

## AN ABSTRACT OF THE THESIS OF

Jill K. Pawlowski for the degree of Master of Science in Exercise and Sport Science presented on December 13, 2013

Title: Effectiveness of an Educational Health Promotion Program on Influencing Physical Activity Behaviors in Individuals with Mobility Disabilities

Abstract approved:

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### **Abstract**

Participation in regular physical activity is important for individuals with a mobility disability to decrease risk of chronic disease, improve quality of life, and maintain and improve functional ability. Consequently, there is a need for programs that can facilitate the adoption and maintenance of regular physical activity for adults with a mobility disability. **Purpose:** To pilot test a physical activity centered education (PACE) program for individuals with a mobility disability. **Methods:** A case study approach was adopted and consisted of two participants with a mobility disability, one in the support and one in the awareness group. The participant in the support group completed the 8-week (1 90minute session/week) PACE program in person at the *Health Promotion for People with Disabilities Lab*. The participant in the awareness group was mailed the PACE materials and completed the program independently at home. Thus, the primary between group differences was the intensity and type of support provided for physical activity

adoption. Participants in each group completed pre, and post assessments, with the participant in the support group completing an additional follow-up assessment measuring: (1) amount of weekly physical activity (self-report), (2) self-efficacy to be active, and (3) barriers to physical activity. Finally, after the follow-up assessment, the participant in the support group completed an interview to evaluate the program.

**ANALYSIS:** Descriptive analysis of quantitative data was calculated and was reported in frequencies and percentage change over time. Qualitative data was analyzed using a cross-case analysis to identify themes and conceptual patterns in the responses.

**RESULTS:** Both participants reported a decrease in barriers faced. The participant in the support group reported decreased physical activity and increased self-efficacy whereas, the participant in the awareness group reported increased physical activity and decreased self-efficacy. During the follow-up interview, five themes were identified including (1) PA knowledge, (2) PA participation, (3) PA expectations, (4) Program participation, and (5) Program feedback. **CONCLUSION:** The findings from this case study were mixed between amount of activity completed, barriers faced, and self-efficacy. However, these results are difficult to interpret due to a confounding health factor (spinal stenosis) faced by the participant in the support group that likely impacted all outcome measures.

Through the program evaluation, suggested program adjustments included improving program applicability by including community specific information, incorporating personalized activity plans, and providing practical examples of adapted activities of daily living and exercises.

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Effectiveness of an Educational  
Health Promotion Program on Influencing Physical Activity Behaviors  
in Individuals with Mobility Disabilities

by

Jill K. Pawlowski

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I understand that my thesis will become part of the permanent collection of Oregon State University libraries. My signature below authorizes release of my thesis to any reader upon request.

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Jill K. Pawlowski, Author

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## Abstract

Participation in regular physical activity is important for individuals with a mobility disability to decrease risk of chronic disease, improve quality of life, and maintain and improve functional ability. Consequently, there is a need for programs that can facilitate the adoption and maintenance of regular physical activity for adults with a mobility disability. **Purpose:** To pilot test a physical activity centered education (PACE) program for individuals with a mobility disability. **Methods:** A case study approach was adopted and consisted of two participants with a mobility disability, one in the support and one in the awareness group. The participant in the support group completed the 8-week (1 90minute session/week) PACE program in person at the *Health Promotion for People with Disabilities Lab*. The participant in the awareness group was mailed the PACE materials and completed the program independently at home. Thus, the primary between group differences was the intensity and type of support provided for physical activity adoption. Participants in each group completed pre, and post assessments, with the participant in the support group completing an additional follow-up assessment measuring: (1) amount of weekly physical activity (self-report), (2) self-efficacy to be active, and (3) barriers to physical activity. Finally, after the follow-up assessment, the participant in the support group completed an interview to evaluate the program.

**ANALYSIS:** Descriptive analysis of quantitative data was calculated and was reported in frequencies and percentage change over time. Qualitative data was analyzed using a cross-case analysis to identify themes and conceptual patterns in the responses.

**RESULTS:** Both participants reported a decrease in barriers faced. The participant in the

support group reported decreased physical activity and increased self-efficacy whereas, the participant in the awareness group reported increased physical activity and decreased self-efficacy. During the follow-up interview, five themes were identified including (1) PA knowledge, (2) PA participation, (3) PA expectations, (4) Program participation, and (5) Program feedback. **CONCLUSION:** The findings from this case study were mixed between amount of activity completed, barriers faced, and self-efficacy. However, these results are difficult to interpret due to a confounding health factor (spinal stenosis) faced by the participant in the support group that likely impacted all outcome measures. Through the program evaluation, suggested program adjustments included improving program applicability by including community specific information, incorporating personalized activity plans, and providing practical examples of adapted activities of daily living and exercises.

## Effectiveness of an Educational Health Promotion Program on Influencing Physical Activity Behaviors in Individuals with Mobility Disabilities

The number of individuals in the United States living with a disability is increasing every year (Centers for Disease Control and Prevention, 2010). Currently, 22% of the population, which equals roughly 54 million Americans, are living with a disability (Centers for Disease Control and Prevention, 2010; U.S Census Bureau, 2011), compared with 49 million in 2000 (U.S Census Bureau, 2000). One subset of the disability population is individuals with a mobility disability, which includes individuals with impaired physical functioning that limits major life activities (Center for Disease Control and Prevention 2011). Mobility disabilities can include spinal cord injury (265,000 people), traumatic brain injury (1.7 million cases annually), amputation (1.7 million people), stroke (795,000 cases annually), and muscular dystrophy (1 in 5,600-7,700) among others (Center for Disease Control and Prevention, 2011). With the increase in incidence there is a growing challenge presented to specialists to meet the health care needs of individuals with a mobility disability (Chang, Davis, & Damato, 2011; Gaudet, Crethar, Burger, & Pulos, 2001; Gentleman, 2001). This challenge is exacerbated by the fact that individuals with mobility disabilities may face a variety of associated, secondary and chronic health conditions (Rimmer & Rowland (2008).

Associated conditions result directly from the primary disability and likely cannot be prevented entirely but rather managed in a way that decreases the likelihood of further disability (Rimmer & Rowland, 2008). Associated conditions common to individuals with a mobility disability include spasticity, apraxia, and autonomic dysfunction (Rimmer & Rowland, 2008). Individuals may also experience secondary conditions, which The

*Healthy People 2010* (U.S Department of Health and Human Sciences, 2010) report defines as “medical, social, emotional, family, or community problems that a person with a primary disabling condition likely experiences”. Secondary conditions impact function and activity levels but, unlike associated conditions, can be prevented or made less debilitating if individuals participate in healthy behaviors, such as physical activity (PA) (Rimmer & Rowland 2008). Individuals with mobility disabilities can face affective secondary conditions, such as negative self-image, higher anxiety and depression, and negative feelings about their relationships with others (Chang et al., 2011; Gaudet et al., 2001; Gentleman, 2001). These negative feelings create social isolation which makes people less likely to go to public places like the gym or park to be physically active (Chang et al., 2011; Gaudet et al., 2001; Gentleman, 2001) . In contrast, chronic conditions such as heart disease, cancer, and Type 2 Diabetes are typically related to lifestyle factors such as PA or nutrition habits rather than disability (Rimmer & Rowland, 2008). For example, an individual who does not engage in regular PA will have a higher risk of developing heart disease than someone who does participate in regular PA (Center for Disease Control and Prevention 2011). While associated, secondary, and chronic conditions represent separate health states, they are interrelated and thus influence the development of other health conditions (Rimmer & Rowland, 2008).

In addition to health conditions, personal and environmental factors also influence an individual’s health (Rimmer & Rowland, 2008). Personal factors include primary impairment, self-efficacy, motivation, and health behaviors, while environmental factors include transportation and access to health promotion services (Rimmer & Rowland, 2008). Both personal and environmental factors can have a positive or negative

effect on health (Rimmer & Rowland, 2008). For example, an individual with a mobility disability who does not have access to health promotion services (a negative environmental factor) such as a health club will likely be less physically active. In contrast, an individual who does have appropriate access to health services (positive environmental factor) will be more physically active. An individual's health is shaped by the combination of personal and environmental factors along with secondary, associated, and chronic conditions. Therefore, the alteration of one or more of these factors will result in a healthier lifestyle for the individual.

Due to the plethora of health issues individuals with mobility impairments can face, specialists are challenged to find ways to improve the population's health. Health promotion programs (HPP) have been shown to be an effective rehabilitation tool for improving health (Abdullah et al., 2004; Pang, 2005; Ravesloot, Seekins, & Cahill, 2007; Rimmer, 2000; Stuifbergen, Becker, Blozis, Timmerman, & Kullberg, 2003), and the creation and implementation of HPPs for individuals with disabilities is recommended by current state and national initiatives. For example, Healthy People 2020 includes goals to increase the number of health promotion programs for people with disabilities and reduce barriers to participation (U.S Department of Health and Human Services, 2010). These Healthy People 2020 goals are consistent with the Surgeon General's call to action to improve the health of individuals with disabilities by providing accessible health initiatives that reduce the number of barriers to PA (U.S, Department of Health and Human Services, 2005). As a result, a national spotlight has been put on the creation and implementation of HPPs designed specifically for populations with disabilities.

In general, HPPs are designed to address a variety of personal, social, and environmental health concerns including nutrition, PA, prevention of disease, using seat belts, and smoking cessation (World Health Organization, 2012). Health promotion is defined by the World Health Organization (WHO) as the process of enabling people to increase control over and to improve their health (*Health promotion glossary*, 1986). Through the development and implementation of HPP's designed to meet the needs of individuals with disabilities, specialists can empower these individuals to take an active role in their own health through the adoption and maintenance of positive health behaviors. One component of a HPP is PA, which is considered to be a leading indicator of health (U.S Department of Health and Human Services, 2011), with physically active individuals being at reduced risk of morbidity and mortality.

Incorporating a PA based HPP into the rehabilitation program of individuals with mobility disabilities may allow individuals to manage associated conditions and decrease the presentation or severity of secondary and chronic conditions (Gioia et al., 2006; Rimmer & Rowland, 2008). For example, PA has been shown to improve self image, decrease depression and anxiety, increase social relationships, improve health markers, and facilitate functional maintenance and gains (Driver & Ede, 2009; Durstine et al., 2000; Gioia et al., 2006; Rimmer et al., 2000). PA has a wide range of benefits and can help to counteract the secondary and chronic conditions in addition to decreasing the severity of associated conditions (Durstine et. al., 2000).

Despite the many benefits of PA, 53% of people with disabilities get the recommended amount activity, compared to 69% of the general population (Centers for Disease Control and Prevention, 2009). In general, PA recommendations for individuals

with disabilities are consistent with those for the general population which recommend that cardiovascular exercise should be performed at a moderate intensity for 150 minutes or at a vigorous intensity for 75 minutes, or a combination of the two per week (U.S Department of Health and Human Services, 2008). In addition, resistance training incorporating all major muscle groups should be done on two or more days a week (U.S Department of Health and Human Services, 2008). These recommendations are the same for individuals with a disability as long as they are physically capable, otherwise they should strive to be as active as possible (U.S Department of Health and Human Services, 2008).

One factor that limits PA participation is the unique set of barriers that individuals with a disability have to overcome. In the context of health, barriers are any social, economic, personal, or environmental situation that hinders or prevents an individual from engaging in a desired behavior (Glasgow, 2012). One barrier faced by individuals with mobility disabilities is limited accessibility to resources including health clubs, equipment, and information on appropriate activities (Driver, Ede, Dodd, Stevens, & Warren, 2012; Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004; Rimmer, Riley, Wang, & Rauworth, 2005). Another barrier is a lack of knowledge about PA and the associated health and functional benefits (Driver & Ede, 2009; Driver et al., 2012; Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004). Environmental barriers such as uneven sidewalks, plants and tree roots, and poor rain drainage also prevent people with mobility disabilities from being physically active in their communities (Kirchner, Gerber, & Smith, 2008; Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004). Overall,



individuals with mobility disabilities face a unique set of barriers regarding accessibility of health resources and the environment that prevent regular PA.

One way to decrease the perceived barriers individuals face is to increase their self-efficacy, which is their belief in their own ability to be successful in a given situation (Bandura, 1986). Self-efficacy is one of the strongest predictors of PA adoption and maintenance resulting in successful behavior change (Reuter et al, 2010). The four main antecedents that influence self-efficacy are past performance, vicarious experience, social persuasion, and physiological states (Reuter et al., 2010). By positively influencing these antecedents, a HPP can increase self-efficacy and ultimately behavior (e.g., PA behavior). For individuals with mobility disabilities, increased PA has been shown to decrease the number and severity of secondary and chronic conditions experienced, leading to better health over the lifespan (Durstine et al., 2000; Bhambhani et al., 2005). Consequently, there is a need for accessible HPPs that meet the health needs of individuals with a mobility disability. Therefore, the purpose of this project is to examine the effectiveness of a HPP called PACE (Physical Activity Centered Education program).

A case study design will be adopted to examine how the 8-week PACE program affects participant's PA levels, perceived barriers, and self-efficacy. Case studies typically use both qualitative and quantitative data to examine "why" or "how" a phenomenon is happening within a real world setting (Yin, 2002). Small sample sizes are used in case studies making them ideal for providing feedback in the early stages of program implementation. In this study, we will examine the effects of the educational program, which is delivered in a controlled setting (e.g., Health Promotion lab), on participants PA participation, barriers, and self-efficacy in a real world setting (e.g.,

living in the community). Our study will collect data in the early stages of the program implementation allowing for the collection of valuable feedback on program effectiveness, design, content, and implementation.

### **Purpose Statement**

The purpose of this study was to examine the effectiveness of the PACE program on improving PA behaviors and perceptions for individuals with mobility disabilities.

Specific Aim 1: Describe the effectiveness of the PACE program on increasing the participant's weekly physical activity and self-efficacy and reducing the barriers faced. Our *working hypothesis* was that the participant in the support group would report higher self-reported physical activity and exercise self-efficacy, and report facing a lower number of perceived barriers than the participant in the awareness group.

Specific Aim 2: Evaluate the participants experience with the content presented, mode of presentation, and any barriers to participation. We evaluated the program based on a semi-structured interview with the participant in the support group.

### **Limitations**

A case study methodology was utilized and thus this study was confined to the causal limitations associated with case studies. Case Studies lack the ability to control for confounding factors that may have affected outcomes of interest (i.e. the use of randomization to create comparable groups for each condition) as typically only one or two units of interest are examined. The PACE program was delivered to both groups simultaneously. However, history still has the potential to affect results as participants could have been differentially impacted by events not associated with program participation but which affected one or more outcomes of interest.

As is often the case with community based programs, it is difficult to control for confounding factors outside of the program content and delivery that may have impacted PA outcomes. Program delivery was standardized through the utilization of a single researcher to facilitate all sessions, but there was no attempt to control for or measure additional extraneous factors (e.g., different program settings, level of program adherence), thus eliminating the researchers' ability to examine any affects of extraneous variables on program outcomes.

In addition to the case study design, utilization of self-report measures is also a limitation for this study. All outcome measures were subjectively reported which limits the trustworthiness of the data. Participants could have had selective memory causing inaccuracy of responses. Additionally, the participants could have responded to questions based on perceived subjective norms or social desirability instead of what actually

occurred. Subjective measures make it difficult to provide strong evidence for possible interactions.

### **Delimitations**

The population of interest was limited to adults with mobility disabilities who lived in the Pacific Northwest. These inclusion criteria prevent generalizability to (1) children and adolescents with or without a mobility disability, (2) adult males without mobility disabilities, and (3) adult males with mobility disabilities who reside in other geographical locations. Additionally, participants were allowed to self-select into the awareness or support group. Self-selection limits the researchers ability to discern program impacts as systematic differences between those that would choose the awareness versus support group may exist and cannot be categorized based on the limited sample examined. Additionally, the program was delivered during the spring/summer when whether would have been more conducive to outdoor PA and transportation.

## **Literature Review**

Individuals with a mobility disability remain largely inactive with only 53% of the population getting the recommended amount of physical activity for maximal health benefits (this value is 69% in the general population) (Center for Disease Control and Prevention, 2011). Regular physical activity reduces an individual's risk for many chronic health problems including, heart disease, high blood pressure, diabetes, obesity, and some cancers (Center for Disease Control and Prevention, 2011). Due to the extensive health benefits associated with regular activity, the high percentage of individuals with a disability who are inactive is detrimental not only for their individual health but also from an economic perspective. Total treatment costs for individuals with mobility disabilities are upwards of \$150 billion annually (Centers for Disease Control and Prevention, 2012; Centers for Disease Control and Prevention, 2012; MacKenzie et al., 2007; National Spinal Cord Injury Statistical Center, 2010). If individuals with a disability were more physically active then they may be at decreased risk of poor health and reduced burden on the health care system.

### **Health Conditions**

Rimmer and Rowland (Rimmer & Rowland, 2008) created a model describing the interrelationship between secondary, associated, and chronic conditions. Associated conditions are specific to individuals with disabilities and develop as a direct result of their primary disability. Associated conditions common to individuals with a mobility disability include aphasia and autonomic dysfunction. Aphasia refers to damage to the brain that affects any or all of speaking, reading, writing, and listening (American

Speech-Language-Hearing Association, 2012). Autonomic dysfunction is any malfunctioning of the autonomic nervous system which controls all involuntary body functions including blood pressure, heart rate, thermoregulation, and endocrine responses (National Institute of Neurological Disorders and Stroke, 2011). Associated conditions are not entirely preventable but may be managed by medications, therapy, or even PA, thus reducing the risk of further disability (Rimmer and Rowland, 2008). However, when left untreated, associated conditions can prevent individuals from maintaining homeostasis or communicating with others effectively, either of which can negatively affect PA. The reciprocal relationship between associated conditions and PA is an important consideration when developing programs to improve the health of individuals with a disability. However, associated conditions are not the only factor dictating the health of an individual with a disability.

Along with associated conditions, secondary conditions also contribute as a health determinant. The *Healthy People 2010* (U.S Department of Health and Human Sciences, 2010) report defines secondary conditions as “medical, social, emotional, family, or community problems that a person with a primary disabling condition likely experiences”. A study by Gaudet et al. (2011) found that individuals with spinal cord injury (SCI) experience higher levels of anxiety and depression and lower levels of extraversion. Moreover, individuals with SCI that do not participate in sports have even lower scores than those individuals with SCI that do participate in sports (Gaudet et al., 2001). Furthermore, Gentleman et al. (2001) found that individuals with TBI have negative feelings about their own cognition, adaptability, and relationships post injury. Overall, individuals with mobility disabilities report higher levels of psychological

distress (anxiety and depression) than individuals without a mobility disability (Chang et al., 2011; Desmond, 2007). In addition to these affective secondary conditions, individuals with a mobility disability also develop physical secondary conditions (Chang et al., 2011). Physical secondary conditions including pain, deconditioning, and weight problems result in decreased functional ability, which makes activities of daily living difficult (Chang et al., 2011; Couture, Caron, & Desrosiers, 2010). Secondary conditions impact function and activity levels but can be prevented or made less debilitating by healthy behaviors like PA (Rimmer & Rowland, 2008). Positive health behaviors serve as a means for reducing the affects of negative health conditions associated with having a disability and therefore should not be overlooked when designing and implementing rehabilitation programs for individuals with mobility disabilities.

In addition to associated and secondary conditions, chronic conditions also play a role in determining health behaviors (Rimmer & Rowland, 2008). In contrast to associated and secondary conditions, chronic conditions are linked to lifestyle rather than disability and thus can be present even before an individual is diagnosed with a disability (Rimmer & Rowland, 2008). Chronic conditions linked to inactivity include heart disease, cancer, Type 2 Diabetes, and obesity (Center for Disease Control and Prevention, 2011). As chronic conditions are a result of lifestyle, relative risk can be reduced and even prevented with positive health behaviors like regular PA (Rimmer and Rowland, 2008). Associated, secondary, and chronic conditions are all interrelated and, while they represent separate health states, influence the development of other health conditions which makes reducing their presence an important component of health and rehabilitation programs (Rimmer & Rowland, 2008).

In addition to health conditions, personal and environmental factors also influence an individual's health behaviors (Rimmer & Rowland, 2008). Personal factors include primary impairment, self-efficacy, motivation, and health behaviors; environmental factors include transportation and access to health promotion services (Rimmer & Rowland, 2008). Both personal and environmental factors can have a positive or negative effect on health. For example, an individual with a mobility disability that does not have transportation (environmental factor) to go to a gym, park, etc to be active will not be as physically active and as a result are at greater risk to develop secondary and/or chronic conditions. On the other hand, if that individual had available transportation, they would be more likely to get to the gym and be more physically active leading to better health. Taking personal factors into consideration, someone who has greater self-efficacy in their ability to be physically active will likely be more active and experience fewer health conditions than someone who has low self-efficacy to be active. Health conditions and personal and environmental factors can facilitate or hinder PA participation. Consequently, it is the job of health professionals to provide individuals with the tools to overcome or alter those factors that hinder PA, thus allowing for the development of a healthier lifestyle.

### **Health Promotion Programs**

Specialists are challenged to find ways to address the health needs of individuals with mobility disabilities. HPPs that include PA have been shown to be an effective rehabilitation tool for improving health (Abdullah et al., 2004; Ravesloot, Seekins, & Cahill, 2007; Ravesloot 2005; Rimmer, 2000; Rimmer 2002; Rimmer 2002; Stuifbergen, Becker, Blozis, Timmerman, & Kullberg, 2003). HPPs are designed to address a variety



of personal, social, and environmental health concerns including nutrition, PA, prevention of disease, using seat belts, and smoking cessation (World Health Organization, 2012). Health promotion is defined by the World Health Organization (WHO) as the process of enabling people to increase control over and to improve their health (*Health promotion glossary*.1986). In the context of the Surgeon General's Call to Action the WHO definition would mean using HPP as the means to enable individuals to learn how to alter personal and environmental factors allowing them to take greater control over the improvement of their health. Ultimately, the goal of any HPP is to empower individuals so they can adopt and maintain the desired health behavior on their own (World Health Organization, 2012).

Rimmer et al. (2000) examined the effects of a 12-week intervention on health outcomes (lipid profile, strength, flexibility, dietary fat intake, and mental health) in African American Stroke survivors. Participants included 35 people (9 females and 26 males) with an average age of 57 (SD= 8.25) who have had a stroke. The intervention, given 3 days a week for the 12 week period, included nutrition education (60min), exercise (45-70min), and behavior change (60-90min) components. The results show increases in endurance, strength, and flexibility while total cholesterol and fat mass both decreased. The outcome of this study supports the use of a HPP to improve functional ability which leads to improvements in secondary and chronic conditions.

Another study by Rimmer et al. (2002) looked at a 12-week intervention on compliance and health outcomes (strength, endurance, nutrition knowledge, and lipid profile) in African American women with type 2 Diabetes. Participants included 30 women with a mean age of 54.9 (SD=12.6) who had type 2 Diabetes in addition to one or

more chronic conditions (obesity, joint-pain, depression, etc.). The intervention was a university based program that consisted of nutrition, diet, and health behavior components. Compliance for the intervention was 72.5% with participants showing improvements in total cholesterol, nutrition knowledge, endurance, and strength. Again, this study supports the use of a HPP to improve physical markers associated with functional ability.

Stuifbergen et al. (2003) examined the effects of a wellness program for women with multiple sclerosis (MS) on self-efficacy, barriers, quality of life, and health behaviors. Participants included 113 women with an average age of 45.79 (SD=10.09) who were clinically diagnosed with MS. The program consisted of 8 sessions (90 minutes each over 8 weeks) on lifestyle change. Session topics included healthy eating, stress management, exercise for fun, and strength and endurance and provided information on individual behavior assessments, resources, and barriers, as well as strategies for building self-efficacy needed to maintain these health behaviors. In the three months following the intervention, participants received bimonthly telephone calls to encourage progress toward goals and track goal completion. Improvements in health behaviors, self-efficacy, and quality of life measures (pain and mental health) were found. This intervention demonstrates the usefulness of a behavior change component in an HPP in improving long term health.

Raveslout et al. (2005) investigated the effects of a community-based program (*Living Well with a Disability*) on symptom days, health care costs, and secondary conditions for individuals with a mobility disability. The population sample consisted of 188 individual's with an average age of 45 (SD=13.4) who had been living with a

mobility disability for an average of 17.5 years. The intervention group met for 2 hours weekly over an 8 week period. The intervention was led by trained facilitators who led discussions and helped the participants with written assignments and was broken into two sections, establishing goal pursuit and health behavior change to facilitate reaching quality of life goals. Improvements were seen in secondary conditions, along with decreases in symptom days and health care costs (\$807/person) upon completion of the intervention and were maintained 12 months after completion. These results show the benefits of a HPP on long-term quality of life and health care costs.

A study conducted by Rimmer et al. (2009) examined the effects of a health promotion program on the physical activity level in predominantly African American women with a mobility disability and severe obesity. Inclusion criteria for study participation included being 18 years of age or older, a self-reported mobility disability, BMI of 27 or greater, receiving care at an outpatient program, sedentary behavior, and the ability to communicate in English. A total of 92 participants ( $M_{age} = 58.8$  years) were randomized into one of three different groups including: awareness, personalized exercise program with low levels of support, or personalized exercise program with high levels of support. The awareness group received an informational brochure on physical activity and a toolkit (including a pedometer, postcards to record PA and progress, safety precautions for PA, directions for monitoring heart rate, health diet and water information, and the phone number for the national center of disability) to help them begin an exercise program. The low level support group received the toolkit, a monthly newsletter and a weekly phone call with a health professional to plan and facilitate the maintenance of a physical activity program. The high level support group received the

toolkit, monthly newsletter, weekly phone call and a monthly face-to-face exercise support group to provide support and encouragement for physical activity, Participants in the low and high level support groups reported higher levels of physical activity (Physical Activity and Disability Scale) than the awareness group. In addition, the high level support group had a decrease in BMI whereas the awareness and low level support groups did not. The results of this study suggest that interventions that provide more support (e.g., no personal contact < phone contact < face-to-face contact) produce better results than lower intensity health promotion programs.

The creation and implementation of HPPs for individuals with disabilities is consistent with current state and national initiatives. Every decade the U.S Department of Health and Human Services issues a set of goals and objectives for national health promotion and disease prevention efforts (U.S Department of Health and Human Services, 2010). The goals of Healthy People 2020 include a goal to “promote the health and well being of people with disabilities” (U.S Department of Health and Human Services, 2012). To achieve this goal, Healthy People 2020 has objectives to reduce barriers to PA for individuals with disabilities as well as to provide more health services and interventions targeting this population nationwide (U.S Department of Health and Human Services, 2012). These Healthy People 2020 goals are consistent with the 2005 Surgeon Generals call to action to improve the health of individuals with disabilities by providing accessible health initiatives that reduce the number of barriers to activity (U.S Department of Health and Human Services, 2005). As a result, a national spotlight has been put on the creation and implementation of HPPs designed specifically for populations with disabilities.

### **Benefits of Physical Activity**

One area of focus for HPPs is PA, which has been shown to improve both affective and physical health (Gioia et al., 2006). By increasing the PA behaviors of individuals with mobility disabilities both the affective and physical secondary conditions resulting from disability can be improved (Durstine et al., 2000). For example, a study by Driver and Ede (2009) examined the effect of a PA intervention on the mood states of 16 individuals with TBI. Participants ( $Mage = 37.65$ ;  $SD = 2.34$ ) were randomly assigned to the support or awareness group. The support group went through an 8-week aquatics program that met for one hour 3 times a week and consisted of cardiovascular and resistance training. Both groups completed the Profile of Mood States pre and post program to determine changes in chronic mood states. Individuals in the support group experienced significant improvements in mood through decreases in depression, anger, fatigue, and anxiety and increases in vigor when compared to the awareness group. Results indicate that PA is effective in improving an individual's affective state.

Gioia et al. (2006) examined the effect of activity levels on psychosocial variables in 137 men with SCI ( $Mage = 34.21$ ;  $SD = 11.36$ ) who had an SCI at C-5 or below, were dependent upon a wheelchair, and were injured at least 5 years prior to the study. Based on self-report data, participants were grouped into a highly active (three times a week) or not active group. Results demonstrated that individuals who were physically active were less anxious and depressed and more outgoing than those that did not participate in PA. Findings highlight the important psychosocial benefits of regular PA for individuals with mobility disabilities.

Rimmer et al. (2000) examined the effectiveness of a PA program on physical health outcomes (flexibility, strength, body composition, and oxygen uptake) in African American stroke survivors. The 35 participants (9 male and 26 female) were an average age of 53.2 (SD=8.3), could walk 50 feet with or without assistance, and were at least 6 months post stroke. The 12-week program met for three one-hour sessions each week and consisted of cardiovascular endurance (30 min), muscular endurance and strength (20 min), and flexibility (10 min) components along with instruction on how to measure rate of perceived exertion and how to exercise safely (proper machine usage and warning signs to stop exercise). Results revealed that after completing the PA program, participants had improvements in peak  $\text{VO}_2$ , body composition, and strength. Findings demonstrate the importance of PA in improving health markers which leads to a retention of functional ability reducing secondary and chronic conditions.

A study by Bhambhani et al. (2005) examined the effects of a circuit-training program on body composition and cardiorespiratory responses (power output and oxygen uptake) in adults with TBI. Participants had an average age of 31.8 (SD=9.9), were able to pedal a cycle or hand ergometer without assistance, and were on average 17.2 (SD=17) months post injury. The intervention consisted of a 12-week training program that met 3 times a week and consisted of a warm-up (5-10min), a circuit with both cardiovascular and resistance training (45min) and a cool down (5min). While the results showed no changes in body composition, there were increases in power output and oxygen uptake. The results of this study indicate the cardiovascular benefits of PA for individuals with TBI.

Collectively, results from these studies highlight the physical and affective benefits of PA for individuals with a mobility disability. PA programs decrease negative affective states like anxiety and depression while also increasing positive affective states such as extraversion and vigor (Driver & Ede, 2009; Gioia et al., 2006). PA has also been shown to improve physical health markers like strength and endurance allowing individuals to maintain and/or improve their functional abilities ultimately reducing their risk of secondary and chronic conditions (Rimmer, 2000). In addition to these improvements in secondary conditions, PA has been shown to improve associated conditions and decrease the presentation or severity of chronic conditions (Durstine et al., 2000; Bhambhani et al., 2005).

### **Physical Activity Barriers**

Completing the recommended amount of physical activity is difficult for individuals with mobility disabilities because they face many unique PA barriers. Barriers can be internal or external in nature and prevent an individual from performing a desired behavior (Glasglow, 2012). An example of an internal barrier would be how tired an individual is, whereas external barriers include aspects of the built environment and a negative social support system. These barriers all hinder an individual's ability to be active and to continuously do so. Individuals with mobility disabilities face a unique set of barriers that includes both environmental and personal factors (Driver, Ede, Dodd, Stevens, & Warren, 2012; Kirchner, Gerber, & Smith, 2008; Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004; Rimmer, Riley, Wang, & Rauworth, 2005).

A study by Kirchner et al. (2008) examined the prevalence of community barriers for individuals with mobility and visual impairments. A nonrandom sample of 134

individuals with a mobility or visual impairment responded to an initial survey about perceived PA levels and community accessibility as well as a follow up survey on barriers and strategies for outdoor activities. Since the sample was not random, the results were presented as percent of responders that reported an element (i.e narrow sidewalks) to be a barrier. “Problems with sidewalk pavement” (91%), “problems with puddles or poor drainage” (81%), and “Problems with construction” (70%) were the most common barriers reported. These result show that community construction and design are barriers that need to be considered when developing PA plans for individuals with mobility disabilities.

A study by Driver et al. (2012) examined the PA barriers faced by individuals with TBI. Participants consisted of 28 adults ( $M$  age = 44.11,  $SD$  = 16.23) who were part of an outpatient program and did not have significant cognitive impairments, which was determined by clinical evaluation. Participants completed questionnaires assessing amount of weekly PA completed, barriers faced, perceived importance of PA, and exercise stage of change. The average number of barriers reported was 2.25 ( $SD$ =2.526) with the most common environmental barriers being lack of transportation (25%) and lack of an accessible facility (17.9%). The most commonly reported personal barriers were low endurance (28.6%), feeling self-conscious in a fitness center (25%), and a lack of time (21.4%). While the barriers reported were similar to those reported in previous studies, the frequency of the barriers faced was considerably lower. And was attributed to the fact that participants were still in the outpatient care program and thus receiving support from the staff. It is important to recognize that the number of barriers faced may increase when individuals leave the supportive rehabilitation program and enter the real



world, emphasizing the need for programs that can help individuals adjust to real world settings.

In another study (Rimmer et al.; 2004), the barriers to PA faced by individuals with were examined from the point of view of (1) people with disabilities, (2) architects, (3) fitness and recreation professionals, and (4) city planners and park district managers. Consequently, four focus groups were conducted in 10 different regions in the U.S. Each focus group addressed accessibility issues of swimming pools, fitness centers, parks, and trails. Participants in the disability group all had some form of mobility impairment (i.e., limited use of arms/hands/legs, SCI, or back problems) and had an average age of 40.19 ( $SD = 12.84$ ). Results indicated that the major categories of barriers were built and natural environment, cost, equipment, and knowledge among others. These categories are consistent with the barriers reported in other studies, further emphasizing the importance of accessible programming and increasing knowledge about the health benefits of PA.

Stroud et al. (2009) examined barriers faced by individuals with multiple sclerosis through self-report questionnaires. Participants included 93 adults ( $M$  age = 50;  $SD = 10$ ) who received through the mail questionnaires assessing amount of physical activity completed, disability status, and barriers. The most reported barriers included a lack about the knowledge of the benefits of PA as well as low self-efficacy. Results demonstrate the importance of programs that inform individuals on the benefits of PA as well as programs that focus on improving self-efficacy in order to increase total levels of PA.

A study by Damush et al. (2007) examined the PA barriers and facilitators for individuals who have had a stroke. 13 participants with a mean age of 59 ( $SD = 12.3$ )

participated in focus groups discussing barriers and facilitators to PA post stroke.

Common barriers included a fear of exercising post stroke with altered physiological and functional abilities, a lack of accessible transportation, and an inability to participate in favored activities. Results highlight that program accessibility is a main barrier in addition to a lack of knowledge about available PA options and their own capacity for PA.

In another study, Odette et al. (2003) completed a series of focus groups to indentify the barriers to participating in a physical activity HPP. Participants consisted of 45 women who had a chronic condition including CP, MS, stroke, and Polio with a range in age of 18-80 years (*M* age = 43). Barriers to participation included a lack of available programs that meet their specific needs, lack of attention to safety while exercising by program facilitators, physically inaccessible programs, and limited physical capacity to participate. Results further highlight the need for more accessible programs that are run by trained professionals who understand the needs of individuals with mobility disabilities.

In summary, individuals with mobility disabilities have to overcome unique barriers in order to be physically active. Community barriers in the form of both built environment and inadequate supports hinder the ability of individuals to be active in their communities. In addition, personal barriers including a lack of knowledge about the benefits of activity or the appropriate activities to complete limits individuals from engagement in PA. One way to decrease the barriers faced is to change the individual's perceptions of their own ability to overcome obstacles.

### **Theoretical Framework**

The Social Cognitive Theory (SCT) (Bandura, 1986) provides a theoretical framework for how to increase an individual's confidence in his or her own ability to complete a behavior. SCT describes how the interaction between personal, behavioral, and environmental factors can determine the ability of an individual to be successful in a given situation (Bandura, 2004). How an individual reacts in a situation, their behavioral responses, varies greatly. For example, an individual may respond to a situation one way and then have a completely different response the next time they face an identical situation (Jones, 1989). This variability in responses comes from an individual's evaluation of the situation rather than the situation itself (Jones, 1989). Therefore, by changing an individual's belief in their own abilities (self-efficacy), it is possible to change their perceptions of a situation allowing for a desired behavioral response regardless of circumstances (e.g., barriers faced). Thus, increasing an individual's self-efficacy will alter their ability to be successful in given situations (Bandura, 1986).

The SCT has been adopted to explain PA behaviors and goal achievement (Driver, 2006; McAuley, 1993; McAuley, 2000). Self-efficacy is one of the strongest predictors of PA adoption and maintenance resulting in successful behavior change (Halworth et al., 2009; Reuter et al., 2010). As a result, a key goal of HPP implementation is increasing an individual's self-efficacy so they have a greater belief in ability to overcome barriers and be more active. An individual with high self-efficacy will believe they have the ability to overcome their PA barriers (e.g., low energy, poor weather, etc) allowing them to be more active than an individual that has low self-efficacy. The four antecedents of self-efficacy are past performance, vicarious experiences, social persuasion, and physiological states (Reuter et al., 2010). By

manipulating and improving these antecedents through HPP delivery, an individual's self-efficacy can be increased, resulting in increased PA levels. For individuals with mobility disabilities, increased PA participation will decrease the number and severity of secondary and chronic conditions experienced, leading to improved health across the lifespan (Durstine et al., 2000; Bhambhani et al., 2005).

Due to the many health issues that have been linked to inactivity, developing evidence-based strategies that increase the PA participation of individuals with mobility disabilities is a critical step to improve the population's health.

## **Method**

### **Participants**

A case study approach to the project was adopted with data being collected on two participants (one each from the support and awareness group) with a mobility disability. The term mobility disability includes individuals with impaired physical functioning limiting major life activities, including individuals with a spinal cord injury, traumatic brain injury, amputation, stroke, and muscular dystrophy among others (Center for Disease Control and Prevention 2011). Participants were recruited through the trauma or physical therapy outpatient program at Good Samaritan Regional Medical Center (GSRMC), support groups (Stroke, Parkinson's, Traumatic Brain Injury) sponsored by GSRMC, and through a press release issued by the college. Participants were recruited from this population for two reasons. First, participants were not receiving care at GSRMC or alternate medical center, which means they were experiencing what life is like with their disability in a real world setting (e.g., living in the community). While in the rehabilitation program, individuals have access to an accessible location and equipment with qualified specialists to guide their recovery process and will, thus, face fewer barriers to participation. While living in the community without these extra supports it is increasingly challenging to be active as they now face personal and environmental barriers common to real world settings. Second, while there are PA HPPs for individuals with disabilities, most focus on actual PA participation and skill acquisition (e.g., aquatics, strength, and/or endurance programs) rather than PA behavior change and education. For example, during the rehabilitation process, individuals with a

mobility disability are not educated about the benefits of PA, risk of inactivity, or taught social and behavioral strategies critical to the adoption and maintenance of activity.

A purposeful sample was used for this study with inclusion criteria: (1) 18-85 years of age, (2) had a self-reported mobility disability (permanently have difficulty walking one block or more, using an assistive device like a cane, walker, wheelchair, or crutches), and (3) were able to communicate in English. The exclusion criterion was cognitive impairment, which was assessed during the consent process with the MacArthur competence assessment tool (Bellin et al., 2010). Initially, six participants consented to be part of the study (PACE awareness n=2, PACE support n=4). However, four participants dropped out citing medical complications (n=2), lack of interest (n=1), and lack of time (n=1). Thus, one participant remained in each group (Participant A and S).

**Description of Participant A.** Participant A (awareness group) was an 83-year-old male who has Parkinson's disease. Participant A characterized himself as Caucasian and a retired trained professional with a high school degree or equivalent. He was married with grown children who no longer lived in the same residence. Participant A lived in a retirement community and was actively involved in a Parkinson's support group (where he was recruited for the PACE program). Additionally, participant A had a history of PA participation and reported being in the maintenance stage on the behavior stage-of-change scale. Participant A enrolled in the PACE program at the insistence of his wife and was initially unsure of the applicability of PACE content to him individually. However, after participating in the introductory modules and forming new PA goals, participant A expressed interest in the program and commented on the need to have more programs of similar design available to encourage positive health behaviors.

**Description of Participant S.** Participant S (support group) was a 64 year-old male who has Amyotrophic Lateral Sclerosis (ALS) affecting his lower extremities. Participant S identified as Caucasian and as a trained professional with a bachelors degree. Participant S was married with grown children no longer sharing a residence. Participant S was an active member of the disability community serving on community accessibility boards and advocating for improved accessibility of the built environment in his community. Furthermore, participant S was passionate about developing accessible solutions (e.g., lifts for kayak use) and sharing accessible information (e.g., writing a book on accessible trails in Oregon). Participant S had a history of PA participation but scored in the pre-contemplation stage on the stage-of-change scale. Participant S scored in this stage due to medical complications faced immediately before and during program participation. For example, in the months preceding program participation, participant S was experiencing pain and weakness in his neck and upper extremities that was preventing him from completing PA and certain ADL. Initially, it was unclear if these symptoms were indicative of a progression in ALS or due to some other factor. Shortly after the program began, participant S discovered that the symptoms he was experiencing were likely due not to ALS but to a stenosis of the neck which was applying pressure to nerves controlling the upper extremities. As a result, participant S opted to go through with surgery that would attempt to remove the stenosis and relieve the accompanying symptoms. Three weeks after completing the PACE program, participant S underwent surgery which resulted in the removal of the stenosis and reversal of associated symptoms solidifying the belief that the pain and weakness was in fact a result of the stenosis and his ALS had not spread. The progression of participant S's health condition

had a significant impact on his PA behaviors and likely influenced program outcomes (discussed in greater detail in the Results and Discussion sections).

## **Procedures**

Prior to beginning recruitment for this study, the Institutional Review Board at the university approved the study for human subjects ensuring that all procedures were ethical. Three different strategies were implemented to recruit participants for the study. First, patients at GSRMC were informed of the study by their therapist in the last week of their enrollment in the trauma or outpatient physical therapy programs and were provided with a flier that included a description of the program and the study contact information. Second, student researchers attended support group meetings to give a presentation about PA and the PACE program then distributed flyers with contact information. Finally, a press release approved by the University with a program description and contact information was released to the general public. Interested individuals contacted the research team and were informed of open house events at the *Health Promotion for Disabilities Lab* at Oregon State University. These open house events were used to answer any remaining questions about the PACE program and to complete the screening questionnaire and consent form. The screening questionnaire included questions on age, mobility disability (yes/no), ability to communicate in English (yes/no), and cognitive impairment with the MacArthur competence assessment tool (Bellin et al., 2010).

The MacArthur competence assessment tool consists of five questions that measure participant's comprehension of the research study. These questions include: (1) the participant's understanding of the purpose of the study ("What is the purpose of this research?"), (2) activities involved in participation in the study ("How many visits are



you asked to participant in?”), (3) benefits of participating in the study (“In what way might you benefit by volunteering in this study?”), (4) risks and discomforts associated with participation (“Tell me about possible risks associated with participation”), and (5) procedure to withdraw from the study (“What will you do if you decide that you no longer want to participate in this study?”). Responses will be scored on a 0-2 scale (0=inadequate, 1=partial understanding, 2=adequate understanding). Participants must score an 8 out of 10 or higher on the measure to be involved in the study (Bellin et al., 2010). During the consent process, participants were informed that their personal information will remain private and non-identifiable.

Individuals who met the enrollment criteria for the study chose to participate in either the experimental (PACE program with supports) or control group (PACE program without supports). The participant in the support group completed the pre-assessment questionnaires (see Measures section) in a private setting at the *Health Promotion for Disabilities Lab* at Oregon State University one week prior to beginning the PACE program. PACE consisted of an 8-week behavior change intervention (see Driver, Irwin, Woolsey, & Pawlowski, 2012, for complete details of the program) that was administered in a group setting (3 participants) during the first session and then on a one on one basis as one participant dropped out due to health concerns and one due to lack of time. Participant S and the student researcher met once a week for approximately 90 minutes for a total of 8 sessions at the *Health Promotion for Disabilities Lab*. Sessions were all taught by the same student researcher and included discussion over:

Week 1: Introduction to PA (see appendix G)

Week 2: Exercise is Medicine

Week 3: Goal Setting and Overcoming Barriers

Week 4: Tracking Behavior and Self-Reward

Week 5: Managing Frustration and Discouragement

Week 6: PA, Quality of Life, and Community Involvement

Week 7: Re-evaluating Goals

Week 8: How to Maintain Health Habits

Each session consisted of: (1) discussion over their weekly PA efforts (goals met, barriers faced, and facilitators), (2) review of the previous meeting's content, (3) discussion of the current weekly topic, and (4) determining next weeks PA goals. One week after completing the 8-week intervention, the participant completed the post assessment questionnaires.

A follow-up meeting was scheduled four weeks after the completion of the program where the participant completed the same assessment battery, as well as an interview evaluating the PACE program. The interviewer asked the participant about the program content, delivery, strengths, weaknesses, and suggestions for improvement. A moderator guide (see appendix F) including the interview questions was used to help guide the interview and keep the discussion focused. To reduce reactivity, the interviewer was not the same student researcher that delivered the program and the interview was recorded and transcribed at a later date.

Participant A in the awareness group completed the consent process and the pre-assessment questionnaires. Each week, instead of completing the PACE program with an instructor at the *Health Promotion for Disabilities Lab*, the participant was mailed the PACE program materials and completed the program independently each week. In

addition, the participant in the awareness group was contacted weekly over the phone to go over any questions they had about program materials. After 8-weeks, the participant completed the post assessment questionnaires. It is important to note that participant A declined to participate in the follow-up assessment and program evaluation citing a lack of interest in participating in the interview. Thus, no follow-up data is presented for participant A.

### **Measures**

The questionnaires included: (1) a demographic form, (2) amount of physical activity (Rimmer et al., 2001) (3) self-efficacy to be active (Marcus et al., 1992), and (4) barriers to physical activity for people with disabilities (Rimmer et al., 2000) (see appendices A-E). Amount of PA was measured using the Physical Activity and Disability Survey (PADS) (Rimmer et al., 2001). PA measures for individuals in the general population do not measure light intensity activities (i.e. stretching, walking, and gardening) and thus have a base line activity level higher than that performed by most individuals with a disability. As a result, the PADS was developed as a means of measuring this light activity time for individuals with a disability or chronic health condition. The PADS consists of 28 items across 3 subscales: (1) leisure time PA (7 items), (2) house-hold activity (16 items), and (3) exercise (8 items) as well as demographic items. The leisure time activity subscale focuses on unstructured activity such as walking and bowling (How much time do you spend doing the activity?). The household activity subscale measures indoor and outdoor activity such as vacuuming and gardening (“Do you do any outdoor household activities such as gardening?”). The exercise subset measures intentional exercise such as cardio and resistance training

("How would you describe the intensity of your exercise program?"). The demographic section of the PADS will be completed during the pre assessment and includes information on type of disability, level of physical impairment, and demographic information. The three items on indoor time are on a 3 point Likert scale and represent the total time spent indoors and time spent sleeping or sitting. The leisure PA, household activity, and exercise subscales are reported in total amount of time spent in each activity. Totaling the responses for leisure PA, household activity, and exercise time provides total weekly PA time. The PADS measurement has been shown to have good internal consistency as well as reliability and predictive and current validity for individuals with a mobility disability (Rimmer et al., 2001).

Barriers to PA participation were assessed using the Barriers to Physical Activity Scale for People with Physical Disabilities (B-PADS) (Rimmer, et al., 2000). The B-PADS has been used effectively with a variety of groups including African-American women with a physical disability (Rimmer et al., 2000), adults with visual and motor impairments (Kirchner, Corinne E. 2008), adults post stroke (Rimmer, 2008), and adults with a brain injury (Driver et al., 2012). There are 34 items on the B-PADS, 31 have 3 answer choices ("yes", "no", and "don't know") while the remaining 3 are open-ended questions. Items determine an individual's interest, perceived importance, and personal or environmental barriers faced when considering PA. Answers are typically reported in percent of participants that answer either "yes", "no", or "don't know", however are reported here as number of barriers faced due to the low number of participants. Test-retest reliability has been reported as .76 (Rimmer et al., 2000).

The Exercise Self-Efficacy Scale was used to measure an individual's confidence in his/her ability to engage in PA in the face of barriers (Marcus et al., 1992). The questionnaire begins with a qualifying question asking participants how confident they are that they can be physically active when faced with certain barriers including (1) negative affect (i.e., "I am under a lot of stress"), (2) excuse making (i.e., "I feel I don't have the time"), (3) must exercise alone (i.e., "I have to exercise alone"), (4) inconvenient to exercise (i.e., "I don't have access to exercise equipment"), (5) resistance from others (i.e., "I am spending time with friends or family who do not exercise"), and (6) bad weather (i.e., "It's raining or snowing"). The scale is scored using a 5-point Likert scale ranging from 1 (*not at all confident*) to 5 (*completely confident*). Scores from each item are added and the total score is used. High scores indicate an individual is very confident in his/her ability to engage in PA despite barriers, while low scores indicate low confidence. Test-retest reliability for this scale has been reported as .90 over a two-week period, demonstrating stability of the measure over time (Marcus, 1992).

### **Data Analysis**

Quantitative data was gathered to describe changes in participant's number of barriers for PA, total weekly PA, and self-efficacy for PA over the duration of the program. Quantitative data was depicted using frequencies and graphic presentations and percent change was reported between pre-, post, and follow-up scores.

Qualitative data was collected during the post-intervention interview. The interview occurred four weeks after the completion of the program and was conducted at participant S's home at his request as he was still recovering from surgery. The interview lasted one hour and the audio recording of the interview was transcribed including all

interviewer questions, participant answers, and audible behaviors (i.e. intonation, sounds, pauses). Once transcribed, three investigators with backgrounds in PA and disability coded the data (investigator triangulation) to increase the trustworthiness of the data. A cross-case analysis was used to identify themes and conceptual patterns in the responses. To accomplish this analysis, the investigators first met to re-familiarize with the purpose of the study. Investigators then developed codes while highlighting relevant quotes with the data being grouped into smaller related parts and labeled with descriptive codes or titles. Similar sections were labeled with the same code. The three investigators then discussed their individual codes and themes to create a final coded copy of the transcript. In this way, trustworthiness was established in that all investigators agreed on both codes and themes.

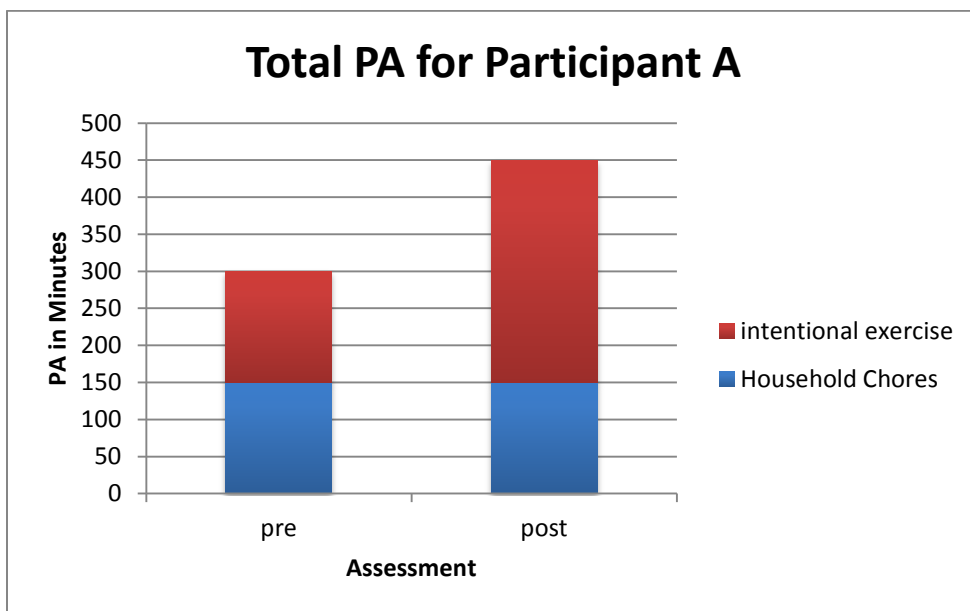
## Results

### Specific Aim 1

Specific Aim 1: Describe the effectiveness of the PACE program on increasing the participant's weekly physical activity and self-efficacy and reducing the barriers faced. Our *working hypothesis* was that the participant in the support group would report higher self-reported physical activity and exercise self-efficacy, and report facing a lower number of perceived barriers than the participant in the awareness group.

**Participant A.** Changes in total time in PA can be seen in figure 1.

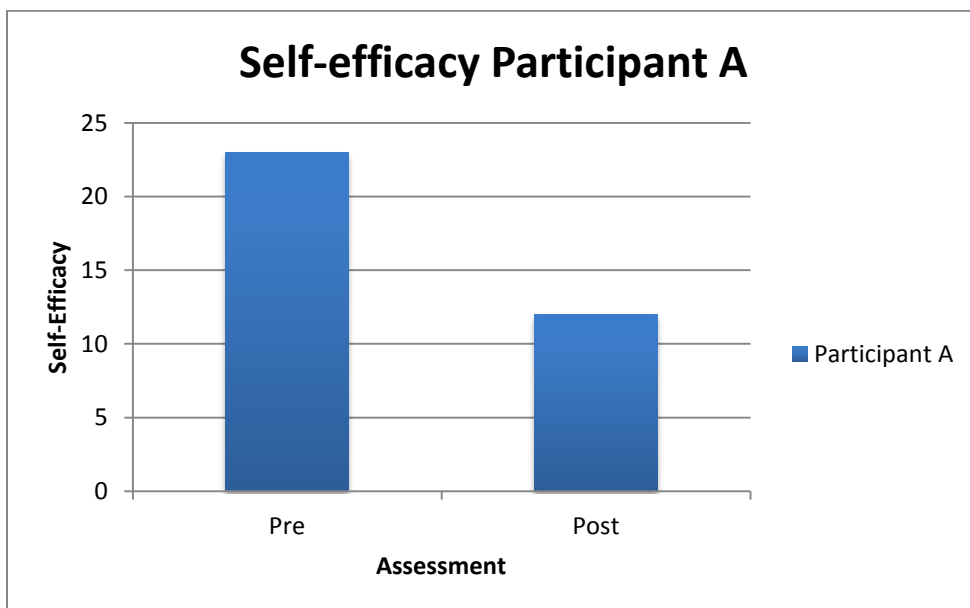
Figure 1: Total PA for participant A



PA from household chores remained constant while PA from intentional exercise increased 50% (150-300) resulting in a 33% (300-450) increase in overall weekly minutes of PA.

Changes in Self-efficacy can be seen in figure 2.

Figure 2: Self-efficacy for participant A

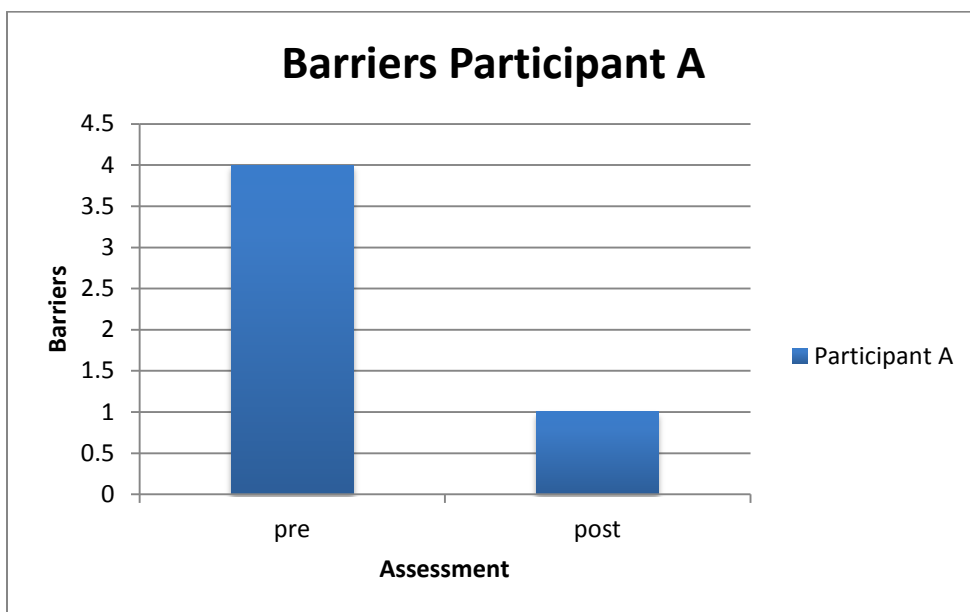


Participant A's total self-efficacy score decreased 47.8% (23 to 12) from pre to post assessment. Item scores decreased for "must exercise alone" (3 points), "inconvenient to exercise" (3 points), "bad weather" (3 points), "excuse making" (1 point), "resistance from others" (1 point) and the item score for "negative affect" remained the same. The average item score decreased from 3.8 ("very confident") to 2 ("somewhat confident") from pre to post.



Change in barriers for PA can be seen in figure 3.

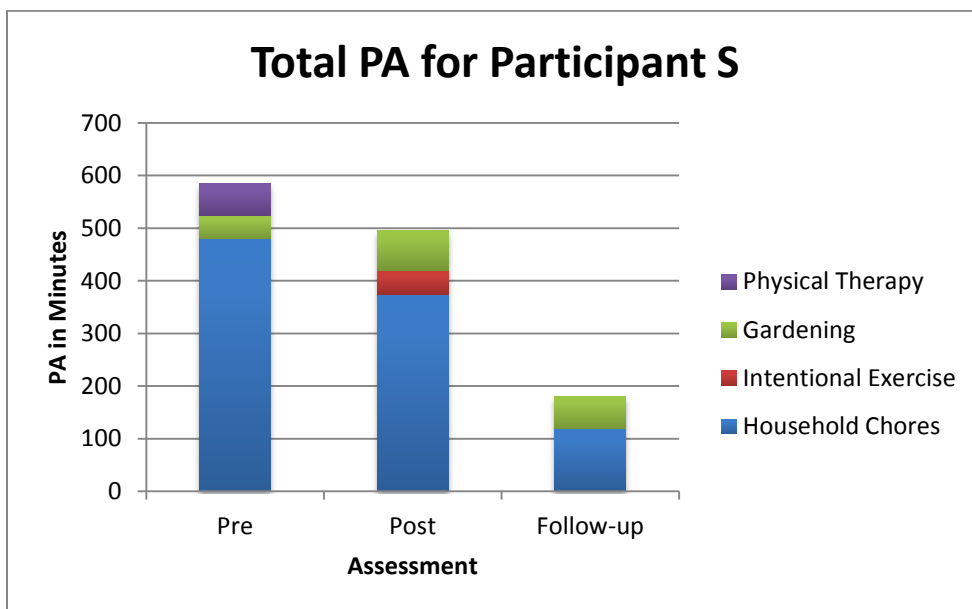
Figure 3: Barriers for participant A



The number of PA barriers faced decreased by 75% (4 to 1) from the pre-assessment to the post assessment. During the pre assessment, the barriers that participant A reported facing were boredom, lack of interest, health concerns preventing PA, and cost of an exercise program. By the post assessment, participant A reported only cost of program as a barrier.

**Participant S.** Changes in total PA can be seen in figure 4.

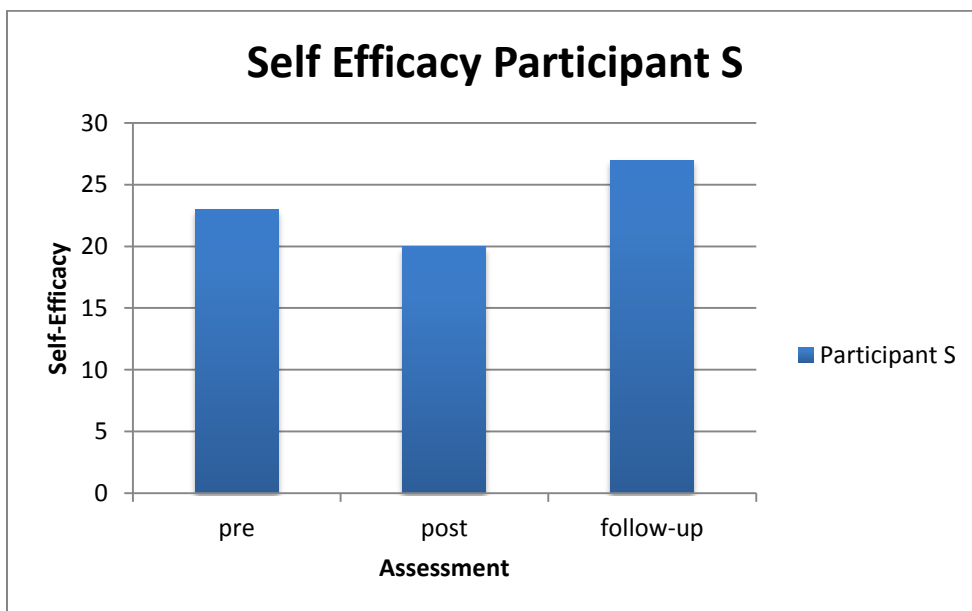
Figure 4: Total PA for participant S



Participant S reported an 8.3% decrease in total PA from pre to post assessment (540 to 495 minutes/week) with a further decrease of 63.6% at the follow-up assessment (549-180). However, at the post assessment participant A reported 45 minutes of intentional exercise compared to none at the pre assessment.

Changes in Self-efficacy can be seen in figure 5.

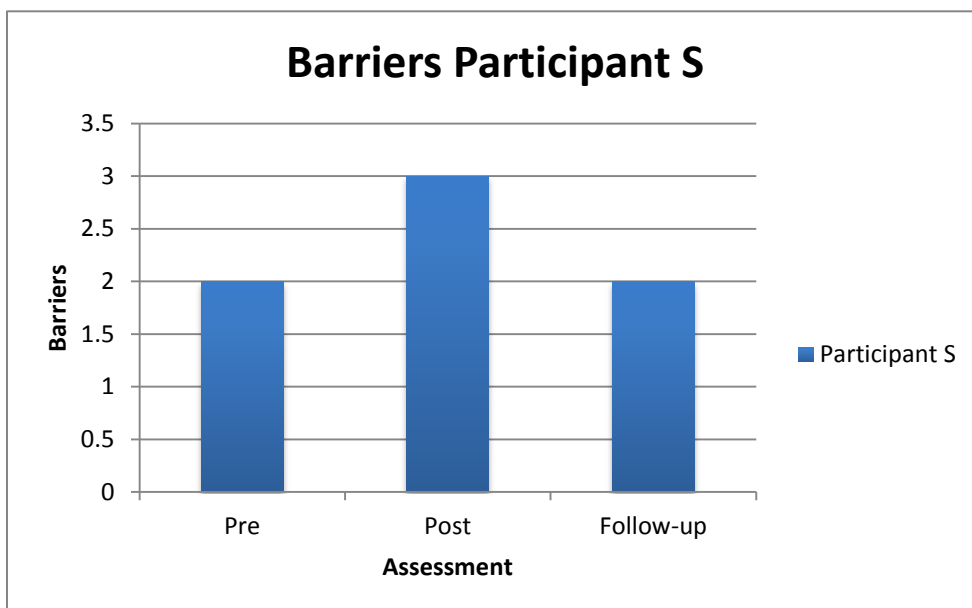
Figure 5: Self-efficacy for participant S



Participant S's total self-efficacy score decreased 13% (23-20) from pre to post assessment. Items decreased for negative affect (2 points), must exercise alone (1 point), and inconvenient to exercise (1 points) decreased, items for excuse making and resistance from others remained constant and the item for bad weather increased (1 point) from pre to post assessment. The average item score decreased from 3.8 ("moderately confident") to 3.3 ("moderately confident"). From post assessment to follow-up, participant S's total self-efficacy score increased 35% (20-27). items for negative affect (2 points), resistance from others (1 point), must exercise alone (1 point), excuse making (1 point), inconvenient to exercise (1 point) all increased and the item for bad weather remained constant. The average subscale score increased from 3.3 ("moderately confident") to 4.5 ("very confident") for post to follow-up.

Changes in PA barriers can be seen in figure 6.

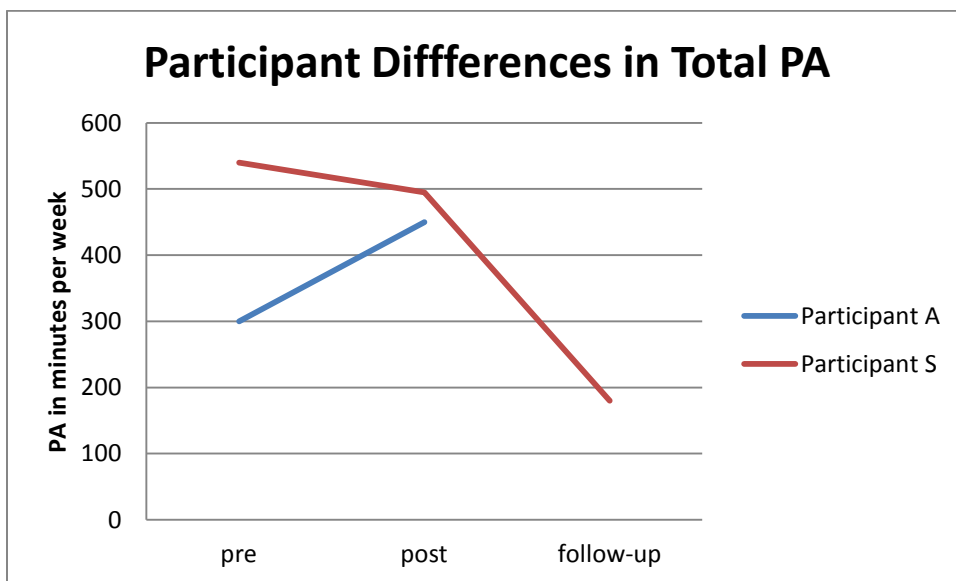
Figure 6: Barriers for participant S



Total number of barriers faced increased 50% from pre (2 barriers) to post assessment (3) but decreased 33% from post to follow-up assessment. At the pre assessment, participant S reported cost of exercise program and pain as barriers. At the post assessment, participant S reported cost of exercise program, pain, and health concerns as barriers. Finally, at follow-up, he reported cost of the exercise program and health concerns as barriers.

Participant differences in PA can be seen in figure 7.

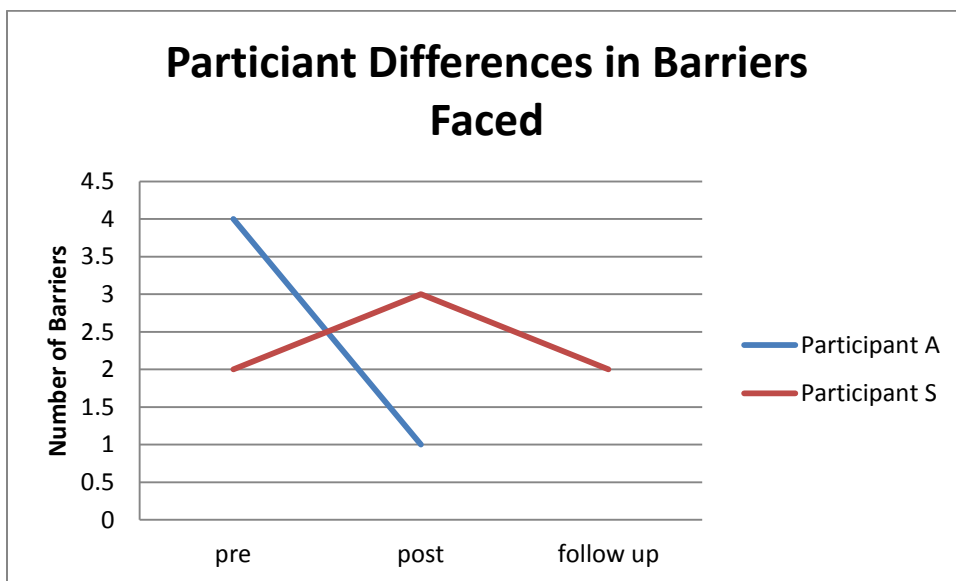
Figure 7: Participant differences in total PA



While Participant S's PA decreased and participant A's PA increased from pre to post, participant S still reported higher total PA than participant A at the time of the post assessment.

Participant differences in barriers faced can be seen in figure 8.

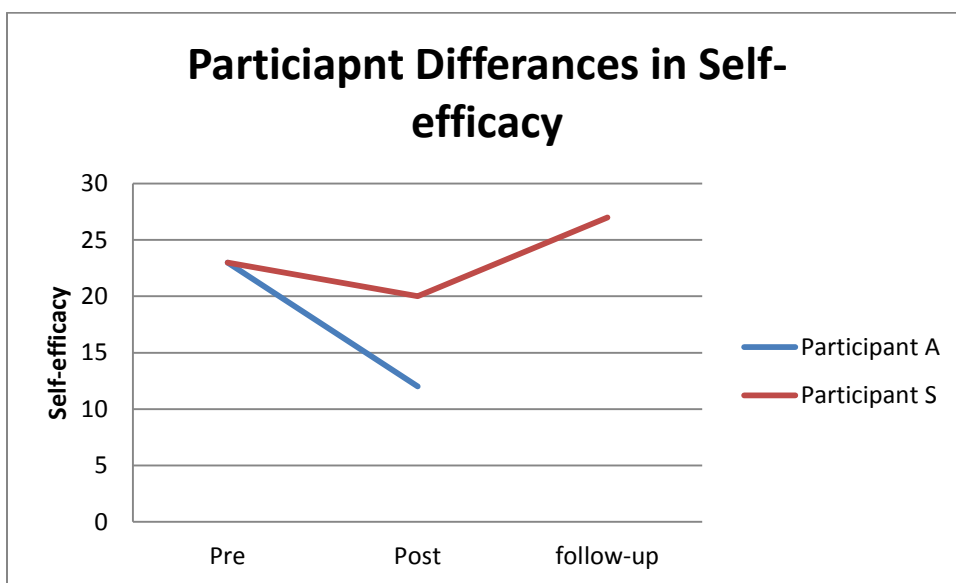
Figure 8: Participant differences in barriers faced



Participant A reported fewer barriers at the post assessment than participant S.

Participant differences in self-efficacy can be seen in figure 9.

Figure 9: Participant differences in self-efficacy



While both participants self-efficacy decreased, participant S reported higher self-efficacy at the post assessment than participant A.

## **Specific Aim 2**

Specific Aim 2: Evaluate the participants experience with the content presented, mode of presentation, and any barriers to participation. We evaluated the program based on a semi-structured interview with the participant in the support group.

The follow-up interview was conducted using questions that were categorized into topics including (1) program feedback, (2) PA experiences/expectations, (3) barriers, and (4) knowledge to focus the discussion. During the data coding, five higher order meta codes were established including (1) PA knowledge, (2) PA participation, (3) PA intentions, (4) program participation, and (5) program feedback. These meta codes were further subdivided into lower level items that included more specific information and quotes from the participant.

**Physical Activity Knowledge.** . Participant S was knowledgeable about PA behavior change tools such as goal setting, overcoming barriers, and increasing self-efficacy before entering the PACE program. As a result, when asked about the extent to which the PACE content added to his knowledge he said, “I don’t think [PACE] added to my knowledge. I think I was pretty aware of all of those things but, I think I am unusual in that regard”. Despite having familiarity with behavior change tools, a discussion about current PA practices suggest that there may still be some gaps in knowledge of what activities constitute PA. For example, when discussing PA the participant stated “I take

my wife out for a walk and we will walk all over the hills [at the park] but I will be in my scooter”. He alludes to the mental and emotional benefit of these walks stating that they “make [him] feel better”. While the mental health effects he feels as a result of these walks may be beneficial it is unlikely that operating a scooter will result in the physiological benefits of PA that are well documented (Haskell et al., 2007).

**Physical Activity Participation.** PA participation was defined as factors that prevented or facilitated PA as well as PA experiences and included the lower level codes included PA barriers, PA facilitators, past PA, and current PA.

**Physical Activity Barriers.** When asked to comment on his PA behaviors, participant S identified a couple barriers preventing PA participation. First, he identified disability as a personal factor stating “I had stenosis of my neck...I really wasn’t exercising...I’m not in a place where I can use [behavior change tools] right now”. Second, he identified lack of time as a barrier stating, “I checked into [an exercise program] but it did not fit into my schedule”.

**Physical Activity Facilitators.** Participant S noted social support and accessible facilities as major facilitating factors for PA participation. The presence of accessible trails and gym facilities as well as transportation had been keys to fostering physical activity. In addition, participant S credited “having a friend come” with being able to maintain regular activity.

**Past Physical Activity.** Participant S reported regular PA before the onset of ALS stating: “Before I was in my wheelchair I was riding my bike everywhere...I was a



serious exerciser before [ALS] happened”. This strong background in PA fostered the continuation of regular PA after diagnosis, as he participated in both cardiovascular and strength training a few times a week.

***Present Physical Activity.*** Despite the strong history of PA participation, participant S’s PA levels declined over the few months leading to the program as well as during program participation due to a stenosis of the neck. When addressing the decline in PA levels, participant S said: “I had stenosis of my neck and so I was trying to decide whether to have surgery and I was not really exercising”.

***Physical Activity Intentions.*** PA intentions were defined by plans for PA participation in the future. By the time of the interview, participant S had gone through surgery to remove the stenosis and had intentions to resume PA. He stated, “Once the doctor releases me, I’d like to be able to participate [in PA] and build my arm strength back up...my goal is to get myself well enough to get back in my manual wheelchair”.

***Program Participation.*** Program participation was defined as factors that prevent or facilitate program participation and included the lower level codes of program barriers and program facilitators.

***Program Facilitators.*** When asked to comment on factors that facilitated program participation, participant S stated solely the accessible transportation he had available: “I have my own van, it’s accessible, I can drive, so I have a lot more advantages than most people”.

***Program Barriers.*** Participant S did not experience any barriers for program participation; however, he did offer some suggestions as to barriers that may hinder the participation of future participants. Barriers mentioned included holding the program during evening hours that can be considered dinnertime, lack of parking and/or public transportation to the program delivery site, and a lack of knowledge of how to get to the delivery site.

***Program feedback.*** Program feedback was defined as all opinions on the PACE program and included lower level codes content, delivery, environment, and recruitment.

***Content.*** Overall, participant S believed that the program content was beneficial and thorough in the presentation of PA and behavior change tools. On specific program content participant S observed “I think [PA behavior change tools] are great, it is good for me to hear them again...goal setting is certainly appropriate for everyone”. When asked if he perceived any gaps in the content participant S felt that the program was well planned stating “[PACE] was pretty comprehensive”. While the participant gave positive feedback on specific program content, he did express concerns about the applicability of the program as he felt that “[PACE] is designed for people who have more mobility, not for people who have less mobility...that is the biggest adjustment that would help the program”.

In addition to the overall applicability of the program, participant S made suggestions on specific content that could be incorporated to make the program stronger. First, he would have liked exercising to have been a part of the weekly meetings saying

“I asked...are we ever going to do exercise or not”. Next, he suggests the incorporation of community information related to program topics. For example, when discussing barriers and transportation, program facilitators should “hand out the Corvallis bus schedule...or the number for a couple of cab companies and the dial-a-bus number, the resources [PACE participants] might need now”. Finally, he suggested mapping out more detailed personal PA plans saying “ask more in depth questions, like ‘Do you have a friend that you could exercise with? Do you know when they have time to exercise?’... Make a personal plan so people have memory prompts when they go home”. Participant S thought the education content of the program was comprehensive but that PACE would benefit from the addition of specific community and personal details that would support PA behavior change.

***Delivery.*** Similar to program content, the current delivery was perceived favorably yet participant S provided some suggestions for additions to improve the program. Comments on overall program delivery were positive: “I thought [the sessions] were well presented...I thought [the presenter] did a really good job...I thought the length of the sessions was great and [8-weeks] did not seem to long”. When asked about specific aspects of the program delivery, participant S responded “the handouts were helpful” and “being a school administrator, I have read a lot of case studies in my life and I’m sure it’s a good way to do this. I think they were well written”. On the other hand, participant S encouraged the researchers to consider other learning styles and incorporate a wider variety of delivery modes to enhance comprehension. Specifically, participant S advocated for the inclusion of demonstrations in program delivery: “use demonstrations,

if your talking about household chores demonstrate how to do them...have people move around and act them out”.

In addition to incorporating demonstrations, participant S felt that social connectivity would further enhance program delivery. When reflecting on the first session attended by three participants he said: “I think it’s nice to have everybody talking and being in a group with people is much more exciting than just [the program facilitator] and I”. In addition, participant S felt that social support and group discussion could help participants put program strategies into action saying participants could “listen to other people talk about why they don’t exercise...and helping and encouraging [each other]”. Participant S felt that current delivery methods were effective but could be enhanced by the use of demonstrations and social connectivity.

***Environment.*** The PACE program was delivered in a Lab in the Women’s building. In order to assess the environment, participant S was asked to evaluate the comfort and accessibility of the lab. Participant S felt that the lab was comfortable, however, he suggested the researchers “think about an extension table top and a table that’s high enough to get a wheel chair under”. Again, participant A considered how future participants would feel and thought the research team “may need to go off campus ...try one off campus and one on and see what happens...it’s an important aspect to go out rather than do [PACE] there”. Participant S thought it was important that the PACE program be relatable and that if researchers “go to where groups are already established and present it there” the social support component would be there as well as a comfort and ease with the environment and other participants. While participant S had small

suggestions for lab accessibility, the biggest critique of program environment was to take the program outside the lab and present PACE in a real word setting.

***Recruitment.*** Participant S was well connected in the disability community and provided various suggestions of organizations to work with on recruitment. These organizations included community disability groups, University disability groups, recreation facilities, and retirement homes. Along with the suggestions of locations to recruit in the future, the participant advocated for connecting with the community to draw in more participants:

“Go into a place and give an exercise class...start to get to know them, build rapport with these people...then make [PACE] flow into their lives. If you got to talking to people and got to know them and take an interest in their lives, I bet you could pull out a lot of people who are in hiding”.

## **Discussion**

### **Specific Aim 1**

The first aim of this study was to describe the effectiveness of the PACE program on increasing the participant's weekly physical activity and self-efficacy and reducing the barriers faced. For this aim, our hypothesis was that the participant in the support group would report greater PA, higher self-efficacy, and fewer barriers to PA than the participant in the awareness group. This hypothesis did not hold true for barriers and while participant S had higher self-efficacy and PA scores than participant A at the post-assessment, participant S's scores decreased from pre to post assessment, thus making inferences about program impact difficult.

**Physical Activity Changes.** Participant A reported an increase in PA after completing the PACE program. This finding aligns with previous studies that have found associations between HPP's and increased PA participation (Rimmer et. al., 2009; Stuifbergen et. al., 2003). While his total PA level decreased, participant S did increase his intentional exercise after completing the program, which is a positive outcome as the purpose of the curriculum is to increase the amount of weekly activity completed. This decrease in total PA can likely be attributed to the altered health status of participant S who reported that the affects of the stenosis (muscle weakness and pain in the arms/neck) prevented him from completing 150 minutes/week of intentional activity. Had stenosis not been a barrier, participant S believed his PA levels would likely have been higher than the levels reported. Taking into consideration participant S's intentions for PA at

follow-up, history of PA, and scores on other measurements (barriers and self-efficacy), it is plausible that the stenosis was a confounder that attributed to the decrease in PA levels (Dobkin et al., 2005, Dobkin et al, 2006).

**Barriers.** Interestingly, Participant A no longer reported boredom as a barrier at post-assessment yet from pre to post reported increased PA via spending a longer amount of time doing the same exercises (stationary biking and weight lifting) rather than increased PA through trying different activities. The change in amount of PA completed without a change in type of activity suggests an attitude change about PA and thus the removal of boredom as a barrier, and while the possibility remains that an outside factor could have altered his attitude (e.g. influence from a friend or family member who values PA), it is plausible that these changes can at least partially be contributed to participation in the PACE program.

The removal of health concerns as a barrier could have been the result of resolved health concern other than those reported by the participant. However, information in the PACE curriculum (i.e., Exercise is Medicine module) could have contributed to a shift in perception about the relationship between PA and disability that led to a reconsideration of this barrier. Cost could have remained as a barrier due to a ceiling affect where individuals will be unwilling/unable to pay more than a certain amount for a program regardless of their willingness to participant in PA. Participant A's decrease in barriers suggest that it is possible that PACE participation taught participant A that PA can be fun, generated an interest, and debunked any concerns about health concerns preventing participation.

For participant S, changes seen in barriers faced, like changes in PA, may be attributed to the development and resolution of spinal stenosis. For example, the pattern of the frequency of the barriers faced reflected the path of the participant's stenosis progression. At the pre-assessment, pain is reported and persists through the post assessment but is no longer reported at the follow up, at which time the stenosis had been successfully removed. In addition, health concerns are not reported at the pre assessment when the stenosis was still undiagnosed but was present at the post assessment after the diagnosis was made and again at follow-up when rehabilitation following surgery became participant S's main priority. Similar to participant A, cost was the constant barrier through all assessment periods and could again be attributed to a ceiling effect.

Of note is that neither participant reported accessibility, either of the built environment or transportation, as barriers to PA. This could be confounded by the presence of the National Center for Accessible Transportation (NCAT), which is based at Oregon State University. The presence of the NCAT facilitating community wide activism and compliance in accessibility concerns could provide a means of preventing accessibility barriers that are present in other geographical areas. Another possible explanation is that both participants are simply outliers of the population as accessibility has been repeatedly reported as a main barrier for PA participation by individuals with mobility disabilities (Damush et. al., 2007; Driver et. al., 2012; Kirchner et. al., 2008; Rimmer et. al., 2004). As past research supports the incorporation of accessibility issues as a pillar of program content, results from participants A and S should not be taken as an



indication that discussion regarding accessibility issues should be removed from the PACE curriculum.

**Self-efficacy.** Participant A reported a decrease in self-efficacy, which contradicts the findings of previous PA intervention studies for individuals with mobility disabilities (Halworth, 2009; Reuter, 2010). The observed decrease in self-efficacy could be due to a learning effect wherein, over the course of the PACE program, participant A gained a better understanding about what constitutes PA and the effort required to increase activity. As a result, participant A may have a more realistic perception of his own abilities and, subsequently, has a more accurate self-efficacy score.

The self-efficacy scores for participant S may be a reflection of the stenosis progression (decrease from pre to post with a rebound at follow-up to above the pre assessment score). Scores for negative affect, must exercise alone, and inconvenient to exercise were all lower at post than at pre assessment. Participant S regularly reported feeling stress over having surgery as well as negative feelings about PA while experiencing the pain and weakness associated with stenosis as found in other individuals with stenosis (Steven, 1999). Furthermore, participant S commented that he was unable to participate in types of PA that he was accustomed to due to the loss of independence that accompanied arm weakness. For example, decreased arm strength prevented participant S from completing transfers independently, thus hampering his ability to utilize weight machines in the gym and pool facilities. This restriction resulted in feelings of negative affect towards PA and even ADL that he was previously completing independently. Inconvenience to exercise may also have been affected by complications

of the stenosis as participant S was required to have someone else available for transfers making PA less convenient. Considering negative affect, inconvenience, and must exercise alone returned to pre assessment levels at the follow-up after the removal of the stenosis, it could have been a confounding factor on self-efficacy as well as amount of weekly PA.

Participant S' scores for excuse making, resistance from others, and bad weather were consistent from pre to post but increased at follow-up. Much like other self-efficacy items, the increase at follow-up could have been caused by having the stenosis removed as, post surgery, participant S was returning to range of motion and activity levels experienced before the development of stenosis. Additionally, for much of the program duration, participant S was unsure if his symptoms were the result of stenosis or the progression of his ALS. Having discovered that stenosis was causing his symptoms and the resulting relief of both symptoms and worry after successful surgery, this may have facilitated a general increase in positivity that influenced the increase in his belief in his own abilities (self-efficacy).

## **Specific Aim 2**

The second aim of this study was to evaluate the participants experience with the content presented, mode of presentation, and any barriers to participation. We accomplished this aim through the use of a semi-structured interview with participant S.

**Program barriers.** Comparable to PA barrier outcomes, participant S did not find accessibility of the program facility or transportation to be barriers to program

participation. Similar to PA barriers, accessibility had been a highly reported barrier to HPP participation in previous studies (Odette et. al., 2003). Again, lack of accessibility concerns could be attributed to the presence of the NCAT in the program area or to personal resources (e.g. the ability to drive himself) rather than or in addition to the accessibility of the building where the program was delivered.

Participant S believed that while accessibility was not a barrier for him, it could affect program participation for future participants. As a result, participant S offered the suggestions of handing out maps with directions to the program site and delivering the PACE program at other locations in the community. However, maps with directions were distributed to participants who were unfamiliar with the area via email when they contacted the lab to inquire about the program and open house sign-up sessions. It is important to note that participant S was already aware of how to get to the program location and thus did not receive a map. Including a variety of program locations within the community may provide a viable avenue to increase future enrollment, as familiarity and comfort with the location could be a facilitating factor for participation.

**Program Content and Delivery.** Based on the provided evaluation, PACE program content and delivery was strong with a few suggestions for enhancement. Incorporation of community specific information on transportation, recreation, and community services would provide participants with information on readily available and accessible community programs to facilitate positive PA behaviors. In addition, implementing personal action plans for PA could be incorporated into the PACE curriculum as a tool to facilitate putting program discussions into action. Personal action

plans are detail oriented and provide participants with a personalized step-by-step plan for positive health behaviors (Hughes et. al., 2003). This system has been shown to be effective in increasing PA behaviors for individuals with physical disabilities when incorporated into an educational HPP (Hughes et. al., 2003, Robinson-Whelen et. al., 2006).

In addition to community information and detailed action plans, practical demonstrations may also be utilized to strengthen program outcomes. Participant S suggested the incorporation of practical demonstrations of modifications to PA activities and ADL. Practical demonstrations could be done in the gym or in a video and performed by the person delivering the program or a model who has similar characteristics to participants. Following the demonstration, participants could be given time to practice the movements themselves and provide feedback to each other in order to gain a better understanding of the activity being demonstrated as suggested in previous literature on models (Buman et al., 2011; Geriatr et al., 2011). These demonstrations could help participants gain an understanding of how to adapt activities to their own ability levels facilitating increased PA.

Participant S provided favorable feedback on program components such as case studies, activities, and the PACE workbook with minor critiques to add some variety to case studies. PACE materials were adapted from a more targeted version for individuals with TBI, and while specific details that pertain to TBI were removed/altered from the case studies to make them more generalizable, revisiting the written case studies to alter details may make them more applicable. Providing models that more closely resemble the

experiences of all participants in the PACE program could increase the relevance and meaningfulness of the case studies (Bandura, 1986)

Comments on program delivery were likewise favorable with suggestions for minor alterations. Participant S thought he would have benefited from the ability to move through the program with a cohort rather than individually. Originally, the PACE program was delivered in a group format (Driver et. al., 2012) and was supposed to be conducted in the same manner during this study. However, due to issues with recruitment and participant attrition only participant S remained in the support group. In future program cycles, emphasis on creating and sustaining the group dynamic and social support component of PACE may facilitate the adoption of positive PA behaviors.

Participant S also provided suggestions for recruitment which included contacting established groups (e.g. retirement communities or community groups) and building long-term relationships with recruitment sites. Recruitment based on already created groups may benefit the PACE program in that future audiences could be more readily accessible and even consist of already formed groups. In addition, individuals in pre-established groups who are already familiar with each other may facilitate discussion as a within-group comfort level may already exist that would not be in place for a group of strangers.

Furthermore, approaching an already existing group could facilitate program participation by providing the opportunity to build rapport. Reaching out to a set group would give program implementers the ability to go into the group beforehand and

establish a relationship with potential participants. In a retirement home for example, researchers could attempt to create a relationship with the facility directors as well as residents by offering a free exercise class to residents. Through this class researchers could get to know residents and build a rapport that may lead residents to participate in the PACE program. Showing investment in the community could garner more program participation and serve as a method to get a wider range of participants and community members involved (Israel et al., 1992; Plough & Olafson, 1994).

However, it is important to note that targeting existing groups may undermine the intention to reach a greater population of individuals with mobility disabilities, as people already in a group setting may be more socially connected than the average member of the population. However, to establish internal validity, it may be fortuitous to forgo generalizability in favor of gathering support for the effectiveness of the program in small trials. Once mechanisms of program successes in content, delivery, and accessibility are better understood, a larger scale RCT can be utilized to establish generalizability of the program.

An important aspect for the growth and development of the PACE program is to consider what adaptations could be made to accommodate individuals with a degenerating condition. Previous research on PA and MS, ALS, and MD has shown positive effects of PA participation for mobility, range of motion, and QOL for individuals with degenerative conditions (Motl et al., 2012; Phukan & Hardiman, 2009; Sveen et al., 2008). Despite these findings, little evidence about self-efficacy and PA attitudes for individuals with degenerative conditions exists. Future application of the

PACE program could benefit from the investigation of these aspects as program delivery may be improved with the addition of information/examples geared toward degenerative conditions. Furthermore, establishing the researchers understanding and empathy for attitudes, experiences, and beliefs of individuals facing degenerative conditions could enhance program effectiveness for influencing PA outcomes in this population.

Considering that individuals with mobility disabilities face unique barriers and life experiences, program participation and effectiveness could be enhanced if the program were delivered by a member of this population or therapist/social worker who interacts closely with individuals with mobility disabilities. These individuals would be more familiar with the experiences of individuals with mobility disabilities and more relatable to participants, thus facilitating discussion during program meetings. For example, a mentor system could be utilized where the mentor is similar to the participant on key demographic characteristics (e.g. gender, age, disability status) to facilitate program adherence (Buman et al, 2011; Dorgo et al., 2011; Layne et al., 2008).

## **Conclusion**

The finding of this case study did not support the hypothesis that the participant in the support group would have better outcomes on all measures than the participant in the awareness group. However, accepting the null hypothesis should be made with caution due to the confounding health factor (stenosis) faced by participant S that likely impacted all outcome measures. Aim two was fulfilled through program feedback provided by participant S. Adjustments to the program that were suggested include making the program more relatable to individuals with higher mobility limitations, including community specific information, incorporating personalized activity plans, and providing practical examples of adapted ADL and exercises that participants can complete on their own. These program adjustments could be incorporated to strengthen program content and increase the programs ability to positively impact PA health behaviors. Building from results of this case study, the next step would be to complete the program adjustments and then administer the PACE program in a small scale efficacy trial to determine if and to what extent participation in the PACE program will result in positive health outcomes. Furthermore, a future question of interest is to examine PA experiences, beliefs, and attitudes of individuals with degenerative conditions to determine if program adjustments could be made to facilitate compliance and positive health outcomes in these populations.



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## Appendix

## Appendix A: Demographic Questionnaire

Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_ Age: \_\_\_\_\_

Gender: \_\_\_\_\_

Height: \_\_\_\_\_ Weight: \_\_\_\_\_

Date of injury/disability: \_\_\_\_/\_\_\_\_/\_\_\_\_

How did the injury/disability occur: \_\_\_\_\_

Where do you reside (pre-injury)?

City, State: \_\_\_\_\_

What is your primary language?

- ☐ English
- ☐ Spanish
- ☐ Other \_\_\_\_\_

What is your current marital status?

- ☐ Divorced
- ☐ Living with another
- ☐ Married
- ☐ Separated
- ☐ Single
- ☐ Widowed
- ☐ Would rather not say

If you have children, how many children do you have?

\_\_\_\_\_ (include age)



How many children under the age of 16 year old live in your household?

- ☐ None
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4 or more

How would you classify yourself?

- ☐ Arab
- ☐ Asian/Pacific Islander
- ☐ Black
- ☐ Caucasian/White
- ☐ Hispanic
- ☐ Indigenous or Aboriginal
- ☐ Latino
- ☐ Multiracial
- ☐ Would rather not say
- ☐ Other \_\_\_\_\_

What is the highest level of education you have completed?

- ☐ Grammar school
- ☐ High school or equivalent
- ☐ Vocational/technical school (2 year)
- ☐ Some college
- ☐ Bachelor's Degree
- ☐ Master's Degree
- ☐ Doctoral Degree
- ☐ Professional Degree (MD, JD, etc.)

Which of the following best describes the area you live in?

- ☐ Urban
- ☐ Suburban
- ☐ Rural

How much time do you usually spend sitting or reclining on a typical day?

Pre-Injury (Hours:Minutes) \_\_\_\_\_

Post-Injury (Hours:Minutes) \_\_\_\_\_

In a typical week, on how many days do you do moderate-intensity sports, fitness or recreational (*leisure*) activities?

Pre-Injury (# of days): \_\_\_\_\_

Post-Injury (# of days): \_\_\_\_\_

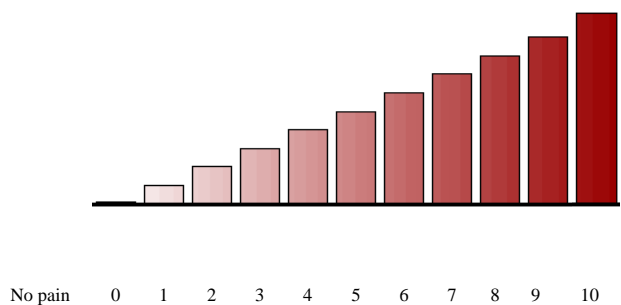
Which of the following best describes your role in industry (pre-injury)?

- ☐ Upper management
- ☐ Middle management
- ☐ Junior management
- ☐ Administration staff
- ☐ Support staff
- ☐ Student
- ☐ Trained professional
- ☐ Skilled laborer
- ☐ Consultant
- ☐ Temporary employee
- ☐ Researcher
- ☐ Self-employed
- ☐ Other: \_\_\_\_\_

What is your current household income in U.S. dollars (pre-injury)?

- ☐ Under \$10,000
- ☐ \$10,000-\$19,999
- ☐ \$20,000-\$29,000
- ☐ \$30,000-\$39,000
- ☐ \$40,000-\$49,000
- ☐ \$50,000-\$74,000
- ☐ \$75,000-\$99,000
- ☐ \$100,000-\$150,000
- ☐ Over \$150,000
- ☐ Would rather not say

Pain Numeric: Please circle the number below that describes your pain in the past 2 weeks.



During the past 30 days, for about how many days did pain make it hard for you to do your usual activities, such as self-care, work, or recreation?

- ☐ \_ \_ =Number of days
- ☐ None
- ☐ Don't know
- ☐ Refused

Because of any impairment or health problem, do you need the help of other persons with your personal care needs, such as eating, bathing, dressing, or getting around the house?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Refused

Because of any impairment or health problem, do you need the help of other persons in handling your routine needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?

- ☐ Yes
- ☐ No
- ☐ Don't know

Would you say that in general your health is?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ DK/NS
- ☐ Refused

## Appendix B: MacArthur competency scale

1. What is the purpose of this research?

- a) To improve your knowledge of how physical activity can improve your health.
- b) To create a physical activity health promotion program to supplement the existing MS exercise program here at OSU.
- c) To improve your knowledge of how better nutrition can improve your health.
- d) All of the above.
- e) Both a & b.

2. How long are you asked to participate in the study?

- a) Three terms (one week at the beginning of the first term and one week at the end of the first term, once a week for 10 weeks during the second term, and during week 10 of the third term).
- b) One term (once a week for 10 weeks during the second term).
- c) During week 10 of the third term (for one 60 minute meeting).
- d) Only during the summer.
- e) None of the above.

3. In what ways might you benefit from volunteering to participate in this study?

- a) You will learn about your current state of physical activity and information about how to increase your physical activity.
- b) You may not benefit at all.
- c) You will obtain tools that will help you maintain an active lifestyle.
- d) All of the above.
- e) Both a & c.

4. What are the possible risks associated with participation?

- a) There are minimal risks.
- b) Your body fat may increase.
- c) If you increase your physical activity, you could potentially worsen your MS symptoms.
- d) None of the above
- e) Both a & c

5. What should you do if you no longer want to participate in this study?
- a) Continue with the study.
  - b) Stop at any time, let one of the research assistants know you would like to withdraw.
  - c) Call the Dean of the College of Public Health and Human Sciences to let her know.
  - d) Both b & c.
  - e) None of the above

### Appendix C: Exercise: Self-Efficacy

This part looks at how confident you are to exercise when other things get in the way. Read the following items and enter in the box the number that best expresses how each item relates to you in your leisure time.

Please answer using the following 5-point scale:

1= Not at all confident

2= Somewhat confident

3= Moderately confident

4= Very Confident

5= Completely confident

#### How confident am I to exercise when...

##### Negative Affect

I am under a lot of stress.

1      2      3      4      5

##### Excuse Making

I feel I don't have the time.

1      2      3      4      5

##### Must Exercise Alone

I have to exercise alone.

1      2      3      4      5\

##### Inconvenient to Exercise

I don't have access to exercise equipment.

1      2      3      4      5

**Resistance from Others**

I am spending time with friends or family who do not exercise

1      2      3      4      5

**Bad Weather**

It's raining or snowing.

1      2      3      4      5

## Appendix D: Barriers to Physical Activity and Disability Scale (BPADS)

### 1. Assistive devices (check all that apply)

	Part-time	Full-time	N/A
Walker			
Braces			
Cane			
Wheelchair			
Scooter			

### 2. Use of arms (check one)

- ☐ Full
- ☐ Partial
- ☐ No Use

### 3. Use of legs

- ☐ Full
- ☐ Partial
- ☐ No Use

Regular Exercise is any *planned* physical activity (e.g., brisk walking, aerobics, jogging, bicycling, swimming, rowing, etc.) performed to increase physical fitness. Such activity should be performed *3 to 5 times* per week for *20-60 minutes* per session. Exercise does not have to be painful to be effective but should be done at a level that increases your breathing rate and causes you to break a sweat.

### 4. Do you exercise regularly according to that definition?

- ☐ Yes, I have been for MORE than 6 months.
- ☐ Yes, I have been for LESS than 6 months.
- ☐ No, but I intend to in the next 30 days.
- ☐ No, but I intend to in the next 6 months.
- ☐ No, and I do NOT intend to in the next 6 months.



5. How confident are you that you could exercise three times per week for 20 minutes if:

Not Confident

Very Confident

0 1 2 3 4 5 6 7 8 9 10

- a. The weather was bothering you
- b. You were bored by the program or activity
- c. You felt pain when exercising
- d. You had to exercise alone
- e. You did not enjoy it
- f. You were too busy with other activities
- g. You felt tired
- h. You felt stressed
- i. You felt depressed

Barriers to Physical Activity:

6. Would you like to begin an exercise program?

- ☐ Already in an exercise program
- ☐ Yes
- ☐ No

7. Have you ever exercised?

- ☐ Yes
- ☐ No

- 21a. IF "Yes" Did you ever have any health problems that caused you to stop exercising?

- ☐ Yes
- ☐ No

- 21b. Have you ever been injured from exercising?

- ☐ Yes
- ☐ No

8. Do you know of a fitness center that you could get to?

- ☐ Yes
- ☐ No

- 22a. IF "Yes" Would you have a means of transportation to get there?

- ☐ Yes
- ☐ No

- 22b. IF "Yes" Would you have to pay to be transported to the exercise facility?

☐ Yes

☐ No

22c. IF "Yes" Could you afford to spend this amount of money?

☐ Yes

☐ No

22d Would you be willing to spend this money?

☐ Yes

☐ No

9. Would you have any concerns about exercising in a facility like a YMCA?

☐ Yes

☐ No

23a. IF "Yes", what are your concerns?

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10. Do you feel that an exercise instructor in a fitness center like a YMCA would know how to set up an exercise program to meet your needs?

☐ Yes

☐ No

11. Do you feel that an exercise program could help you?

☐ Yes

☐ No

12. Are you ever afraid to leave your home?

☐ Yes

☐ No

13. Has your doctor ever told you to exercise?

☐ Yes

☐ No

27a. IF "Yes" Did your doctor tell you to do anything specific?

☐ Yes

☐ No

14. Are any of the following statements, concerns why you might not be involved in an exercise program or not exercising as much as you would like?

- ☐ Cost of the exercise program
- ☐ Lack of transportation
- ☐ Lack of time
- ☐ Lack of interest
- ☐ Lack of energy
- ☐ Lack of motivation
- ☐ Exercise is boring or monotonous
- ☐ Exercise will not improve my condition
- ☐ Exercise will make my condition worse
- ☐ Exercising is too difficult
- ☐ Don't know how to exercise
- ☐ Don't know where to exercise
- ☐ Health concerns prevent me from exercising
- ☐ Pain prevents me from exercising
- ☐ Too lazy to exercise

15. Can you think of any other reasons why you might not be involved in an exercise program or not exercising as much as you would like? If so, please list:

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## Appendix E: Physical Activity And Disability Scale (PADS)

## EXERCISE:

16. Do you currently exercise?

- ☐ Yes  
☐ No

IF NO, PLEASE GO TO THE LEISURE ACTIVITY SECTION.

17. What kind of exercise do you do?

Directions: List up to four (4) activities below that you do on a regular basis for primary purpose of increasing or maintaining fitness. Aerobics are done for a sustained period of time and result in an increase in your heart rate and breathing rate. Examples include walking, jogging, attending an aerobics class, and bicycling. Strength activities include lifting weights or using elastic bands or weight training machines. Flexibility refers to activities that involve muscle stretching

## Activity Type

Code: Description

A: Aerobic Exercise

S: Strength Exercise

F: Flexibility Exercise

Activity Type (check one)	Activity	Days/Week	Minutes/Day	Months/Year
<input type="checkbox"/> A <input type="checkbox"/> S <input type="checkbox"/> F				
<input type="checkbox"/> A <input type="checkbox"/> S <input type="checkbox"/> F				
<input type="checkbox"/> A <input type="checkbox"/> S <input type="checkbox"/> F				
<input type="checkbox"/> A <input type="checkbox"/> S <input type="checkbox"/> F				

18. Have you been exercising for more than one year or less than one year?

- ☐ More than one year  
☐ Less than one year

19. How would you describe the average intensity of your exercise program?

- ☐ Light exercise: Don't sweat or breathe heavily
- ☐ Moderate exercise: Breathe a little harder and may sweat
- ☐ Vigorous: Breathe hard and sweat

#### LEISURE ACTIVITY

20. Do you engage in leisure time physical activity?

- ☐ Yes
- ☐ No

IF NO, GO TO THE GENERAL ACTIVITY SECTION ON THE NEXT PAGE.

What type of activities do you do?

Directions: List up to four (4) activities below that you do for leisure or recreation. These activities can be done on a regular or irregular basis and may not necessarily result in sustained increases in heart rate and breathing rate. Examples include hiking, boating, skiing, dancing and sports activities. Please indicate whether the activity is an endurance activity or a Non-Endurance activity. Examples of endurance activities include: hiking, tennis, dancing, skiing. Non-endurance activities include boating, softball and horseback riding. Do not list activities here that you already listed under exercise.

Activity Type

#### Code Description

E Endurance

NE Non-Endurance

Activity Type (check one)	Activity	Days/Week	Minutes/Day	Months/Year
<input type="checkbox"/> E <input type="checkbox"/> NE				
<input type="checkbox"/> E <input type="checkbox"/> NE				
<input type="checkbox"/> E <input type="checkbox"/> NE				
<input type="checkbox"/> E <input type="checkbox"/> NE				

#### GENERAL ACTIVITY

21. From Monday through Friday, how many waking hours a day do you usually spend inside your home?

- ☐ Less than 6 hours a day
- ☐ 6 to 10 hours a day
- ☐ More than 10 hours a day

22. On Saturday and Sunday, how many waking hours a day do you usually spend inside your home?

- ☐ Less than 6 hours a day  
☐ 6 to 10 hours a day  
☐ More than 10 hours a day

23. On average, how many hours a day do you sleep including naps?

\_\_\_\_\_ hours

24. On average, how many hours a day are you sitting or lying down, excluding sleeping?

\_\_\_\_\_ hours

25. Are most of your indoor household activities done by you or someone Else?

- ☐ Done by you  
☐ Done by someone else

IF DONE BY SOMEONE ELSE, GO TO QUESTION 42.

26. Please list up to four (4) indoor house hold activities you do and the number of minutes a week you spend on each activity.

Activities:

Minutes/Week


27. Do you do any outdoor household activities such as gardening?

- ☐ Yes  
☐ No

IF NO, GO TO QUESTION 44.

28. Please list up to four (4) outdoor household activities you do and the number of minutes a week you spend on each activity.

Activity	Days/Week	Minutes/Day	Months/Year

29. How much assistance do you need to perform activities of daily living such as dressing and bathing?

- ☐ No assistance  
☐ Some assistance  
☐ Full assistance

#### THERAPY

30. Do you currently receive physical or occupational therapy?

- ☐ Yes  
☐ No

IF NO, GO TO EMPLOYMENT SECTION ON THE NEXT PAGE.

31. How many days a week do you receive therapy?

\_\_\_\_\_ Days.

32. How long does each therapy session usually last?

\_\_\_\_\_ Minutes

#### EMPLOYMENT / SCHOOL

33. Are you currently employed / attending school?

- ☐ Employed Retired  
☐ Not employed Attending school

IF UNEMPLOYED OR RETIRED, GO TO WHEELCHAIR SECTION.

34. For most of your work / school day, do you:

- ☐ Move around
- ☐ Stand
- ☐ Sit

35. Do you climb any stairs during the work / school day?

- ☐ Yes
- ☐ No

IF NO, GO TO QUESTION 54.

36. How many flights of stairs do you climb? \_\_\_\_\_ flights

37. How many times a day do you climb the stairs? \_\_\_\_\_

38. In your transportation to and from work / school, do you get any physical activity?

- ☐ Yes
- ☐ No

IF NO PLEASE GO TO WHEELCHAIR SECTION.

39. Please list up to four (4) employment-related physical activities you do and the number of minutes you spend on each activity.

Activity	Days/Week Months/Year	Minutes/Day	

#### WHEELCHAIR USERS

40. Do you use a wheelchair?

- ☐ Yes
- ☐ No

IF NO, STOP HERE.



41. How many years have you used a wheelchair? \_\_\_\_\_  
years?

42. During the time that you are awake, how much time do  
you: spend in your wheelchair?

- ☐ All day
- ☐ Most of the day
- ☐ A few hours

43. What type of wheelchair do you primarily use?

- ☐ Manual wheelchair
- ☐ Powered wheelchair

IF POWERED WHEELCHAIR, STOP HERE

44. Who usually pushes your wheelchair?

- ☐ Myself
- ☐ Someone else

IF SOMEONE ELSE, STOP HERE.

45. On average, how many minutes a day do you push  
yourself in your wheelchair?

- ☐ Less than 60 minutes
- ☐ Sixty minutes or more

## Appendix F: Physical Activity Centered Education program Post Intervention

### Focus Group Moderator's Script

#### Introduction and Informed Consent Procedures:

A greeter (a researcher) will welcome participants. Participants will meet in small groups with the Research Assistant to (a) review the main elements of the informed consent document, (b) discuss any questions or concerns, and (c) obtain participants' signatures of consent to participate in the focus groups. Name tents with participants' first names will be created as well.

#### Welcome and Introductions:

Hello and welcome! I'd like to thank you for taking time out of your busy lives to join us for this wrap up session. We very much appreciate your willingness to share your insights with us. As you may know, the purpose of this focus group is to discuss your experience in the PACE intervention.

Our work here, today, will be used to learn about what you felt was beneficial, helpful, enjoyable, and also things that you may not have found helpful, topics that may have been boring and more. Your feedback will be helpful to use in future PACE programs.

My name is \_\_\_\_\_ and I will be your moderator for this discussion. This is (name of researcher)\_\_\_\_\_, also a researcher on this project and will be taking notes to make sure that we get as much information as possible.

Before we begin, I'd like to provide you with guidelines for our discussion.

- First, we are audio taping our conversation so that we don't miss any of your important comments. This is necessary because we can't write everything down fast enough to remember it all. To maintain confidentiality, these tape recordings will be shared only with researchers and with the person who transcribes the tapes. In order to maintain a high level of confidentiality, we will use only first names.
- While those of us collecting your information will keep your comments confidential, we can't speak for those participating in the focus group. We do urge everyone, however, to respect the confidentiality of others by not revealing who participated in the group and by not telling anyone else what is said in the group.
- As you can see, we each have name tents. These tents help me remember names, but they can also help you. If you want to follow-up on something that someone has said—if you want to agree or disagree—feel free to do that. You do not have to respond to me all the time. I want to encourage you to have a conversation with one another about these questions.
- Take turns talking with the group

- Also, it is important for you to remember that there are no right or wrong answers. We expect that there will be differing points of view. Please feel free to share your point of view even if it differs from what others have said.
- I am here to ask questions, to listen, and to ensure that everyone has a chance to share. We're interested in hearing from each of you.

Is there anything else you would like to add to the discuss guidelines?

Do you have any questions?

Before we get into the questions about your experience as a participant in the PA education sessions, we have listed the weekly topics we discussed over the past 12 weeks during our education sessions as a reminder. We have them listed on the wall post-its (or on the computer screen). We'll give you a few minutes to read through the topics.

Do you have any questions?

#### Discussion Questions:

##### *Discussion topics:*

We will first discuss these different topics that you learned about over the past 12 weeks.

- What topics did you found to be beneficial?
- What topics were not beneficial?
- What topics did you find enjoyable?
- What sessions were not enjoyable?
- Were there any topics that were helpful?
- Were there any topics that were not helpful?
- Can you talk about topics that you would be interested to hear more about?
- Are there things you would change about the sessions?

##### *Presentation:*

We used different modes to present the materials to you, including lecture, Power Points, handouts, videos, and activities.

- What did you think about our ways of presenting the materials to you all?
- How were our presentations effective?
- How were our presentations not effective?
- How did you feel about the length of time each session lasted?
- How did you feel about the environment of the room the sessions were held?
- How did you feel about the time of day and day of each session?

- How did you feel about the length of the whole intervention- 20 weeks?
- Are there any presentation methods you would change?

*Barriers/Attendance:*

We would like to explore how we could have increased attendance, if you missed any sessions, or if you wanted to skip sessions.

- If you missed any of the sessions, was there anything we could have done to help to get you here?
- Can you talk about any strategies to overcome barriers you may have encountered in order to attend sessions?

*Conclusion:*

Is there any other feedback that you would like to add ?

Thank you so much for helping us better understand your experience participating in the PA education sessions. Your information will be used to help us better understand PA for people with mobility disorders.

*The Pause and Probe Techniques:*

- Would you explain further?
- Would you give an example of what you mean?
- Would you say more?
- Tell us more.
- Is there anything else?
- Please describe what you mean.
- I am not sure I understand what you mean.

# Session 1

## INTRODUCTION TO PHYSICAL ACTIVITY



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### Why is this program important for me?

#### BACKGROUND:

- Many people don't fully understand what physical activity is and its role in rehabilitation and a healthy life.
- Physical activity is the leading indicator of health.
  - Physical, mental, emotional, and social health
- People who have a mobility disability are at a greater risk of developing many health complications. Physical activity can help prevent many of these conditions.

## PROGRAM GOAL FOR ME:

- This program will help me learn about physical activity and change my behavior to increase the amount of physical activity in my life.
- 

## What will we talk about?

- WEEK 1 – Introduction to physical activity
- WEEK 2 – How exercise is medicine for you
- WEEK 3 – How you can set goals and overcome barriers
- WEEK 4 – How you can change your behavior
- WEEK 5 – How to deal with things that get in your way
- WEEK 6 – Physical activity and your quality of life
- WEEK 7 – Reviewing your goals
- WEEK 8 – How to maintain the new you

## What is physical activity?

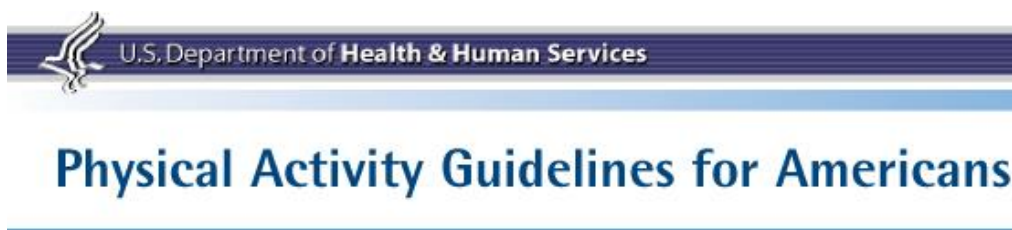
- Physical movement for the purpose of getting healthier or maintaining a good level of health that results in using energy.

## How does physical activity affect my health?

- Key part of your rehabilitation
  - Increases heart health
  - Increases lung and blood vessel health
  - Increases muscle strength and endurance
  - Increases balance and flexibility
  - Helps maintain a healthy body weight
  - Helps increase energy and ability to complete daily activities
-

## How often should I exercise?

- The U.S. Department of Health and Human Services has National Guidelines for Adults
- *How did they come up with these guidelines?*



150 minutes per week of *moderate intensity* activity

**OR**

75 minutes per week of *vigorous intensity* activity

**AND**

2 or more days per week of muscle strengthening exercises

**\*\* Each bout of aerobic activity should last at least 10 minutes \*\***

**\*\* Splitting activity up into at least 3 days per week is most beneficial \*\***

**\*\* Flexibility and stretching are important parts of physical fitness \*\***

## How hard should I exercise?

### *What is Light, Moderate, and Vigorous Activity?*

- Intensity – “Physical Activity Effort Scale”
- What is a **MET**?

## What types of activities count as exercise?

Read each example and decide if the activity meets the guidelines for healthy physical activity

Playing basketball on the driveway – Breathing hard and sweating – Total time is 20 minutes

**YES**

**NO**

Vacuuming the house – Breathing a little harder than rest – Total time is 7 minutes

**YES**

**NO**

Vacuuming the house and carrying laundry upstairs – Breathing hard – Total time is 15 minutes

**YES**

**NO**

Taking a leisurely walk with a family member – Not breathing harder than rest – Total time is 20 minutes

**YES**

**NO**



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## Case Study

Melissa's doctor told her she needed to start getting more physical activity in order to stay healthy. However, Melissa hates running and there is no gym close to her house. She enjoys taking her dog for walks, but usually only gets around to it once a week, and then only makes time for a short walk around the block. Melissa decides to turn her weekly dog walk into a good source of physical activity. She begins gradually increasing the length of time she walks and how fast she walks. Now Melissa takes her dog on a walk five days a week and typically walks at a quick enough pace to make

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***What activities do you enjoy?***

***How can you modify them to turn them into a good source of physical activity?***

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## Quote of the Day:

**"I don't exercise to add years to my life, I exercise to add life to my years."**