

## AN ABSTRACT OF THE DISSERTATION OF

Kerri Ayame Vanderbom for the degree of Doctor of Philosophy in Exercise and Sport Science presented on April 12, 2013.

Title: Exploring Physical Activity Behaviors in Adults with Spina Bifida: A Mixed Methods Approach

Abstract approved: \_\_\_\_\_

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**Background:** Spina bifida (SB) is the most common birth defect, affecting approximately 1 to 2 in 10,000 live births. SB is a complex disability with many associated, secondary, and chronic conditions that require lifelong medical care. Individuals with spina bifida (SB) are living longer with advances in medical care, and the majority of the estimated 166,000 individuals in the US living with SB are adults. Consequently, secondary conditions (SC) are more apparent and healthcare costs to treat SC are high. The National Center on Birth Defects and Developmental Disabilities' approach to decrease SC is to increase the number of accessible health promotion programs (HPP) available and increase levels of physical activity (PA). For persons with SB, a sedentary lifestyle is common, thus placing individuals at greater risk of experiencing SC. Furthermore, there is a lack of PA HPP for individuals with SB and there is a significant need to find approaches to increase PA behaviors in this population. However, if HPP are to effectively increase PA behaviors they have to be well designed, include the target population, and use previous research to guide development. Consequently, the first step in creating a PA HPP for individuals with SB is a needs assessment. Therefore, PA needs assessment was developed and implemented for adults with SB. **Methods:** The needs assessment included information about (1) demographics, environment, current PA behaviors, attitudes and motivation; (2) the individuals PA stage of change (SOC); and

(3) perceived PA barriers (personal and environmental). A mixed method approach was used to collect data for the needs assessment that included a national, online survey (quantitative) and 1-1 interviews (qualitative). Results: Adults with SB lead a sedentary lifestyle. From the quantitative study, barriers, self-efficacy, and being female predicted participants PA levels. Main themes identified from the qualitative study included (1) a lack of PA knowledge, (2) facing personal barriers, and (3) a strong intention to become active. Conclusion: Future research needs to focus on developing PA interventions to educate adults with SB about the health benefits and ways to increase activity. The results from the needs assessment will guide the development of a future PA HPP that will aim to facilitate the adoption and maintenance of PA behaviors in adults with SB.

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Exploring Physical Activity Behaviors in Adults with Spina Bifida: A Mixed Methods  
Approach

By

Kerri Ayame Vanderbom

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

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Kerri Ayame Vanderbom, Author

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## CONTRIBUTION OF AUTHORS

For manuscript 1 & 2:

Kerri Ayame Vanderbom, M.A., conceptualized the sequence of studies, collected all data, conducted and interpreted data analyses, and drafted the manuscripts.

Simon Driver, Ph.D., assisted in the development of the research design, checked data analyses, provided editorial comments, and made suggestions on the interpretation of the findings.

Manuscript 1:

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Manuscript 2:

Mara Nery, Jill Pawlowski, and Jessica Wack assisted with the thematic coding of the data.

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## Chapter 1: General Introduction

### **Challenge of Spina Bifida**

Spina bifida (SB) is the most common birth defect, affecting approximately 1 to 2 in 10,000 live births (Boulet et al., 2008). SB occurs when the neural tube fails to fuse in the embryo (Patten, 1953) and causes problems in four main areas: the central nervous system, the genitourinary tract, musculoskeletal system, and skin (Harris & Banta, 1996). Generally, the higher the lesion is located on the spine, the poorer cognitive and motor outcomes are, due to impairments in the brain structure (Fletcher & Brei, 2010).

Since the mid-1970's, there have been improvements in medical care, and individuals with SB are living longer. Consequently, the majority of the estimated 166,000 individuals in the US living with SB are adults (Liptak & Samra, 2010; Ouyang, Grosse, Armour, & Waitzman, 2007). Thus, as people with SB are living longer, they experience long term chronic and secondary conditions that can negatively affect health. Therefore there is a significant need to find approaches that improve health and prevent secondary conditions.

### **Conditions in Spina Bifida**

Due to the complexity of SB, there are many associated, secondary, and chronic conditions that usually require extensive medical care throughout life. The effect and interaction between these conditions can be examined using Rimmer and Rowland's (2008) conceptual model of health promotion. The model contains five key areas including: *personal* and *environmental* factors, *associated*, *secondary*, and *chronic* conditions. If the individual's primary disability (personal factor) required them to use a wheelchair to get around, but their environment (environment factor) was not accessible, then the person may have limited access to the community resources, social experiences and lead a sedentary life. This may increase their risk of developing secondary conditions, such as obesity, which over time can lead to a chronic condition such as type 2 diabetes, and ultimately early death. Because of the increased risk of morbidity and mortality in this population, associated, secondary, and chronic conditions must be considered and well understood in order to develop an effective health promotion intervention (Rimmer & Rowland, 2008).

### **Associated Conditions**

Associated conditions are directly related to the primary disability and are not preventable (Krahn, Hammond, & Turner, 2006), however they can be controlled or managed to prevent further complications (Rimmer & Rowland, 2008). Examples of associated conditions in SB include hydrocephalus, a neurogenic bladder, and scoliosis (Thomson & Segal, 2010). Management of scoliosis in individuals with SB, for example, may include surgery to implant metal rods along the spine to prevent further curvature. Because of the high number of associated conditions, there is an increased probability of experiencing one or more secondary conditions (Simeonsson, McMillen, & Huntington, 2002)

### **Secondary Conditions**

There are many definitions of secondary conditions since the term was coined in 1986 (Rimmer, 2011). One common definition is that secondary conditions are medical *conditions* that occur directly or indirectly from the disability. This may confuse some to define risk factors or chronic conditions as secondary conditions. Another common definition of secondary conditions is a *condition* that occurs secondary to the disability, but directly because of the disability. To clearly define secondary conditions, Rimmer et al. (2011) used five criteria: (1) the condition must occur after an individual acquires or is born with a disability, (2) the characteristics of the conditions are not associated with the trauma or the progression of the disability, (3) it is more prevalent in people with disabilities than those who do not have a disability, (4) it is not caused by medication or interventions, and (5) it is a health condition (versus a risk factor for a health condition). Secondary conditions are often seen in late adolescence, early adulthood, or adulthood and can be a cause of premature aging (Turk, 1994, p. 46). Examples of secondary conditions for the SB population include: obesity and physical deconditioning, pressure sores, isolation, depression, and chronic pain (Dopler-Nelson et al., 2007; Mahmood,

Dicianno, & Bellin, 2011; Marge, 1994). Secondary conditions are preventable, yet common in the SB population and can lead to premature morbidity.

### **Effects of Secondary Conditions on Adult Outcomes**

Secondary conditions are the most important factors affecting overall quality of life (QOL) in young adults with SB (Barf et al., 2007). Further, the adverse health conditions not only impact physical health, but also mental health (Field & Jette, 2007, pg. 137). Social isolation (or a lack of participation in everyday life) and depression are commonly reported in SB literature and lead to a failure or delay in achieving adult milestones (Holmbeck & Faier-Routman, 1995; Hunt & Oakeshott, 2003; Verhoef et al., 2005; Zukerman et al., 2011; ). Youth and young adults with SB are at high risk of depression and low self-worth, which negatively impact employment, self-care, and other areas of functioning (Judd et al., 2000). It has been reported that more than half of adults with SB were unemployed and lived with parents, over 70% were not married or in an intimate relationship, and only 2% had attended college (Bellin et al., 2010; Hunt & Oakeshott, 2003; Roach, Short, & Saltzman, 2011).

Despite the increased risk of morbidity, secondary conditions can be prevented or managed by using health promoting behaviors and education in order to reduce costs, poor health, and increase quality of life (Rimmer & Rowland, 2008). However, if secondary conditions are not prevented or treated, they can lead to the development of chronic conditions.

### **Chronic Conditions**

Chronic conditions are health conditions that are related to lifestyle and behaviors (Rimmer & Rowland, 2008), and are the most preventable, yet the most costly of all health problems in the United States (US) (Center for Disease Control and Prevention [CDC], 2010). Examples include cardiovascular disease, type 2 diabetes, cancer, stroke and asthma. Chronic conditions are the leading cause of mortality in the United States,

responsible for over 70% of all deaths (Kung et al., 2005). Together, heart disease, cancer and stroke account for 50% of all deaths in the US (Kung et al., 2005).

In the general population, obesity is a strong risk factor for T2D (Lindmark et al., 2005), and in long-term, large cohort studies, overweight adults were three times more likely to develop diabetes (Field et al., 2001) and the highest mortality rates among the overweight were due to diabetes. In obese (BMI of  $\geq 30$  kg/m<sup>2</sup>) men, the rate of death was five times higher compared to lean male subjects and for obese women the rate was eight times higher (Lew & Garfinkel, 1979). For individuals with SB, obesity has been reported to be as high as 50% for adults with SB (Spina Bifida Association, 2011). With a high percentage of individuals with SB being obese, there is a greater risk of T2D and other chronic conditions associated with obesity, such as metabolic syndrome. Metabolic syndrome is a clustering of conditions that increase the risk of chronic heart disease by threefold (Isomma et al., 2001). Metabolic syndrome is high in youth and young adults with SB. For example, Dopler-Nelson et al. (2007) examined 11-20 year olds with SB and found that 32.4% of them had metabolic syndrome and of those, 46% were obese. These results are from child and young adults, so how this tracks into adulthood is unknown in the SB population. However, it is known in the general population that obese children who become obese adults have a very high risk of developing metabolic syndrome and that childhood obesity alone increases the risk for metabolic syndrome in adulthood (Vanhala, Vanhala, Kumpusalo, Halonen, & Takala, 1998.). These findings are important to note because, when coupled with the knowledge that adolescents with SB are overweight and have a higher incidence of metabolic syndrome (Dopler-Nelson et al., 2007), they suggest that there is potentially life-long, poor health and quality of life for the majority of the SB population due to chronic conditions. Due to the high risk of poor health, there is significant need for HPP that help individuals avoid developing secondary and chronic conditions.

### **Cost of Spina Bifida**

Due to the range of adverse health conditions that affect people with SB there are high health care costs, estimated to be approximately \$560,000 across the lifetime (Grosse et al., 2008). However, this is only an average and the costs for some are thought to be well over 1 million dollars (Spina Bifida Association, 2011). These healthcare costs are estimated to be three to six times higher for adults with SB when compared to adults without SB (Kinsman & Doebling, 1996).

Secondary conditions for adults with SB are preventable, yet common as previously described, and the financial costs are substantial. For example, costs for secondary conditions were estimated to be \$437,262 for a 12.5 day hospital stay (Kinsman & Doebling, 1996). This figure is based on the dollar in the mid-1990's, so the inflation-adjusted figure over the past decades makes this figure likely higher. In a more recent study, over 97% of the 18-64 year old SB participants had received some sort of outpatient care in 2003 and they estimate that healthcare costs for adults with SB are approximately \$16,000 per year (Ouyang et al., 2007). This study illustrates that secondary conditions not only affect the person, but are a great monetary burden in this population and aging individuals with SB are high users of medical care. Once patients with SB become adults and leave pediatric care, they are often lost in the medical system and there is no surveillance of secondary or chronic conditions (Webb, 2010). Therefore, it is conceivable that the costs reported by Ouyang and colleagues (2007) are lower than what might be observed in a publicly insured SB population. Furthermore, these figures do not take into account the personal or caregiver loss and psychological costs to the person with spina bifida.

The problems faced by individuals with SB are a public health issue due to the combination of a growing population of adults with SB, the high risk of developing secondary and chronic conditions, and the high costs of health care. Therefore, there is a great need for interventions to increase health, cut costs, and improve adult outcomes (Dicianno et al., 2008).

### **Importance of Physical Activity Program Interventions for Adults with Spina Bifida**

The health benefits of physical activity (PA) are well documented (Blair et al., 1989; Haskell et al., 2007; Paffenbarger, Hyde, Wing, & Hsieh, 1986; Wannamethee, Shaper, & Walker, 1998;), and PA is a leading indicator of health associated with decreased mortality and morbidity (US Department of Health and Human Services [USDHHS], 2008). Those who are more active, have lower rates of coronary heart disease, depression, breast cancer, type II diabetes, metabolic syndrome, and stroke (USDHHS, 2008). Yet, the majority of Americans fail to meet the recommended guidelines (CDC, 2008). Additionally, it is recognized that Americans with disabilities are even less active than the general population and there is a need to increase access to HPP for people with disabilities (USDHHS, 2010a).

Most recently, the National Center on Birth Defects and Developmental Disabilities has made it a top priority to decrease obesity and other preventable conditions in children and adults with disabilities (CDC, 2011). Two approaches to decrease obesity and other conditions include increasing the number of accessible HPP available and to reduce the proportion of adults with disabilities who report no leisure time PA (CDC, 2011).

The importance of increasing PA may be even more important for individuals with disabilities, since a reduction in strength or fitness may lead to a loss of physical function and independence, causing even further impairments or limitations (Rimmer, 2005). For example, active individuals with SB, compared to those with SB who are not active, report more functional independence and a higher QOL, and perceived less problems performing activities of daily living (Buffart, van den Berg-Emons, van Meeteren, Stam, & Roebroek, 2009). Also, those who reported more time spent participating in PA and sports had higher athletic competence, physical appearance, and self-worth (Buffart et al, 2008).

Studies focusing on PA levels for individuals with SB are limited, but have demonstrated that individuals are even more inactive than their peers without disabilities. In children with SB, significant differences between youth with SB and healthy youth



were found using accelerometers (van den Berg-Emons et al., 2001). Youth with SB only spent 91 minutes per 23-hours in dynamic activities compared to their non-disabled peers who spent 178 minutes in dynamic activities. Dynamic activities included walking, wheelchair-driving, cycling, and general movement (van den Berg-Emons et al., 2001). Their conclusion that youth with SB are hypoactive is in agreement with other studies (Schoenmakers et al., 2008; van den Berg-Emons et al., 2003). These sedentary lifestyle patterns adopted in childhood often persist into adulthood (Raitakari et al., 1994). For example, Buffart and colleagues (2007) examined adults with SB and found that 39% of their participants were inactive and another 37% were extremely inactive. van den Berg-Emons et al. (2003) found similar results assessing the relationship between PA levels, body fatness, and fitness. They observed that adults with SB spent only 2.3% of their day in dynamic activities.

Despite the known benefits of PA, a sedentary lifestyle is common for individuals with SB, thus placing individuals at greater risk of experiencing secondary and chronic conditions. Therefore, it is essential to increase PA behaviors in this population. One way to increase PA behaviors is through the use of a HPP tailored for the SB population.

### **Increasing Physical Activity through Health Promotion Programs**

The Ottawa Charter (WHO, 1986) defined health promotion as the process of enabling people to increase control over the determinants of health, and to improve their health. HPP topics can include PA, nutrition, smoking, health screening (breast and prostate cancer), safety, and alcohol and drug use. The Ottawa Charter specified that it was essential for individuals to participate in the decision making-process in order to sustain health promotion action and to make it effective (WHO, 1986). Also, by including the individual in the decision making process and teaching skills and strategies to overcome barriers, self-efficacy increases. The individual is given a sense of accomplishment or success managing their own health (Rimmer & Rowland, 2008). In alignment with the Ottawa charter, Marge (1994, p. 91) recommended that individuals with SB need to be taught personal responsibility for a majority of their health status and

should become a joint manager in his or her own long- and short-term health and wellness. Further, it is a very important to include their beliefs, practices, values, and personal choice in the development and implementation of a HPP (Peterson, Hammond, & Culley, 2009, p. 159).

### **History of Health Promotion Programs for Individuals with Disabilities**

Historically, public health used a medical model approach to disability where the goal was to treat, cure, and prevent disability, versus encouraging those living with disability to engage in healthy behaviors. This meant that all efforts were spent on SB prevention, and for those living with SB, health promotion was overlooked and the treatment of associated conditions was the focus. For example, SB prevention campaigns began in the early 1990's including the U.S. Public Health Departments recommendation for women of child-bearing age to take a supplement of 0.4mg of folic acid. In 1996, the Food and Drug Administration started an optional folic acid fortification to grain products with mandatory compliance by 1998 (Williams et al., 2002). It was about this same time that a paradigm shift started to take place- from a prevention (medical) model, to more of a health promotion model that not only took into consideration the person and disability, but also social, public policy, and the environment (Drum, 2009, p. 27).

### **Health Promotion Programs for Individuals with Disabilities**

With a shift away from the medical model of health, HPP developed for people with disabilities became more numerous over this past decade (Drum et al., 2009) and have shown some success in positively changing health behaviors. For example, Rimmer and colleagues (2000a) employed a 12 week exercise instruction, nutrition education, and health behavior change program for stroke survivors. They found high adherence to the program since they removed barriers such as transportation, cost, and peer and staff support. Those who were in the treatment group, reduced body weight, increased strength, flexibility, and increased psychological health (Rimmer et al., 2000a). In another example, Zemper et al. (2003) conducted a holistic intervention for individuals

with spinal cord injuries for three months. The educational sessions in their HPP covered topics such as PA, nutrition, lifestyle management and secondary conditions. Their participants increased self-efficacy, increased their knowledge and behaviors about nutrition, had better stress management and increased their PA, and reported fewer secondary conditions (Zemper et al., 2003). The *Living Well with a Disability Program* also focused on reducing secondary conditions in people with physical disabilities (Raveslout, Seekins, & White, 2005). The program was developed using data collected from a needs assessment conducted with individuals with physical disabilities and includes PA, nutrition, goal-setting, problem solving, depression, information seeking, advocacy, and maintenance (Raveslout et al., 2005). Their results were positive, finding that those who completed the program had less secondary conditions than those who did not complete the program, equating to significant healthcare cost reductions (Raveslout et al., 2005). Finally, Cardinal and colleagues (2004) found that a HPP that uses behavior strategies derived from the transtheoretical model (increasing knowledge, social support, etc.) may positively influence individuals with mobility impairments' SOC for exercise behaviors. Overall, the study results show that HPP provide health benefits to the participants by increasing their awareness of healthy behaviors.

### **Health Promotion Programs For Adults with Spina Bifida**

In 1994, a working group of healthcare professionals stated that there was a high-priority need “*to study the efficacy of interventions to prevent secondary conditions and to promote general health and wellness in persons with SB*” (Campbell et al., 1994, p. 125). The group selected health-related physical fitness to discuss in more detail (Campbell et al., 1994, p. 120). They developed recommendations for healthcare professionals, as well as for research to be conducted. Two important research questions developed by the working group that need to be answered in order to promote health in this population are as follows: “*what are the barriers to health and wellness, and what are the means for overcoming the barriers?*” and “*how can persons with disabilities best*

*be educated about physical fitness, wellness, and health?”* (Campbell et al., 1994, p. 121).

Going beyond their recommendations and focusing not only on PA barriers and knowledge, but identifying other correlates of PA, is important in order to target HPP strategies that will maximize the effectiveness of a HPP. However, there is a paucity of research focusing on the correlates of PA and PA behaviors for the SB population. Within this small body of research, major themes emerge related to the PA behaviors and levels for people with physical disabilities. First, in a study of adults with SB, personal barriers were found to be one of the main factors that influence PA levels. For example, adults with SB cited low motivation (38%) as the greatest barrier to community participation, which included PA (Boudos & Mukherjee, 2008). Low motivation was followed by a lack of knowledge (25%), and then not having time (21%) (Boudos & Mukherjee, 2008).

Similarly, in a study of individuals with physical disabilities (including SB) Warmes and colleagues (2007) found that there is evidence that attitudinal barriers, including motivation and support from others, may be more influential on PA behaviors than environmental barriers. PA levels were significantly correlated to SOC, but interestingly, SE and environmental barriers were not correlated to PA levels (Warmes, Belza, & Whitney, 2007). The low correlations observed may have been due to the instruments chosen to measure PA levels and due to a small sample size. In contrast, Kinne et al. (1999) found that personal barriers, including SE and motivation, were the most significant barriers amongst individuals with physical disabilities. Further, those who reported more barriers to PA also reported lower health (Kinne, Patrick, & Maher, 1999) and those who had a higher SE, had a higher probability to maintain their PA behaviors.

Buffart et al. (2009), after conducting a focus group with adults with SB, found that fatigue and health conditions related to SB reduced PA participation. Some participants felt that there were no health benefits of PA, others did not have the motivation (attitudinal barriers), while many had a lack of information (Buffart et al., 2009).

It has been 17 years since the call for HPP for the SB population, however there remains a lack of HPP to prevent adverse health conditions (Buffart et al., 2008; van den Berg-Emons et al., 2001). Furthermore, there is little research examining correlates of PA in the SB population and clearly there is a need for more in order to create PA HPPs that effectively facilitate healthful behavior change. Without a PA based HPP, the SB population will continue to experience adverse health conditions and with the increasing population of adults with SB, the poor health and the high costs associated with secondary and chronic conditions, there is a great need for a HPP. Therefore, this study will develop a needs assessment of the PA and barriers for adults with SB that will be used to guide the development of a PA HPP.

### **Guidelines for Creating A HPP**

In order to foster PA behavior change, it is important to tailor the HPP for the target audience, in this case, adults with SB. In order to successfully increase PA behaviors, there are recommended guidelines to follow when developing a PA HPP (USDHHS, 2010b, p.79). The USDHHS guidelines include 12 steps that are from theory- and evidence-based interventions that were successful in increasing individual PA behaviors (USDHHS, 2010b, p.79). Steps one through four include developing a PA needs assessment that will help guide the development of a PA HPP- identifying and increasing an individual's PA knowledge, intentions, and barriers. Steps five through 12 include the steps to develop, implement, and maintain a PA HPP. Specifically, the steps to carry out the needs assessment are: (1) increase an individual's knowledge and awareness about PA; (2) determine their readiness to change; (3) identify perceived barriers to increase PA; and (4) explore potential solutions to the barriers. Steps five through 12, in order to develop and implement a PA HPP, include: (5) identifying the individual's goals for PA ; (6) The types and amount of PA to meet their goals; (7) assess skill level, and if necessary, the individual must learn the skills needed to meet their goals; (8) identify social supports to call upon to encourage PA; (9) monitor PA to ensure progress towards goals; (10) resolve problems if there is no progress towards goals; (11)

reward for progress towards goals; and (12) anticipate and plan for relapses of decreased PA behaviors and regression into a previous SOC (USDHHS, 2010b, p. 79). Utilizing the USDHHS PA HPP guidelines (steps one through four), the current study involved creating and implementing a PA needs assessment for adults with SB.

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### Research Aim and Hypothesis for Manuscript 1:

*Aim:* To identify which factors (barriers, self-efficacy (SE)) predict physical activity levels of adults with spina bifida ages 18-60 years old

*Hypothesis:* Barriers (personal and environmental) and SE will predict physical activity levels

*With a greater number of barriers and less SE lower physical activity levels will be reported*

### *Assumptions:*

- 1) It was assumed that all respondents had spina bifida
- 2) It was assumed that all of the participants answered the survey independently and answered accurately

### *Limitations:*

- 1) All of the measures were self-report, so that responses may have been influenced by social desirability or memory recall
- 2) The study was internet based, which may have excluded individuals with no access to the internet or computer

### *Delimitations:*

- 1) An objective measure (such as accelerometers) was not used to measure physical activity levels to address the issue of valid self-reporting
- 2) In the analysis, listwise deletion was utilized, which may have decreased power by reducing sample size
- 3) The results from the *Physical Activity Disability Survey* were not used for the amount of physical activity, as it had low reliability

### *Operational definitions:*

- 1) Spina bifida is defined as a neural tube that occurs when the spinal column fails to close completely during fetal development
- 2) Regularly active= those who reported currently and consistently doing physical activity (stages 4-5 of stage of change)

3) Not regularly active=those who reported not currently doing any physical activity (stages 1-3 of stage of change)

#### Research Aim and Approach for Manuscript 2:

*Aim:* To conduct one-on-one interviews to identify information about physical activity knowledge, attitudes, intentions, motivations, expectations, and barriers towards physical activity in adults with spina bifida ages 18-60 years old

*Approach:* 10 qualitative interviews were conducted to discuss the participant's knowledge, attitudes, intentions, motivations, expectations, and barriers towards physical activity

#### *Assumptions:*

- 1) It was assumed that all participants had spina bifida
- 2) It was assumed that all of the participants answered accurately

#### *Limitations:*

- 1) The researcher was somewhat new to conducting interviews. This could have influenced the way questions were asked
- 2) The sample included more males than females
- 3) It was self-reported information, so responses may have been influenced by social desirability or memory recall
- 4) The ability to extrapolate the results to a wider population of adults with spina bifida is limited
- 5) The nature of qualitative analysis is somewhat subjective according to the researcher's interpretation of the data, however that is why multiple researchers are used in the analysis process

*Delimitations:* Results may have been limited by the questions asked in regards to the topic

*Operational definition:* Spina bifida is defined as a neural tube that occurs when the spinal column fails to close completely during fetal development

## Chapter 2: Manuscript 1

Determinants of Physical Activity Participation in Adults with Spina Bifida

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### **Abstract**

**Objective:** The purpose of this study was to examine factors (self-efficacy and barriers to participation) that predict physical activity participation for adults with spina bifida.

**Design:** An online national survey was conducted with participants being recruited from the National Spina Bifida Association, Spina Bifida clinics, and through social media.

**Survey measures included:** demographics, 5 eligibility questions, amount of weekly physical activity, barriers and self-efficacy, and stage of change. A logistical regression was computed to determine which factors predict participation. **Results:** 61.7% (n=161) of participants were not regularly active (stage of change 1-3). After controlling for level of activities of daily living assistance, sex, and age, persons who were regularly active had significantly higher odds of self-efficacy (AOR: 1.4; 95% CI 1.2, 1.6) and were 33% less likely to report barriers compared to persons who were not regularly active (AOR: 0.67; 95% CI 0.57, 0.78). Being female significantly predicted activity level, as females were 61% less likely to report participating in regular activity when compared to males (AOR: 0.39; 95% CI 0.20, 0.78). **Conclusion:** Future interventions should focus on removing barriers to physical activity and increasing self-efficacy in order to increase the physical activity behaviors of adults with SB.

**Keywords:** Disability, Online Survey, exercise, Self-efficacy, Barriers

## Determinants of Physical Activity Participation in Adults with Spina Bifida

### **Spina Bifida**

Spina bifida is the most common birth defect, affecting approximately 1 to 2 in 10,000 live births (Boulet et al., 2008). Spina bifida occurs when the neural tube fails to fuse in the embryo (Patten, 1953) and causes problems in four main areas: the central nervous system, the genitourinary tract, musculoskeletal system, and skin (Harris & Banta, 1996). Since the mid-1970's there have been improvements in medical care, and individuals with SB are living longer (Mukherjee, 2007). Consequently, the majority of the estimated 166,000 individuals in the U.S. living with spina bifida are adults (Liptak & Samra, 2010; Ouyang, Grosse, Armour, and Waitzman, 2007). However, because people with spina bifida are living longer, their risk of experiencing long-term chronic (e.g., hypertension, heart disease) and secondary (e.g., obesity, cardiovascular disease, pressure sores, depression, chronic pain) conditions (Dopler-Nelson et al., 2007; Mahmood, Dicianno, and Bellin, 2011; Marge, 1994) is increased. In fact, secondary conditions account for more than half of the healthcare problems in adults with spina bifida (Kinsman & Doehring, 1996). Due to the range of secondary conditions that can affect people with spina bifida the resultant health care costs are high, estimated to be approximately \$560,000 across the lifetime (Grosse et al., 2008). However, this is only an average and the costs for some are thought to be well over 1 million dollars (Spina Bifida Association, 2011). With the growing population of adults with spina bifida, the increased risk of developing secondary conditions, and escalating health care costs, there is a great need for interventions that promote healthy aging (Dicianno et al., 2008).

One approach to improving the health of individuals with spina bifida is through physical activity participation. The health benefits of physical activity are well documented (Blair et al., 1989; Haskell et al., 2007; Paffenbarger, Hyde, Wing, and Hsieh, 1986;), and physical activity is a leading indicator of health associated with decreased mortality and morbidity (US Department of Health and Human Services [USDHHS], 2008). Those who are more active, have lower rates of coronary heart disease, depression, breast cancer, type II diabetes, metabolic syndrome, and stroke

(USDHHS, 2008). Yet, the majority of Americans fail to meet the recommended guidelines (Center for Disease Control and Prevention [CDC], 2008) and Americans with disabilities are even less active than the general population. From the National Health Interview Survey-Disability (NHIS-D) (2008), 36 percent of adults with disabilities engaged in no leisure-time physical activity compared to 25.1 percent of the general population (CDC, 2008).

Increased physical activity participation may be even more important for individuals with disabilities, since a reduction in strength or fitness may lead to a loss of physical function and independence, causing even further impairments or limitations (Rimmer, 2005). For example, active individuals with spina bifida report more functional independence and a higher quality of life compared to those with spina bifida who are not active (Buffart, van den Berg-Emons, van Meeteren, Stam, & Roebroek, 2009). Also, those who reported more time spent participating in physical activity and sports had higher athletic competence, physical appearance, and self-worth (Buffart et al, 2008). Despite the known benefits of physical activity, a sedentary lifestyle is common for individuals with spina bifida (Buffart et al., 2007; van den Berg Emons et al., 2001; van den Berg Emons et al., 2010 ), thus placing individuals at greater risk of experiencing secondary and chronic conditions. Van den Berg Emons et al. (2001) found that participants with spina bifida who used wheelchairs were hypoactive and spent significantly less time in dynamic activity (91 minutes/week) compared to able-bodied participants (178 minutes/week). In a later study, van den Berg Emons et al. (2010) reported that participants with spina bifida who used a wheelchair were 40% less active than the age-matched controls, and reported the lowest level of activity when compared to other disability groups (including post-polio, spinal cord injuries, and cerebral palsy).

Given the known benefits of physical activity and the sedentary behaviors in the spina bifida population, ways to facilitate participation are needed. When developing strategies to change behaviors for individuals with disabilities, such as increasing participation in physical activity, use of a theoretical framework is critical to help guide research and increase the likelihood that behaviors will change (Drum et al., 2009),

However, in the disability and health promotion field, including spina bifida research, there is a lack of research that includes underlying theoretical frameworks (Drum et al., 2009). From the general physical activity literature three variables, from different theories, have been consistently linked to the adoption and maintenance of physical activity behavior and include an individual's stage of change, self-efficacy, and perceived barriers to participation (Fishbein, 2006; Kahn et al., 2002).

Stage of change is one component of the transtheoretical model that is often used to understand the process individuals move through while making a behavior change, such as adopting or maintaining physical activity. The transtheoretical model provides a framework to examine a person's motivations, barriers, benefits, and specific strategies for changing physical activity behaviors (Marcus & Forsyth, 2009, pp. 10). The transtheoretical model postulates that when individuals attempt to change a specific behavior, they move through the stages of pre-contemplation, contemplation, preparation, action, and maintenance (Prochaska & DiClemente, 1983). An individual's stage of change is a central factor to consider for practitioners working to facilitate physical activity participation as specific social and behavioral strategies have been identified to help individuals progress to the next stages and ultimately maintain the behavior. For example, a strategy that has been used to effectively move individuals from pre-contemplation to contemplation is to increase knowledge and awareness about the benefits of physical activity and identifying supports (Kahn et al., 2002). In the general population, identifying the current stage of change and targeting interventions to the specific stages has shown to effectively increase physical activity behaviors (Cardinal, 1997). Further, the stages of change have been demonstrated as a valid method to identify the current physical activity behaviors for individuals with physical disabilities (Kosma, Cardinal, & McCubbin, 2004), and tailoring intervention strategies for individuals with physical disabilities according to their stage of change has successfully increased individual's physical activity behaviors (van der Ploeg et al., 2007). Therefore, stage of change is an important variable to consider when examining the physical activity behaviors of individuals with spina bifida.



Increased self-efficacy is one variable that has been linked to an individual's ability to move through the stages of change (Cardinal, 1997; Marcus et al., 1992). Self-efficacy is an individual's belief in their ability to complete a specific task (e.g., be active when it is raining), and determines an individual's cognitions and behaviors about the specific task (e.g., I don't enjoy running in the rain so I'm not going to again) (Bandura, 1994). While self-efficacy is recognized as one of the strongest correlates to physical activity behavior in the general population (Sallis, et al., 1989), the relationship between self-efficacy and physical activity is not well understood for individuals with spina bifida. Warm, Belza, and Whitney (2007) found that physical activity levels of individuals with physical disabilities (including spina bifida) were significantly correlated to their stage of change, but interestingly, self-efficacy was not correlated to physical activity levels. In contrast, Kinne et al. (1999) found that low self-efficacy and motivation were the most significant predictors amongst individuals with physical disabilities and those who had higher self-efficacy, had a higher probability to maintain their physical activity behaviors (Kinne, Patrick, & Maher, 1999). Given the central role that self-efficacy has been shown to play in physical activity participation and the fact that little research exists for individuals with spina bifida, there is a need to better understand the role of self-efficacy on physical activity behaviors.

As self-efficacy is situation specific, individuals must have belief in their ability to be active even when faced with barriers (e.g., weather, fatigue, pain, cost). For individuals with spina bifida, barriers can be personal or environmental and have been demonstrated to influence physical activity access and participation. For example, Boudos and Mukherjee (2008) found that adults with spina bifida cited low motivation (38%) as the greatest barrier to community participation (including physical activity participation), followed by a lack of knowledge (25%), and not having time (21%). Buffart et al. (2009) reported similar results after conducting focus groups with adults with spina bifida. Specifically, participants indicated that personal barriers were the main factor preventing them from being active, including lack of motivation and attitude. Other barriers reported included a fear of becoming injured and a lack of information or general

knowledge of physical activity. Finally, in a sample of individuals with physical disabilities (including spina bifida), Warm's and colleagues (2007) suggested that attitudinal barriers, including motivation and support from others, might be more influential on PA behaviors than environmental barriers. Therefore, identifying barriers and developing strategies for individuals to overcome them is critical to facilitate access to and participation in health promoting behaviors (e.g., physical activity participation) (USDHHS, 2011).

In summary, there is a critical need to examine factors that influence the physical activity behaviors (Fishbein, 1995) of individuals with spina bifida to facilitate participation. Collecting data to predict what influences the physical activity behaviors is essential in order to identify ways to facilitate participation (Booth et al., 1997; USDHHS, et al., 1999, p. 43) for adults with spina bifida. Thus, the purpose of this study was to examine factors (stage of change, self-efficacy, and barriers to participation) that predict physical activity participation for adults with spina bifida (18-60 y/o). Based on previous research, it was hypothesized that stage of change, barriers (both personal and environmental), and self-efficacy would predict physical activity levels of individuals with spina bifida (Warm's, 2007), with individuals facing a greater number of barriers and lower self-efficacy reporting less activity (Warm's et al., 2007).

## Method

### Participants

A total of 367 adults with spina bifida accessed the online survey. However, the final sample size was 303 as (1) 25 participants were not included because they scored lower than eight on the MCAT (2) 36 participants started the survey, but did not respond to any questions beyond the informed consent, and (3) 3 declined to participate. Participants were enrolled if they met the following inclusion criteria: (1) were between the ages 18-60 years old, (2) had spina bifida (3) could understand English, and (4) had access to the internet. Exclusion criteria included: (1) inability to cognitively comprehend the study information (score of  $<7$  on the MacArthur Competence Assessment Tool), and (2) did not have access to the internet.

Of the 303 participants, 68.7% received the survey through social media (e.g., Facebook), 22.4% received the survey through the Spina Bifida National Association online newsletter or a Spina Bifida Chapter (e.g., SBA Alabama, SBA of California, SBA of Oregon Support Group), 8.6% received the survey through email from a friend, and 0.3% from a doctor. The majority of the respondents were female (68.5%), had never been married 70%, and identified as being Caucasian (85%). The majority of participants were between the ages of 25-34 (41%), followed by 35-44 (28.5%), 18-24 years old (16%), 45-54 (11.5%), and 55-60 years old (3%). Of the adults with spina bifida who knew their lesion level ( $n=164$ ), 76.8% reported that it was at the L1-5 level, 11.6% was at the S1-7 level, 8.5% at the T12-6 level, 2.4% at the T5-1 level, and 0.7% at the C1-7 level. Further, 66.4% reported having hydrocephalus. Body mass index (BMI) was calculated from self-reported height and weight and ranged from 16.27-57.89 ( $M = 29.96$ ,  $SD = 8.32$ ). 116 participants (43 %) were classified as 'obese', 67 participants (25%) as 'overweight', 78 participants (29%) as 'normal', and 9 (3%) as 'underweight'.

To assess whether a participant was able to cognitively comprehend the instructions and purpose of the study an adapted version of the MacArthur Competence Assessment Tool (MCAT) (Bellin et al., 2010) was used. Since many individuals with spina bifida have cognitive deficits that include problems with reading and language comprehension (Fletcher & Brei, 2010), it was important to ensure that participants understood not only the purpose and instructions of the study, but also their rights as participants taking part in the study. The adapted version of the MCAT consisted of five questions, measuring comprehension in five domains of the study: (1) the participant's understanding of the purpose of the study (e.g., What is the purpose of the research?), (2) activities involved in the study participation (e.g., How many visits are you asked to participate in?), (3) benefits of participating in the study (e.g., in what way might you benefit by volunteering to participate this study?), (4) risks and discomforts associated with participation (e.g., tell me the possible risks associated with participation.), (5) and procedure to withdraw from the study (e.g., what will you do if you decide that you no longer want to participate in this study?). Responses were scored on a 0-2 range (0=inadequate understanding; 1=partial understanding; 2=adequate understanding). To be included in the study, participants needed to score 8 or above (out of 10) on the measure (Bellin et al., 2010).

### **Recruitment and procedures:**

Approval from an Institutional Review Board was received, ensuring the procedures were ethical. Participants for the survey were recruited from the Spina Bifida Association National Conference; 29 National Spina Bifida Chapters plus the National Spina Bifida Association; adult spina bifida clinics and physical medicine and rehabilitation clinics, disabled sports organizations (Oregon Adapted Sports, Oregon Disability Sports, BORP,), and through online advertisement (*facebook*, and blogs). The approach to recruitment is a form of "anonymous snowball sampling" where the researcher is not given any of the participant's personal information (Berg, 2009).

All participants were directed to follow the study link where individuals completed the informed consent, demographic form, and study questionnaires (See

Appendix A). The survey consisted of 88 questions and took approximately 20-30 minutes to complete.

## Measures

**Demographics:** participants were asked a number of demographic questions including age, sex, race, height, weight, education and work status, socioeconomic status, and disability information.

**Type and amount of physical activity:** Type and amount of physical activity was measured using the physical activity disability survey [PADS] (Rimmer, Riley, & Rubin, 2001). The PADS was developed to measure physical activity for individuals with disabilities and chronic health conditions. It contains three subscales including: exercise (8 items), leisure time physical activity (7 items), and household activity (16 items). The PADS has demonstrated adequate psychometric properties as the test-retest reliability scores were high and ranged from 0.78 for the time indoor subscale, to 0.95 for the leisure time physical activity subscale. The concurrent and predictive validity was also established as the exercise, leisure time physical activity, and household subscales and the total activity score all correlated significantly with absolute  $VO_{2peak}$  (Rimmer et al., 2001). Cronbach's alpha for this study ranged from  $\alpha = 0.30$  (leisure & household) to 0.65 (exercise).

**Barriers to physical activity:** Barriers were measured using *Barriers to Physical Activity and Disability Survey* [B-PADS] (Rimmer, Rubin, & Braddock, 2000b). The B-PADS was developed for individuals with disabilities. The B-PADS consists of 34 questions where participants answer "yes", "no", and "I don't know", except for the last three questions, which are open ended (Rimmer et al., 2000b). For the 31 categorical questions, B-PADS had a test-retest reliability of 0.76 using Cohen's kappa and the interrater reliability kappa was 0.86 (Rimmer et al., 2000b).

**Stage of change:** The Stage of Change Scale (Prochaska & DiClemente, 1983) was used to determine which stage individuals with spina bifida were categorized into for physical activity. The measure has been used successfully in different physical disability

populations (Cardinal, Kosma, & McCubbin, 2004; Driver, Ede, Dodd, Stevens, & Warren, 2012; Kinne, Patrick, & Maher, 1999). The measure consists of one-item where individuals identify which of the five stages they are in: pre-contemplation (*does not perform physical activity and has no intention of doing so in the next six months*), contemplation (*is thinking about adopting the desired behavior within the next six months*), preparation (*plans to perform the desired behavior in the next month, maybe trying out the behavior, but is not consistent*), Action (*performs the desired behavior consistently, but has been doing it less than six months*), and maintenance (*has continued to perform the desired behavior consistently for six months or more*). The one-item measure has been shown to be reliable (Cohen's Kappa of .78; Marcus et al., 1992) and valid (Marcus & Simkins, 1993).

**Self-efficacy to regulate exercise:** As self-efficacy is context and situational dependent, the *Self-Efficacy for Exercise Scale* was utilized, which includes nine-items measuring the individual's belief in their ability to be active in different situations (e.g., bad weather, being stressed, busy time schedule) (Resnick & Jenkins, 2000). The scale utilizes a Likert-type scale where individuals indicate their level of confidence for being physically active in the different situations (from 0='Not confident' through 10='very confident'). Evidence of the internal consistency of the instrument ( $\alpha=0.92$ ) and construct validity ( $\lambda$  of 0.61 or more) have been provided (Resnick & Jenkins, 2000). Cronbach's alpha for the current study was  $\alpha=0.93$ .

### Statistical Analysis

All statistical data analyses were conducted using Stata version 12.1. Prior to running the analyses, data was screened for individuals who did not pass the MCAT or who declined to consent. First, participant's responses to the 5 MCAT questions were scored and summed and individuals with scores lower than 8 out of 10 points were not included in the analyses. Second, participants who declined to participate, as indicated on the waiver of documentation, were not included in the analyses. Missing data was

handled using listwise deletion; observations with missing data were removed from the analyses.

Descriptive statistics were computed for demographic and outcome variables. Cronbach's alpha was computed for the measures of self-efficacy, barriers, and type and amount of physical activity. To assess multicollinearity between independent variables (i.e., self-efficacy and barriers) and selected covariates, a correlation matrix was computed. Logistical regression models were conducted, to examine the relationships between the dependent variable (i.e., activity level) and the predictor variables (i.e., physical activity barriers and physical activity self-efficacy). Three covariates were used in the regression model including controlling for age, sex, and ADL assistance level.

To determine covariates, relationships between the covariate and dependent and independent variables were assessed by comparing the crude logistical regression models to an adjusted model with the added covariate. If the covariate changed the relationship between the dependent and independent variable it was considered a covariate and included in the final adjusted model. Sex, and age were the only significant covariates ( $p < 0.05$ ) and were subsequently used in the model. ADL assistance level was not significant, but to have a measure of disability, it was left in since it did not change the results.

Due to the low internal consistency of the PADS reported in the current study ( $\alpha = 0.30$  (leisure & household) to  $0.65$  (exercise)), the measure was not used in the logistic regression analysis as an indicator of the participant's physical activity level (the dependent variable). As a result, physical activity level was determined by the participant's response to the stage of change scale, where individuals were grouped into one of two groups including (1) not regularly active (stages 1-3), or (2) regularly active (stages 4-5). This approach has been used in previous research (Jackson, Morrow, Bowles, Fitzgerald, & Blair, 2007; Kinne, Patrick, & Maher, 1999), and this grouping data was subsequently used in the logistic regression analysis.

## Results

### Demographics and Descriptive Data

From the total sample size of 303, only 261 respondents that answered the stage of change question. Of the 261 respondents, 11.1% reported being in the pre-contemplation stage (n=29), 28.4% in the contemplation stage (n=74), 22.2% in the preparation stage (n=58), 13% in the action stage (n=34), and 25.3% in the maintenance stage (n=66). Once participants were dichotomously grouped as being either regularly active (stages 4-5) or not regularly active (stages 1-3), 38.3% (n=100) participated in regular physical activity, and 61.7% (n=161) did not participate in regular physical activity.

Table 1 compares demographic characteristics of respondents separated by persons who are regularly active and persons who are not. Descriptive results indicate that those who are regularly active are more likely to have greater independence (either need no assistance, some assistance, or full assistance with activities of daily living (ADL's)), have a lower BMI, and are less likely to be female, when compared to adults with spina bifida who were not regularly active.

Table 2 displays the percentage of specific barriers reported by participants who are regularly active compared to those who are not. In general, the data demonstrates that people who are regularly active perceive facing fewer barriers to participation compared to individuals who are not active. Participants who reported being regularly active generally perceived fewer personal barriers (i.e., motivation, time, and energy). Interestingly, a high percentage of individuals in both groups believed that barriers to physical activity included “won’t improve condition” and “or will make it worse”.

Table 3 includes the mean self-efficacy scores based on whether the individual was regularly active or not. Individuals who reported being regularly active had higher belief in their ability in all categories when compared to inactive participants.



### **Logistical Regression Analysis of Physical Activity Self-Efficacy and Barriers**

Table 4 provides the crude and adjusted models for physical activity level, barriers, and self-efficacy. A direct logistic regression was performed on physical activity level as the outcome and total barriers, mean self-efficacy score, and three demographic predictors: age, sex, and ADL assistance level. The adjusted model with all four predictors was statistically reliable,  $\chi^2 (5, 209) = 57.44$ ,  $p < 0.001$ , indicating that all of the predictors, as a set, reliably distinguished between regularly and not regularly active. Table 5 shows regression coefficients, z scores, odds ratios, and 95% confidence intervals (CI). Controlling for level of ADL assistance, sex, and age, persons who were physically active were 29% less likely to report barriers compared to persons who were not regular active (AOR: 0.71; 95% CI 0.60, 0.84). Those who were physically active were 1.3 times more likely to have higher self-efficacy (AOR: 1.3; 95% CI: 1.12, 1.5) after controlling for ADL assistance, sex, and age. The only covariates that were significantly related to physical activity level were sex and age. Females were 58% less likely to be physically activity when compared to males (AOR: 0.42; 95 % CI 0.21, 0.85). Age predicted physical activity level, where with increasing age, the individual is 4% less likely to be active (AOR: 0.96; 95% CI 0.96, 0.99).

## Discussion

The purpose of the study was to examine the factors that would predict the physical activity behavior of individuals with spina bifida. Overall, results indicated that self-efficacy, barriers, sex, and age were significant predictors of physical activity participation. Thus, individuals who were regularly active had greater self-efficacy and perceived fewer barriers. Conversely, participants who were not regularly active had low self-efficacy and perceived more barriers. Assistance to complete ADLs was not found to be a significant predictor of activity level. In general, adults with spina bifida reported facing many barriers to physical activity and, contrary to what one might expect, personal barriers (i.e., depression, knowledge) were more of a problem than environmental barriers (i.e., inaccessible facilities, transportation).

Alarming, 37-58% of participants from both groups reported physical activity as a barrier that would not improve their condition and would actually make their condition worse. With the overwhelming evidence in support of the benefits of physical activity participation, this is of concern for the population of individuals with spina bifida, which is exacerbated by the fact that only 26% of participants from the regularly active group and 42% of the not active group had been told to be active by their physician. Furthermore, less than 15% had been told by the physician to do specific physical activity. Evidently, there was a disconnect between the participant's understanding of the benefits and risks of physical activity and their disability. An increased knowledge of physical activity and the associated health benefits is important if the individual is to make informed choices about whether to be active or how to implement it into their life (UDHHS, 1999, pg. 88). Increased awareness is a critical component of several behavior change approaches (e.g., health awareness/belief model; transtheoretical model) as it is the first step to changing behavior, and individuals need to have an increased awareness of the benefits in order to want to change their behavior (Vega et al., 1987).

Other personal barriers included laziness and lack of motivation. Similar to the Boudos & Mukherjee (2008) findings, results from the current study indicated that

motivation and laziness were major barriers to participating in physical activity. Specifically, 73% (n=190) of the sample reported laziness as a reason why they are not active and 51% (n=132) indicated motivation was an issue. The percentage of individuals citing laziness and lack of motivation as barriers is considerably higher than previous studies (i.e., motivation = 37-54%; laziness = 32-34%) that examined barriers faced by different disability groups (Rimmer, Rubin & Braddock, 2000; Rimmer, Wang, & Smith, 2008; Scelza, Kalpakjian, Zemper, & Tate, 2005). Interestingly, motivation was considered a barrier for both individuals who were and were not regularly active (24% compared to 25%). Lack of motivation has been linked to low achievement levels (e.g., living independently, performing activities of daily living, having employment) in individuals with spina bifida, and it has been suggested that this apathy is a result of problems related to hydrocephalus and intracranial pressure (Hunt, Oakeshott, & Kerry, 1999). However, a study examining the goal-setting behaviors of children with spina bifida reported that low achievement was not related to cognitive deficits per say, but rather a result of a being unable to sustain goal-directed behaviors and a need for more guidance to reach concrete goals (Landry, Copeland, Lee, & Robinson, 1990). Thus, in light of the current findings, individuals with spina bifida may need more support developing an action plan (e.g., including equipment, time schedules, places, goal reassessment, etc.) to overcome barriers to physical activity participation.

Another finding of concern was the fact that sex predicted physical activity levels. Being female is associated to health behaviors and outcomes and women with physical disabilities (including spina bifida) are more likely to be sedentary and are at higher risk of developing secondary conditions (Nosek, Howland, Rintala, Young, & Chanpong, 2001; Nosek, et al., 2006; Rimmer, Rubin, & Braddock, 2000; Santiago & Coyle, 2004 ). In the current study, being female was found to be a strong predictor of physical inactivity.

Previous research has demonstrated that females with spina bifida experience lower self-worth and greater depression and self-blame when compared to their non-disabled peers (Appleton et al., 1997). Another reason for low physical inactivity for

females with spina bifida could be due to socialized behavior and how they view themselves and their role in their social community (Gough, 1960). If females view their role as observers of physical activity and males as the ones who participate, then females will assume that role. Also, it could be possible that females have a preconception that being physically active will cause a certain physical appearance (e.g., too muscular), thus avoiding physical activity. Future research should examine whether depression and or socialized behaviors are factors associated with lower physical activity levels.

Regardless of the reason, physical activity strategies may need to be even more targeted towards females with spina bifida. It has been recommended that strategies for women with spina bifida include increasing self-management knowledge, skills, and use of goal setting (Sawin, Bellin, Roux, Buran, & Brei, 2009). Examples of increasing self-management knowledge may include anticipating and preventing bowel and bladder issues during activity or how to anticipate and overcome barriers to participation; increasing skills may include mastery development in specific activities (which will increase self-efficacy); goal setting can incorporate how to set SMART goals, reassess goals, and implement self-reward. Further, for women it may be important to incorporate personal physical activity counseling, education, and the use of self-rewards (Frolich-Grobe & White, 2004), which would provide additional support and help improve self-management. Strategies using peer support, have also been shown to significantly improve self-management skills in females with spina bifida (Sawin et al., 2009), which would be important when starting and maintaining physical activity behavior change.

Results from the present study also found self-efficacy to be a significant predictor of whether an individual was regularly active. Those that reported that they were regularly active had an average self-efficacy score just above the mean, while those who were not active had a below average self-efficacy score. This result is consistent with self-efficacy and social cognitive theory as individuals typically avoid activities they feel exceed their abilities, while they take part in activities they perceive themselves capable of managing (Bandura, 1982; 1986). Ways to enhance self-efficacy for adults

with spina bifida are needed as belief in ability plays a central role when changing health behaviors, such as increasing physical activity (O'Leary, 1985; Strecher, McEvoy-DeVellis, Becker, & Rosenstock, 1986). Reasons for low self-efficacy in this group of adults with spina bifida may be due to one of many factors including developmental competence (e.g., self-esteem, physical and behavioral) and adolescent and family factors (i.e., decision making, coping, support from others) (Sawin, Buran, Brei, & Fastenau, 2003).

Bandura's (1977) self-efficacy theory states that self-efficacy is derived from four antecedents: performance accomplishments (either failure or success of participating in physical activity previously), vicarious experiences (i.e., seeing someone else with spina bifida be active successfully), verbal persuasion (i.e., social support from others to keep trying), and physiological states (i.e., the activity causes them stress, fatigue, or a headache). By addressing Bandura's four antecedents, practitioners are increasingly likely to facilitate the physical activity behavior of adults with spina bifida. First, individuals need to have successful experiences participating in physical activity. Affording opportunities to learn how to use a gym, for example, with guidance to ensure success would be important. For example, during the initial learning phase, an individual could focus on mastering two weight machines and, once they feel comfortable and confident, another exercise or machine could be added into the workout until the individual feels confident accessing the whole gym. A lack of mastery experiences may be a particular issue for individuals with spina bifida as previous research has demonstrated that individuals often have a lack of responsibility from a young age, which leads to a lack of opportunities to master skills (Sawin et al., 2003). By providing support and gradually teaching the individual skills, there will be a greater sense of accomplishment from learning and succeeding at a new skill which is likely to further increase belief in ability and future behavior.

In alignment with the antecedent of vicarious experiences (Bandura, 1982), the importance of using mentoring and role modeling is recognized and recommended for youth with spina bifida transitioning into adulthood (Spina Bifida Association, 2013).

The use of role modeling and mentoring to increase belief in ability in areas such as disability-related self-efficacy, community-based knowledge, and self-confidence was found to be successful in youth with physical disabilities (including spina bifida) compared to the control group (Powers, Sowers, & Stevens, 1995). While there is a lack of literature examining the use of mentors with adults with spina bifida, the idea should be explored in the future. As adults with spina bifida are often isolated (Blum, Resnick, Nelson, & St. Germaine, 1991), the use of mentors would not only help with exposure to someone with similar abilities, it would also provide a form of socialization. The third antecedent, verbal persuasion, can lead to the individual trying harder and not giving up as quickly. Family members and friends could utilize positive reinforcement to help support the individual to be physically active. Finally, for the fourth antecedent, the physiological state, individuals with spina bifida may need to more knowledge about the body's response to exercise, what is normal versus abnormal (i.e., increased heart rate, sore muscles versus pain) to ease anxiety or stress about performing higher intensity activities. As participants in the current study who were inactive reported very low confidence in their ability to be active, strategies to increase confidence for this subgroup are needed.

It is important to note that there were limitations to the present study. First, the PADS was originally the measure of physical activity, however due to the low reliability, stage of change was used. From the PADS, it was originally hoped to have specifically identified participants who were meeting the physical activity guidelines (USDHHS, 1999). Reliability may have been low for several reasons including: (1) some of the questions required recall of information, which may have not been accurately reported, and (2) there may have been low variance between answers from participants.

Second, the study was internet-based, and it is estimated that 54% individuals with disabilities in the U.S. lack access to the internet in their homes (compared to 19% in the general population) (PEW, 2011). Thus, the sample of adults with spina bifida may not have been representative of the overall population of individuals with spina bifida.

## **Conclusion**

Despite the documented benefits of physical activity (Blair et al., 1989; Haskell et al., 2007; Paffenbarger, Hyde, Wing, & Hsieh, 1986; Wannamethee, Shaper, & Walker, 1998), many individuals with spina bifida are sedentary and at a high risk of developing adverse health conditions (Dopler-Nelson et al., 2007; Harris & Banta, 1996; Marge, 1994; Mahmood, Dicianno, & Bellin, 2011; Simeonsson, McMillen, & Huntington, 2002). Consequently, there is a need to identify strategies to facilitate the adoption and maintenance of physical activity participation for this population. However, due to the unique needs of this population (i.e., physical, intellectual, and psychosocial), strategies need to be targeted specifically for adults with spina bifida in order to increase physical activity effectively. Further, physical activity research related to spina bifida is in the early stages of development, with a vast majority of research focusing on linking health outcomes to behaviors and factors influencing behaviors (Vanderbom, Driver, & Nery, 2013). As a result, there is very little translational research examining the effectiveness of physical activity health promotion programs or disseminating evidence-based programs. Results from the current study suggest that future interventions should focus on helping individuals with spina bifida identify and overcome barriers to activity as well as increasing self-efficacy. Further, interventions should include strategies specifically for women with spina bifida who are at increased risk of low activity and poor health outcomes. Results from this study should be used to develop evidence-based interventions to increase the physical activity behaviors of individuals with spina bifida to meet their unique needs.

Table 1: Characteristics of Participants Based on Physical Activity Grouping

	Regularly active	Not regularly active
	38% (n=100)	62% (n= 161)
Age, mean (SD)	32.2 (8.6)	34.7 (9.8)
Sex, %		
Male	53	47
Female	32	68
ADL assistance level %		
No assistance	39	61
Some assistance	36.36	63.64
Full assistance	25	75
Hydrocephalus status (%)		
Yes	40	60
No	36	64
BMI, %		
Underweight	3.9	3
Normal weight	35.3	23.2
Overweight	25.5	23.8
Obese	35.3	50
Race, %		
White	36.5	63.5
Black	46	54
Hispanic	37.5	62.5
Other	39	61
Work Status, %		
Part-time	40	60
Full-time	35.6	64.4
Student	44.8	55.2
No work	38.6	61.4
Income , %		
<11,999	39.6	60.4
12,000-34,999	33.9	66.1
35,000-74,999	38.3	61.7
>75,000	41.7	58.3



Table 2. Mean Percentage of Barriers to Participating in Physical Activity

	Regular PA	No regular PA
	(n=100) %	(n= 161) %
Costs too much	24	29
Lack of transportation	29	44
Fitness staff would not be able to help	15	25
Concerns exercising at a facility	8	21
Doctor told you to exercise (Yes)	26	42
Doctor told you to do anything specific (No)	11	13
Lack of time	24	42
Lack of interest	35	46
Lack of energy	27	33
Lack of motivation	24	26
Physical activity is boring	34	48
Physical activity won't improve condition	37	54
Physical activity will make condition worse	37	58
Physical activity is too difficult	37	50
Don't know how to do it	36	48
Don't know where to go	37	49
Health concerns prevent participation	36	51
Pain prevents participation	31	44
Too lazy to participate	33	40

Table 3. Mean Scores of Self-Efficacy to be Physically Active

	Regularly Active (n=100) <i>M</i> (SD)	Not Regularly Active (n=161) <i>M</i> (SD)
If the weather was bad	5.8 (3.6)	4.4 (3.2)
If the activity was boring	5.4 (3.2)	3.5 (2.8)
Felt pain when exercising	4.5 (3.2)	2.8 (2.5)
Had to do activity alone	7.5 (3.2)	4.5 (3.3)
Didn't enjoy activity	4.5 (3.2)	2.9 (2.6)
Was too busy with other activities	4.5 (3.1)	3.0 (2.5)
Felt tired	5.0 (3.3)	3.0 (2.6)
Felt stressed	6.0 (3.5)	4.1 (3.2)
Feld depressed	5.2 (3.8)	3.2 (3.0)
Overall mean self-efficacy score	5.4 (2.7)	3.5 (2.2)

Table 4. Analysis of Physical Activity Level Crude and Adjusted Model

		Total Barriers	Mean Self-Efficacy Score
Physical Activity Level	Crude OR	0.72 (0.61, 0.85)	1.3 (1.13, 1.5)
	Adjusted OR	0.71 (0.60, 0.84)	1.3 (1.12, 1.5)
OR, odds ratio; AOR, adjusted odds ratio Adjusted for age, sex, ADL level			

Table 5. Parameter Estimates for Physical Activity Level on Barriers, Self-Efficacy & Demographic Variables

	$\beta$	Z score	Significance of independent variables	AOR	% change of OR	95% CI
Barriers	-0.34194	-4.05	$p < 0.000$	0.71	-29	0.60, 0.84
Self-efficacy	0.23874	3.34	$p < 0.001$	1.3	30	1.1, 1.5
Sex	-0.86013	-2.43	$p < 0.015$	0.42	-58	0.21, 0.85
Age	-0.04681	-2.43	$p < 0.015$	0.96	-4	0.93, 0.99
ADL level of assist	0.00411	0.01	$p < 0.990$	1.0	0	0.51, 2.0

### Chapter 3: Manuscript 2

Qualitative Exploration of the Physical Activity Behaviors of Adults with Spina Bifida

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### **Abstract**

Spina bifida is a significant public health issue due to the incidence, complexity of adverse health conditions, and the high costs associated with lifelong treatment. The purpose of this study was to interview adults with spina bifida to determine physical activity (PA) knowledge, barriers, motivations, expectations and intentions, and attitudes. Ten participants completed individual interviews about their PA behaviors. Qualitative research methods were utilized and trustworthiness was established using triangulation. Content analysis was conducted to identify themes and patterns. Main themes identified included: (1) a lack of PA knowledge, (2) many personal barriers, and (3) a strong intention to become physically active. Future research needs to focus on developing PA interventions to facilitate participation in individuals with spina bifida.

*Keywords:* Qualitative, disability, needs assessment, health promotion

## Qualitative Exploration of the Physical Activity Behaviors of Adults with Spina Bifida

### Introduction

Spina bifida (SB) is a complex disability that causes lifelong health problems, but with improvements with medical care, most individuals are now living into adulthood (Mukherjee, 2007). As a result, it is estimated that majority of the 116,000 individuals with SB living in the United States are adults (Liptak, Garver, Dosa, 2013; Liptak & Samra, 2010; Ouyang, Grosse, Armour, & Waitzman, 2007). However, as individuals with SB age, their risk of developing secondary conditions (e.g., pressure sores, depression, and obesity) is high. Admission rates to hospitals for adults with congenital disabilities (including spina bifida) have been found to be nine times higher than the general population and each person had on average 11.5 outpatient doctors visit over 12 months (Young et al., 2005). These adverse health conditions come at a high health care costs, and are estimated to be potentially over 1 million dollars (Spina Bifida Association, 2011). For example, results from a recent national sample of 37,464 adults with SB who were hospitalized found that 33.8% of the admissions were due to secondary conditions and over a two year period cost over \$364 million (Dicianno & Wilson, 2010). Collectively, results from these studies illustrate that secondary conditions affect the health of the individual and present a significant financial burden, which is likely to be exacerbated as individuals with SB continue to age. Therefore, there is a significant need to find ways to improve the health of this population. One way to improve health is through increased physical activity (PA) participation, with the mental and physical health benefits being well documented (Blair et al., 1989; Haskell et al., 2007; Paffenbarger, Hyde, Wing, & Hsieh, 1986; Wannamethee, Shaper, & Walker, 1998;).

It has been recommended that targeted preventative efforts are needed to address the unique health care needs of the SB population (Wilson, Lewis, & Dicianno, 2011), and to increase PA participation, similar targeted efforts might be needed. One way to increase PA for a specific population is to implement an evidence-based health promotion program. The results of several research studies have demonstrated the effectiveness of health promotion programs in reducing secondary conditions for individuals with

physical disabilities such as pressure sores, body weight, and improving mental health (Cardinal et al., 2004; Rimmer et al., 2000; Zemper et al., 2003).

Despite this evidence, there is currently a lack of health promotion programs for individuals with SB, and this shortage has been recognized since 1994 when a working group of healthcare professionals stated that there was a high-priority need *“to study the efficacy of interventions to prevent secondary conditions and to promote general health and wellness in persons with spina bifida”* (Campbell et al., 1994, p. 125). The group selected health-related physical fitness to discuss in more detail (Campbell et al., 1994, p. 120) and developed recommendations for future areas of research. Two important research questions that emerged from the working group remain unanswered, but are critical in order to promote health in this population. Specifically, the questions were: (1) *“What are the barriers to health and wellness, and what are the means for overcoming the barriers?”*, and (2) *“How can persons with disabilities best be educated about physical fitness, wellness, and health?”* (Campbell et al., 1994, p. 121). While it has been almost 20 years since this call for improved intervention research, there remains a lack of preventative programs for individuals with SB (Buffart et al., 2008; van Den Berg-Emons et al., 2001; Vanderbom, Nery, Driver, 2013). Consequently, with the increasing number of adults with SB, poor health of the population, and high costs associated with secondary and chronic conditions, there is a clear need for health promotion programs.

### **Designing a Health Promotion Program**

In order to successfully increase PA behaviors, there are recommended guidelines to follow to develop a tailored PA health promotion program (USDHHS, 2010, p. 79). The USDHHS guidelines are theoretically based and stem from evidence-based interventions that have been shown to successfully increase individual’s PA behaviors (Kahn et al., 2002). According to these guidelines, the first step is to complete a PA needs assessment of the target population (i.e., adults with SB), with results being used to help guide the development of a tailored health promotion program. Specifically, it is



recommended that the needs assessment includes collecting data (1) assessing the target population's knowledge and awareness about PA, (2) determining the population's readiness to change (including their values, beliefs, and attitudes), and (3) identifying barriers to being active. A health promotion program developed without understanding the unique characteristics of the targeted population will likely not be effective in successfully changing behavior (USDHHS, 1999, pp. 44). Therefore, the present qualitative study aimed to identify information about the PA knowledge, attitudes, intentions, motivations, expectations, and barriers of adults with SB ages 18-60 years old by conducting semi-structured interviews.

## **Method**

### **Participant Recruitment**

Approval to complete the study was received from an Institutional Review Board at a university in the Pacific Northwest, ensuring that all procedures were considered ethical. Participants for the interviews were recruited through the Oregon SB Chapter, sports organizations in Oregon (e.g., Oregon Adapted Sports & Oregon Disability Sports), and in person, from the National SB conference. Individuals were informed about the purpose of the study and that they would receive a \$30 gift card for completing the interview. Participants were included in the study if they: (1) were between the ages 18-60 years old, (2) had spina bifida (3) could understand English, and (4) had access to the internet. Exclusion criteria included: (1) inability to cognitively comprehend the study information (score of  $\leq 7$  on the MacArthur Competence Assessment Tool), and (2) did not have access to the internet.

To assess whether a participant was able to understand the instructions, purpose of the study, and participate in the interview, an adapted version of the MacArthur Competence Assessment Tool (MCAT) (Bellin et al., 2010) was used. Since many individuals with SB have cognitive deficits that include problems with reading and language comprehension (Fletcher & Brei, 2010), it was important to ensure that participants understood not only the purpose and instructions of the study, but also their rights as participants taking part in the study. The adapted version of the MCAT consisted of five questions, measuring comprehension in five domains of the study: (1) the participant's understanding of the purpose of the study (e.g., What is the purpose of the research?), (2) activities involved in the study participation (e.g., How many visits are you asked to participate in?), (3) benefits of participating in the study (e.g., in what way might you benefit by volunteering to participate this study?), (4) risks and discomforts associated with participation (e.g., tell me the possible risks associated with participation.), (5) and procedure to withdraw from the study (e.g., what will you do if you decide that you no longer want to participate in this study?). Responses were scored

on a 0-2 range (0=inadequate understanding; 1=partial understanding; 2=adequate understanding). To be included in the study, participants needed to score 8 or above (out of 10) on the measure (Bellin et al., 2010).

### **Participants**

Results were obtained from 10 individual interviews (4 female, 6 male). Originally, fourteen participants were contacted to participate in the interviews. However, three could not be reached to set a time to complete the interview and one participant did not pass the MCAT questionnaire. Participants ranged in age from 20-46 years old ( $SD=9.3$ ,  $M=36$ ), none had been married, all 10 were Caucasian.

### **Interview Procedures**

After agreeing via email to participate in the study, each participant was emailed an ID number and the web link to complete an electronic informed consent and MCAT questionnaire. Individuals who agreed to participate and passed the MCAT questionnaire were then contacted to schedule a time to conduct the interview. All the interviews were conducted telephonically.

Each interview lasted 30-60 minutes and involved the researcher asking a series of semi-structured, open-ended questions about PA. Probes were used throughout to encourage responses from the participant (see Appendix B for the interview guide) (see table 2 for detail on the process of question development). Utilizing a semi-standardized format allowed for consistency throughout the interviews, but also allowed for the participants to expand on their point of view or situation (Berg, 2009). At the beginning of the interview, each participant was reminded about the purpose of the study and that all of the information collected would be confidential, non-identifiable, and audio recorded for transcription at a later date.

### **Qualitative Analysis**

Upon completion of the final interview, audio files of the interviews were transcribed verbatim. The transcriptions included all questions from the interviewer and responses from the participants. The analysis of the content included condensing the raw data into themes based on valid inference and interpretation (Zhang & Wildemuth, 2009). A team of three researchers (investigator triangulation) with a background in PA read through each interview independently, coding the major and minor themes while looking for thematic saturation of meaning in the data (Berg, 2009). The researchers extracted themes from the data through careful examination and constant comparison of the data. Once the researchers had independently analyzed the interviews, they met to establish inter-coder agreement (Zhang & Wildemuth, 2009). Establishing common themes and eliminating overlapping areas is part of investigator triangulation that helps to establish trustworthiness of the study (Creswell & Miller, 2000).

Trustworthiness of the study was established using investigator triangulation (Goodwin & Compton, 2004; Meadows & Morse, 2001). Investigator triangulation involved using multiple researchers with a background in physical activity to analyze the interview data and determine the themes. First, three researchers coded the data. Then, to confirm that the coding was consistent throughout the interviews, a critical friend with a background in physical activity verified that the coding was in alignment with the research aims. The critical friend was given the aims of the study along with the quotes and codes to ensure the consistency of the coded data. Finally, a stakeholder check was used to further triangulate the data and increase trustworthiness. The stakeholder, an adult with spina bifida, was provided with the quotes and codes to ensure the credibility of the interpreted transcriptions and findings (Guba, 1981).

Approximately 49 codes were created after the initial coding process with the three researchers. Once the coding was complete, it was uploaded into Atlas t.i. to create code lists. Atlas t.i. is a qualitative analysis program used to systematically organize codes from text that allows researchers to locate, code, reduce, and evaluate the importance of designated pieces of the data. A codebook that consisted of all the code

lists was created to ensure consistency of coding throughout the interviews and allow researchers to systematically compare new text with text that had already been coded. The codebook was constantly updated when new codes were discovered. Once the critical friend and the stakeholder examined the data, the 49 codes were then reduced to 21 codes after accounting for redundancy and overlap (Thomas, 2003).

## **Results & Discussion**

The six categories that were used to develop the questions and guide the interviews included participant's PA knowledge, attitudes and expectations, intentions, motivations, expectations, and barriers. Through the data analyses, five meta codes emerged: (1) understanding of PA, (2) environmental and personal barriers to PA, (3) facilitators of PA, (4) expectations of PA, (5) PA intentions over time and attitudes toward PA (see table 3).

### **Understanding of Physical Activity**

The participant's understanding of PA was determined if the participants talked about or described the different aspects of activity (e.g., amount, duration, intensity, modes, health benefits, etc.). Knowledge is important for the individual to have in order to make informed choices whether or not to take action and participate in PA, or how to apply PA in their lives (UDHHS, 1999, pg. 88). Increased awareness is a critical component of several behavior change approaches (e.g., health awareness/belief model; transtheoretical model) as it is the first step to changing behavior and individuals need to have increased awareness in order to want to change their behavior (Vega et al., 1987). For example, by using the transtheoretical model, individuals who are identified as pre-contemplators may need to be made aware of the benefits of physical activity in order to increase awareness and contemplate participation.

Participants in the current study demonstrated a general understanding of PA by discussing the physiological responses, health benefits, and different modes. All 10 participants were able to describe what PA is and at least one characteristic of PA and/or the types of PA. Three people incorporated intensity into their definition of PA by discussing increases in heart rate and sweating in response to participation, "...it means going out and doing an activity that involves movement. Usually at an intensity that will increase my heart rate, and usually at a duration of at least a half an hour" (male 6). Others described PA more generally including "it means going and doing, getting

exercise, workout, or just go out and having a social activity that includes any rolling around in my wheelchair” (female 3).

When asked about types of PA, participant’s answers ranged from listing sports to specific types of exercises (e.g., “Rolling around. Finding a track or a parking lot...rolling around for 30 min. and lifting weights for a half hour or so...not on the same day- playing basketball, tennis, swimming” male 5), or general movement (e.g., “just not being a couch potato, just getting out doing things...just try to stay active doing things, going for walks, or like I said just not being a couch potato” male 5). Three participants made the distinction between activities for individuals with and without disabilities, “like for able-bodied people it’s like taking a walk. For us, it could be like taking a walk, but pushing our chair” (female 4).

All of the participants, whether they engaged in PA regularly or not, were able to identify the link between PA and health. Four participants mentioned health in their definition of PA, and described it as “anything from just walking or pushing your chair to actually doing sports or anything in between. Something that will improve your overall health” (male 3). Another participant talked about how PA was about “taking steps to be fit so my body won’t wear out....Being pro-active about keeping your body in shape so that you’ll be more healthy down the road in later life” (male 5).

Participants also discussed depression amongst individuals with SB and the role of PA, which is not surprising due to the high rates of depression among young adults with spina bifida (Bellin et al., 2010). For example, male 6 indicated, “I think it [PA] would play a large role [with depression]. I experience a lot of loneliness, a lot of depression, and being inactive is a very strong contributor to that [well-being].” For individuals with medical problems who are at a high risk of becoming depressed, PA has been shown to have a positive effect on mental health and can help with coping with stressful events (Harris, Cronkite, & Moos, 2006). Given the positive effects of PA on mental health, the responses of individuals in the current study are encouraging since they

demonstrate an awareness of their risk for depressive symptomology and role that activity can play in preventing it.

Individuals also regularly mentioned how weight management was a health benefit associated with PA participation. For example, female 11 stated that, “doing PA keeps my weight down and it does keep me strong so I am able to transfer.” Obesity is a major problem in this population and it is estimated that 50% of children with SB are overweight, and by adulthood, 50% are obese (Spina Bifida Association, 2012). This statistic is consistent with the findings of the current study, as 50% of participants would be classified as obese based on their BMI. Nevertheless, the fact that 9 of the 10 participants recognize the importance of weight management and link to PA participation and overall health (e.g., independence) is encouraging. The importance of maintaining weight for independence is described appropriately by male 5:

Because I use a wheelchair and I am not able to walk very long distances, it gets hard if I got fat, to move around. The most I walk on a day to day basis is the front of my car to the back where I keep my wheelchair...but my mom keeps telling me that would be hard or impossible if I gained a lot of weight. (male 5)

For individuals with SB, physical therapy is a common intervention during childhood that typically focuses on muscle tone and flexibility to prevent contractures (Schoenmakers, Uiterwaal, Gulmans, Gooskens, & Helders, 2003). In this study, eight of the 10 participants reported that they participated in physical therapy when they were younger. It was evident that the participants were familiar with physical therapy and all but one participant was able to distinguish the difference between physical therapy and PA. Most of the responses defined physical therapy as something that was done for rehabilitation for specific conditions that had an end point (i.e., after recovery from surgery):

I think physical therapy is different because it's getting a person to gain something they lost. So, it's getting them back to the level they were before the reason they are getting PT. Where PA is gaining more strength- so the more PA you do, the stronger you get. You go beyond where you were at before. Therapy is- you can't consider it exercise...you can, but it's not something you are going to do for the rest of your life. You do it until whatever you're doing it for gets better. (female 4)



In contrast, PA was considered something they chose to participate in, “Physical therapy is something you have to do. PA is something you want to do. PA is like I said, going and doing tennis, like I love to do tennis, and that is PA. Physical therapy is something that has to be done to maintain your muscle movements” (female) 3.

Eight participants did not mention any health benefits of PA when comparing PA to physical therapy, which is consistent with the results of previous research with adults with traumatic brain injuries (Self et al., 2012), and suggests a disconnect between linking PA to the health benefits that participants describe they get from physical therapy. For example, half of the descriptions of physical therapy included flexibility and stretching, “Physical therapy is more about stretching, increasing flexibility, and learning more of the basic core skills of the desired movement we are trying to get back.” However, the responses did not mention that stretching can be a physical activity and can improve flexibility. This may suggest that the health benefits of PA are not fully realized in this population of adults with spina bifida. Thus, adults with SB need to be made aware of the health benefits of PA activity and how PA can help conditions related to the disability (i.e., flexibility, cardiorespiratory fitness).

### **Environmental and personal barriers to physical activity participation**

Barriers are another factor that may limit or prevent participation in regular PA (Booth et al., 1997). For individuals with disabilities, fewer motivational barriers have been related to a higher probability of maintaining exercise (Kinne, Patrick, & Maher, 1999). Further, Rimmer and colleagues (2000) found that 81% of their sample of women with physical disabilities wanted to participate in PA, but faced many environmental barriers (i.e., cost, transportation) and few personal barriers (i.e., knowledge of a facility, energy). Barriers were defined in this study as perceived or real obstacles, personal (i.e., lack of time) or environmental (i.e., lack of accessible facilities), that prevented access to PA. The 10 participants reported many barriers to PA, with personal barriers being the most commonly mentioned.

Personal barriers for this group included barriers related to their disability, motivation, a lack of knowledge and time, age, safety issues, and depression. The number of disability specific barriers experienced by adults with SB can range greatly, depending on their age, lesion level, hydrocephalus status, self-care skills, and access to healthcare (Webb, 2010). Furthermore, due to the many health problems, individuals with SB will often have multiple surgeries during their lifetime for things such as ventricular shunting, bladder augmentations, and spinal rods. In one study, the number of surgeries ranged from zero to 35 (Verhoef et al., 2004). As a result, it is no surprise that one younger female participant (female 3) spoke about how hospital stays were one of her biggest barriers to PA:

So, you know I have spina bifida. And I've had many surgeries in my life and I think those were the only times I was not active. And in retrospect that kind of doesn't sound like much time. But, for someone who likes to be active, sitting still for a month, or however long it takes to heal, can be really frustrating. Yeah. I think the biggest block has been surgeries or operations that prevented me. (female 4)

Participants reported other health problems that were barriers. For example, one participant experienced chronic pain that limited his participation:

Right now, knee pain. Trying to walk for an extended period of time, or talk to someone while standing on cement that causes me a lot of pain for me. So, having a lot of leg strengthening intensive exercise workout is very important to me to get the leg strength back. (male 2)

Another common personal barrier that was reported to limit activity was related to aging. A 46 year-old male participant explained how he is more cautious when exercising, "I joined a gym back in August and I've already seen improvements and I am trying not to injure myself since I am older" (male 2). Another participant explained why he quit playing hockey, "I played sledge hockey for about 10 years. But, things changed in my life-I felt the urge to change, I got old and couldn't keep up with the young kids anymore, and it was no longer fun" (male 6). While some mentioned barriers caused by aging and not knowing what to do to, one participant had some good insight about anticipating age related barriers and how he is planning to overcome them:

I think I will need different things in the future because wheelchair racing is not always going to be there. Although, there are people in their 60's who are still racing. But, you can't count on it always being there. So, you have to modify your routine to stay active based on what your body is telling you. Your body can break down if you are overdoing it, so you have to be able to say that it's time to change up what I am doing...you have to constantly look at it at certain points in your life and figure out how to stay physically active...gotta keep it fresh and interesting. (male 3).

A lack of knowledge about how much PA to complete to be healthy was another barriers reported by participants. In the current study, only one participant knew the recommended guidelines (USDHHS, 2008) and the number of minutes they should be active, although they did not include discussion of intensity in her definition. However, in a study of the general population, only 25.6% of adults included knew what the PA guidelines were (Moore, Fulton, Kreuger, & McDivitt, 2010).

Knowledge about PA (e.g., modes, intensity, duration, etc) is an important factor that has been related to PA participation (Sallis et al., 1992). Current participants demonstrated a lack of knowledge about the recommended PA guidelines, and unsure of what modes of activity they should be completing or were capable of participating in. One participant explained, "I don't know exactly what the guidelines are, but like I said, I know that you should get exercise daily- things like that. Get out and do things, I'm not exactly sure how much they want to do during the week-what they want the average person to do" (male 2). Seven participants stated that they needed more information about what exercises they should do and thought it would be helpful to have someone knowledgeable who could help them. Consequently, efforts should be made to communicate targeted messages about the PA guidelines and what constitutes appropriate activity for health benefits (Meischke et al., 2000) for individuals with SB. Increased knowledge has been linked to positive behavior change and improved health (Morrow et al., 2004).

Participants also discussed many barriers related to access, with common issues being a lack of knowledgeable staff ("Someone who is knowledgeable that deals with people with disabilities--that understands that I can't do everything that Joe Blow can

do”(male 2)), transportation (“Getting transportation since I don’t really have transportation and I have to depend on another person to get to the tennis courts, or to get to where I need to go. Even the gym” (female 1)), accessible facilities and equipment (“it was really hard to find a pool that I could get in and out of on my own. I can transfer if it’s not level...there aren’t many pools that have the chair lift things that go into the pool. I have yet to find one here” (female 2)), and cost (“I was seriously looking into getting a bike [hand cycle] and we have been looking for a long time, and it’s so expensive...” (female 3)). Other frequently mentioned access issues included location (“I am from a small town, and I don’t have the option of going to a YMCA or a Bally’s or any kind of fitness place. So I’ve never had anything away from home. If I can try a gym, I’d like that. If I can find a place like that...”), or distance:

One thing that contributed to me stopping with sledge hockey was that...they changed where they rented ice time to an outlying community and it ended up that instead of a maximum of a thirty minute drive, now it would be a 45 minute or an hour drive each way... (male 6)

The implications of access barriers are serious and there is mounting evidence that demonstrates poor social, economic, and health outcomes are associated with an inaccessible environment (Srinivasan, O’Fallon, & Dearry, 2003). Riley and colleagues (2008) state that having a physical disability compounds these problems. The removal of access barriers is recognized as an important issue for individuals with disabilities and was subsequently included as a Healthy People 2020 objective (i.e., DH-8: *‘Reduce the proportion of people with disabilities who report physical or program barriers to local health and wellness programs’* (USDHHS, 2010).

With the high number of barriers individuals with SB face that prevent them from participating in PA, it is important to identify ways for this population to overcome them. Interestingly, some participants mentioned how they have adapted to overcome some of these barriers on their own. For example, one participant enjoys taking part in general exercise classes, “I also go to a lot of dance studios in the area. A lot of those classes aren’t adapted, but I go any ways to see what I am capable of doing and adapt myself” (female 4). Another participant, who was self-conscious of his fitness level and

appearance, found alternative places to be active such as parks and at home until his fitness improved, “I wanted to have a certain level before I went to the gym, so I wasn't doggin' it the whole time- all of these people here-so yeah, I tried to get some sort of base fitness before I signed up” (male 1).

In order to increase PA participation, barriers for adults with SB need to be addressed and, based on the present findings, interventions should focus on increasing knowledge and providing information on where to be active. Specifically, health promotion programs may focus on helping individuals identify barriers and implement strategies to overcome them.

### **Facilitators to physical activity**

Facilitators to PA were included when the individual described a process that initiated or guided their goal-related PA behaviors and caused them to act. There were a wide variety of facilitators mentioned that included fun, goal setting, health benefits and quality of life, and physical function. The “fun factor” was mentioned in about half of the interviews, and even by one participant who reported having no intention of increasing his activity levels. Another participant talked about how “fun” motivated him, “I think you need to keep PA and sports fun and interesting is important. If it's not interesting and fun then you won't be motivated to keep doing it” (male 3).

Participants also reported goal-setting as a facilitator to PA, and previous research has demonstrated that goal-setting can improve motivation (Pemberton & McSweigen, 1989). Further, when goals are lacking, not believed in, or not valued, there will be little motivation to accomplish the task at hand (Jackson & Csikszentmihalyi, 1999, pp. 81).

One participant talked about how he uses goal setting as his way to maintain activity:

'cause even though I have been PA for so many years I think what keeps me motivated as far being PA is setting goals for myself. So, what I try to do is either have some kind of a race, or some kind of PA in the future so that when I am training I have something to look forward to. So, that's what keeps me motivated to keep exercising and I don't see myself stopping any time soon. (male 3)

Another talked about how his past fitness and appearance was his motivation, and what he uses to gauge his goal achievement:

Unfortunately, I can remember my high school days--I would like to get a sustained two hours on the bike by next summer or fall. And get back within 10 lbs. of high school weight and sustain 2 hours on the bike or near there...that is the ultimate goal, anyways. Turn back the clock a little. (male 2)

Health and wellness emerged as a main facilitator to activity, which is consistent with previous research examining PA for women with physical disabilities (Goodwin & Compton, 2004) who reported that losing physical functioning, which would then jeopardize their ability to be independent, was a major concern. In the current study, 9 of the 10 participants were motivated by their overall health and wellness to stay or become active and were very concerned with their future health and ability to maintain independence. When talking about what motivated him to be active, a 46 year-old male (male 4) explained, “health and weight management-manage my health and weight. Plus, it helps to keep me active and going to work. Keeps my mind going. It helps keep me from being depressed.” Another participant talked about the motivating results he experienced from participating in PA:

The nice thing is that you might start seeing results. You know- a 5 lb. weight loss or I can stand that much longer, or walk that much further. In that- those little motivators- personally keep me motivated to continue to do exercises longer and continue my regiment than having to rely on someone else. But, there are peaks and valleys- you plateau. You just have to keep reminding your self- this is where I was. My blood pressure was 160/90 and now it's near what the doctors said it should be. (male 2)

Social support was another significant facilitator of participants PA participation, and previous literature has consistently demonstrated the important role of social support on health outcomes and promoting healthy behaviors (Berkman & Syme, 1979). Having someone to talk with, ask questions to, and share experiences with is an important part of changing behavior (USDHHS, 1999, pp.119). For individuals with SB, social support is associated with better psychosocial adjustment outcomes (Wallander & Varni, 1989) and those who reported having social support from family (1.12 times more likely) and friends (1.17 times more likely) have higher odds to participating in sports (Buffart et al., 2008).

One participant explained how having the support of a peer helped to motivate him to be active:

I met him at the [spina bifida] conference and he was going to complete- and he did- the Chicago marathon. So, I've been keeping in touch with him and we're kinda passing along" hey what are you doing? this is what I'm doing" so having that kind of a person even if you don't actually go to the gym together, just having a Facebook or an email or phone call to keep up with somebody to compare notes. That's some kind of accountability for each other. Because I think if you lose accountability, and you're not the type to be self-motivated, then you're gonna fall off of your regiment." (male 2)

For others, support from family and role modeling were important motivators:

I think what helps, too, is to think this through is that both of my parents were active and athletes in high school and college. My mom, she still runs different K's- 25 k's. So she is still quite active. So, I think having that in your family is a good motivator....but, you know I can be active well into my 50's so why not get a good base now and have something I can sustain for the next 20, 30, 40 years. (male 6)

One individual spoke about how not having support has prevented him from being active, "A couple of years ago I was working out with a couple of friends with spina bifida, but that fell apart because a few of them moved away, but I would like to get back involved with that if I could find the right setting with new people and workout and stuff. I haven't been able to find that group yet" (male 1). Social support is an important facilitator of PA and future strategies should include group activities and strategies for individuals to develop a social support network.

### **Expectations to be physically active**

Expectations were defined as a strong belief that there will be a specific outcome as a result of being active, and it is critical that outcome expectations are realistic (Fishbein, 1995). For example, if an individual expects to look like a body builder after two weeks of strength training, they may be disappointed when it does not occur, and may lead to feelings of failure and disappointment which may influence future intentions negatively. Participants in the present study indicated that there were a variety of outcomes (i.e., physical health, psychological health) that they expected from being

active. For example, male 3 stated that “The top benefit is obviously... if you participate in PA then your overall health- physiologically is better. Then that affects- I believe it has a direct correlation to your mental health and how a person feels. How you handle stress” (male 3).

Participants also expected to be active at or near their home (“Probably within a mile or two from my residence, wheeling around my neighborhood instead of jumping in the car and going to a mall I might wheel there” (male 6)), places they could easily access in their community (“The big lake- Lake Michigan. Going swimming there for hours” (male 2)), and places where they felt comfortable (“I would like it more personable, not in a crowd, you know because of the self-image--you're over weight and just to get that pressure off” (male 1)). While not all participants currently had someone to be active with, they each stated that they expected support to be active from friends (“Usually people with the same age, similar abilities. Sometimes, similar interest in the types of activities I’m involved with” (female 2)) or family (“I usually go to work out with my dad on Friday and Saturday mornings” (male 5)).

### **Intentions to be active over time**

For the purposes of this study, intentions were contextualized as activities participants intended or planned to take part in, be it in the past or the future. According to Fishbein (2006) the strength of an individual’s intention is a key determinant to changing behavior. Of the current sample, only one out of the 10 participants had no intention to become physically active. “I don't like exercising... it's boring, too. Yeah. It's boring” (Female 1). As a pre-contemplator (Prochaska & DiClemente, 1983), female 1 has yet to form a strong intention to become physically active and would benefit from specific strategies to facilitate participation. For example, strategies might include addressing gaps in her knowledge and correcting any misconceptions she might have, building her self-efficacy, finding what will motivate her to be physically active, and identifying sources of social support (USDHHS, 1999, p. 107).



All of the participants reported being involved in past physical activity and that they were active as youth (“I played basketball, swam, and rode a hand bike. So, yeah I was pretty active as a kid” (female 2)). For some, the activity was self-started in their neighborhood or with their family (“People that grew up around me remember that I used to ride a skateboard all of the time. It was my number one transportation. And also I rode a regular bicycle. My father modified and made stirrups that I could put my feet in. We would lean the bike up against a tree and then push off” (male 3)).

For all of the participants, their activity dropped off once they became adults (approximately when they graduated high school), which is consistent with PA trends in the general population and has been shown to decline slowly in the early 20’s (Stewart, 2005):

I was very active up until about my early thirties and that’s when things started to decline quite rapidly - part of that was changing of priorities. I went back to school in my mid-thirties, so just really not having as much energy to do a full time college program and then go out and do a heavy duty PA program as well. (male 6)

All but one participant reported that they would like to be active in the near future (“I was at rock bottom for a while, so even just that has helped, but I would like to increase that to maybe 5 days a week. Hopefully this winter” (male 1), and others expressed long-term goals (“I want to be stronger. I don’t feel like I’m strong enough to move around, the biggest thing I think I need to work on is the weight issue...maybe lose 30 pounds in the next two years” (male 2)).

Attitude is an important component of intention. Fishbein (1995) states that attitude is based on the beliefs of the benefits and consequences of performing PA. These beliefs are then reflected in their PA behavior (Fishbein & Yzer, 2003). For example, many individuals in this study believed that PA would help them maintain their weight, despite barriers, and they are more likely to be active. As a whole, participants in the current study had a positive attitude towards PA, which reflects the high intention of these adults with SB to be physically active. One quote that epitomizes the definition of a positive attitude was voiced by a 25 year old participant:

Yeah, I do. I do for sure. Like I've said before if you don't use it, you lose it. There's so much to gain from exercising, that yeah. I don't see a reason to stop. I think once you get into that mode of exercising and then you stop you can really damage your body. Yeah. I don't think I'll ever stop. (female 4)

## **Limitations**

Limitations to this study should be noted. The researcher was somewhat new to conducting interviews. This could have influenced the way questions were asked and the answers given. The results were self-reported information, so responses may have been influenced by social desirability or memory recall. The nature of qualitative analysis is somewhat subjective according to the researchers interpretation of the data, however that is why multiple researchers are used in the analysis process.

## **Implications for the future**

Previous research has demonstrated that PA health promotion programs that are tailored to the unique needs of a specific population can be effective in improving the health of individuals with disabilities (Cardinal, Kosma, & McCubbin, 2004; Driver et al., 2012; Ravesloot, seekins, & White, 2005; Rimmer, Braunschweig, Silverman, Riley, Creviston, & Nicola, 2000; Zempfer et al., 2003). Individuals with SB face significant health challenges with aging that could be mitigated with the use of an appropriately designed health promotion program. From the current study, participants expressed a desire to increase their PA levels for health and overall wellness and conveyed a general understanding of PA (e.g., modes, intensity, duration) and associated health benefits (e.g., physical and emotional). However, participants reported many barriers that are preventing them from being active. The barriers, perceived or real, included personal (i.e., disability related health problems) and environmental factors (i.e., transportation).

The removal of environmental barriers is recognized as an important issue for individuals with disabilities and was subsequently included as an objective in Healthy People 2020 (i.e., DH-8: *'Reduce the proportion of people with disabilities who report physical or program barriers to local health and wellness programs'* (USDHHS, 2010).

In order to increase PA for adults with SB, personal and environmental barriers need to be addressed.

While the participants had a general understanding of PA, they did not have specific knowledge about, for example, the national PA guidelines (USDHHS, 1999). Also, many of the health benefits reported were also not specific (i.e., ‘PA is good because it makes it makes my heart healthier’ or ‘I need to be stronger’). Further, there were also a lot of comments about being fearful of injuring themselves while participating in PA, which may in turn prevent some from either increasing intensity or trying new modes of PA. Since knowledge (or lack of) may be related to perceived risks, future PA health promotion programs should focus on communicating specific SB information in order to more effectively inform individuals (Meischke et al., 2000). The specific information should explicitly state the recommended PA guidelines (i.e., the amount, intensity, and what constitutes as PA), the specific conditions that individuals with SB are at high risk of developing (i.e., depression, obesity, lymphedema, problems of joints and flexibility).

Almost all of the participants (n=9) reported intentions to maintain their physically activity, become more physically active, or start being active. Because an individual’s knowledge, intentions and self-efficacy differ depending on their readiness to change behaviors, future interventions to increase PA need to be tailored to the individual and their readiness to change, versus a “one size fits all” approach (Prochaska & DiClemente, 1983). A tailored PA health promotion program is more likely to increase PA behaviors, which will lead to less secondary conditions experienced, decreased healthcare costs, and an increased quality of life for adults with SB. Results from this study will allow for the future development of a tailored PA health promotion program for adults with SB.

Table 1. Participant Interview Characteristics

Participant	Age	SB Lesion Level	Hydrocephalus	BMI
Female 1	20	L1-5	Yes	26.1
Female 2	38	--	Yes	33.2
Female 3	42	--	Yes	22.5
Female 4	25	L1-5	Yes	27.4
Male 1	28	L1-5	Yes	29.0
Male 2	46	L1-5	Yes	37.8
Male 3	45	L1-5	Yes	29.6
Male 4	41	--	Yes	40.3
Male 5	31	S1-5	Yes	24.3
Male 6	44	L1-5	Yes	36.6
-- =Missing data				

Table 2. Steps in Developing Group Interview Questions

Step 1	Use a semi-standardized interview methodology  Researcher can adapt wording to the context of the interview and can use unscheduled probes and participants can provide details about experiences from their perspective (Berg & Lune, 2012)
Step 2	Questions derived from review of PA health promotion literature (Kahn et al., 2002; Self et al., 2013) and guidelines from USDHHS (2010)
Step 3	Categories of questions utilized  (1) knowledge, (2) attitudes and expectations, (3) intentions and motivations, and (4) barriers
Step 4	Questions used with participants

Table 3. Meta Codes, Codes and Quotes

Meta Codes	Codes	Frequency	Example of Quotes
Knowledge	PA knowledge	21	"It keeps your muscles strong...it's good for your heart health...."
	Type of PA	15	"They could lift weights if they are able and do cardio-cardiovascular exercises- like running on treadmills."
	PT vs. PA	9	"PT is different because it's getting a person to gain something they lost..."
	Knowledge of barriers for others	5	"... some people might not know what to do to stay fit. Some people might not have transportation."
Barriers	Access	40	"... if you wanted to go swimming most of the places don't have the chair lift that transfers you from the chair to the water. I have yet to find one here."
	Time	11	"...time management. Sometimes it's hard to find time in the day due to busy schedule at work, other commitments."
	Personal	107	"Not having the motivation. Thinking it's too hard or I could be doing something else right now."
	Overcoming	13	"You don't have to do everything in one sitting. You can kind of space it out so your goal gets accomplished."
	Social support	11	"Just having someone to motivate me and someone to do things with so I am not doing them by myself."
	Weather	7	"...we took a foot of snow last Wednesday...For me to get out and get active in my community is a lot more challenging than in the middle of July."
	Nutrition knowledge needs	6	"How to balance exercise and nutrition so it doesn't create a problem ... how to fit the two together and how to stay healthy would be really important to me."
Facilitators	General	22	"...more opportunities throughout a community in order for people with disabilities to be involved...like YMC or YWC program..."
	Personal	66	"Mostly because it helps me stay positive about things instead of being depressed. Just keep active so I don't think about things."
	External	24	"There is a social aspect; just getting out there are being with other people. Whether it's people with disabilities or people who don't have disabilities..."
Expectations	Benefits	26	"You're gonna feel better...then you're gonna have things happen in your life that you can handle that as far as emotional mental health."
	Participating	98	"I would like to do something using... - a cardio workout to get my Heart rate up."
	Past PA	26	"When I was younger up until the age of 13 I was training for getting into the Paralympics so that required a lot of time."
Intention	Current PA behaviors	23	"I will go down to our high school...then roll back to my office."
	Future PA	17	"...the joke is I'm going to race until my arms fall off. I think it will always be a part of my life."
	Goal setting	19	"I try to do is either have some kind of a race, or some kind of PA in the future so that when I am training I have something to look forward to."
	Attitude	57	"I am an athlete, but the benefits of exercise have been proven, so I am definitely going to continue. Because if you don't use it, you lose it."
Total	21		

### Chapter 3: General Conclusion

### **General Conclusion**

This research explored the factors that contribute to physical activity participation for adults with spina bifida by using both quantitative and qualitative methods. Improving the health of adults with spina bifida is of particular interest due to the combination of a growing population, increased risk of poor health, and the high health care costs. Physical activity is one way to improve health. From the quantitative study, barriers, self-efficacy, and being female all predicted whether a person was regularly active or not. From the qualitative study, adults with spina bifida had a strong intention to participate in physical activity, although barriers, such as a lack of knowledge, prevented participation. Identifying the factors that contribute to the physical activity behaviors of this population is important in order to increase behavior. The results from this study allow for the future development of a tailored physical activity program for adults with spina bifida. By identifying an individual's stage of change, perceived barriers, and self-efficacy, specific strategies (i.e., increasing knowledge, social support, and removing barriers) can be implemented through an intervention to increase physical activity participation for this population, and lead to improvements in overall health.

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## APPENDICES

## APPENDIX A

## Online Survey Questions

**DEMOGRAPHICS:**

1. **How did you hear about this survey?**
  - ☐ From a doctor or other health professional
  - ☐ From a social media website (Facebook, etc.)
  - ☐ From the Spina Bifida Association (National or local Chapter)
  - ☐ From a friend
  - ☐ Other: \_\_\_\_\_
2. **What is your sex?**
  - ☐ Male
  - ☐ Female
3. ***What year were you born?*** \_\_\_\_\_
4. ***What is your Age?*** \_\_\_\_\_
5. ***What is your marital status?***
  - ☐ currently married
  - ☐ Widowed
  - ☐ Divorced
  - ☐ Separated
  - ☐ Never married
6. **Do you have children?**
  - ☐ Yes
  - ☐ No
7. ***What is the highest degree or level of school you have completed? If currently enrolled, mark the previous grade or highest degree received.***
  - ☐ No schooling completed
  - ☐ Pre-school to 8th grade
  - ☐ Some high school, no diploma
  - ☐ High school graduate - high school diploma or the equivalent (for example: GED)
  - ☐ Some college credit, but less than 1 year
  - ☐ 1 or more years of college, no degree
  - ☐ Associate degree (for example: AA, AS)

- ☐ Bachelor's degree (for example: BA, AB, BS)
- ☐ Master's degree (for example: MA, MS, MEng, MEd, MSW, MBA)
- ☐ Professional degree (for example: MD, DDS, DVM, LLB, JD)
- ☐ Doctorate degree (for example: PhD, EdD)

**8. Employment Status**

***Are you currently...?***

- ☐ Employed part time
- ☐ Employed fulltime
- ☐ Self-employed
- ☐ Out of work and looking for work
- ☐ Out of work but not currently looking for work
- ☐ A homemaker
- ☐ A student
- ☐ Retired
- ☐ Unable to work

**9. Which best describes your annual family income?**

- ☐ Less than \$5,000
- ☐ Between \$5,000 to \$11,999
- ☐ Between \$12,000 to \$15,999
- ☐ Between \$16,000 to \$24,999
- ☐ Between \$25,000 to \$34,999
- ☐ Between \$35,000 to \$49,999
- ☐ Between \$50,000 to \$74,999
- ☐ \$75,000 and greater
- ☐ Don't know
- ☐ No answer

**10. Please specify your race.**

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ White
- ☐ Other

**11. What region do you live in?**

- ☐ **Northeast** (Maine, New Hampshire, Vermont, Massachusetts, Rhode Island, Connecticut, Pennsylvania, New Jersey)



- ☐ **Midwest** (Wisconsin, Michigan, Illinois, Indiana, Ohio, Missouri, North Dakota, South Dakota, Nebraska, Kansas, Minnesota, Iowa)
- ☐ **South** (Delaware, Maryland, District of Columbia, Virginia, West Virginia, North Carolina, South Carolina, Georgia, Florida, Kentucky, Tennessee, Mississippi, Alabama, Texas, Arkansas, Louisiana)
- ☐ **West** (Montana, Wyoming, Nevada, Utah, Colorado, Arizona, New Mexico, Alaska, Washington, Oregon, California, Hawaii)

12. What type of community do you live in?

- ☐ Rural (country)
- ☐ Suburban (outskirts of a city)
- ☐ Urban (in a city)

13. **Your Height (inches)** \_\_\_\_\_

14. **Your weight (lbs.)** \_\_\_\_\_

15. **Do you know your lesion level?**

- ☐ Yes
- ☐ No

13a. if yes, please write it in: \_\_\_\_\_

16. Has a doctor ever told you that you have hydrocephalus?

- ☐ Yes

17. No

18. **Assistive devices (check all that apply)**

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

Wheelchair			
Scooter			

**19. Use of arms (check one)**

- ☐ Full  
☐ Partial  
☐ No Use

**20. Use of legs**

- ☐ Full  
☐ Partial  
☐ No Use

**Barriers to Physical Activity:**

**21. Would you like to begin an exercise program?**

- ☐ Already in an exercise program  
☐ Yes  
☐ No

**22. 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

**23. 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

**24. 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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**25. 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

**26. Do you feel that an exercise program could help you?**

- ☐ Yes
- ☐ No

**27. Are you ever afraid to leave your home?**

- ☐ Yes
- ☐ No

**28. Has your doctor ever told you to exercise?**

- ☐ Yes
- ☐ No

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

- ☐ Yes
- ☐ No

**29. 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

**30. 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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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.

**31. 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.

#### **EXERCISE:**

**32. Do you currently exercise?**

- ☐ Yes
- ☐ No

**IF NO, PLEASE GO TO THE LEISURE ACTIVITY SECTION.**

**33. 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				

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

- ☐ More than one year  
☐ Less than one year

35. 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**

36. Do you engage in leisure time physical activity?

- ☐ Yes  
☐ No

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

37. 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**

**38. 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

**39. 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

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

\_\_\_\_\_ hours

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

\_\_\_\_\_ hours

**42. 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.**

43. 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:

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

- ☐ Yes  
☐ No

**IF NO, GO TO QUESTION 44.**

45. **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

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

- ☐ No assistance  
☐ Some assistance  
☐ Full assistance

## **THERAPY**

47. **Do you currently receive physical or occupational therapy?**

- ☐ Yes  
☐ No

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

**48. How many days a week do you receive therapy?**

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

**49. How long does each therapy session usually last?**

\_\_\_\_\_ Minutes

**EMPLOYMENT / SCHOOL**

**50. Are you currently employed / attending school?**

- ☐ Employed Retired
- ☐ Not employed Attending school

**IF UNEMPLOYED OR RETIRED, GO TO WHEELCHAIR SECTION.**

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

- ☐ Move around
- ☐ Stand
- ☐ Sit

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

- ☐ Yes
- ☐ No

**IF NO, GO TO QUESTION 54.**

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

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

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

- ☐ Yes
- ☐ No

**IF NO PLEASE GO TO WHEELCHAIR SECTION.**



56. 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	Minutes/Day	Months/Year

### **WHEELCHAIR USERS**

57. Do you use a wheelchair?

- ☐ Yes  
☐ No

IF NO, STOP HERE.

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

59. 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

60. What type of wheelchair do you primarily use?

- ☐ Manual wheelchair  
☐ Powered wheelchair

IF POWERED WHEELCHAIR, STOP HERE.

61. Who usually pushes your wheelchair?

- ☐ Myself  
☐ Someone else

IF SOMEONE ELSE, STOP HERE.

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

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

**63. 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

## APPENDIX B

### *SB & PA Interview Moderator Guide*

#### **Introduction and Informed Consent Procedures:**

The interviewer will welcome the participant. The interviewer will explain the format of the session. The interviewer will go over the informed consent and make sure the participant agrees. The interviewer will explain that the participant does not have to use their real name during the interview, but can use a made up name that they would like to be called for the duration of the discussion. The interviewer will go over what will happen if they get disconnected from each other.

#### **Welcome and Introductions:**

*Hello! My name is Kerri and I will be interviewing you. I'd like to thank you for taking time out of your busy lives to join us for this discussion. We very much appreciate your willingness to share your insights with us. As you may know, the purpose of this interview is to talk about physical activity. I will be asking you questions about your knowledge, experiences and issues related to physical activity. I am going to use the information learned by you all to develop a physical activity program that is specifically designed for adults with spina bifida. Your involvement is important in this process since you are contributing to information that will help me best design a PA program for adults with spina bifida.*

#### **Ground Rules**

*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.*
- *I will keep your personal information and your comments confidential, so that what you say will not be tied to you- your name or anything that can identify you.*
- *Also, it is important for you to remember that there are no right or wrong answers.*
- *I am here to ask questions, to listen, and to ensure that you have a chance to share. I am interested in hearing from you.*

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

*Do you have any questions before we begin?*

***ICE BREAKER QUESTIONS:***

1. What is your favorite food?
2. What is your favorite thing to do on the weekends?
3. What is your favorite physical activity/sport to play or watch?

***QUESTIONS RELATED TO KNOWLEDGE:***

1. What does the term physical activity mean to you?
  - a. What are some examples of PA?
  - b. What is the difference between PT and PA?
  - c. What types of PA should people conduct?
    - i. Can you describe these activities for me?
  - d. Are you familiar with the national guidelines for PA sufficient for a health benefit?

***QUESTIONS RELATED TO EXPECTATIONS:***

2. What are the top 3 benefits associated with PA participation?
  - a. Which health benefits are most important to you?
  - b. Why are those health benefits most important to you?
3. How much PA do you need to complete to get those health benefits?
  - a. How realistic is it that you complete that amount of PA?
  - b. What barriers are preventing you from engaging in PA?
    - i. I can't set and stick to goals.
    - ii. I don't have the social support I need
    - iii. I'm not motivated enough
    - iv. I don't have the time or the resources (equipment, too tired, accessible facilities)
    - v. I don't have the money
    - vi. I don't have enough confidence
    - vii. I don't know enough about how to do the exercises, use the machines, or design a workout
    - viii. I need help in my self-care, like going to the bathroom
  - c. How much PA do you think you will be able to complete?
4. What do you hope to learn from a PA promotion program?
  - a. What types of PA I should do?
  - b. The amount of PA I should do?
  - c. Where I should go to be PA?
  - d. How to set goals?
  - e. How to overcome barriers?
  - f. How to create a social supportive network?
  - g. What would you like to learn?

5. Do you intend to be PA in the near future?
  - a. Why or why not?
  - b. Do you have long-term PA goals? (1-year, 2 year, etc).
  - c. Who are you most likely to be PA with?
  - d. Where do you think you will be PA?

#### ***QUESTIONS RELATED TO ATTITUDE:***

6. Is PA something you do as part of your daily life?
  - a. What role does PA play in your well-being?
  - b. What role does PA play in helping you overcome secondary health issues? (pain, range of motion, weight management, depression)
  - c. Why would you not be PA? (it is painful, not good for me)

#### ***QUESTIONS RELATED TO MOTIVATION:***

7. What are the main motivating factors for you to be PA?
  - a. What are your top 3 motivating factors?
  - b. Why do these motivate you?

#### ***QUESTIONS RELATED TO BARRIERS:***

8. What 3 things do you need to help you be PA in the future?
  - a. I need more skills- goal setting? Someone showing me how to do it?
  - b. Support from others?
  - c. Someone to be PA with?
  - d. Greater motivation?
  - e. Resources? (equipment, transport, accessible facility)

#### ***QUESTIONS RELATED TO INTENTIONS:***

9. Were you PA when you were younger?
  - a. Were you PA enough to meet the guidelines?
  - b. Do you want PA to be a part of your life in the future?

#### ***PROBES & CLARIFYING QUESTIONS/COMMENTS TO BE USED THROUGHOUT DISCUSSION:***

1. "Please tell me (more) about that..."
2. "Could you explain what you mean by..."
3. "Can you tell me something else about..."
4. "Is there anything else?"
5. "Are there any more comments?"

We are out of time, but I just want to thank you all for a great discussion. I truly appreciate you taking the time to be here and participate in this interview. The recordings of the discussion will only be heard by myself and another student researcher and will be held in a locked filing cabinet in our lab at the University. If you have any questions about this interview later on, please contact me.