INFLUENCE OF PHYSICALLY ACTIVE LEISURE PARTICIPATION ON OBESITY IN YOUTH WITH SPINA BIFIDA

Erin McCabe, B.S.

Thesis Prepared for the Degree of

MASTER OF SCIENCE

UNIVERSITY OF NORTH TEXAS

December 2004

APPROVED:

Jan S. Hodges, Major Professor
John R. Collins, Jr., Committee Member and Program Coordinator for Recreation and Leisure Studies
Sharon McKenzie, Committee Member
M. Jean Keller, Dean of the College of Education
Sandra L. Terrell, Dean of the Robert B. Toulouse School of Graduate Studies

Childhood obesity and resulting secondary complications in youth with disabilities are occurring in epidemic proportions, due in part to a trend of physical inactivity. The purpose of this study is to report the prevalence of overweight, the leisure time activity patterns, and the association between frequency of physically active leisure participation and body mass index for age, in a sample of 50 youth with spina bifida, ages 4.5 to 17.9 years.

Results indicate that 52% of the sample are classified as at risk of overweight or overweight; 36% were male and 16% were female. The top five leisure time activities and team sport participation are identified. Subjects who did not use a wheelchair for ambulation participated significantly more in physically active leisure than subjects who used a wheelchair. Future research and rationale for physically active leisure as an intervention for youth with spina bifida are discussed.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>I.  INTRODUCTION</strong></td>
<td>1</td>
</tr>
<tr>
<td>Significance of the Problem</td>
<td></td>
</tr>
<tr>
<td>Purpose Statement</td>
<td></td>
</tr>
<tr>
<td>Definition of Terms</td>
<td></td>
</tr>
<tr>
<td>Limitations of the Study</td>
<td></td>
</tr>
<tr>
<td><strong>II. LITERATURE REVIEW</strong></td>
<td>5</td>
</tr>
<tr>
<td>Physical Health</td>
<td></td>
</tr>
<tr>
<td>Psychosocial Health</td>
<td></td>
</tr>
<tr>
<td>Intervention</td>
<td></td>
</tr>
<tr>
<td><strong>III. METHODS</strong></td>
<td>14</td>
</tr>
<tr>
<td>Introduction</td>
<td></td>
</tr>
<tr>
<td>Participants</td>
<td></td>
</tr>
<tr>
<td>Instrumentation</td>
<td></td>
</tr>
<tr>
<td>Data Collection</td>
<td></td>
</tr>
<tr>
<td>Data Analysis</td>
<td></td>
</tr>
<tr>
<td><strong>IV. RESULTS</strong></td>
<td>19</td>
</tr>
<tr>
<td>Prevalence of Overweight</td>
<td></td>
</tr>
<tr>
<td>Leisure Time Activities</td>
<td></td>
</tr>
<tr>
<td>Frequency of Physically Active Leisure Participation</td>
<td></td>
</tr>
<tr>
<td><strong>V. DISCUSSION</strong></td>
<td>22</td>
</tr>
<tr>
<td>Prevalence of Overweight</td>
<td></td>
</tr>
<tr>
<td>Leisure Time Activities</td>
<td></td>
</tr>
<tr>
<td>Frequency of Physically Active Leisure Participation</td>
<td></td>
</tr>
<tr>
<td>Implications for Therapeutic Recreation</td>
<td></td>
</tr>
<tr>
<td><strong>REFERENCES</strong></td>
<td>27</td>
</tr>
</tbody>
</table>
CHAPTER I

INTRODUCTION

Significance of the Problem

The perceived value of physical activity for children and adolescents has declined as a societal priority over the last few decades. This is evident by examples such as schools reducing the number of days of physical education classes, amount of recess participation throughout the week, and by the dramatic rise in daily television viewing hours by children (Mokdad et al., 2001). The prevalence of sedentary lifestyles adopted by children in the U.S. is supported by statistics that report nearly half of youth ages 12-21 years are not vigorously active on a consistent basis and 19% of high school students report physical activity for only 20 minutes or more during physical education classes (Centers for Disease Control and Prevention [CDC], 1996).

As a result of this trend of inactivity and other maladaptive behaviors, such as eating an excess of unhealthy foods, rises in childhood obesity and complications from this condition have occurred in epidemic proportions (Southern & Gordon, 2003). Obesity is a health crisis resulting in noted reductions in the obese child’s quality of life (Schwimmer, Burwinkle, & Varni, 2003). Obese children are over five times more likely to report having an impaired health-related quality of life and significantly lower levels of both physical health and psychosocial health compared to children who are not obese (Schwimmer et al.). Children with obesity report a quality of life similar to the quality of life reported by youth diagnosed with cancer (Schwimmer et al.). To confront the epidemic of childhood obesity, physical activity is recommended as an essential element (Southern & Gordon).
Physical inactivity is common among many demographic groups across the general population, but occurs at a disproportionately high rate among individuals with disabilities (Cooper & Quatrano, 1999). Children with disabilities are among the least physically active populations in society and much like children with obesity, are at an additional risk for a variety of secondary health conditions associated with a sedentary lifestyle (Cooper & Quatrano). These secondary health conditions affect both physical and psychosocial health. Youth with disabilities show activity patterns in which more of their daily time is spent in dependent activities and in quiet recreation, with less participation in social engagements or energy-using activities like physically active leisure and household tasks (Brown & Gordon, 1987). Children with disabilities also spend less time in out-of-home activities and more time in social isolation (Brown & Gordon). These atypical activity patterns may be contributing factors that increase the risk of secondary physical and psychosocial health conditions for youth with disabilities.

Purpose Statement

As a baseline for future studies on the effectiveness of interventions, the purpose of this study is to report (1) the prevalence of overweight, (2) the leisure time activity patterns, (3) the association between frequency of physically active leisure participation and body mass index for age, in a sample of youth with spina bifida.

Definition of Terms

Spina Bifida and Related Conditions

Spina bifida, or myelomeningocele, is a congenital condition identified by a “bony defect in the spine, protrusion of the nervous tissue from the spinal cord, and a lack of skin covering the defect” (Adams, 2000 p. 2). A less severe form of spina bifida, meningocele, is a variation of the defect where the spinal cord tissue is usually less disrupted, and skin covers the defect or lesion.
In addition, fatty tumors known as lipomas can occur in combination with meningocele, creating pressure effects on the spinal cord, a condition known as lipomeningocele (Adams).

Other related conditions include caudal regression syndrome, which is a disorder characterized by abnormal development of the lower spine, resulting in a wide range of abnormalities including partial absence of the tailbone end of the spine causing no apparent symptoms, to extensive abnormalities of the lower vertebrae, pelvis, and spine (National Organization for Rare Disorders [NORD], 2000). Sacral agenesis, a closely related condition to caudal regression syndrome, is characterized by failure of part or all of the sacrum to form properly (NORD). These conditions can result in limited mobility, and orthopedic function varies dramatically in relation to the level of lesion on the spinal cord (Adams, 2000).

Children with a higher level lesion have more limited mobility than children with a lesion located lower on the spinal cord. This varying degree of mobility produces the need for assistive devices to be used by most children with spina bifida on a daily basis. Orthoses or braces are utilized by many individuals with spina bifida to aid in mobility. Crutches, wheeled standers, and wheelchairs are additional equipment that assist with movement as well. Reduced mobility is only one outcome associated with spina bifida. Due to “the range of biomedical conditions found among children, adolescents, and young adults with spina bifida, there is a high probability they will experience secondary conditions manifested in functional limitations, reduced participation and a lower quality of life” (Simeonsson, McMillen, & Huntington, 2002, p. 201).

Physically Active Leisure

For the purposes of this study, physically active leisure is defined as a freely chosen activity or experience during which the participant primarily displays gross motor movement.
Limitations of the Study

The study is limited by the fact that the subjects were selected from a convenience sample and included a relatively small sample size. In addition, response to the questionnaire was through a self-report, which is subject to reliance on memory, and therefore data may be less reliable from youth, especially young subjects. Respondent’s parents/caregivers may have also prompted subjects to give specific answers or suggested additional answers to the questions, possibly altering the reliability and validity of the data. Self-report is also a more subjective method of data collection than direct monitoring or behavioral observation.
CHAPTER II
LITERATURE REVIEW

Physical Health

Obesity is one of the most prominent secondary physical health conditions associated with spina bifida (Simeonsson et al., 2002). Many studies agree that the prevalence of increased body fat and obesity in youth with spina bifida is greater than that of their typically developing peers (Hayes-Allen & Tring, 1973; Roberts, Shepherd, & Shepherd, 1991). In a study by Fiore et al. (1998) 40 out of 100 youths ages 6 months to 19 years, were classified as obese, BMI greater than the 95th percentile for age, as defined by the CDC. In addition, Mita et al. (1993) found that 58% of children with spina bifida over six years of age displayed an increased percentage of body fat compared to their peers without spina bifida.

Youth with spina bifida are prone to develop low levels of physical fitness, contributing to an increased risk for obesity compared to children without spina bifida (Roberts, Shepherd, & Shepherd, 1991). One contributing factor to these poor fitness levels results from the inherent risk for youth with spina bifida to develop an inactive lifestyle, due to the loss in motor function associated with the disability. Individuals with a chronic health condition or disability are likely to be effected by the downward spiral of the cycle of deconditioning. Physical inactivity often leads to the deconditioning of the individual’s physiologic systems, resulting in further inactivity and the risk for greater disability (Cooper & Quatrano, 1999; Durstine et al., 2000). This cycle has also been suggested to specifically apply to individuals with spina bifida (Berg-Emons et al., 2001). Berg- Emons et al. suggested that hypoactivity leads “to a reduction in functional capacity and increase in body fat, leading to further hypoactivity” (p. 880).
In order to document hypoactivity in individuals with spina bifida, Berg-Emons et al. (2001) compared 14 adolescents with spina bifida to 14 individuals without spina bifida, all ranging in age from 14 to 26 years. An activity monitor, which is “based on long-term ambulatory monitoring of signals from body-fixed accelerometers during every day life and is aimed at the measurement of mobility related activities,” was used to assess physical inactivity (Berg-Emons et al., p. 881). Results of the study revealed the percentage of the day that adolescents with spina bifida performed dynamic activities was significantly smaller than percentage of the day that adolescents without spina bifida. Dynamic activities were defined as the composite measure of walking (including running and walking stairs), wheelchair driving, cycling, and general movement. The total number of wheelchair-driving or walking periods for individuals with spina bifida was also significantly lower than walking periods in the comparison group (Berg-Emons et al.).

As a possible contributing factor to physical activity levels in individuals with spina bifida, a moderate correlation ($r=0.55$) was found between functional ambulation (non-ambulator, household ambulator, community ambulator) and time spent on dynamic activities (Berg-Emons et al., 2001). Individuals without spina bifida were found to engage in the highest percentage of dynamic activities throughout the day, followed by ambulators with spina bifida, and non-ambulators with spina bifida (Berg-Emons et al.). This finding helps to account for variations of every day physical activity for individuals with spina bifida, as the diagnosis of the condition does not predict uniform mobility patterns.

In addition, Berg-Emons et al. (2001) measured sport participation between adolescents with spina bifida and comparison subjects. No significant differences were found in time spent weekly on sport activities between adolescents with spina bifida and the subjects without spina
bifida, nor were significant correlations found between time spent on everyday dynamic physical activities and participation in sport. However, it is important to note that the above study only surveyed 28 subjects and cautioned that a lack of correlation between potential determinants of physical activity (i.e. sport participation) and time spent in everyday physical activity were tentative.

Children who are obese often exhibit low levels of cardiovascular fitness and a reduction in physical activity levels for children with obesity has also been shown to lead to a reduction in exercise tolerance (Southern, 2001). These findings appear applicable for youth with disabilities as well. During exercise tests, children with spina bifida and adolescents with multiple disabilities have demonstrated reduced cardiovascular fitness levels compared to their peers without disabilities, presumably due in part to a more sedentary lifestyle (Agre et al., 1987; Pitetti, Jongmans, & Fernhall, 1999). Compounding this finding, children with spina bifida have greater energy expenditure during physical activity, due to the decreased motor function inherent in the condition, which can lead to early fatigue, and thus lower exercise tolerance (Agre et al.). Children with spina bifida who participate in physically active leisure activities such as basketball, tennis, or swimming on a regular basis demonstrate lower energy expenditure than children with spina bifida who lead more sedentary lifestyles (Sawatzky, Macdonald, & Valentine, 2003). Thus, consistent participation in physical activity can act as an important tool to improve exercise tolerance and potentially promote greater adherence to an activity regimen. It is likely that the overall tendency for children with spina bifida to have reduced daily physical activity, lower cardiovascular fitness, and increased energy expenditure of movement leading to a reduced exercise tolerance contribute to the increased risk for youth with spina bifida to be obese.
The quantity and quality of physical activity is an additional influence on children’s physical health. Quality daily physical education (QDPE) includes daily instruction, maximum active participation, a wide range of movement experiences, fitness activities in each lesson, a program based on child growth and development characteristics, an opportunity to develop positive attitudes toward physical activity, and the provision of suitable competition (Turkington, 1987). Children in Canada classified both as obese and non-obese and who participated in QDPE programs were found to be more competent in regards to gross motor skills than children who participated in physical education programs that did not adhere to the standards of QDPE (Marshall & Bouffard, 1997). In certain instances, children who participated in QDPE were also found to have higher cardiovascular fitness levels than children who participated in non-QDPE, as measured by heart rate and a 20 meter shuttle run (Marshall & Bouffard).

Overall, children with and without disabilities who consistently participate in physical activity have shown superior components of physical health compared to youth who do not participate in physical activity, including reduced risk for obesity, better cardiovascular fitness, improved exercise tolerance and lower energy expenditure during activities. As children with disabilities often have poorer physical health than children without disabilities, it is critical that these youth participate in regular physical activity (i.e. physically active leisure, physical education, exercise) to maintain or improve their physiologic systems, and therefore degree of disability.

Psychosocial Health

Children with chronic illnesses are at a significant risk for developing psychosocial problems, poor self-concept, and social withdrawal (Austin, 1989; Breslau, 1985; Thompson, Zeman, Fanurik, & Sirotkin-Roses, 1992). However, physical activity may play an active role in
the psychosocial health and well-being of children with disabilities. Taub and Greer (2002) found physical activity to be a normalizing experience where children with disabilities may engage in common childhood experiences, validate a social identity, and develop perceptions of competence and self-enhancement. Improved self-confidence, improved view of self, and enhanced beliefs about fulfilling a greater range of life possibilities are all specific benefits of physical activity reported by children with disabilities. Physical activity has also been found to strengthen social ties for students with disabilities by providing the opportunity to form new relationships and strengthen existing relationships, as show by students indicating some aspect of physical activity participation when asked what they prefer doing with their friends (Taub & Greer).

One study involved youth with disabilities, including spina bifida, who reported an overall improvement in self-concept after the intervention of a one-week summer camp (Briery & Rabian, 1999). These children reported more positive attitudes toward their illness at the end of camp than before. The authors speculated that this was likely due to the children’s experience of developing a true peer group and developing new relationships, but they were not able to determine if this was an individual component for the change. Participation in summer camps may provide children with disabilities a normalizing and enjoyable experience that compliments other therapeutic modalities that address children’s attitudes about their medical conditions (Briery & Rabian).

Children with physical disabilities have also been found to note many positive conceptions after participating in a three-year interventional sports program. These included aspects of both physical and psychosocial health categorized as, “getting new friends, learning,
strengthening one’s physique, becoming someone, experiencing nature, and having a good time” (Kristen, Patriksson, & Fridlund, 2002).

Participation in physical activity has been shown to benefit children with disabilities both psychologically and socially. As leisure is often inherently social, regular participation in physically active leisure may prove a natural and effective intervention for children with spina bifida and other chronic health conditions to improve their psychosocial well-being.

Intervention

Compared to the typically developing child or youth with obesity, there is little outcome-based evidence that has specifically focused on children with spina bifida and physical activity, sport, or physically active leisure as behavioral interventions to improve physical or psychosocial health. Research with children with obesity has suggested the critical importance of physically active leisure in the treatment of obesity. Increasing sports and physically active leisure time coupled with family interventions, including education regarding the importance of physical activity, are measures shown to be effective in reducing childhood obesity (Southern & Gordon, 2003). It is very possible that similar measures would prove valuable for children with spina bifida. Further, research has also shown that forcing children to participate in structured exercise programs that are not enjoyable to the child may negatively impact adult physical activity patterns (Janz, Witt, & Mahoney, 1999; Taylor, Blair, Cummings, Wun, & Malina, 1999).

Participation in physical activity may be employed as a beneficial medium to strengthen both physical and psychosocial health for children with spina bifida. Facilitation of physically active leisure opportunities can help combat secondary health conditions and work to alleviate functional limitations, improve participation, and enhance the quality of life for youth with spina bifida. However, physically active leisure is only a valuable interventional tool if programs are
readily accessible for children and their families. Unfortunately children with disabilities often experience more barriers to leisure participation compared to their peers without disabilities (Field & Oates, 2001; Kristen et al., 2002). Missuina and Pollock (1991) “have suggested that children with physical disabilities who are deprived of normal recreation activities have a second disability that hinders their potential for independent behavior and performance” (as cited by Field & Oates, 72). Cooper and Quatrano (1999) noted that sports and recreation activities lead to an increase in the quality of life for individuals with a disability. With the documented health benefits of physical activity and recreation experiences for individuals with a disability, it is important to ask whether recreation resources and opportunities for children with spina bifida exist, and to what extent.

In an Australian study comparing children with spina bifida and cystic fibrosis, parents of the subjects were asked their views about recreation activities available for their children. Cystic fibrosis is an impairment where the outward physical disability is less noticeable than spina bifida. Parents of children with spina bifida and cystic fibrosis both felt there were barriers to their child’s participation in recreation, however, parents of children with spina bifida were more than twice as likely to indicate this (Field & Oates, 2001). Seventy percent of these parents believed there were barriers to their child’s participation in recreation activities. Opportunities to participate in sport and recreation activities were reported to be significantly lower for children with spina bifida than for children with cystic fibrosis, and 63% of parents of children with spina bifida believed there was an inadequate variety of recreation activities available, compared to 23% of parents of children with cystic fibrosis (Field & Oates).

An additional alarming statistic in this study reported that 21% of parents of children with spina bifida believed that recreation is more important for children without a disability, and 56%
of these parents agreed that they have little knowledge of recreation opportunities available for their child, as compared to 15% of parents of children of cystic fibrosis (Field & Oates, 2001). Family leisure education would likely prove effective to reduce barriers to physically active leisure participation, as this strategy has been suggested to be essential in the treatment of childhood obesity (Southern & Gordon, 2003).

Harrell et al. (2003) detailed the most frequently reported leisure time activities of typically developing adolescents ages 11-14 years in America. The participants were asked to identify the top three activities that they “usually do the most” for 15 minutes or more. The top five reported activities for boys were football, basketball, bicycling, running and baseball, while the top five reported activities for girls were talking, running, walking, bicycling, and dancing. When comparing the intensity of these activities in terms of energy expenditure (MET levels), the top three activities of males reported greater MET levels than the top three activities of the females. Six of the top ten activities reported by the boys were of moderate to high intensity, while only four of the top ten activities reported by the girls were of similar intensity. In addition, the sixth graders top three activities had a significantly higher MET level than the top three activities reported by the eighth graders. In summary, the males showed higher physical activity levels than the females and as the students aged, their physical activity levels decreased.

Significant to note as well, all of the top five activities in which the boys participate are physically active leisure time activities, and four of the five activities reported by the girls are physically active leisure activities as well. Television watching, while reported in other studies to be a highly indicated leisure time activity, was only noted by 12% of the participants in this study. Admittedly, the study concedes one of its limitations is that the participants may have reported their favorite leisure time activities instead of the actual activities in which they
participate on a consistent basis. In addition, the frequency of the top three reported leisure activities was not asked of the participants.

Studies have not yet looked at children with disabilities to report their participation in physically active leisure and these active leisure pursuits are not yet fully utilized as a prevention and treatment tool against both physical and psychosocial secondary health conditions for children with disabilities. Evidence suggests that sedentary individuals can be influenced positively by health care professionals to become more physically active, improving their health (Chakravarthy, Joyner, & Booth, 2002; Cooper & Quatrano, 1999).

Knowledge of clients’ current physical activities, including enjoyable physically active leisure-time activities, can help health care providers develop targeted interventions to increase physical activity levels (Harrell et al., 2003). Consistent and active support from an individual’s health care team to incorporate physically active leisure into their overall health care plan is essential in altering the attitudes and expectations of youth with chronic disease and disabilities and their families. This increased emphasis on physically active leisure by health care providers can lead to the adoption of enjoyable and healthy activity patterns early in life, work to prevent secondary health conditions, and improve quality of life of youth with spina bifida.
CHAPTER III
METHODS

Introduction

This research is part of a larger study on children with spina bifida and obesity being conducted at Texas Scottish Rite Hospital for Children in Dallas, Texas, one of the nation’s leading centers for the treatment of pediatric orthopedic conditions, certain related neurological disorders, dyslexia and other learning disorders. The broad study seeks to identify how genetic, endocrine, nutritional, and physical activity variables contribute to the development of obesity in children with spina bifida. Anthropomorphic data including height, weight, humeral length, ideal body weight, percent ideal body weight, skinfold measurement, middle arm circumference, body mass index, and body mass index for age collected at clinic visits is routinely used to chart a pattern of physical development for each patient. This pattern can help the interdisciplinary team assess the risk of overweight or obesity for each patient compared to normed age and gender values. A secondary analysis of the clinical data including height, weight, body mass index, body mass index for age, and leisure activity patterns was performed in this study. An institutional review board (IRB) approved the study and participants’ rights were protected in accordance with the Health Insurance Portability and Accountability Act.

Participants

The convenience sample consisted of 50 youth with spina bifida, ages 4.5 to 17.9 years, who attended appointments at the spina bifida outpatient clinic between June 2002 and May 2003. The mean age of the respondents was 13.5 years. This sample included 26 males and 24 females. Participant were 54% \((n=27)\) Caucasian, 24% \((n=12)\) Hispanic, 4% \((n=2)\) African American and 18% \((n=9)\) Other. Thirty six percent of the youth \((n=18)\) were non-ambulatory
(use a wheelchair full-time), 24% of the youth ($n=12$) were part-time ambulators (household and exercise ambulation/use a wheelchair part-time), and 40% of the youth ($n=20$) were full-time ambulators (community ambulation).

Instrumentation

A semi-structured interview was used to ask respondents about their leisure and physical activities. The interview was adapted from the Physical Activity and Disability Survey (PADS) (Rimmer, Riley, & Rubin, 2001), designed to measure the physical activity behavior of persons with disabilities and chronic health conditions, and the Youth Risk Behavior Survey Questionnaire (CDC, 2002) which focuses on high priority risk-behaviors established during youth including tobacco use, unhealthy dietary behaviors, sexual behaviors, alcohol and other drugs use, violent behaviors, inadequate physical inactivity, and overweight or obesity. The leisure and physical activity interview consisted of five sections in which respondents identified their involvement in (1) leisure activities (activities they “like to do for fun”), (2) community organizations, (3) sports teams, (4) physical education, and (5) exercise in which they participate. The interview was designed to determine leisure time and physical activity behaviors of youth with spina bifida. The participants indicated their frequency of weekly participation in each activity except physical education, using a four-point Likert-type scale ranging from once in a while (1–2 days per week), often (3–4 days per week), very often (5–6 days per week), and every day (7 days per week). Regarding physical education, respondents identified the number of days per week they engaged in physical education class and the amount of time they were physically active during class, (no physical education, less than 30 minutes, 30–60 minutes, greater than 60 minutes).
Data Collection

Clinic patients above the age of four years with a primary presenting condition of spina bifida were eligible to participate in the interview. Patients typically visit the spina bifida clinic every six months to a year. Patients and their caregiver(s) meet with all or some of the interdisciplinary team consisting of a physician, a nurse practitioner, a physical therapist, an occupational therapist, a prosthetist, a therapeutic recreation specialist, and a dietician, each visit. During the clinic visit, the interview process and objectives were explained to the patient and caregiver(s) and verbal consent to proceed with the interview was requested before the interview. Interviews were conducted in clinic appointment rooms, the family resource and information center, or other private areas within the hospital to ensure confidentiality. The object of the leisure and physical activity interview was to learn the youth’s responses to the questions. However, in many cases the participants’ care-giver(s) either prompted the youth to give a response or suggested additional responses to the questions. Both of these scenarios were included as valid responses during the interview as long as agreement between the participant and caregiver(s) was apparent. All interviews were conducted by the author. Each interview lasted approximately 20 minutes. In addition to the interview, height and weight measurements taken during the clinic appointment, were recorded from the subject’s medical records after each interview.

Data Analysis

Descriptive statistics were used to report the incidence of obesity by gender for this sample of youth with spina bifida, the most common identified leisure time activities, and frequency of team sport participation. While many previous studies (Hayes-Allen & Tring, 1973; Mita et al. 1993; Roberts, Shepherd, & Shepherd, 1991; Simeonsson et al., 2002) have reported
the prevalence of “obesity” in youth with spina bifida, the Centers for Disease Control and Prevention guidelines were employed in this study to measure *overweight*, where the classification indicates a severe problem with weight management and in essence obesity. For the purposes of this study, the words “obesity” and “overweight” will be used interchangeably.

Statistical analyses were conducted using the Statistical Package for the Social Sciences (SPSS) software. The minimal level of statistical significance for all analyses was set at \( p < .05 \). A one-way analysis of variance (ANOVA) was employed to determine if a significant relationship existed between frequency of physically active leisure participation and multiple independent variables including sex, level of lesion, mobility, and body mass index for age (BMI-for-age). The variable frequency of physically active leisure was collapsed to include leisure activities, sport teams, and exercise, if subjects indicated they enjoyed exercise when asked. Level of lesion was categorized as the following: Thoracic (lesion site at T-12 or above), High Lumbar (lesion site at L-1 to L-2), Lumbar (lesion site at L-3 to L-4), Lumbosacral (lesion site at L-5 to S-1), sacral agenesis, caudal regression, and lipomeningocele. The participants’ mobility was categorized as non-ambulatory (full-time wheelchair use), part-time ambulation (household and exercise ambulation/part-time wheelchair use), and full-time ambulation (community ambulation). Body mass index for age was categorized using two different grouping systems. The first classified the subjects into four BMI-for-age categories: <25\(^{th}\) percentile, 25\(^{th}\)-<50\(^{th}\) percentile, 50\(^{th}\)-<85\(^{th}\) percentile and 85\(^{th}\) percentile and up. The second grouping system collapsed the four categories into three BMI-for-age categories: <25\(^{th}\) percentile, 25\(^{th}\)-<50\(^{th}\) percentile, and 50\(^{th}\) percentile and up. This was done to analyze if a significant difference could be determined between subjects that were at or above the normed half-way point for BMI-for-age (indicating a potential for weight management issues now or in the future) in relation to
those that were below the norm of their peers (not indicative of a weight management problem). Tukey’s honestly significant difference (HSD) test was then used to show the difference between groups when the minimal significance level was met using the ANOVA procedure. Pearson’s correlations were conducted for age in relation to frequency of physically active leisure participation.

The General Linear Model (GLM) procedure was used to determine if a significant relationship existed between frequency of physically active leisure participation and both BMI-for-age and participation in physical education. BMI-for-age was classified using the four group categories detailed above and the subjects classified as “yes” or “no” for physical education participation. One participant did not indicate her participation in physical education. In addition, a Chi-Square analysis was conducted to compare physical education participation and BMI-for-age, using both the four group and three group categories for BMI-for-age in two separate analyses.
CHAPTER IV

RESULTS

Prevalence of Overweight

The Centers for Disease Control and Prevention defines *overweight* as greater than or equal to 95\textsuperscript{th} percentile of the age- and sex-specific body mass index (BMI), also referred to as BMI-for-age (National Center for Health Statistics, 2002). A measure of the 95\textsuperscript{th} percentile means that compared to children of the same gender and age, 95\% have a lower BMI. BMI-for-age is gender and age specific because as children mature, males and females differ in body fatness (CDC, n.d.). Thirty-six percent \((n=18)\) of the total subjects were classified as overweight with a BMI-for-age equal to or greater than the 95\textsuperscript{th} percentile, 26\% \((n=13)\) were male and 10\% \((n=5)\) were female. Males were more likely to be overweight than females with 50\% of the total male participants \((n=13)\) greater than or equal to the 95\textsuperscript{th} percentile, compared to 20.83\% \((n=5)\) of the total female participants. In addition, subjects who were classified as *at risk of overweight* (85\textsuperscript{th} - <95\textsuperscript{th} percentile), indicating a less severe but recognized weight management problem, comprised an additional 16\% \((n=8)\) of the total subjects; 10\% \((n=5)\) were male and 6\% \((n=3)\) were female. In summary, over half of the total participants (52\%) were classified as *at risk of overweight* or *overweight*, signifying a serious physical health concern; 36\% \((n=18)\) were male and 16\% \((n=8)\) were female.

Leisure Time Activities

Overall, the participants reported 56 leisure activities in which they participated “for fun”. The top five reported activities of boys were video games (26\%), watching television (22\%), basketball (18\%), playing with pets (14\%) and using the computer (14\%). The top five
activities for girls were watching television (24%), arts and crafts (18%), playing with pets (14%), swimming (12%), and listening to music (12%).

During the interview, respondents were asked if they participated on any sport teams (school or otherwise) within the past year. Thirty percent ($n=15$) of the youth with spina bifida participated on sport(s) teams. Nine males (18%) and 6 females (12%) were members of teams. Sport teams participation for males included, basketball (10%), baseball/softball (6%), sled hockey (2%), soccer (2%), tennis (2%), and track and field (2%). Sport team participation for females included baseball/softball (4%), drill team (2%), soccer (2%), swimming (2%), track and field (2%), and bowling (2%). Seven (46.6%) subjects who participated on sport teams, used a wheelchair full-time for ambulation, six (40%) were full-time ambulators, and two (13.3%) were part-time ambulators.

Frequency of Physically Active Leisure Participation

The range of scores for frequency of physically active leisure participation was from 1 to 22. No significant differences were found for sex, age, or level of lesion, or BMI-for-age and frequency of physically active leisure participation. The $p$-value when analyzing the difference between sexes was non-significant at 0.83. The correlation for age and frequency of participation was non-significant with a $p$-value of 0.33 ($r=-0.14$). Level of lesion was close to statistically significant with $p=0.06$. Upon further examination, the mean for caudal regression was higher than Lumbar, Thoracic, and High Lumbar. However, only one subject was categorized with caudal regression. In addition, when limiting the levels of lesion to only Lumbar and Lumbosacral, no significant difference were found between the two ($p=0.12$). In an attempt to determine a connection between physical activity and body size, the frequency of physically active leisure participation and body mass index for age was examined. No significant
differences were found in either the four BMI-for-age grouping ($p=0.7$) or in the three BMI-for-age grouping ($p=0.53$).

When mobility was examined in relation to frequency of participation in physically active leisure using three categories (non-ambulatory, part-time ambulators, and full-time ambulators) no significant differences were found ($p=0.12$). However, because the non-ambulatory and part-time ambulatory subjects were classified in this study as using a wheelchair at least part of the time or more for mobility, they were then combined into one group to compare against the subjects who did not use a wheelchair for ambulation. A significant difference was found between the subjects that used a wheelchair and those that did not use a wheelchair for ambulation ($p=0.04$). The subjects that did not use a wheelchair participated significantly more in physically active leisure than did the subjects that used a wheelchair for mobility.

In relation to frequency of physically active leisure participation, participation in physical education classes and the four-group BMI-for-age were examined in a two-way analysis of variance. No significant differences were found for either BMI-for-age ($p=0.73$) or physical education participation ($p=0.74$). Additionally, no significant relationship was found between physical education participation and the three-group or four-group BMI-for-age classifications.
CHAPTER V
DISCUSSION

Prevalence of Overweight

Following the trend found in much of the literature about youth with spina bifida, over half of the youth in this sample displayed weight management concerns. Thirty-six percent were classified as overweight using the criteria established by the Centers for Disease Control and Prevention. This finding supports the results by Fiore et al. (1998), where 40% of the participants were classified as being overweight using the same criteria. An additional 16% of the subjects in this study were at risk for being overweight, also indicating the presence of excess body weight and concerns that they may likely progress into the highest percentile for BMI-for-age compared to their peers. Obesity is an epidemic that affects numerous children, both with and without disabilities. Future research employing longitudinal data, looking at the pattern of development of obesity across the life span in youth with spina bifida, may provide a more descriptive picture of the ages, gender issues, ethnicities, mobility patterns, and behaviors which may contribute to weight management issues in this population. In addition, employing a control group of typically developing youth of similar ages and demographics would help to determine if the rate of obesity in youth with spina bifida is indeed significantly exceeding youth without disabilities as previous studies have found (Hayes-Allen & Tring, 1973; Mita et al., 1993; Roberts, Shepherd, & Shepherd, 1991).

Leisure Time Activities

The majority of preferred leisure time activities reported by this sample of youth with spina bifida were sedentary activities. Of the top five most frequently reported activities for both males and females, three did not involve gross motor movement. For boys, these were playing
video games, watching television, and using the computer. For girls, these activities were watching television, arts and crafts, and listening to music. In addition, both genders reported playing with pets as one of their top five preferred leisure activities; which while considered physically active leisure for the purposes of this study, is likely only of moderate intensity when compared to other leisure activities such as basketball or swimming. This finding supports the study by Brown and Gordon (1987), who reported that children with disabilities are more likely to engage in activities found within the home, in social isolation, and sedentary.

A recent study by Harrell et al. (2003), detailed the most frequently reported leisure time activities of typically developing adolescents. Of the top five activities reported by boys, all five would be considered physically active leisure as defined in this study. For girls, four of the top five most frequently reported activities were physically active in nature. Because Harrell et al. and this study did not use the same instrument to report leisure time activities, it is impossible to determine if the difference between the activity patterns of youth with spina bifida and those without spina bifida is significant. However, it is an important finding that both genders in this study preferred leisure activities that were more sedentary and solitary in nature. Future studies, comparing the leisure time activity patterns of youth with spina bifida and youth without spina bifida may help to determine if significant differences in leisure behavior exist.

In regards to sport participation in this study, more males were members of sport teams within the past year than females. Thirty percent of the respondents participated on sport teams, and of that group, seven subjects used a wheelchair full-time for ambulation, two used a wheelchair part-time for ambulation, and six did not use a wheelchair at all for ambulation. It is worthy to note that more subjects who participated on sport teams were considered “non-ambulatory” than subjects who were considered “ambulatory”. While there is not likely a
significant difference between the two groups, the acceptance and growth of wheelchair sports throughout the world such as rugby, basketball, and tennis, has likely played a role in increasing the availability of sport teams for athletes who use a wheelchair, and may have contributed to the finding in this study that as many non-ambulatory subjects participated on sport teams as did ambulatory subjects. Future research reporting on the availability of wheelchair sport teams for individuals with disabilities, compared to sport teams for individuals with disabilities who use limited or no assistive devices, may show a discrepancy between the needs and resources available for this subpopulation.

Frequency of Physically Active Leisure Participation

Multiple independent variables including age, sex, BMI-for-age, and level of lesion, were analyzed in relation to frequency of physically active leisure participation. Mobility was the only variable which displayed a statistical significance. Subjects who did not use a wheelchair (were ambulatory) participated significantly more frequently in physically active leisure than subjects who used a wheelchair (were non-ambulatory, or ambulatory part-time). This finding may follow a logical pattern of thought in relation to previous studies on youth with spina bifida, other disabilities and physical activity participation. Berg-Emons et al., (2001) reported a correlation between functional ambulation (mobility) and time spent on dynamic or physical activities per day. Youth with spina bifida who were ambulatory engaged in more physical activities than youth with spina bifida who were non-ambulatory. In relation to this finding, it may then be reasonable to predict that youth with spina bifida who are ambulatory will participate significantly more in physically active leisure than youth with spina bifida who are non-ambulatory, as was the case in this study.
In addition, much of the literature agrees that youth with disabilities who participate in physical activities report better physical health than youth with disabilities who are not physically active (Agre et al., 1987; Pitetti, Jongmans, & Fernhall, 1999; Sawatzky, Macdonald, & Valentine, 2003; Southern, 2001). Youth with spina bifida who engage in physically active leisure on a consistent basis may avoid the spiral of deconditioning which has been suggested to lead to a reduction in functional capacity (including ambulation), an increase in body fat, further inactivity, and in essence decreased physical health (Berg-Emons et al., 2001).

Implications for Therapeutic Recreation

Disability, physical activity participation, obesity, and secondary health conditions are all complex issues that are inter-related for the individual with spina bifida. One issue affects the other, ultimately working to create a total picture of the health of a person with spina bifida. Therapeutic Recreation professionals are accustomed to viewing the client holistically, a practice consistent with the need to provide purposeful and effective intervention for youth with spina bifida who are at risk for developing obesity. Youth with disabilities have been consistently reported to be less physically active than their peers (Brown & Gordon, 1987; Cooper & Quatrano, 1999). Similarly, youth with spina bifida have been reported to be less healthy than their peers, including a higher rate of obesity and resulting secondary health conditions (Fiore et al., 1998; Mita et al., 1993; Simeonsson et al., 2002). This study serves as a baseline for future research on the effectiveness of physically active leisure participation as an intervention for youth with spina bifida. Results, while limited, propose some ideas for future study and intervention. Prospective research directions may include longitudinal investigations of the development of obesity in children with spina bifida, comparing current rates of obesity for youth with spina bifida and youth without spina bifida to determine if a significant difference
exists between the groups, and determining the availability of sport and leisure resources for
individuals with spina bifida who are ambulatory, but who have a “hidden” disability that does
not allow for equal participation with their peers. In addition, the study has provided a rationale
for using physically active leisure participation as an intervention to keep individuals physically
active, lessening the effects of the spiral of deconditioning, and maintaining ability. Outcome-
based evidence of the effectiveness of therapeutic recreation interventions for obesity is the next
step to improve the health, well-being, and quality of life of youth with spina bifida.
REFERENCES


*British Journal of Preventative Social Medicine, 27*, 192-196.


