skills, and supportive environments. While all caregivers reported learning new, pragmatic information, those who attended MY-OT reported experiencing more complex and robust modes of learning. For example, 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. We also found that caregivers experienced a change in perspective potentially leading to greater feelings of hope and gratitude. Additionally, after MY-OT, caregivers reported improved coping strategies, feeling less stress, more flexibility, and a shift in awareness; this is consistent with outcomes found in yoga research [16, 38, 39]. These positive outcomes are possibly due to the multi-modal approach of using yoga and OT together to address individual and group needs. Consistent with previous research, our findings also show that skill-building, education and training, supportive social environments, a collaborative health care team and positive lifestyle changes were of value to caregivers [40, 41]. Furthermore, a sense of community was important to build trust between healthcare professionals and the caregiving dyad, potentially leading to greater learning opportunities. These findings suggest that interventions targeting the caregiving dyad may provide an opportunity to meet multiple needs for both individuals across their continuum of care.

Multiple researchers recommend providing interventions for caregivers throughout the continuum of care [42] as needs change based on severity of the care recipients' stroke symptoms and ability to engage in daily activities. MY-OT, a program that could someday be provided in a community setting, may provide social supports, provide access to health professionals and teach techniques for self-management in the caregiving dyad's daily life [13]. Perhaps it is most relevant to develop and test interventions that simultaneously address the needs of both individuals in the caregiving dyad. Limited dyad intervention research has been completed, and is mostly limited to care recipients with dementia, but dyad-based interventions appear to be feasible and beneficial to both members of the dyad [28, 29]. A dyadic may have greater effects than other interventions due to a focus on dyadic interactions. Outcomes may be greater in dyad interventions, because care recipients' adherence increases when individuals engage in an intervention together [28] and when both members provide social support to each other [43, 44]. Our study provides preliminary evidence that using yoga in conjunction with OT led self-management groups creates positive experiences by addressing psychosocial, physical, and learning needs for both members in they dyad. Additionally, we learned the importance of providing a venue for increased socialization through a group intervention, likely to be an important piece of future intervention development. These experiences may mitigate the effects of caregiver burden and provide opportunities for positive change in daily life for both the caregiver and the care recipient many years after the stroke occurs.

#### **4.1 Limitations**

As with all studies, limitations exist. The primary limitation in this study is that the intervention was initially created as a fall prevention program for people with stroke, and not the caregivers. However, the data collected shows that involving caregivers in the intervention was still greatly informative and beneficial for caregivers. Future studies should focus on creating interventions targeting both the caregiver and the care recipient together [4]. Another limitation is that we cannot say what part of the intervention 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. Other limitations include a non-blinded assessor and no control group, limited sample, homogeneity of race, education levels, and gender. The very small sample

size does not allow for true conclusions to be made; however appears to provide a first glimpse into the caregiver experience for this type of merged intervention. 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.

#### **4.2 Future research**

As previously mentioned, future studies should look at group OT and yoga for caregivers and care recipients together across populations. This may allow for a wider range of assessments and data collection as well as adapting the intervention to the needs of the individuals. Likewise, a continued focus on programs for caregiving dyads are still needed [45]. Caregivers and care recipients require different types of information and instruction beyond information provided in the acute phase of stroke. It is possible that OT led education and self-management groups combined with yoga may be beneficial following completion of stroke related outpatient therapies. We also recommend 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 throughout the study, 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, such as during the outpatient phase of recovery, may prevent unwarranted difficulties later in the process (information about falls and fatigue, reduction of isolation, opportunities for health and wellness). Additionally, it will be necessary to complete a larger randomized controlled trial to better understand the impact of the yoga and occupational therapy intervention versus a social group or other controlled intervention.

#### **4.3 Clinical implications**

Professionals working with caregiver dyads are advised to provide client- and family-centered interventions, which involve the caregiver, to best address the needs of the dyad and improve quality of care. We recommend professionals take a strengths-based approach to build positive experiences for the caregiver which can bolster feelings of hope, improve quality of life, change negative perceptions, and affect positive change within the caregiving relationship. There continues to be a need for targeted intervention and education with this population. Specifically, OT led groups and yoga together may be a powerful tool for affecting positive physical and emotional change, providing stress relief, teaching management skills, and providing coping tools for the dyad.

#### **5. Conclusions**

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. 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 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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### **Author Contributions**

Schmid, Hinsey, Bolster were all involved in the intervention and in data collection. All authors were involved in development of focus groups questions and choice of assessments. Hinsey, Adler, Fruhauf, and Schmid were all involved in qualitative data analyses. Schmid, Hinsey, and Van Puymbroeck were involved in quantitative analyses. All authors were involved in writing and reviewing the manuscript.

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### **Competing Interests**

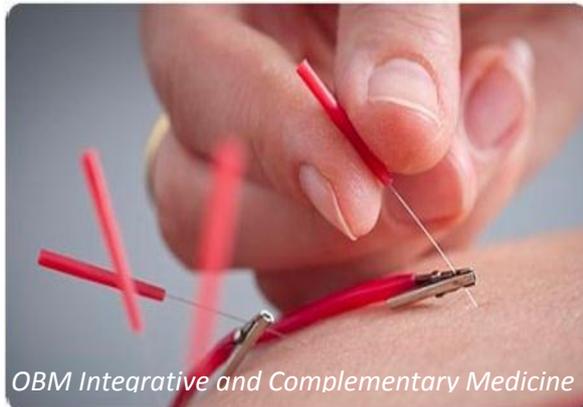
The authors have declared that no competing interests exist.

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