A Manual for Occupational Therapy Student-Run Wellness Program Targeting Persons with Chronic Stroke

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Project Chair
Sue Doyle PhD OTR/L CFE

Director, Occupational Therapy Program
Yvonne Swinth PhD OTR/L FAOTA

Dean of Graduate Studies
Sunil Kukreja, PhD
Abstract

It is not uncommon for stroke survivors to encounter a number of mental and physical barriers that impede on their ability to engage in everyday occupations. In order for these individuals to successfully live a meaningful lifestyle, it is necessary that they be educated on how to use their resources and re-integrate themselves back into the community. Participation in group interventions aimed at increasing self-management skills has been effective for persons with other chronic diseases and show potential to increase overall wellness and participation for those living with chronic stroke. A manual was created to educate occupational therapy students on the process of running a wellness program for persons with chronic stroke at the University of Puget Sound onsite clinic. The manual contains six modules, with directions for leaders that aid participants in regaining independence and adopting a healthier and more productive lifestyle. A pilot study was conducted to determine the usability of the manual; three students who piloted the manual running one session with stroke survivors reported increased knowledge concerning strategies that can help them effectively self-manage their chronic symptoms and maximize participation in their everyday occupations. Feedback was elicited from each participant and student leaders after modules were piloted, in order to determine overall level of satisfaction concerning the wellness program, as well as improvements to the manual and leaders guide.

Key Words: Stroke, wellness program, chronic illness self-management, student-run program
Introduction

A wellness program for individuals living with the physical and psychological symptoms of chronic stroke has the potential to make a tremendous impact on their recovery process and increase their overall level of personal satisfaction. Chronic stroke is defined as being six months or greater post-stroke (Combs-Miller et al., 2014). It is not uncommon to see persons with chronic stroke no longer receiving therapy interventions. The reasons for this may be due in part to lack of coverage by insurance, or because they have reached a point in their recovery process where they are no longer making significant progress, as measured by tools that focus on impairments versus participation. Rehabilitation in the United States tends to focus on the acute stages of stroke recovery with as little as 30.7% of survivors receiving any outpatient services (Xie et al., 2007). Participation in valued occupations and roles are often overlooked and simply not addressed during the acute stages of recovery (Wolf, Baum & Connor, 2009). A wellness program for individuals with chronic stroke has the potential to address these specific areas, as well as educate the stroke survivor regarding disease self-management skills (Schulman-Green et al., 2012; Novak, Costantini, Schneider, & Beanlands, 2013; Jones, 2006; Damush et al., 2011; Howard & Ceci, 2012). Research has shown that wellness programs created to improve health behaviors, self-efficacy, and health status are particularly beneficial to assist individuals living with a chronic illness (O'Toole, Connolly, & Smith, 2012). Therefore, it is vital that we create a program that aids individuals post-stroke in all areas of daily living, so that they will be able to re-integrate themselves back into society in the near future. By helping those with chronic stroke get back into the community and participate in their desired occupations, we are helping them enhance their overall level of participation and fulfillment in life. (Eriksson, Aasnes, Tistad, Guidetti, & von Koch, 2012).
After reviewing the literature regarding the concerns of individuals with a chronic illness, as well as interviewing an occupational therapist and a chronic stroke survivor, we have been able to identify a number of concerns among this population. There are a multitude of ongoing areas of concern for chronic stroke survivors which include, but are not limited to: a decrease in participation of valued occupations, lack of appropriate resources, social integration and community reintegration, lack of knowledge in terms of recurrent stroke prevention and stroke recovery, increased incidence of depression, higher levels of stress and anxiety, and difficulties regarding sleep, pain, and fatigue management. According to the Occupational Therapy Practice Framework Domain and Process (OTPF), all of these areas of concern fall within the domain of occupational therapy (OT) practice (American Occupational Therapy Association [AOTA], 2014). A properly designed wellness program could potentially provide a new role for occupational therapists to support those with stroke beyond the normal service delivery time frames, as well as meet some of the changes in the health care funding acts. At the same time it would address stroke survivors’ ongoing concerns, improve their levels of participation, increase quality of life, and prevent further declines in overall health status. Furthermore, a wellness program will allow for patient engagement in order to increase self-management skills post-stroke.

Background

Stoke Demographics and Etiology

In the United States, more than four million individuals currently live with the life-altering effects of stroke (University Hospital, 2013). The age of incidence is becoming younger as 34% of persons with stroke are under 65 years of age (Centers for Disease Control and Prevention [CDC], 2013). Affected individuals can experience an array of symptoms, such as...
unilateral impairment of motor control (hemiparesis), visual perceptual disturbances, cognitive impairment, incontinence, aphasia, reduced sensation, and increased safety risk (Burton, 2000; Doyle, Bennett, & Dudgeon, 2014). Not only does stroke impact a person physically, but it also impacts one’s social and emotional state (Burton, 2000). Experiencing a stroke often is associated with social isolation, disrupted and changed relationships with family and friends, financial strain, altered daily routines, and may lead to unemployment (Burton, 2000).

Additionally, sustaining a stroke can result in an individual living with uncertainty about his or her future, potentially leading to frustration, anxiety, and fear of death due to the severity of symptoms (Burton, 2000).

**Stroke and Occupations**

It is well understood in occupational therapy literature that engagement in a wide variety of occupations promotes health, participation, well-being and life satisfaction (AOTA, 2014). Living with stroke often causes a decline in terms of an individual's health by limiting their ability to participate and engage in occupations. Doyle et al. (2014) found that stroke survivors were often frustrated by the negative impact their stroke had on their leisure, work activities, and life satisfaction. Eriksson et. al, (2012) conducted a study with 161 persons with CVA. Of these participants, 87% of individuals reported ongoing occupational gaps in the areas of leisure and instrumental activities of daily living (IADL). Moreover, these gaps are limitations in an individual’s ability to participate in their chosen activities due to a level of inconsistency between what they desire to do and what they actually do (Eriksson et. al, 2012). Half of the individuals reported being unable to do three or more activities that held value to them one year following their stroke, resulting in wider occupational gaps. The study also found that the higher the number of occupational gaps were for an individual, the lower their perceived post-stroke
recovery was (Eriksson et. al, 2012). Currently, rehabilitation services focus heavily on re-engaging the individual in activities of daily living (ADLs), but falls short in helping the individual return to leisure roles, employment, community/social activities and other complex occupations (Wolf et al., 2009).

**Gaps in Stroke Rehabilitation**

The current medical and rehabilitation health care system may be inadequate for meeting the needs of the stroke survivor community, especially those with milder CVA. A cohort study by Wolf et al. (2009) followed 7,740 participants with stroke over nine years to learn how the needs and impairments stroke survivors face are changing. The study showed that due to improvements in medicinal care, the overall severity of stroke has decreased, with approximately 82% of the stroke survivors classified as having experienced a mild or moderate stroke. Of these individuals, 71% were given minimal to no rehabilitation services. Wolf et al. (2009) concluded that one reason may be due to the fact that current stroke outcome measures do not identify the concerns related to participation that this group experiences. The current outcome measures are focused narrowly on impairments and basic ADLS, detecting whether or not the patient is mobile, completes toilet transfers, can perform basic ADLs, and experiences aphasia and/or neglect. These measures frequently fail to identify the broader areas of participation deficits in valued roles, employment or in other complex occupations beyond basic ADLs. The narrow lens of current outcome measures used for stroke survivors does not consider the complexity of all of human occupation. The participants in the above study were considered independent in self-care and were discharged home. However, the stroke survivors were unsuccessful in reintegrating back into their former everyday lives, likely in part because their rehabilitation did not address their community, social, work, driving or participation needs (Wolf et al., 2009). Rehabilitation
services need to expand beyond ADLs to include employment services, social and community participation, and potentially roles such as being a parent, to improve stroke survivors overall perception of recovery.

Another limitation of the current stroke rehabilitation system is a lack of understanding among the stroke survivor community regarding how to prevent a recurrent, or secondary stroke (Bendz, 2003; Clark & Sharma, 2013; Schmid, Butterbaugh, Egolf, Richards & Williams, 2008; White, Magin & Pollack, 2009). The American Heart Association estimates that out of the 700,000 CVAs that occur in the United States each year, 200,000 of them are secondary strokes (Sacco et al., 2006). A survey conducted by the Department of Veteran Affairs found that only half of physical therapy and occupational therapy practitioners reported addressing reducing the risk of recurrent stroke with their patients who have had a stroke (Schmid et al., 2008).

Additionally, in two separate qualitative studies, persons with stroke reported being unaware of what caused their stroke and how to prevent another. They were shown to continue to struggle with these concepts even one to five years post-stroke (Bendz, 2003; White et al., 2009). Qualitative studies such as these give insight into the unmet needs of the stroke community. This gap in stroke knowledge coupled with the high incidence of recurrent stroke highlights the need for education on stroke and its risk factors.

Another important, unmet need of the stroke community, as identified by qualitative research, is the lack of knowledge concerning stroke recovery (White et al., 2009; Wiles, Ashburn, Payne & Murphy, 2002). These studies found that participants expected to return to prior levels of functioning and were frustrated and discouraged when these expectations were not met (Wiles et al., 2002; Doolittle, 1992). These unmet expectations interfered with the clients’ emotional well-being. Stroke survivors report receiving inadequate information on stroke
management and a lack of explanation during both inpatient and outpatient rehabilitation on what realistic recovery will look like (Bendz, 2003; Wiles et al., 2002). Wallenbert and Jonsson (2005) also identified that persons living with stroke often do not want to adapt or establish new habits and routines in place of their former, pre-stroke habits and routines. The reluctance to change the way one performs their routine may result from the survivor’s perspective of wanting to wait for old abilities to return (Wallenbert & Jonsson, 2005). It is necessary that care providers explicitly portray the long-term outcomes that are expected, provide their clients with realistic goals and meaningful activities, as well as explain the importance of establishing new habits and routines as full pre-stroke recovery may not be attainable or take a significant period of time (White et al., 2009; Wallenbert & Jonsson, 2005).

Care providers must maintain a balance between providing clients with realistic expectations without removing hope. Maintaining hope is often a motivating factor for clients to persevere in terms of taking an active role in their recovery (Doyle et al., 2014). A study by Doyle et al. (2014) found that if therapists had low expectations of the client’s recovery, the client’s hope was weakened. Therefore, therapists should be aware of the impact that they have not only on their client’s physical health, but emotional health as well. Moreover, they should work to build hope and self-efficacy in their clients and allow them to discover their strengths. This is yet another gap within stroke rehabilitation that needs to be addressed within therapy in order to improve client outcomes and prevent post-stroke comorbidities.

**Comorbidities Post-Stroke**

According to Salter, et al. (2013), one-third of persons post-stroke experience some form of depression during their recovery. Depression can result in additional challenges for stroke survivors, such as a slower functional recovery, less interest in social activity, and decreased
cognition (Salter et al., 2013). Post-stroke depression negatively impacts quality of life, participation, engagement in meaningful occupations, and social interactions (Falk-Kessler, 2010; Wolf & Baum, 2010). These emotional and mental changes can decrease the individual’s reintegration back into their former life roles (Wolf & Baum, 2011). Depression disrupts a person’s life, and without being given education regarding realistic goals or expectations post-stroke, participants can begin to feel hopeless and helpless.

Although depression is the most common psychological condition in individuals post-stroke (35% to 50% of people), anxiety has also been shown to be present in 20% to 36% of survivors and often goes untreated (Hildebrand, 2015). Feelings of fear related to the unknown future as well as whether or not one will experience another stroke contribute to anxiety as well as stress, and is not always fully addressed in therapy (Burton, 2000). In addition, there was also stress caused by not understanding the recovery process (Burton, 2000). According to Falk-Kessler (2010), 22% of individuals experience Generalized Anxiety Disorders three months post-stroke, 30% are diagnosed with Post Traumatic Stress Disorder, 18% have emotional lability, 14% live in states of worry, and 13% of individuals with stroke have an anxiety disorder with no depression comorbidity. These anxiety-related disorders are often comorbid with depression (Falk-Kessler, 2010). In a qualitative study of stroke survivors’ perspectives of the post-stroke lived experience, Burton (2000) found that this uncertainty of the future can impede upon their ability to utilize coping skills and result in daily feelings of worry and apprehension. Many of these stroke survivors reported feelings of isolation and being trapped. A huge contribution to these feelings was the fact that individuals were not well educated on what they will experience post-stroke, further intensifying the feelings of fear and anxiety (Burton, 2000). Education and
support in this chronic phase may potentially reduce the impact of these comorbidities on stroke survivors, and result in higher levels of overall quality of life and participation.

Chronic mental stress, anxiety and depression are not the only comorbidities that impact participation post-stroke. Many people living with stroke are affected by problems concerning fatigue, sleep, and pain. Between 40 to 70 percent of individuals who have had a stroke will experience fatigue on a daily basis, which affects both their physical and psychological well-being (National Stroke Association, 2012). Post-stroke fatigue is often different than what most people experience when they feel tired, often developing rapidly and does not decrease with rest (National Stroke Association, 2012). Doyle et al. (2014) found that the mental effort to focus and adapt to stroke impairments increased both their physical and emotional post-stroke fatigue. Fatigue management strategies, exercise and proper sleep hygiene may help to increase health behaviors, health status and decrease fatigue, but still may not fully eliminate fatigue (McGeough et al., 2009).

Pain is also a common post-stroke sequela. Research by Jonsson, Lindgren, Hallstrom, Norrving, and Lindgren (2006) measured the pain intensity of 416 first-time stroke patients at four and 16 months after their stroke. At the 16-month follow-up, 21% of participants reported still experiencing moderate to severe pain (Jonsson et al., 2006). Experiencing a stroke leaves many individuals with various types of physical discomfort, such as nerve and muscle pain. Of individuals with stroke, 72% of them report shoulder pain in the hemiplegic arm, which can limit the individual’s ability to participate in various activities (Gillen, 2011). Chronic pain and fatigue are often related to one another (Fisher et al., 2007) and the need for self-management skills to aid those who live with these symptoms on a daily basis is crucial to their recovery. Hence, it would be important for any ongoing wellness program for stroke survivors to address these
common post-stroke co-morbidities and provide participants with strategies to self-manage and prevent them.

**Chronic Illness Self-Management**

The World Health Organization includes stroke in its list of chronic illnesses (World Health Organization, 2014). Therefore, it may be potentially beneficial to view stroke within a similar lens as other chronic illnesses. Several studies have demonstrated that the use of self-management strategies can improve health behaviors and sustain a satisfying quality of life in individuals with chronic illnesses (Schulman-Green et al., 2012; Novak et al., 2013; Jones, 2006; Damush et al., 2011; Howard & Ceci, 2012). Richard and Shea (2011) describe self-management as the individual’s ability to manage their disease, make lifestyle changes, monitor symptoms and treatment, and perform activities for health promotion that cater to their specific chronic illness needs.

Self-management encourages a shift from the medical-model style of treatment to a collaborative relationship between the person with chronic illness and the healthcare provider, where an individual’s ability to participate activities to take care of one’s self is supported (Verma, Forsyth, & Flynn, 1999). In the traditional medical model, patients often heavily rely on their healthcare provider, like their doctor, to manage their chronic illness symptoms. As a result of this, many individuals with chronic illness become susceptible to learned helplessness and are increasingly dependent on the medical system, rather than using their resources and taking personal responsibility for their lifestyle choices (Verma et al., 1999). However, patient-provider relationships that are more collaborative in nature are shown to enhance self-management activities (Novak et al., 2013). A collaborative patient-provider relationship supports the patient as they begin to participate in activities to take of themself and promotes
patient-centered approaches to care. Patient-centered care or a collaborative patient-provider relationship enables self-management activities and allows the patient to participate in the decision-making process and helps the provider better understand the patient’s life context (Novak et al., 2013).

Self-management skills should be individualized to patients and their specific lifestyles given each persons’ unique needs and context. Receiving coaching and education may help clients to gain these types of self-management strategies (Howard & Ceci, 2012). Health coaching is a strategy or healthcare provider who supports the individual to self-manage their chronic illness. The key to health coaching is to empower individuals to take the responsibility of their chronic illness management activities (Howard & Ceci, 2012). It highlights the need for the shift in the clinician from the role of expert to that of coach. The affected individual needs to be able to motivate him or herself and use health information to the best of their ability to achieve necessary goals and improved chronic illness outcomes (Howard & Ceci, 2012).

Jones (2006) researched several different chronic illness self-management programs and defined what characteristics of disease management programs need to be applied to stroke recovery. The most successful programs are those that are not simply educational, but enable behavior change through the promotion of self-efficacy, or the self-belief one is capable to produce a desired action (Jones, 2006). She suggested that self-management programs should be applied to the stroke population through the emphasis of action plans that set reasonable goals to be completed in a short amount of time (Jones, 2006). These goals should target achievable activities that are valued by the individual. This type of goal setting along with programming education to improve one’s ability to interpret chronic illness signs or symptoms, like pain and fatigue, help the participant to develop skills that better manage their disease (Jones, 2006). Her
research showed that stroke survivors would benefit from specific self-management programs targeting them.

A randomized trial involving 63 veteran stroke survivors by Damush et al. (2011) compared a stroke specific self-management program to an attention placebo control group. The stroke self-management group received biweekly phone calls for six weeks that focused on increasing self-efficacy to self-manage symptoms and decreasing secondary stroke risk, while the control group received biweekly phone calls to ask how the participants were doing. Researchers found that participants enrolled in the stroke self-management program showed significant differences in increased time spent exercising, improved quality of life and improved self-efficacy. In a randomized, controlled trial of 143 stroke survivors, Cadilhac et al. (2006) found that a stroke specific self-management program, when compared to a generic self-management program, had better participation and completion rates among stroke survivors. The stroke self-management program improved positive and active engagement in life and reduced depression and anxiety more than the generic intervention. Stroke self-management programming is effective in positive behavioral change when it targets the many dimensions of their health and wellness.

Wellness Programs for Chronic Illness

Other forms of support for persons with chronic illness are wellness programs, which are often used in conjunction with other forms of health care to support chronic illness management and improve quality of life (Verma et al., 1999). Wellness programs are designed to help individuals incorporate healthy living into their daily routines (Verma et al., 1999). Similar to chronic illness self-management programs, wellness programs seek to promote social support through weekly meetings and typically include a form of fitness promotion (Verma et al., 1999).
One study found that after completing a wellness program designed for a wide range of chronic conditions, 76% of participants reported a more favorable health status and improved quality of life (Verma et al., 1999). In a different study, a wellness program for older adults educated the participants on the importance of meaningful occupations and community and social participation (Matuska, Giles-Heinz, Flinn, Neighbor, & Bass-Haugen, 2003). The program ran for six months with weekly meetings and topics including transportation, aging, safety, stress, lifestyle balance, and communication. Matuska et al. (2003) found that participants reported increased frequency of activity, improved mental health, improved social functioning and increased quality of life after the program. Researchers from the University of Southern California conducted the Well Elderly Study (Mandel, D.R., Jackson, J.M., Zemke, R., Nelson, L., & Clark, F.A., 1998), a preventative occupational therapy intervention for older adults. This study looked at the therapeutic development of lifestyle redesign in older adults in order to enhance physical and mental health, level of functionality, and overall life satisfaction. It was found to be extremely successful, indicating the importance of occupation-based interventions (Mandel et al., 1998).

One study found that community reintegration, or re-establishing or developing new roles and relationships, was vital for participants to engage in meaningful roles and promote positive self-perception among those living with stroke (Wood, Connelly, & Maly, 2010). Furthermore, the study found that it community reintegration goals are best achieved when set by the person with stroke, indicating that community reintegration is most successful when driven by the individuals personal desire (Wood et al., 2010). Hence why it is important for individuals with chronic stroke to develop the motivation and skills to manage their own symptoms and rely on
their own abilities. Many individuals with chronic stroke need to have learning opportunities and instruction on how to do this in their own life. Group programs can help in this area.

A systematic review by Lennon, McKenna and Jones (2013) examined 15 studies to determine the evidence base for stroke self-management and found that the evidence is growing and shows support for these programs in the lives of stroke survivors. Another systematic review on self-management intervention programs for stroke survivors by Boger, Demain, and Latter (2013) looked at the outcome measures used by those intervention programs. This review found that outcome measures used are not able to sensitively measure the specific concept of self-management, and that further work is needed on developing assessments to measure self-management (Boger et al., 2013). These systematic reviews along with studies completed by Damush et al. (2011) and Jones, Livingstone and Hawkes (2012), which also described stroke self-management programs, presented a variety of mediums in which to conduct a stroke self-management program, such as using educational programs, group interventions, one-on-one interventions, over the telephone, through home visits, and by working through a work book (Boger et al., 2013; Damush et al., 2011; Jones et al. 2012; Lennon et al., 2012).

This review of stroke self-management programs also described a wide range of topics covered and presented to participants. These topics included the following and many more: overview of stroke, post-stroke changes, stroke recovery and prognosis, stroke prevention, stroke risk-factors, co-morbidities post-stroke, goal setting, adapting to disability, social and community participation, new roles after stroke, self-efficacy, post-stroke mood, physical functioning, exercise, utilization of resources, engagement in activity, and health behaviors (Boger et al., 2013; Damush et al., 2011; Jones et al. 2012; Lennon et al., 2012).
These studies point to the benefits of wellness programs and their effectiveness in improving participants’ quality of life, participation, and health behaviors. If designed to incorporate education in self-management skills for chronic illness, such programs could positively impact many areas of a stroke survivor’s life, health, and participation.

**Occupational Therapy and Wellness**

Due to its holistic lens, occupational therapy is well suited to address the ongoing needs of persons living with chronic stroke. The Occupational Therapy Practice Framework places the realms of education, health management, habits, roles, routines, leisure, and community engagement within the domain of occupational therapy (AOTA, 2014). Occupational therapists are well equipped to educate individuals on effective coping strategies, lifestyle and health modifications, habit development and task adaptation (Fisher et al., 2007). All of these components are consistent with the goals of self-management training incorporated with those of a wellness program. Community-based, group occupational therapy can use the wellness and self-management program models to support the needs of chronic stroke consumers by empowering and teaching them to manage their physical, emotional, and social needs, while improving their occupational performance (White et al., 2009).

**Purpose Statement**

The purpose of this project is to develop a manual for occupational therapists and occupational therapy students at the University of Puget Sound on how to implement a wellness program that also incorporates self-management training for individuals living with chronic stroke, in order to supply the participants with the tools to learn strategies necessary to self-manage their chronic symptoms, promote a healthy lifestyle, and maximize their participation in everyday occupational performance.
**Procedure**

The idea for this project began when Professor Sue Doyle PhD OTR/L recognized large populations of individuals living with chronic stroke who have received past treatment at the UPS pro bono on-site therapy clinic, but would not benefit from direct therapy anymore. This community of persons with stroke continues to have unmet needs regarding quality of life and participation and still wanted to be involved with UPS in some way. Simultaneously, due to the curriculum change with the UPS occupational therapy program, OT students needed to have more opportunities to engage in more authentic learning experiences to obtain their degree. Dr. Doyle believed a student run wellness program would benefit both this community of persons with stroke and the OT students, who would be seeking additional authentic learning opportunities.

This project started with a needs assessment and research into the context of chronic stroke to determine barriers for these individuals. Following this preliminary research, a literature search and background review into the stroke demographics, chronic stroke symptoms, and stroke patient perspectives and concerns was performed, identifying common needs for individuals living with chronic stroke. We reviewed current research on chronic disease and stroke self-management programs, wellness programs, and health coaching to determine their effectiveness, the medium in which to conduct a wellness program, what topics the program should cover, and theories or models used when designing these programs.

After reviewing the literature, we have chosen to do an in-person, group format for our wellness program as group interventions have the most evidence, provides an additional social component for participants, and provides the best learning opportunity for occupational therapy.
students who run the program (Boger et al., 2013; Damush et al., 2011; Jones et al. 2012; Lennon et al., 2012).

After interviewing stroke survivors, therapists who work with persons with stroke, reviewing qualitative research on the needs of stroke survivors, and the types of modules used in other stroke self-management interventions, we have chosen to include the following topics in our modules as they reflect the needs of stroke survivors: occupational engagement, stroke recovery, overcoming barriers, motivation, stroke prevention, physical exercise, stroke healthy diet, changing habits, improving sleep, managing pain and fatigue, depression, anxiety, community reintegration and community resources. These areas became topics for the weekly wellness program modules.

Using theory to design an intervention is helpful and for this project we reviewed several potential theoretical models to help guide the module development and implementation strategies.

Our wellness program for persons with chronic stroke will employ three different theories to ensure the most effective translation of improved health behaviors: the Theory of Planned Behavior (TPB) (Ajzen, 1991), Adult Learning Theory (ALT) (Rothwell, 2008), and the Model of Human Occupation (MOHO) (Kielhofner, 2002). According to O’Connor and Armitage (2006), the Theory of Planned Behavior allows for an understanding of how an individual’s behavior can be changed. TPB proposes that behavior can be predicted by one’s intentions to perform the behavior and whether or not the individual believes the behavior is under their control. Within the wellness program, participants will be completing action plan worksheets to identify supports and barriers with regard to the weekly module themes, and ways they can overcome these to change their behaviors. By identifying these, participants are more likely to
believe they have control over their behavior and make intentions to change. By knowing the components of what affects a person’s behavior, our wellness program is designed to motivate individuals to change their understandings of their stroke symptoms, promote positive intentions to change, and prompt health behavior changes. We aim to present the program material and facilitate discussions that increase the participants’ perceived behavioral control; that they can take charge of their health behaviors and produce actions that serve to improve their health. Guided by the TPB, participants will identify barriers in their lives and come up with an action plan on how they can overcome these barriers and facilitate meaningful occupations (O’Connor & Armitage, 2006).

Adult Learning Theory is used to guide the wellness program facilitators’ actions, to teach them how to step beyond education and help participants learn (Rothwell, 2008). Moreover, ALT is concerned with how adults learn effectively. Knowing the manner in which adults learn guides the direction of how the content for this wellness program is designed in order to promote interest and encourage retention. While educating participants to increase their knowledge on stroke and better health behavior is important, it is simply not enough on its own. Participants must learn steps they can take to independently improve their health behaviors to improve functioning during their recovery. Principles behind ALT include ideas that adults are relevancy oriented, goal oriented, practical, intrinsically motivated, self-directed, bring their life experiences and knowledge to learning, and like to be respected (Knowles, 1973). We will incorporate these concepts into program design to guide the roles of group facilitators. Utilizing active learning principles, leaders will relate why the program is relevant and practical to participants and provide ways for them to actively be involved in goal setting. Participants are invited to bring their experiences and life circumstances to help guide discussions, solutions, and
goals. Thus, ALT provided us with effective strategies to design our wellness program and will be beneficial in helping participants learn improved health behaviors.

The Model of Human Occupation (MOHO) views the human as a dynamic and open system, constantly receiving information from the environment, and processing that information to perform a behavior (Bruce & Borg, 2002). According to Bruce and Borg (2002), individuals engage in the environment and constantly adapt to its demands. At the core of MOHO is occupation; the model suggests that through purposeful and meaningful occupations humans can positively impact themselves and their environment. MOHO states that the person is made of three subsystems. The volitional subsystem suggests that people are motivated by what they value, what they are interested in, and what they feel they are capable of doing. Additionally, volition drives the person to act and persist (Bruce & Borg, 2002). The habituation subsystem is made up of the habits that provide framework and guide their days. It is also made up of internalized roles, which consists of self-awareness of the individual’s social identity and the obligations that follow. The last subsystem is the performance subsystem. This is made up of body structures and functions, allowing the individual to process information and act on their environments. When the individual exhibits occupational dysfunction, we examine their volition, habituation, performance and environmental contexts. MOHO aims to restore occupation in daily life by altering these subsystems and creating positive experiences through meaningful occupational performance (Bruce & Borg, 2002). Within our wellness program, we want to target the participants’ volition through the use of meaningful occupations, to motivate them to take control of their own health behaviors and change it for the better. We will use exercises that help participant identify their personal causations, current routines and abilities to help them
write clear, attainable goals to show them the power of occupations and their effects on their lives.

We believe by utilizing these various theories, our wellness program will be effective in teaching participants and motivating them to take control of their health behaviors to improve their occupational engagement and quality of life. Identifying methods used in other stroke management programs helped us incorporate these theories into effective program design.

Studies on stroke self-management programs (Boger et al., 2013; Damush et al., 2011; Jones et al. 2012; Lennon et al., 2012) reviewed several different methods in which to present program content. Our wellness program will utilize educational programming, case vignette problem solving, participant driven discussion topics, and work-book based formatting as these modes are utilized by other stroke programs and by both the Theory of Planned Behavior and Adult Learning Theory as effective modes for helping individuals learn and change their behavior (Boger et al., 2013; Damush et al., 2011; Jones et al. 2012; Lennon et al., 2012; Rothwell, 2008; Sutton et al., 2008). A particular emphasis will be placed on weekly goal setting in the form of action worksheets (see Appendix A for sample action worksheets). Research by Jones (2006) found that goal setting in conjunction with programming serves to improve an individual’s ability to manage their chronic disease symptoms.

After the research phase, we began to develop the model for the weekly wellness program modules. Handouts and participant packets for this wellness program were designed to be at an 8th grade reading level to ensure understanding among all participants (T. Kaminsky, personal communication, January 26, 2015). After the project modules and program curriculum were designed, two modules were selected to implement in a pilot study. These two pilot group sessions were conducted from a draft of the manual, which included a leader’s guide, scripting,
module content, and participant handouts and worksheets. Community dwelling stroke survivors who had received therapy services in the past at the UPS physical and occupational on-site therapy clinic, and who had previously given consent, were contacted and invited, via phone call and mail, to participate in the pilot study. One module was piloted by the program creators with a group of 12 people with chronic stroke. Three first year occupational therapy student volunteers observed during this session. The three first year occupational therapy student volunteers then piloted a second module one week later with program creators observing. This group session included eight stroke survivors who had attended the first session. Feedback was gathered based on feedback sheets from the stroke survivor participants, student therapist report, and observation and goal evaluation. This information was then reviewed to identify changes needed in the program. After adjustments were made, the manual containing the wellness program modules and instructions for implementation, along with a manual introduction, was designed using Apple Pages and printed as a spiral bound book through a print center. The manual also contained a flash drive with an electronic version of the manual in its back cover pocket. This was made available through the UPS occupational therapy resource room for OT students and community occupational therapists to have access to so they might implement this wellness program in their communities.

The following skills and knowledge are necessary in order to successfully recreate the project and instruct the wellness program:

Writing skills, computer use (using Microsoft Word and Google Drive) teaching skills, leadership skills, interpersonal skills, computer skills, computer design skills (using Apple Pages 5.2.2), collaboration skills, problem solving skills, active listening and observation skills, therapeutic use of self, APA citation, activity analysis, creativity, group facilitation skills,
knowledge of stroke and chronic stroke symptoms, knowledge of chronic stroke needs, knowledge about wellness programs, knowledge of self-management programs for chronic illnesses, knowledge of local stroke community resources, knowledge of Occupational Therapy Practice Framework, knowledge of how to establish positive group dynamics, knowledge of MOHO, Adult Learning Theory and Planned Behavior Theory, knowledge of good health behaviors, knowledge of stroke symptom management, knowledge of reading and applying research-based evidence, ability to teach, instruct and communicate with persons with chronic stroke.

**Description of Final Product**

The University of Puget Sound (UPS) is unique in that it has a pro bono, on-site clinic where students, supervised by licensed occupational therapists, perform evaluations and provide treatment for community members seeking occupational therapy services. Student therapists at UPS treat a large number of individuals recovering from stroke, many of whom are more than six months post-stroke (S. Doyle, personal communication, October 20, 2013). These clients are often independent in most of their basic ADLs, however they are frequently unable to fully participate in their desired social, community, and leisure occupations. Many of these individuals are no longer eligible for traditional therapy services but still have unmet needs related to their occupational status (S. Doyle, personal communication, October 20, 2013). The occupational therapy program at the University Puget Sound wished to provide this group with further services that extend beyond traditional therapy intervention in the form of a wellness program, with the aim of increasing their quality of life, participation, and self-management skills.

The final product of this project was an educational manual for occupational therapy students at the University of Puget Sound. The manual will assist students in implementing a
wellness program for chronic stroke survivors, in particular, those who have completed traditional therapy services. The manual consisted of seven sections, including an introduction with background information, the purpose of the manual and recommendations/instructions, and the six weekly modules with accompanying participant handouts and worksheets, and references (see Appendix B for sample pages from the manual). Background information included material on strokes, common post-stroke needs and rehabilitation deficits, the effectiveness of chronic illness self-management programs and wellness programs, implications for OT, program design, and material on the theories and models behind program design and implementation (Model of Human Occupation, Theory of Planned Behavior, and Adult Learning Theory). The six weekly modules and participants handouts/worksheets contributed to the bulk of the manual, which included: activity instructions, materials needed, key points and topics addressed, scripting for leaders, discussion questions, and worksheets/handouts for the participants. Modules are designed to last two hours and occur weekly for six consecutive weeks. Module topics included:

Module 1: What is occupation?, impact of stroke on occupation, and benefits of exercise.
Module 2: Stroke recovery, overcoming barriers, and how to exercise.
Module 3: Changing volition, stroke prevention, and stroke healthy diet.
Module 4: Changing habits, improving sleep, and managing pain and fatigue.
Module 5: Community and social reintegration, depression, and motivation for exercise.
Module 6: Community resources, stress and anxiety, and community exercise programs.

Participant handouts and worksheets were designed to facilitate maximum participant engagement in program topics and to promote learning and behavior change.

At the end of this stroke wellness program, OT students will have gained valuable hands-on experience leading and conducting group wellness sessions and interacting with stroke
survivors. They are provided with the opportunity to gain knowledge specific to stroke survivors and what this population needs to manage their chronic illness and maximize their participation in desired occupations. The stroke survivor community benefits from this wellness program as they learn valuable resources, new skills, stroke-specific knowledge on healthy living, creating healthy habits, chronic illness management skills, and strategies to promote engagement, behavior change, combat common post-stroke co-morbidities, and improve overall quality of life.

**Outcomes of the Project**

The following goals are the anticipated long-term outcomes of the full six weeklong wellness program. We did not expect to meet many of these goals with the implementation of the pilot, due to only two modules being piloted. The goals and objectives are divided to target two groups of people. Goals 1-6 and their subsequent objectives target the occupational therapy students implementing the wellness program. Goals 7-9 and their subsequent objectives target participants in the wellness program with chronic stroke.

**Goal 1.**

Upon reading the manual, group leaders will demonstrate effective education techniques on stroke causes, risk factors, prevention, recovery and prognosis.

**Objective 1.** Upon reading the manual, group leaders will educate participants on two ways in which stroke may occur.

**Objective 2.** Upon reading the manual, group leaders will teach participants at least four risk factors of having a stroke and four ways to prevent having another one.

**Objective 3.** Upon reading the manual, group leaders will independently describe the process of stroke recovery and its prognosis.
**Goal 2.**

Upon reading the manual, group leaders will discuss with participants general wellness and health behaviors after stroke.

- **Objective 1.** Upon reading the manual, group leaders will describe three types of exercise specific to needs for the stroke survivors.

- **Objective 2.** Upon reading the manual, group leaders will outline three types of emotional changes due to stroke and ways stroke survivors can manage them.

**Progress towards goal:** Not yet met

**Goal 3.**

Upon reading the manual, group leaders will be able to describe fatigue management and sleep hygiene skills.

- **Objective 1.** Upon reading the manual, group leaders describe and teach three strategies for stroke survivors to manage fatigue and pain.

- **Objective 2.** Upon reading the manual, group leaders will describe and teach three sleep hygiene skills for the participants.

**Progress towards goal:** Goal met. After reading the module on sleep, pain and fatigue, first year OT students were successful in teaching three pain/fatigue management strategies and sleep hygiene strategies through implementation of this module in the wellness program pilot.

**Goal 4.**

Upon reading the manual, group leaders will describe pain management and stress reduction skills.

- **Objective 1.** Upon reading the manual, group leaders will demonstrate three relaxation
techniques for pain reduction and facilitate these with stroke survivors.

**Objective 2.** Upon reading the manual, group leaders will describe three coping skills for stress management.

**Progress towards goal:** Not yet met

**Goal 5.**

Upon reading the manual, group leaders will discuss with participants ways to improve their social participation and re-integration into the community.

**Objective 1.** Upon reading the manual, group leaders will describe two ways to help stroke participants educate family and friends on changes caused by stroke

**Objective 2.** Upon reading the manual, group leaders will educate participants on two ways that they can continue to engage in either familial and/or friend relationships.

**Objective 3.** Upon reading the manual, group leaders will identify three ways to access transportation throughout the community.

**Progress towards goal:** Not yet met

**Goal 6.**

Upon reading the manual, group leaders will describe new or adaptive ways for stroke survivors to engage in leisure activities.

**Objective 1.** Upon reading the manual, group leaders will identify four local community resources for the participants to use to engage in exercise programs, cultural activities, and leisure groups.

**Objective 2.** Upon reading the manual, group leaders will demonstrate three ways for participants to engage in various leisure activities around the home while being mindful of their stroke symptoms.
Progress towards goal: Not yet met

Goal 7.
Upon completing the six-week wellness program, participants will create plans to participate in a regular exercise program and improve their stress management behaviors and sleep hygiene routine.

Objective 1. Upon completing the six-week wellness program, participants will be able to identify two ways to manage emotional changes.

Objective 2. Upon completing the wellness program, participants will be able to create, with assistance, and implement an exercise program outside of therapy.

Objective 3. Upon completing the six-week wellness program, participants will independently be able to create a sleep hygiene routine for themselves.

Progress towards goal: Partially met-objective 2 met. After participating in the pilot program, participants learned how to design exercise regimens during the first session, and reported during the second session their implementation of said exercise.

Goal 8.
Upon completing the six-week wellness program, participants will be able to describe coping strategies for symptom management, recurrent prevention and stroke recovery.

Objective 1. Upon completing the six-week wellness program, participants will be able to identify two strategies for pain and fatigue management.

Objective 2. Upon completing the six-week wellness program, participants will be able to name three ways to prevent a recurrent stroke.

Objective 3. Upon completing the six-week wellness program, participants will be able to effectively communicate the stroke recovery process to their friends and family.
Progress towards goal: Partially met-objective 1 met. After participating in the pilot program, participants were able to describe two strategies for pain and fatigue management.

Goal 9.

Upon completing the six-week wellness program, participants will be able to identify ways to improve their social participation

Objective 1. Upon completing the six-week wellness program, participants will be able to identify two new leisure activities that they can engage in with others outside of the wellness program.

Objective 2. Upon completing the six-week wellness program, participants will be able to communicate to caregivers/family/friends two ways stroke impacts their social participation and ways in which they can overcome them.

Progress towards goal: Not yet met

Currently, only one goal with its subsequent short-term objectives have been met. The first year occupational therapy students have only piloted one module on sleep, pain, and fatigue. As such, goal 3 and its objectives have been met to date. Additionally, objective 2 of goal 7 and objective 1 of goal 8 has also been met. The six-week wellness program will be implemented in the fall of 2015 at the University of Puget Sound by the same three OT students who volunteered to participate in the pilot. Goals 1 through 6 will be assessed based on observation of performance and participant feedback. Goals 7 through 9 will be assessed based on observation and participant report.

Implications for Occupational Therapy

A wellness program can assist individuals with chronic stroke to take ownership of their physical and psychological symptoms and learn the strategies necessary to promote healthy
living and engagement in meaningful occupations. Through active participation, the use of group discussion, in-class exercises/worksheets, and homework, this type of program can change both an individual’s health and occupational patterns. The OTPF places the topics of education, health management, habits, roles, routines, leisure, and community engagement within the domain of occupational therapy (AOTA, 2014). Additionally, it acknowledges that occupational therapists have the skill set necessary to assess each domain and treat clients accordingly (AOTA, 2014).

Stroke impacts the individual’s client factors and body structures such as areas involved in the brain, and body functions such as motor control and sensation (Woodson, 2014). This in turn can affect all areas of occupations including activities of daily living, instrumental activities of daily living, rest and sleep, education, work, play, leisure and social participation (AOTA, 2014). Performance patterns such as habits, roles, and routines are also impacted by stroke (AOTA, 2014; Wallenbert & Jonsson, 2005). Occupational therapists are knowledgeable in these areas to allow them to address these ongoing needs of individuals post-stroke. They work to educate them on effective coping skills, lifestyle and health modifications, medication management, and task adaptation (Fisher et al., 2007). This can create an improvement in a person's daily activities and ameliorate the symptoms that are impeding on their ability to thrive in their environment while living with chronic stroke.

Our wellness program serves as an intervention to educate clients on how to take care of themselves in the best way possible. Establishing healthy life habits will impact their overall health and the use of specific strategies will allow for increased wellness as well as participation in valued roles and activities in a variety of contexts and environments. Contexts and environments often pose barriers to those living with chronic stroke (Eriksson, Baum, Wolf, & Connor, 2013). An outcome we hope to achieve through our wellness program is to provide
participants with the skills necessary to overcome these obstacles that are now found in their environment. Additionally, a wellness program with a self-management focus would aid individuals in managing their physical, emotional, and social needs, while improving their occupational performance patterns on a daily basis (White et al., 2009). By constructing a manual used to implement our wellness program, we hope to have consistent outcomes that will improve quality of life, engagement in meaningful activities, participation, health behaviors, social interaction, community reintegration, and the level of education necessary to those living with chronic stroke. The design of this group outlines a relatively new form of intervention (group therapy for wellness and self-management) in a new area for occupational therapists (chronic stroke) that is consistent with the overall theoretical perspectives of OT, addresses some of the concerns of persons with chronic stroke, and responds to some of the changes and recommendations in health policy in the USA (e.g. the affordable care act).

Limitations

The primary limitation of the project was the inability to pilot all six modules. During the development of the program, two were selected and prepared for the pilot. There was not enough time to complete all six modules for 6 weeks of piloting. Additionally, due to time restraints within the UPS OT program schedule, room availability, and scheduling conflicts between project supervisor, program creators and first year volunteers, only two sessions could be feasibly piloted in order to make sure all stakeholders were available. Another limitation was that feedback received from the two modules piloted had to be generalized to the remaining four modules. Had these been piloted as well, feedback could have been more content specific. Lastly, due to the wide range of impairments each stroke participant experiences, and because each client is unique, handouts and worksheets within the manual may be too difficult for some
and too simple for others. Some stroke survivors are able to write and use a pen, while others are completely unable. Should future OT students implementing this wellness program run into participants who are unable to write, the manual contains solutions and ideas to complete the handouts and worksheets as a group through discussion. However, this can take away from the uniqueness of each participant, as handouts and worksheets are most effective when each participant reflects on their own abilities and completes the handout on their own, rather than generalizing it to the entire group.

**Recommendations for the Future**

The manual will be stored in the resource room in Weyerhaeuser Hall at the University of Puget Sound. Students must inform and coordinate with professor and clinic director Dr. Sue Doyle to organize and conduct a program. If any difficulties should arise, or if additional handouts need to be made for participants, speak with Dr. Doyle. In the future, students may want to expand on the number of modules created, adding more topics that might be of interest to the individuals involved in the program. Specifically, module topics on additional common co-morbidities post-stroke would be helpful to program participants. This would in turn expand the number of weeks that the program is set to run. Students should make sure to update the manual as needed, so that it is relevant to the most current research on stroke wellness. In addition, students may also want to design a website in which they can share this information with other stroke survivors and their families. This manual may also potentially benefit other therapists and programs throughout the country.
References


MD: Lippincott Williams & Wilkins.


Appendix A

Sample Action Worksheets

**Action Plan Sheet #1**

Based on the information covered in this section of the workshop, answer the following questions.

1. What aspects of the information today are new to me?

2. What is one thing I learned today that I could do this week?

3. What would I need to do to be able to use this information in my daily life?
Action Plan Sheet #2

Based on the information covered in this section of the workshop, answer the following questions.

a. What is one activity you can do supports positive mental health in my life?

b. What items/steps will you need to take to achieve this?

c. Will this be something you have never attempted before?

d. What was the first step you took to incorporate it into your life?

e. What do you plan to do next week to achieve this?
Appendix B

Sample Pages from the Manual

Sleep Quiz
1. T or F Adults need 7-9 hours of sleep per night
2. T or F Poor sleep increases my risk for obesity
3. T or F Not getting enough sleep increases my risk for diseases like heart problems and diabetes
4. T or F I can focus better and learn more when I don’t get enough sleep
5. T or F Getting too much sleep (more than 9 hours) is healthy for me
6. T or F Leaving the television on in the bedroom is a good way to fall asleep and help me get a better night’s sleep
7. T or F When I can’t sleep, one thing I can do is go into another room and do something relaxing until I feel tired

Figure 3: Sleep Quiz
Worksheet:
Participants’ Handout Page 3

down how they spend each hour of their day. (If participants are reluctant to volunteer, explain how there is no condemnation over how individuals choose to spend their time and that volunteering benefits the group as a whole). Together as a group, answer the accompanying questions (this option tends to be ideal when several participants have a hard time writing). The final five questions don’t need to be volunteer specific. Thank the volunteer for sharing.

Option 2: Have them complete activities wheel individually and accompanying questions

Should time allow, choose a couple of the additional discussion questions to ask the group.

Discussion Questions

• Name two habits you use every day that you found through your activity wheel.
• Were there habits you were able to maintain after your stroke? Or adapt and learn in a new way? How did that feel?

(give an example as this may be hard to identity, i.e. “like eating dinner at the same time every day, or the order in which you wash your hair and body in the shower?”

“Maybe you learned to put your shirt on with a one handed technique or use a reacher to help you put your pants on.”)

• What is something you want to make a habit? Where in your activity wheel can you fit that in?
• Are there any bad habits in your life that you could improve or change?
• What is something you would like to add to your daily routine but seems too hard to do or one you’ve tried before but was too hard to stick with?
• How do habits affect our activity?
• How do they affect our completion of them?
• How can a habit prevent our completion of another activity or task?

Sleep

Ask participants to turn to page 3 in their participants packets and complete the T or F quiz (Figure 3). Read the questions out loud. Ask them to raise their hands if they think it’s true, raise their hand if they think it’s false. Tally up the T or F answers on the board for each question. Tell
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1. Adding salt to my food to taste it better
2. Drinking 1 or fewer alcoholic beverages a day
3. Smoking only 1 pack a day
4. Getting more exercise
5. Already having a stroke
6. Switching to whole grain bread and cereal
7. Eating less red meat
8. Eating until I’m stuffed and super full at every meal
9. Not managing my diabetes
10. Working to lower my blood pressure
11. Having hypertension
12. Cutting out fruits and veggies from my diet (who needs ‘em?!)