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## Perspectives on Adaptation in a Stroke Self-Management Program: A Multiple Case Study

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# Perspectives on Adaptation in a Stroke Self-Management Program: A Multiple Case Study

## Abstract

*Background:* Occupational Adaptation occurs when a person develops a response to meet an occupational challenge. This process is disrupted when a person experiences a life altering event, such as stroke. Stroke self-management programs equip persons with stroke with education and skills to manage the daily tasks associated with their condition. Few studies have explored the adaptive process survivors experience as they seek to effectively use the tools provided through stroke self-management programs. The objective was to explore the adaptive process of three individuals following participation in a stroke self-management program.

*Method:* A multiple case study design was used. Three participants completed an interview focused on their adaptive experiences as they learned to self-manage personal stroke risk factors. Each case study interview was analyzed to identify themes across cases.

*Results:* Four themes were identified: (a) knowledge acquisition to generate an adaptive response, (b) behavioral change and adjustment in routines, (c) increased proactivity and personal responsibility and, (d) evaluating the adaptive response-Physiological and emotional changes in health.

*Conclusion:* The participants' increased awareness and understanding of personal stroke risk factors facilitated the adaptive process, which resulted in increased efficiency, effectiveness, satisfaction, and engagement in health promoting behavior to self-manage their stroke condition.

## Keywords

chronic conditions, health promotion, lifestyle management, occupational adaptation, occupational therapy, secondary prevention

## Cover Page Footnote

Author's Note Riqiea F. Kitchens ORCID ID: 0000-0002-1184-4175 Gayle Hersch ORCID ID: 0000-0001-7120-9950 Wayne Brewer ORCID ID: 0000-0002-4841-5454 Marsha Neville ORCID ID: 0000-0002-7945-8924 Conflicts of Interest: None declared. Research Ethics and Patient Consent: This study was approved through the Institutional Review Boards at Harris Health System and Texas Woman's University. IRB Protocol Number: TWU 19675 (eProtocol 17-08-1735) Correspondence concerning this article should be addressed to Riqiea F. Kitchens, 301 University Boulevard Galveston, TX 77555-1142. E-mail: rikitch@utmb.edu Acknowledgements The authors wish to thank the rehabilitation team at Quentin Mease Hospital and Harris Health System for supporting this program. In addition, we are grateful to each survivor for sharing their personal experiences of life after stroke. Portions of this study were accepted for poster presentation at the 2020 AOTA Conference in Boston, MA [conference cancelled].

## Credentials Display

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Stroke is a leading cause of long-term disability in the United States (Centers for Disease Control and Prevention, 2020). Persons with stroke (PWS) may experience residual effects that include changes in physical, cognitive, and emotional abilities that result in loss of roles, increased burden of care, and decreased quality of life (Mellon et al., 2015; Rangel et al., 2013). These changes are often chronic and result in the need for survivors to adapt to new ways of living, coping, and being. PWS may encounter difficulty adapting to these changes, which may lead to decreased participation in desired activities, slower recovery, and further deterioration in their condition, potentially increasing the risk of a recurrent stroke. Recurrent stroke occurs in 1:4 persons who have had a stroke (Tsao et al., 2022). Persons who have multiple risk factors, such as hypertension, diabetes, hyperlipidemia, or obesity, are at even greater risk of having another stroke (Tsao et al., 2022).

The United States Healthy People 2030 Initiative suggests that the risk of developing and dying from cardiovascular diseases, such as stroke, can be significantly decreased. Ways to decrease these risks include addressing and modifying lifestyle factors, including diet, physical activity, controlling blood pressure and cholesterol intake, and smoking cessation (U.S. Department of Health and Human Services, 2023). Self-management education uses a comprehensive approach to promote lifestyle changes necessary to improve an individual's overall health. Self-management interventions facilitate change through education, behavioral change principles, and experiential learning. By engaging individuals in health-promoting activities and/or occupations, self-management interventions address the multiple factors that can impact people living with chronic disease with the goal of improving health and minimizing complications from the condition. Lorig and Holman (2003) identified five core self-management skills: problem-solving, decision-making, resource utilization, forming partnerships with health care providers, and making and implementing an action plan. Stroke self-management programs (SSMPs) incorporate self-management strategies tailored to the needs of PWS. These programs have benefited PWS in areas of activities of daily living and occupational participation (Lee et al., 2017), utilization of resources (Damush et al., 2011), self-efficacy, and quality of life (Fryer et al., 2016). This study aimed to expand on this literature by exploring the adaptive processes of PWS who participated in SSMPs. The authors believed that participation in SSMPs with an emphasis on adaptation could result in a change in health behaviors and influence stroke risk factor modification.

Healthy H.E.A.R.T.s is a weekly 12-week SSMP that was adapted and expanded from principles of the Chronic Disease Self-Management Program (Lorig et al., 2001). Patients in this outpatient program attended weekly 1.5-hr in-person sessions co-facilitated by an occupational therapist and physical therapist. The program content focused on developing and using skills to self-manage medical issues; role responsibilities, including participation in desired occupations; and the emotional needs of clients following a stroke. The program educated and equipped patients with five self-management skills: problem-solving, decision-making, resource utilization, communication with health care providers, and goal setting. These skills were integrated throughout the program as patients received stroke-specific education and were encouraged to engage in health-promoting activities, such as exercise modification, risk factor management and modification, healthy coping strategies, healthy nutrition, and weekly health-related goal setting. The structure of the program is described in Kitchens (2018). The benefits of program participation have included positive changes in self-reported lifestyle modifications in physical activity, nutrition, and health responsibility (Kitchens et al., 2016).

The Theory of Occupational Adaptation (OA) posits that adaptation is an internal, naturally occurring process experienced by individuals to meet occupational challenges. Engagement in occupations is the means used to facilitate the adaptive process. The adaptive process involves the interaction between the person, the occupational environment, and the task demands. When an individual encounters an occupational challenge, the individual will generate a response to meet the challenge. The response can be maladaptive, such as using an unhealthy coping mechanism in a stressful situation. Conversely, the response can be adaptive, such as employing stress management techniques when encountering stressful situations. The ability to generate a successful response can be impacted by physical, mental, and emotional impairments or stressful life events, such as experiencing a stroke. OA-focused interventions attempt to increase the client's adaptive abilities, assuming that increased adaptability promotes improved function to engage in one's desired activities (Cole & Tufano, 2020). Successful OA is measured by the individual's ability to achieve the desired goal effectively (effectiveness), to use available resources efficiently (efficiency), and to obtain an optimal level of satisfaction in the performance of their desired occupations (satisfaction). The Theory of OA has been applied and found appropriate for PWS (Gibson & Schkade, 1997; Williams & Murray, 2013). However, it has not been applied in the context of SSMPs. Consequently, this study aimed to understand the individual's perspectives following participation in a SSMP in which adaptation of lifestyle and behavior after stroke is promoted.

This research sought to explore the effects of a self-management program with a sample of PWS to identify factors that support or hinder the adaptive process of making lifestyle changes and behavioral modifications to improve overall health.

The study addressed the following questions:

1. How did participating in a SSMP influence a person's adaptive process to perform their chosen occupations?
2. How was the desire to improve personal control and self-management affected during participation in a SSMP?
3. How were efficiency, effectiveness, and satisfaction in the performance of chosen occupations perceived and affected by SSMP participation?

### **Method**

The Institutional Review Boards at Harris Health System and Texas Woman's University approved this study. The study occurred in an outpatient hospital located in a large community-owned hospital system in Houston, TX, USA. This hospital system provides services to a traditionally medically underserved population, and most patients served are classified as uninsured or self-pay (54.1%) (Harris Health, 2020).

### **Design**

A holistic, literal, multiple-case design was used for this study. As Yin described (2018), multiple case studies provide robust information to strengthen study results. Literal replications were used, as the study conditions for each case were the same, and similar results were expected for each case. For literal replications, 2–3 cases are recommended (Yin, 2018), and this guided the selection of participants for this study. Each participant was treated as a holistic single case with one area of interest, OA. This design sought to understand how OA occurred in each individual to explore the adaptive process.

### **Recruitment**

Participants were selected from the pool of all participants who had completed the SSMP during between July 2016–June 2017 (N = 17). Inclusion criteria included males or females at least 18 years of

age or older, a history of ischemic or hemorrhagic stroke, and at least 6 months post-stroke onset. In addition, the participants needed to speak and understand English, as this was the primary language of the lead researcher. The participants' cognitive and communication status to participate in an interview were also considered. Cognitive and communication status was gathered through documentation of standardized or non-standardized measures reported in the medical record. When the information available in the medical record was not available or insufficient to determine the client's status, additional data were gathered from recommendations from the referring provider, related health care providers (e.g., speech-language pathologist), and the clinical judgment of the primary researcher to determine the participant's appropriateness for this study. Exclusion criteria were moderate to severe aphasia with an inability to complete the interview as determined by documentation in the medical record and clinical recommendations from the referring health providers. Nine survivors met the inclusion criteria and were invited to participate in the study. Two survivors did not participate because of scheduling conflicts, and two survivors could not be contacted. Five PWS were eligible to participate, and three individuals were included in this study based on the breadth and depth of their lived experience with stroke. Informed consent was obtained for each of the participants before the interview.

### **Procedures**

Each participant was invited to complete an individual interview with the primary researcher. At the participant's request, caregivers were permitted to be present and contribute during the interview if they were present during the SSMP.

An in-depth interview was the primary source of data collection. An interview guide containing 12 open-ended questions was developed. The questions focused on understanding each participant's OA process, feelings of effectiveness, efficiency, and satisfaction. In addition, the participants were asked how they applied the self-management skills in their daily lives following SSMP participation. Finally, the questions explored feelings of perceived confidence regarding understanding and self-managing their stroke condition. The authors reviewed, refined, and agreed on the questions before the interview. Follow-up questions and/or probes were offered as needed to clarify any statements and derive the most meaningful reflections and responses from the participants. All interviews were audio-recorded with the participant's consent. Additional data were collected using a notebook to record observations during and after the interview to include the presence of companions, tone of conversation, participant demeanor, and the primary researcher's reflections at the conclusion of the interview. The length of each interview ranged between 45 to 75 min.

### **Data Analysis**

A descriptive framework was used to organize the data for analysis. Each participant was assigned a pseudonym prior to data analysis to ensure confidentiality. Qualitative methods were employed to analyze the participant interviews. Each interview was transcribed verbatim and coded by the primary researcher and two trained independent coders with expertise in coding qualitative data. Pattern coding, a technique used to identify repetitions in the data, was also used. Additional codes were added as they emerged from the interviews. In addition, the researcher used coding notes to capture thoughts and ideas about the themes that emerged from the interview transcripts. The list of codes from the participants was compiled and reviewed by the independent coders for clarity and consistency. The data were then refined to develop categories. Themes were identified in each case and then across cases. Quotes from the participant interviews were extracted to support each of the themes.

We used the following techniques to ensure the trustworthiness of the data: thick description, the use of multiple coders, reflective journaling, and the use of an audit trail. Thick description was used to provide rich, detailed, and specific information about each participant, giving additional meaning to the person's context. Using multiple coders during the data analysis process strengthened the reliability of the results. Reflective journaling acknowledged thoughts, feelings, and emotions experienced during the research process and improved transparency. An audit trail described each step of the research process and added rigor to the findings.

## Results

### Case Descriptions

Kevin, a 59-year-old male, experienced a stroke resulting in left hemiparesis. His stroke risk factors included hypertension and type 2 diabetes. As a result, Kevin was unable to remain employed, participate in exercises, and had difficulty managing his medications and nutritional habits. His goals for SSMP participation were to increase knowledge about his personal stroke risk factors, improve his symptom and condition management, and learn how to engage safely in physical activity post stroke.

Hannah, a 49-year-old female, experienced three strokes prior to participating in the SSMP. Her stroke risk factors included type 2 diabetes, hypertension, morbid obesity, physical inactivity, previous history of strokes, and being a former smoker. The strokes affected her short-term memory and resulted in the need to use compensatory techniques and caused loss of employment and the need for a full-time, live-in caregiver to complete her daily activities. Hannah's goal was to learn how to improve her nutrition management; symptom and condition management, specifically her diabetes condition; and engage in meal preparation to decrease her risk of having another stroke. Hannah's caregiver was very involved with her care and actively participated in the SSMP and the interview.

Michael, a 53-year-old male, experienced a stroke caused by uncontrolled hypertension. As a result, he experienced partial right hemiparesis that decreased his effectiveness and efficiency with his activities of daily living. A cook by vocation, Michael's goals for SSMP participation were to improve his nutrition management, meal preparation, and coping strategies; better manage his comorbid conditions of hypertension, hyperlipidemia, and smoking risk factors; and identify productive leisure occupations (see Table 1 for demographic information).

**Table 1**  
*Demographic Information*

Name	Gender	Stroke Onset	Age*	Race	Edu.	MarSta	Lvn Status	Yrly Income	Ins. Cov.
Kevin	Male	2015	59	NA/L	College degree	Single	Lives alone	\$12,001-\$20,000	None/ self-pay
Hannah	Female	2005, 2015 x2	49	W	College degree	Divorced	Lives with friend	< \$12,000	None/ self-pay
Michael	Male	2016	53	AA	Some college	Widowed	Lives alone	< \$12,000	None/ self-pay

*Note.* \*Age at time of interview. NA = Native American, W = White, AA = African-American, L = Latino, Edu = Education, MarSta = Marital Status, Lvn = living, Ins. Cov. = Insurance Coverage.

## Themes

Four themes emerged from the analysis across cases: (a) knowledge acquisition, (b) behavioral change and adjustment in routines, (c) increased proactivity and personal responsibility, and (d) physiological and emotional changes in health (see Table 2).

**Table 2**

*Overall Qualitative Themes*

Themes	Illustration
Knowledge acquisition to generate an adaptive response	“There was a lot of stuff I learned in that class that I’d never known before.” – Hannah
Behavioral change and adjustment in routines	“It’s become part of our routine. You know, to check blood pressure, to figure out, plan what we’re gonna eat . . . much better at picking our foods.” – Hannah
Increased proactivity and personal responsibility	“I feel like I have more control in um, my choices that I pick, and how they affect my body.” – Kevin
Evaluating the Adaptive Response -Physiological and Emotional Changes in Health	“I have more energy. My stress level is way down here.” – Michael

### Theme 1: Knowledge Acquisition to Generate an Adaptive Response

All of the participants reported that before participating in the SSMP, they did not know much about stroke and how it would affect them. Each person acknowledged an increased awareness and understanding of their health and personal risk factors for stroke following SSMP participation. Hannah stated, “There was a lot of stuff I learned in that class that I’d never known before.”

Kevin echoed these feelings and reported, “I started paying more attention to what I was doing when I was eating.” In addition, Michael stated, “I pay more attention now to the things I do now than I did before my stroke” (Michael). This newly acquired knowledge from SSMP participation helped the participants use self-management skills and increased their confidence in self-managing their stroke condition.

The increase in the participants’ stroke knowledge and awareness of their personal risk factors helped them to master components of self-management, including problem-solving, decision-making, communicating with health care providers, and sharing learned information. Kevin, Hannah, and Michael specifically discussed their experiences with their health care providers. They reported increased adherence to attending scheduled medical appointments, increased comfort in asking questions of their health care providers, and a greater ability to understand the information provided during their health care visits.

### Theme 2: Behavioral Change and Adjustment in Routines

Each participant reported a desire to make changes in at least one aspect of their health because of the information learned in the SSMP. Behavioral changes, such as self-monitoring vitals, medication adherence, nutrition changes, and coping and stress management, were reported.

The participants reported an increase in monitoring their blood pressure, blood glucose (if diabetic), and energy expenditure during exercise as a regular part of their routine following SSMP participation. Medication adherence was a challenge for Kevin before participating in the SSMP. He reported increased adherence to his medication regimen following class participation. Kevin discussed this change as he described the struggle prior to class participation: “I was kinda dragging my feet, you know? Cause I was getting tired of taking them. And now I’m not tired of taking ‘em. I know it’s gonna make me feel better.”



Nutritional changes were important for all of the participants following the program. Removing unhealthy foods and increasing consumption of healthier foods were strategies used by Michael. He reported decreased coffee and soda intake and increased fruit and water intake as a way to manage his comorbid conditions.

Kevin and Hannah adopted food substitutions and portion size monitoring as strategies to improve their nutritional habits. Kevin discussed how he managed his portion sizes when he reported that “Instead of eating like two or three hamburgers . . . I just eat one hamburger, and that’s it.” Hannah reported that she monitored her food portions, stating,

Serving sizes, which before sometimes you look on the back of a bottle and you see the fat or the sugar content, and that’s all I would only look at and then eat all of it or drink all of it and not realize it was more than one serving, you really have no idea if you’re not measuring it.

The participants also reported changes in their response to social and psychological stressors present in their respective environments following SSMP participation. Kevin discussed how he became aware that stress was affecting him and described how he adapted his response to stress by taking walks or watching TV. Michael adopted new coping mechanisms, reporting, “I don’t get angry anymore, I don’t let nobody stress me out. Cause stress what causes, I think, stress and alcohol cause me to have my stroke.”

### **Theme 3: Increased Proactivity and Personal Responsibility**

Each participant reported taking a more active role in their health in at least one area that contributed to decreasing their stroke risk. The participants reported responding to occupational challenges in new ways that included maintaining a regular exercise regimen, using social support to promote health, and finding or resuming productive occupations.

#### ***Subtheme: “Without Exercise, You Just Fall Back into Your Same Routine”***

All of the participants discussed how they began or adjusted their exercise routines because of what they learned in the class. Kevin began using the exercise equipment and pool at a local community center and incorporated some of the exercise modifications learned in the SSMP. Regarding the effects of exercise on health, Hannah reported, “With the exercise, I was surprised that your blood pressure actually goes down.”

#### ***Subtheme: Social Support***

The presence or absence of social support and its impact on the participants’ mental, emotional, and social health after stroke was also discussed. Hannah had a caregiver who was actively involved in the interview. Aspects of socialization were discussed as being either stressful or used as a coping mechanism to manage their health and adjust to life after stroke. Michael identified that his sister encouraged him and kept him on track with monitoring himself. He also discussed how he changed his social environment to keep his stress level low: “If I’m around you, and I don’t like the way I’m feeling around you, and it’s . . . I stay away from stress. I stay away from drama.”

#### ***Subtheme: Discovering or Resuming Occupations***

Some of the participants discovered or resumed preferred occupations and/or leisure interests to manage their health in positive ways. Michael discovered new hobbies, such as gardening, cooking, and sketching, as a means to stay productive. His role as a grandfather also gave him motivation to take steps to better manage his health.

#### **Theme 4: Evaluating the Adaptive Response - Physiological and Emotional Changes in Health**

Several of the participants reported favorable health outcomes, such as decreased blood pressure readings, decreased blood sugar readings, and weight loss, as they became more effective and efficient in self-managing aspects of their health. Hannah reported decreased insulin dosages as a result of her improved control of her diabetes following the class participation. She reported, “It’s made my blood sugar come down; they’ve lowered my insulin down some.” She went on to say, “I feel more confident in making food choices and portion control, definitely.”

Michael discussed the emotional effects and change in perspective experienced because of SSMP participation. He reported, “Having this stroke, it really, psychologically and physically it, it tore me down a lot.” Michael continued, “I made up my mind that I’m not gone let this beat me and I’m not gone let this beat me up.” He reported feeling more patient with himself and having more control over his health choices and his environment.

Kevin’s health outcomes included reported weight loss and improved A1c readings during his physician’s visits, which were a result of changes in his nutrition, physical activity, and medication adherence. When asked about his satisfaction with his health and ability to implement and maintain healthy lifestyle changes following his participation in the Healthy H.E.A.R.T.s class, he reported, “I’m real happy with myself now.”

#### **Discussion**

This study explored the adaptive process of three PWS following participation in a community-based SSMP. Based on current stroke literature, this study is the first to explore self-management through an OA lens in a stroke population. Across cases, the participants experienced challenges in the areas of medication management, nutrition management, meal preparation, engagement in productive leisure occupations, and physical activity. Using theory-based self-management interventions helped to support the clients as they increased self-efficacy and independence in self-managing their occupations and life roles. These findings are aligned with the outcomes described by Lau et al. (2022). The OA process was evident as the participants adapted their behaviors, perceptions, and routines to manage and modify their stroke risk factors in more effective, efficient, and satisfactory ways. Each participant experienced a level of adaptation necessary to self-manage at least one aspect of his or her stroke-related health.

Packer (2011) recognized a need to focus on occupations in self-management programs. This need was strengthened in this study as the engagement in preferred occupations and the presence of social support helped support goal achievement. Kevin used the knowledge gained in the SSMP to participate in a modified physical activity program, adapt his nutritional habits, and adjust his medication routine to improve adherence. Hannah, who, prior to participating in the SSMP, had a maladaptive response to nutrition management, was able to use the knowledge and tools offered in the SSMP to generate an adaptive response to engage successfully in nutrition management and meal preparation. Hannah’s changes resulted in a significant improvement in the management of her comorbid diabetic condition. Michael used the occupations of productive leisure, nutrition management, and meal preparation to adapt to his social environment, improve his emotional health, and improve self-management of his comorbid health conditions. The use of meaningful occupations in a self-management context supports the role of occupational therapy in the delivery of self-management programs and supports findings reported by O’Toole et al. (2013). In addition, Pearce et al. (2015) expressed a need to address the social and emotional aspects of stroke, and this study provided evidence that the SSMP structure can support stroke survivors in this aspect.

## Limitations

The number of cases selected for this study was small; however, each case was thoroughly explored and carefully selected to provide diversity in the participants' health backgrounds, demographics, and SSMP experiences. While each participant experienced a level of OA, some continued to have challenges. Hannah shared that despite her efforts to change her eating patterns and adhere to her medication and exercise regimen, she experienced another stroke after SSMP participation. Despite this setback, Hannah reported that she continued to use the tools acquired from the SSMP to help maintain her health and felt more informed about her health when communicating with her health care provider. Hannah's caregiver elaborated on the behavioral changes she had observed with Hannah by stating that she was:

Settling into what and who you had become, I think. And then after the program, you thought, well, I can make a difference, I can change some things . . . made you realize that, you know, you can control some of this.

The SSMP elements the participants reported as motivating factors in the adaptive process included the program facilitators, the SSMP structure, and the session delivery, which provided a safe space for experiential learning.

The primary author for this study served as the facilitator of the SSMP and, for several of the participants, was the primary occupational therapist for their outpatient rehabilitation before entering the SSMP. During the researcher's extended time with these participants, she established a therapeutic relationship with the participants, their families, and their caregivers. This served as a benefit to the study, as she had earned the participants' trust and, as a result, the participants were willing to share their personal struggles and successes adapting to life after experiencing a stroke. This also allowed the researcher to observe the participants' growth from the early stages of their recovery following stroke and observe and support their transition into the Healthy H.E.A.R.T.s SSMP as they learned how to manage and cope with life after stroke. However, this extended period of exposure may present a bias to overestimate or underestimate the progress of the participants.

A significant discovery in the study is that while the participants received the same information in the SSMP, each participant selected different components of self-management on which to focus. This speaks to the comprehensiveness of the SSMP and the benefits of tailoring the program to address the specific needs of stroke survivors. Occupational therapists have a role in using meaningful occupations to support the OA of stroke survivors with SSMPs to improve overall health, well-being, and self-efficacy. This study offers several opportunities for future research. Future studies could incorporate quantitative measures to assess if the participants' reported improvements are reflected through objective measures. In addition, further exploration of the impact of SSMPs in different settings is needed. Finally, more research is needed to identify additional occupations that can be supported in the stroke self-management context. As interest in SSMPs grows, it is imperative to identify tangible and meaningful ways to support participants as they adapt to life after stroke.

## Conclusion

This study described the experiences of three PWS following participation in a structured SSMP. The study findings suggest that participation in community-based SSMPs can facilitate the adaptive process, increase participation in health-promoting behaviors, facilitate positive changes in habits and

routines, and improve personal responsibility to mitigate stroke risk factors. Stroke self-management provides a comprehensive approach to addressing the complex needs of PWS. Occupational therapists can use SSMPs as part of the care plan to equip PWS with the essential skills necessary to maintain healthy, productive, and meaningful lives following a stroke.

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