Adaptive Skiing/ Snowboarding Affects the Quality of Life of Children With Disabilities

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Abstract

Aim: To examine the impact of participation in an adaptive ski and snowboard program on Health-Related Quality of Life (HRQL).

Methods: Participants completed the KIDSCREEN-52 HRQL questionnaire prior to and upon completion of a winter sport season. The questionnaire was distributed for five seasons. Participants who completed three or more years were further analyzed as a long-term cohort.

Results: Seventy-six athletes met inclusion criteria. After one year, athletes demonstrated significant improvement in physical well-being and bullying; guardians reported improvement in six of the 10 HRQL domains. Twenty-nine athletes met criteria for the long-term cohort, reporting significant improvements in financial resources, peers and social support, and bullying, but a significant decrease in self-perception. Parents reported improvements in financial resources and bullying.

Conclusions: Perceived changes in HRQL of children with disabilities are evident after one season of participation, and guardians are more likely to report significant improvements than child-athletes.

Keywords: *Adaptive recreation, adaptive sports, cerebral palsy, disabilities, quality of life, skiing*

Introduction

The positive physical, psychological, and social benefits of sports participation in child-athletes are well documented. Despite demonstrated benefits of physical activity, studies have found that children with cerebral palsy (CP) are not as physically active as their able-bodied peers (Zwier et al., 2010). Individuals with disabilities who participate in sports have been shown to have improved strength, stamina (Blauwet, 2005; Groff, Lundberg, & Zabriskie, 2009; Taylor, Dodd, & Larkin, 2004), cardiovascular health, fitness (Groff, Lundberg, & Zabriskie, 2009; Seaman, Corbin, & Pangrazi, 1999; Wells & Hooker, 1990), and do not develop as many or as severe secondary health conditions (Centers for Disease Control and Prevention [CDC], 2002; Groff, Lundberg, & Zabriskie, 2009; Santiago & Coyle, 2004; Seaman, Corbin, & Pangrazi, 1999). Children with CP, central nervous system injuries, limb deficiencies, neurologic diagnoses, various syndromes, and cancer have shown gains in these realms similar to their typically developing peers; improved mood, wheelchair mobility, and perception of health and overall well-being have been reported (Campbell, 1995; Greenwood, 1990; Groff, Lundberg, & Zabriskie, 2009; Muraki, Tsunawake, Hiramatsu, & Yamasaki, 2000). These particular sports participants can greatly improve their social integration and peer acceptance (Nelson & Harris, 1995). They frequently undergo physical therapy and other interventions to maintain strength, mobility, balance, and to assist with activities of daily living. However, they often cannot overcome several barriers to sports participation, including a lack of adaptive equipment, parental concerns, personal motivation, and poor availability of programs with adequate supervision.

In the Surgeon General's "Call to Action to Improve the Health and Wellness of Persons with Disabilities," four specific goals to help improve healthy lifestyles, health, and independence of individuals with disabilities were set forth. The report stated that the Surgeon General believes that good health can be encouraged simply by promoting an active lifestyle (Office of the Surgeon General, 2005). By having children participate in physical activities at an early age, the idea of fitness, strength and improved health can be instilled and maintained throughout their lifetime (Sterba, 2006). In the past 20 years, advances in adaptive athletics have made safe participation more possible for children with disabilities. A participation possibility chart, developed in the 1970s and accepted by many professional organizations, demonstrated that there are very few combinations of medical pathology and sports selection that cannot be adapted or individualized (Chang, 1994). This led to a shift in dogma from a traditionally restrictive paradigm, advising against participation for fear of injury or perceived limitations, to an integrative one. Adaptive snow sports have been shown to be one such enjoyable activity, with trained instructors assisting the ath-

lete's safe navigation of the ski slope environment (Barbin & Ninot, 2008; Leung, 1988).

While the benefits of adaptive sports participation are extensive, no study has assessed their impact on participant health-related quality of life (HRQL). Furthermore, caregiver perception of HRQL has not been addressed. The purpose of this study was to quantify the impact of participation in our institution's adaptive skiing/snowboarding program on parent-perceived and participant-reported HRQL. We hypothesized that children would benefit in all domains of life from participation in our program. We also believed these benefits would continue to improve with continuous annual participation, and that there would not be a significant difference between child and guardian reporting.

Methods

Study subjects were participants in the Adaptive Recreation for Childhood Health (ARCH) ski/snowboard program at Winter Park, Colorado, from 2011 through 2015. This program has been sponsored by Children's Hospital Colorado and organized through the National Sports Center for the Disabled (NSCD) since the 1970s, and provides children with physical disabilities between the ages of 8 and 21 an opportunity to learn adaptive skiing and snowboarding each winter. Each season, 60 to 70 children participate in the ARCH program, with diagnoses including CP, spina bifida, traumatic brain injury, spinal cord injury, arthrogryposis, limb deficiency, among others. Each ski season entailed comprehensive adaptive equipment fitting, followed by one-on-one ski or snowboard instruction for five nonconsecutive Saturdays from January to March. Instructors were volunteers trained by NSCD in Winter Park. Guardians of participants were permitted to attend sessions, observe, and offer support.

A validated, cross-cultural survey, KIDSCREEN-52, was utilized to monitor the impact of the ARCH program on participant HRQL (Robitail et al., 2006). KIDSCREEN-52 is applicable to both healthy and chronically ill children and adolescents. A "proxy" measure has also been developed for use with the primary caregivers of the children. KIDSCREEN-52 contains 52 questions that measure 10 domains of HRQL: physical well-being (five questions), psychological well-being (six questions), moods and emotions (seven questions), self-perception (five questions), autonomy (five questions), parent relations and home life (six questions), financial resources (three questions), social support and peers (six questions), school environment (six questions), and bullying and social acceptance (three questions).

Following Institutional Review Board approval, ARCH program participants were prospectively enrolled in the study. All participants were eligible for this study. Written informed consent and assent were obtained for all child-athletes and primary caregivers prior to involvement in research procedures. KIDSCREEN-52 was administered to each enrolled participant and his or her guardian at the time of equipment fitting, prior to the first day of the season. The survey was then administered between two and four weeks after completion of the winter season. Subjects were excluded if they participated in fewer than four sessions per winter season. Paired *t*-test analysis was completed only for athletes and/or guardians who completed both pre- and post-season surveys. Those who completed the pre-season survey were included in trend analyses only. The questionnaire was administered in paper format during the first year of the study (2011), and distributed and completed electronically using Research Electronic Data Capture (REDCap) for the following four years (2012-2015) (Harris et al., 2009).

SAS 9.4 (SAS Institute, Cary, NC) was used for all analyses. Total and subscale *t*-scores of KIDSCREEN were summarized with mean and standard deviation at each time point. Higher scores correlate with better HRQL. A paired *t*-test was used to assess the statistical significance of the change in KIDSCREEN scores following program participation. Significant change was defined as $p<0.05$. This was done separately for athletes and guardians. Differences in HRQL results between athletes and their guardians were then contrasted.

Athlete-guardian pairs that participated in at least three consecutive seasons were included in our long-term participation cohort. A linear mixed-effects model with compound symmetry covariance structure was used to model the time course of pre-season HRQL score over multiple years.

Results

Seventy-six participants met inclusion criteria and participated in the program for one or more years. Participant's age at enrollment ranged from 8-18 years at enrolment (mean=12 years, 9 months, SD=2 years, 9 months), 45% of whom had a diagnosis of CP. Other diagnoses included myelodysplasia, limb deficiency, traumatic brain or spinal cord injury, arthrogryposis, and cancer. Demographic and clinical characteristics are summarized in Table 1.

Forty-five child athletes who participated only one year completed both the pre-and post-season survey. Significant improvement was found in two of the 10 HRQL domains: physical well-being ($p<0.001$) and bullying ($p=0.010$). Results are shown in Figure 1. No HRQL domain showed a significant decrease after one year.

Guardians of these participants reported more domains with significant improvement after the first year of participation compared to the athletes' reports. As displayed in Figure 1, six of 10 HRQL domains were reported by guardians as improved for their children: physical well-being, psychological well-being, moods and emotions, financial resources, peers and social support, and bullying ($p=0.002$, 0.028, 0.005, 0.003, 0.031, 0.026). The remaining four domains showed mean improvements, but these were not significant ($p>0.05$). No domain decreased after one year of participation.

Table 1
Patient Demographics and Characteristics for All Participants and Long-Term Cohort Participants

		All participants (*n*=76)	Long-term cohort participants (*n*=29)
Sex	Female	29 (38.2%)	12 (41.4%)
	Male	47 (61.8%)	17 (58.6%)
Primary Disability	Cerebral Palsy – Hemiplegic	20 (26.3%)	5 (17.2%)
	Cerebral Palsy – Diplegic	5 (6.6%)	3 (10.3%)
	Cerebral Palsy – Quadriplegic	2 (2.6%)	1 (3.4%)
	Cerebral Palsy – Unspecified	7 (9.2)	2 (6.9%)
	Spina Bifida	2 (2.6%)	0 (0%)
	Genetic Disorder	2 (2.6%)	1 (3.4%)
	Limb Deficiency	4 (5.3%)	0 (0%)
	Arthrogryposis	3 (3.9%)	2 (6.9%)
	Traumatic Brain Injury	2 (2.6%)	1 (3.4%)
	Scoliosis	2 (2.6%)	1 (3.4%)
	Club Foot	2 (2.6%)	1 (3.4%)
	Myotonia	6 (7.9%)	2 (6.9%)
	Mitrochondrial Disorder	2 (2.6%)	1 (3.4%)
	Other diagnoses	18 (23.7%)	8 (27.6%)
Ski Style	2 Track	38 (50%)	17 (58.6%)
	3 Track	1 (1.3%)	1 (3.4%)
	4 Track	2 (2.6%)	1 (3.4%)
	Snowboard	21 (27.6%)	7 (24.1%)
	Sitski	12 (15.8%)	2 (6.9%)
	Ski Bike	2 (2.6%)	1 (3.4%)

When contrasting athlete and guardian reporting after one year of participation, the only significant post-season change was observed in the self-perception domain. Parents reported a perceived improvement in their children's self-perception, while children reported an average decline in this domain. Overall parent and child agreement across all domains demonstrated a moderate correlation with an average Spearman coefficient of 0.488.

There was only one significant gender-related difference observed. Female athletes were more likely to report an increase in peers and social support than their male counterparts (p=0.021) after one year of participation. There was no significant difference in parent reporting with respect to athletes' gender.

Twenty-nine athlete-guardian pairs met inclusion criteria for our long-term participation cohort. Trends in participant-reported HRQL change observed after multiple years of participation are shown in Figure 2. Athletes reported trending improvements that were significant in three domains after three or more years: financial resources, peers and social support, and bullying (p=0.002, 0.010, 0.011). Parents also reported significant multi-year improvement trends in financial resources and bullying (p=0.024, 0.003). Interestingly, athletes reported a significant decrease in self-perception (p=0.022) after multiple years of participation; no significant trend was observed in parent reporting. No other domains exhibited significant trends.

Discussion

Previous research has shown that participation in adaptive sports can improve gross motor function in children with cerebral palsy (Sterba, 2006). Adaptive skiing and snowboarding are examples of such activities that are safe, beneficial, and fun for children with disabilities (O'Leary, 1989). Due to

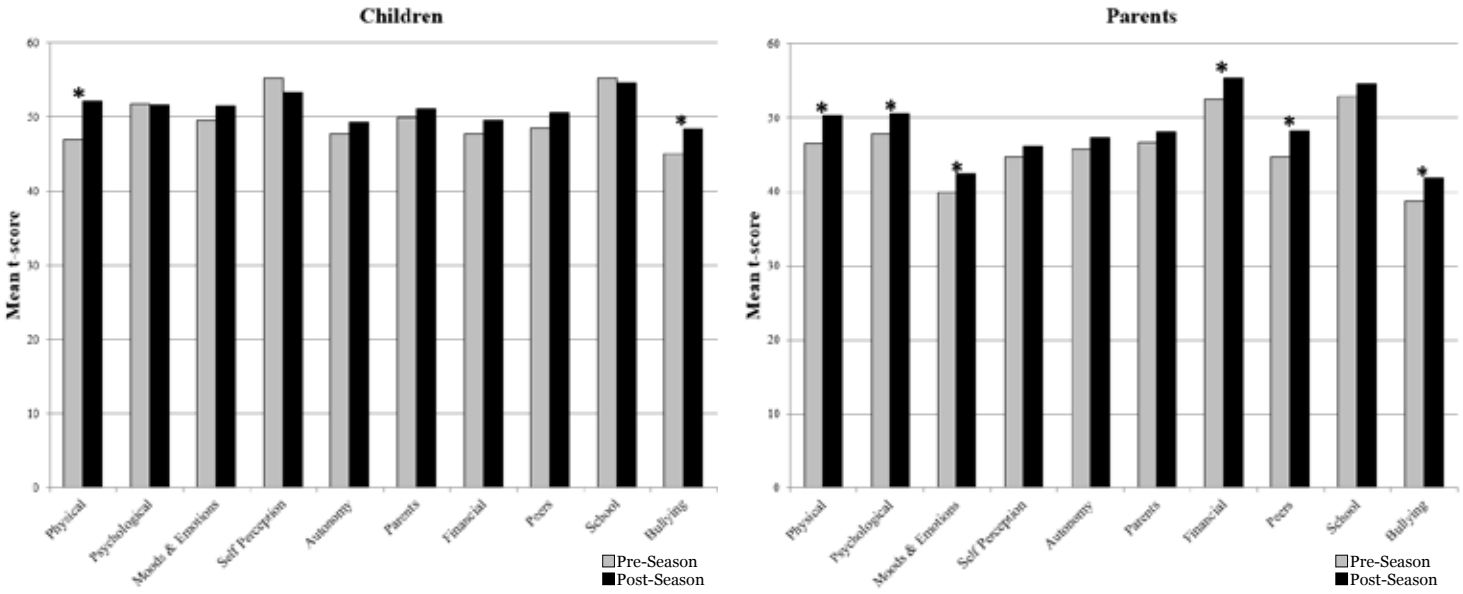

Figure 1. Change in *t*-score for children after first year of participation. *indicates p<0.05

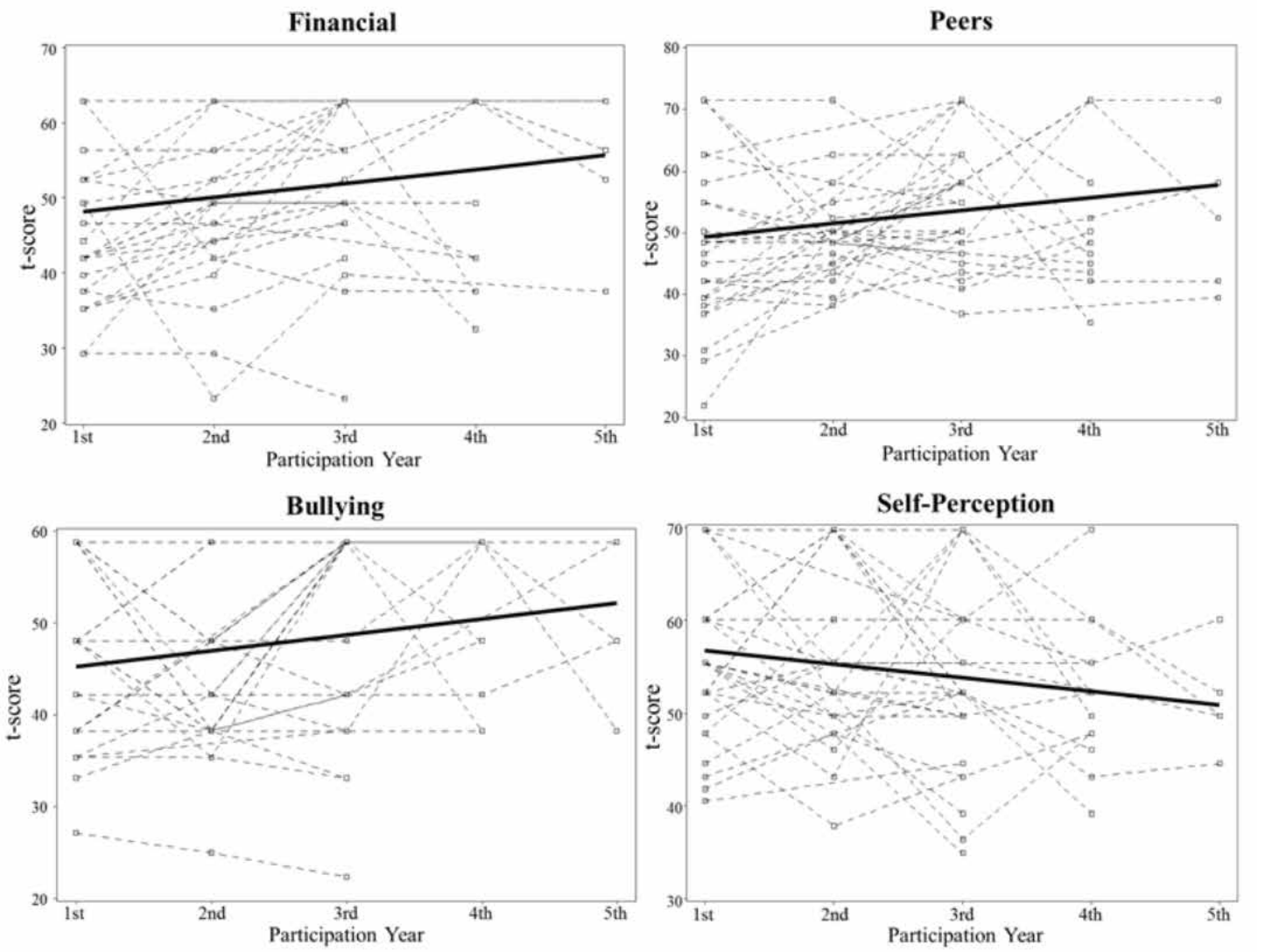

Figure 2. Trends for child *t*-score over three or more years ($p<0.05$ for all slope testing)

the precise turning and other complex movements associated with skiing and snowboarding, participants may increase muscle strength, joint flexibility, coordination, balance, and posture (Sterba, 2006). Participation also affords children with disabilities an opportunity to compete with or parallel to their able-bodied peers. Regardless of the participant's particular disability, sports participation enhances personal motivation, improves coping skills, promotes independence, gives participants the opportunity to be compared on the same social level as their peers, builds self-confidence, supports competitiveness, and fosters teamwork (Patel & Greydanus, 2010; "Special Olympics Reach Report"). Exercise- and strength-based programs have been shown to elevate the physical and mental functioning in adults with CP (Groff, Lundberg, & Zabriskie, 2009; Santiago & Coyle, 2004; Taylor, Dodd, & Larkin, 2004; van der Slot et al., 2007). Whether these improvements are also seen in children participating in adaptive ski/snowboard programs has not been elucidated.

Prior research on the efficacy of adaptive sports programs focused on self-concept and athletic identity, but not all areas of HRQL. Self-concept is an individual's attitude and feelings regarding his or her identity and abilities, while athletic identity refers to the degree to which an individual identifies with the role of an athlete (Brewer, 1993; Brewer, Van Raalte, & Linder, 1993). Groff reported that among adults with CP, the effect of sports participation on HRQL correlated with their athletic identity (Groff, Lundberg, & Zabriskie, 2009). In other words, participants that considered themselves athletes were more likely to report an improved HRQL. However, there have been no comprehensive assessments of HRQL in child-athletes with disabilities.

Our data show that an adaptive skiing/snowboarding program affects the HRQL children with disabilities after just one season of participation. A significant change in the athletes' perception of their physical well-being occurred, as they were able to participate in a new, physically taxing activity. Previous research has found an overall greater sat-

isfaction with life and health in people with disabilities who become and remain physically active (Groff, Lundberg, & Zabriskie, 2009; Santiago & Coyle, 2004).

Unfortunately, this improvement in physical well-being did not translate into a significant multiple-year trend. However, it is important for children with disabilities to understand the importance of exercise and physical health in order to prevent the secondary disabilities (deconditioning, heart disease, obesity, hypertension) for which they are at risk (Wind, Schwend, & Larson, 2004).

Bullying is a significant cause of psychological distress among all children but is inherent to those with disabilities (Flynt & Morton, 2004). After one year, children reported a significant improvement in the HRQL domain of bullying. We believe this is due to improved socialization and/or improved coping ability after completion of the season. Guardians reported an improvement in the domain of peers and social support, supporting the former explanation. Children reported a mean improvement in this social domain that was not significant after one year, but did improve significantly over multiple years of participation. This suggests repeated exposure to other adaptive athletes may foster feelings of equality and remove barriers of insecurity. The positive change in bullying continued to improve significantly with continuous participation over multiple years, as reported by athletes and guardians alike. The ability of an adaptive sports program to mitigate the effect of bullying behavior and improve socialization among children with disabilities is a key finding of this study.

The Spearman coefficient of 0.488 demonstrates that parent and child reporting are only moderately correlated. Parents were more likely to report significant improvements than their children. There may be a component of reporting bias, as parents may view an adaptive program with more optimism. Parents may simply be thrilled that their children can actively participate in specialized activities that would otherwise be unavailable or too cumbersome for them to safely do themselves. We believe their observations give important insight into the lasting effects of the program, especially over multiple years. A prior study demonstrated that sports had a greater impact on the HRQL of athletes with disabilities when they participated with a family member (Groff, Lundberg, & Zabriskie, 2009). Being present throughout the season allowed guardians to better observe their children's accomplishments, and may have conversely allowed children to have better outcomes.

Adaptive skiing and snowboarding had a remarkably different effect on the HRQL domain of self-perception when reported by athletes who participated in the program for three or more years compared to their guardians. There was not a significant decrease in self-perception among athletes in their first-year reporting, but this decrease became significant over multiple years of participation. Additionally, athlete reporting was significantly different from what guardians perceived, with guardians reporting an overall improvement in self-perception. One explanation is that long-term exposure may enable children to realize their limitations, particularly when the season is complete and there is not a new adaptive sport in which they may compete. Alternatively, this may represent a normal self-esteem trend as the athletes transition into adolescence, which is a period of their lives marked by struggles with self-image. Whatever the reason, this finding demonstrates the importance of monitoring this domain in adaptive athletic programs, since guardians may not provide an accurate assessment of their children's self-perception.

This study had several limitations. There was a broad age range included in the study, and younger children may be less likely to report negative self-image attributes than older children, as outlined previously. Many types of disability were included in this study, and because most athletes carried a diagnosis of CP, the study population lacked homogeneity. Finally, adaptive skiing and snowboarding programs are costly, and therefore are not readily available to all children with disabilities. However, we believe the HRQL changes observed in our study may be extrapolated to other adaptive sports.

Historic dogma regarding sports for children with disabilities was restrictive, either from fear of injury or a misperception of the children's limitations (Wind, Schwend, & Larson, 2004). Over the past few decades, the doctrine of sports participation has changed to one of integration, either including children with disabilities into regular sports or allowing them to compete in parallel. Adaptive skiing and snowboarding programs allow the development of a recreational therapy that can improve the health and well-being of children with disabilities. The evidence provided in this study demonstrates a positive impact on the HRQL of children with disabilities. Accordingly, physicians and therapists can safely recommend this adaptive sport.

References

Barbin, J. M., & Ninot, G. (2008). Outcomes of a skiing program on level and stability of self-esteem and physical self in adults with spinal cord injury. *International Journal of Rehabilitation Research 31*(1), 59–64.

Blauwet, C. (2005). *Promoting the health and human rights of individuals with a disability through the Paralympic movement*. Paper presented at the International Paralympic Committee, Bonn, Germany.

Brewer, B. W. (1993). Self-identity and specific vulnerability to depressed mood. *Journal of Personality, 61*(3), 343–364.

Brewer, B. W., Van Raalte, R., & Linder, D. E. (1993). Athletic Identity: Hercules' Muscles or Achilles' Heel? *International Journal of Sport Psychology, 24*(2), 237.

Calfas, K. J., & Taylor, W. C. (1994). Effects of physical activity on psychological variables in adolescents. *Pediatric Exercise Science, 6*(4), 406–423.

Campbell, E. (1995). Psychological well-being of participants in wheelchair sports: comparison of individuals with congenital and acquired disabilities. *Perception Motor Skills, 81*(2), 563–568.

Centers for Disease Control and Prevention. (2002, September). Healthy people with disabilities. *Healthy People 2010*. Retrieved from www.healthypeople.gov/document/HTML/Volume1/06Disability.html

Chang, F. M. (1994). The disabled athlete. In C. L. Stanitski, J. C. DeLee, & D. J. Drez (Eds.), *Pediatric and Adolescent Sports Medicine* (Vol. 3, pp. 48–76). Philadelphia, PA: WB Saunders.

Flynt, S. W., & Morton, R. C. (2004). Bullying and Children with Disabilities. *Journal of Instructional Psychology, 31*(4), 330–333.

Greenwood, C. M., Dzewaltowski, D., & French, R. (1990). Self-efficacy and psychological well-being of wheelchair tennis and wheelchair non-tennis participants. *Adaptive Physical Activity Q*(7), 12–21.

Groff, D. G., Lundberg, N. R., & Zabriskie, R. B. (2009). Influence of adapted sport on quality of life: Perceptions of athletes with cerebral palsy. *Disability Rehabilitation, 31*(4), 318–326. doi:10.1080/09638280801976233

Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap): A metadata-driven methodology and workflow process for providing translational research informatics support. *Journla of Biomedical Information, 42*(2), 377–381. doi:10.1016/j.jbi.2008.08.010

Jackson, R. W., & Davis, G. M. (1983). The value of sports and recreation for the physically disabled. *Orthopedic Clinics of North America, 14*(2), 301–315.

Leung, P. (1988). Let it snow! Let it snow! Let it snow! Persons with diabilities skiing. *Journal of Rehabilitation, 54*(1), 10–13.

Muraki, S., Tsunawake, N., Hiramatsu, S., & Yamasaki, M. (2000). The effects of frequency and mode of sports activity on the psychological status in tetraplegics and paraplegics. *Spinal Cord*(38), 309–314.

Nelson, M. A., & Harris, S. S. (1995). The benefits and risks of sports and exercise for children with chronic health conditions. In B. Goldberg (Ed.), *Sports and exercise for children with chronic health conditions* (pp. 1–29). Champaign, IL: Human Kinetics Publishers.

Office of the Surgeon General (U.S.); Office on Disability (U.S.). (2005). The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities. Rockville (MD): Office of the Surgeon General (U.S.). Available from: https://www.ncbi.nlm.nih.gov/books/NBK44667/

O'Leary, H. (1989). *Bold tracks: Skiing for the disabled* New York, NY: Cordillera Press, Inc.

Patel, D. R., & Greydanus, D. E. (2010). Sport participation by physically and cognitively challenged young athletes. *Pediatric Clinics of North America, 57*(3), 795–817. doi:10.1016/j.pcl.2010.03.002

Petruzzello, S. J., Landers, D. M., Hatfield, B. D., Kubitz, K. A., & Salazar, W. (1991). A meta-analysis on the anxiety-reducing effects of acute and chronic exercise. Outcomes and mechanisms. *Sports Medicine, 11*(3), 143–182.

Robitail, S., Simeoni, M. C., Erhart, M., Ravens-Sieberer, U., Bruil, J., & Auquier, P. (2006). Validation of the European proxy KIDSCREEN-52 pilot test health-related quality of life questionnaire: first results. *Journal of Adolescent Health, 39*(4), 596 e591–510. doi:10.1016/j.jadohealth.2006.01.009

Santiago, M., & Coyle, C. (2004). Leisure-time physical activity and secondary conditions in women with physical disabilities. *Disability Rehabilitation, 26*(8), 485–494. doi:10.1080/09638280410001663139GP-JBCTMNKY9P7C9D [pii]

Seaman, J. A., Corbin, C., & Pangrazi, B. (1999). Physical activity and fitness for persons with disabilities. *President's Council on Physical Fitness and Sports Research Digest, Washington DC, 3*(5).

Special Olympics Reach Report. Retrieved from www.specialolympics.org

Sterba, J. A. (2006). Adaptive downhill skiing in children with cerebral palsy: Effect on gross motor function. *Pediatric Physical Therapy, 18*(4), 289–296. doi:10.1097/01.pep.0000233006.69121.bf

Taylor, N. F., Dodd, K. J., & Larkin, H. (2004). Adults with cerebral palsy benefit from participating in a strength training programme at a community gymnasium. *Disability Rehabilitation, 26*(19), 1128–1134. doi:10.1080/09638280410001712387

van der Slot, W. M. A., Roebroeck, M., Landkroon, A. P., Terburg, M., van den Berg-Emons, R. J. G., & Stam, H. J. (2007). Everyday physical activity and community participation of adults with hemiplegic Cerebral Palsy. *Disability Rehabilitation, 29*(3), 179–189.

Wells, C. L., & Hooker, S. P. (1990). The spinal injured athlete. *Adaptive Physical Activity Quarterly, 7*(3), 249–260.

Wind, W. M., Schwend, R. M., & Larson, J. (2004). Sports for the physically challenged child. *Journal of the American Academy of Orthopedic Surgery, 12*(2), 126–137.

Zwier, J. N., van Schie, P. E., Becher, J. G., Smits, D. W., Gorter, J. W., & Dallmeijer, A. J. (2010). Physical activity in young children with cerebral palsy. *Disability Rehabilitation, 32*(18), 1501–1508. doi:10.3109/09638288.2010.497017

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