Participation in Youth Power Sports

by

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Abstract

Playing team sports provides many benefits including opportunities for children and adolescents to experience physical and social growth. Research regarding child and youth participation in wheelchair sports, particularly power wheelchair sports, is limited and qualitative research that has the potential to provide insight into the experience of children and adolescents who use power wheelchairs to play sports is scarce. The main purpose of this thesis was to provide insight into the experiences of power soccer players and their parents in order to inform rehabilitation practice. This thesis is comprised of two studies: a scoping review (Chapter 2) and a qualitative study (Chapter 3). The scoping review described research related to group physical activities and sports with children and adolescents who used wheelchairs to participate. The results confirmed a lack of studies focused on child and youth power sport participation. The qualitative study focused on gaining insight into player and parent experiences with power soccer (Chapter 3) using interpretive descriptive methodology. Observation and semi-structured interviews with five players and 3 parents were completed. Five themes were developed: 1) Level Playing Field, 2) I am an Athlete, 3) Sports Equate to Life – "Life Lessons", 4) Value of belonging to a Community, and 5) The Roles of Rehabilitation Community in supporting Power Mobility Sports. Recommendations and clinical implications for practitioners are discussed and areas of future research are identified.

Preface

This thesis is original work by Elaine Bragg. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, as "Power Mobility Sport Participation among Children and Adolescents: Player and Parent Experiences", No. Pro00080958, June 28, 2018. No part of this thesis has been previously published, however the scoping review, which comprises Chapter 2, is currently under review by Physical Therapy and Occupational Therapy in Pediatrics.

Dedication

Professionally, this thesis is dedicated to all clinicians, after years of work and curiosity, who take risks in furthering their education, thus allowing new insights, perspectives and theory to challenge and complement their knowledge.

Personally, this thesis is dedicated to the love and support of my family; my husband Bob, who knew all along the importance of this journey for me as a health professional, person, wife and mother; my children, Drew, Joely and Carter – I hope that I modelled lifelong learning, and the value and privilege of education. Thank you for your encouragement and belief in me, especially as we experienced student life together! To my parents, Frank and Cecile and my mother-in-law, Melda, I welcomed your cheers and pride in returning to school. To my sister, Diane for always listening to my ideas; I treasure our conversations and life discussions. Last to my brother-in-law, Wade and numerous family members, friends and colleagues, I express sincere gratitude in your support of my thesis.

"It always seems impossible until it's done" ~ Nelson Mandela (One of our world's greatest pillar of strength and humanity; of which I had the upmost privilege to meet working as a Clinical Tutor at a Children's Rehabilitation Hospital, Riyadh, Saudi Arabia, 1994).

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Interview Guide for Players and Parents

Chapter 1: Introduction

This is a paper-based thesis comprised of 4 chapters. The first chapter is an introduction that includes background information and history regarding rehabilitation and assisted mobility. The purpose of Chapter 1 is to provide readers with a description of the strong influence and breadth of the philosophical underpinnings and paradigm shift regarding power mobility that influence practice in pediatric rehabilitation with an emphasis on the relevance to power sport. Chapter 2 is a scoping review that describes the literature regarding physical activity and sports with youth who use wheelchairs as tools to participate. Chapter 3 is a summary of the qualitative study, the main focus of this thesis, entitled, "Power Mobility Sport Participation among Children and Adolescents: Player and Parent Experiences." The final chapter is a summary of the thesis, highlighting clinically relevant findings, and implications for future research. The discussion emphasizes how rehabilitation professionals can support players and families in their journey to pursue and excel at team power sport.

How I came to Study Power Sport

After working almost three decades in physical therapy, mostly in pediatrics, and with the last 5 years focused on assessing for and prescribing power wheelchairs within an assistive technology service, a curiosity began to develop. How does the use of power wheelchairs (herein referred to as power mobility) affect the lives of the children, adults and families I work with? While working in this clinical area and immersing myself into the literature regarding the philosophical and social influences that affect acceptance of power mobility as a movement option, more questions arose. Why does therapists' willingness to explore power mobility, particularly for young children or children who are able to walk for short distances, lag behind evidence regarding benefits? [1] Hesitancy to explore power mobility for these children is particularly important as it reflects limited consideration of the social contributors to disability

and the associated focus on removing environmental barriers to meaningful participation for young children. As a clinician, the answers that came to mind were numerous and included expertise of therapists, lack of role clarity and knowledge about the timely benefits, missed opportunities to discuss power mobility with families, reluctance of parents, fear, funding challenges, logistics regarding the management and safe implementation of a large device, accessibility issues, timely assessments, assumptions about cognitive capacity, stigma, and the continued rehabilitation and societal focus on walking at all costs for some children. Clinically, the hesitancy to explore power wheelchairs as efficient movement options for all children with disabilities who could benefit, conflicts with research espousing benefits and current thinking about the importance of early, effective mobility options. I had personally witnessed how education, mentorship and capacity building with therapists who order wheelchairs could positively affect their perceptions of the value of power mobility. This experience encouraged me to think about how we can further expand our thinking to ensure all aspects of power mobility use are considered. How could we build on this?

My 'ah ha' moment presented itself when a teenager, also a client, introduced me to "power soccer" and proceeded to show me a YouTube video of the sport. That was it! Another example of how power mobility can be vitally important to children and adolescents...sports! It occurred to me that, if clinicians truly understood the value of the experience to participate in sport from the perspectives of the athletes and families, the insight may change how they approach wheelchair exploration and prescription. Thus, I began the journey of my Master's Thesis. I believe that insight and understanding of the experience of power sport participation may change how therapists approach power mobility exploration and prescription with families.

Background: Disability and Rehabilitation

The research in this thesis was conducted with the intent to inform practice in rehabilitation. In order to understand how this research can inform practice, it is important to understand the historical context and evolution of thinking in regard to mobility options for children in the field of pediatric rehabilitation. Historically, power mobility was considered as a "last resort" movement option for children with physical disabilities. It was only considered once other movement options focused on walking were tried and unsuccessful [2]. Even today, despite evidence to suggest the positive developmental effects of independent mobility, power mobility continues to be underutilized with young children [1, 3]. This hesitancy occurs despite calls for moving away from viewing movement options as a hierarchy and, instead, focusing on the best fit between the individual, the task and the environment [1]. Several contributors to this traditional perspective exist including a clinical focus on the restorative or medical model in rehabilitation and the influence of traditional theoretical frameworks to explain infant and child development. These influences are discussed in greater detail below.

For many years, normal movement and the "restorative model," contributed to a rehabilitation approach that strived to "fix" or eliminate disability [2]. Prior to 1980, the medical model of disease was used in a linear fashion; from etiology to pathology to manifestations of disease and therefore it failed to address the complexity of human functioning and the possibility that achieving a "normal" state was not what individuals with disabilities aspired to [2]. This way of thinking affected therapists' views on power mobility, as receipt of a power wheelchair under the linear medical model represented a resignation to using a wheelchair and giving up on walking. Therefore, it reaffirmed that receiving a power chair for independent movement was most often perceived as "failing" [2].

In the mid-1900's individuals associated with the socio-political Disability Movement, asserted that the assumption that individuals with disabilities aspired to 'normalcy' was highly oppressive. Advocates pushed for equality in a world where they claimed "disability" was the result of societal construction of social, environmental, attitudinal and legal barriers [4]. In response to the need to include functioning in a model of disablement, the World Health Organization (WHO) produced the International Classification of Impairments, Disabilities and Handicaps (ICIDH) in 1980, [5] followed by a revised version called the International Classification of Functioning, Disability and Health, known as the ICIDH-2 and then the ICF in 2001 [6]. The overall aim of the ICIDH-2 classification was to provide a unified and standard language and framework to describe health and health-related states. It took into consideration contextual factors such as environmental and personal influences on functioning [6]. As such, the ICF reflected the acknowledgement that aspects of disability are externally constructed. This shift encouraged rehabilitation professionals to move from focusing on individual impairment to supporting issues that are more meaningful in the lives of all individuals such as community living, employment and educational opportunities [2]. In addition, it encouraged clinicians to consider external barriers to functioning. Participation in meaningful activities including sport, recreation and leisure were recognized as important contributors to the lives of people living with disabilities.

Parallel shifts in theories of motor development (theories which focus on explaining how the gross motor skills of children change over the course of childhood) have also influenced rehabilitation practice. Early theories encouraged a focus on "normalization" of movement and prioritized walking over assisted mobility [2]. Prominence of these theories and associated interventions that focused on typical movement patterns encouraged practitioners to discount the voices of individuals with disabilities, perhaps relying on hierarches of knowledge and

inadvertently reinforcing traditional deficit-oriented views. Fortunately, contemporary theories of motor development have shifted the emphasis to functional and meaningful movement. For example, Dynamic Systems Theory, explains motor behaviour as an outcome of interactions between the person, task and environment and has been applied to motor development therapies for children [7]. The application of Dynamic Systems Theory has resulted in the development of context-focused approaches to intervention [8] that focus on changing the task and environment to facilitate functional and meaningful movement choices. An ecological approach to perceptual learning and development, whose core concept closely relates to Dynamic Systems Theory, also focuses on how infants and children learn through "perception-action" cycles within the environment, influenced by motivation and exploration, and leading to the development of new emergent skills [9]. As such, the concept of self-initiated, independent, exploratory movement becomes a vital factor when considering power wheelchair options for children.

Concurrent with the clinical uptake of new motor development theories and models was the introduction of a newly adopted approach to rehabilitation that emphasized family collaboration. Family-centred care focused on family capacity building and empowerment, and including children and families in decision-making processes about the issues that are fundamentally important to them [10]. This approach emphasizes the importance of engaging parents and children in goal setting processes so that rehabilitation activities are more motivating and meaningful [11]. It has recently been established that even young children can identify feasible and achievable goals [12]. These new goal-setting approaches to therapy have been implemented into rehabilitation and research over the past decade. In relation to power chair assessment, evaluation and prescription, the concept of collaborative goal setting would also give children a voice and could play a significant role in ensuring that children have access to the equipment to facilitate participation in the activities that are important to them.

When examining approaches specific to the field of power mobility, assistive technology models, for example, the "Human Activity Assistive Technology" model (HAAT) emphasize the importance of the interactions among human skills, the activity, the context of the activity and the assistive technology [13], helping to progress therapists' perspectives on the role power mobility could play in children's lives. Other theoretical frameworks specific to assistive technology exist. For example, the Matching Person and Technology (MPT) framework guides assessment for assistive devices. For assistive technology practitioners, these models can assist with integration of evidence into their prescription of devices, including power wheelchairs. These models and/or frameworks also help to classify and describe traits associated with individuals and their contextual environments with the goal of correctly matching the assistive technology to the needs of the person, ultimately improving outcomes but, more importantly, providing a tool that enhances their participation [13].

Other theories and models from the social sciences and humanities have also influenced and informed rehabilitation practice. For example, the Social Model of Disability [14, 15], places disabled people¹ in control of their own lives and focuses on the social and political forces that shape social relations of disability; in essence providing disabled people with a much needed

¹ The term "disabled people" supports the social model of disability and the suggestion that societal and environmental contexts in which people live contributes to the "disabling" experience.¹ Inherent in this perspective is the belief that, through valuing certain abilities over others, disabled people are limited by societal values and beliefs and therefore the term disabled is sometimes preferred over person first language. However, there is still hesitancy to adopt identity first language in the rehabilitation professions due to concerns about appearing disrespectful. To honour both perspectives, identity first and person first language are used interchangeably throughout this thesis.

^{1.} Kattari, S.K., A. Lavery, and L. Hasche, *Applying a social model of disability across the life span*. Journal of Human Behavior in the Social Environment, 2017, **27**(8): p. 865-880.

voice in sharing, directing and co-constructing rehabilitation decisions [16]. Applying a Social Model of Disability across the lifespan continues to be an area of discourse in rehabilitation. By acknowledging impairments as difference, and not as problems, and by creating more accessible and inclusive spaces and polices, the Social Model of Disability advocates that people should be free to engage as they wish in their lives, rather than being driven by societal expectations driven by a focus on normalcy and the assumption that all contributors to disability lie within the individual [15]. Kattari et al., (2017) concluded that "integrating disability content across social work education may promote inclusivity, intersectionality, effectiveness, and practice relevance" and shared how this perspective can be used in practice while within a medical-based system [15]. It must be noted that this is progressive thought in the context of Rehabilitation as tools like the ICF do not acknowledge disability as a result of oppression nor do they address social structures that reproduce marginalization and exclusion.

Power Mobility in Pediatric Physical Therapy Practice

Research has supported the role of early, self-initiated movement experiences in the development, participation and quality of life for children [17, 18]. Butler (1986) studied the effects of power mobility on self-initiated behaviors on young children with motor disabilities and, in doing so, was a leading advocate for the importance of early movement options and their influence on social, cognitive and perceptual development [19]. In fact, the most frequent outcome of restricted self-initiated locomotion is a pattern of passive, dependent behavior – specifically, a lack of curiosity and initiative that persists later in life [20]. Early power mobility, for children who are unable to move independently, which include ride-on toys like adapted cars [21, 22], newly developed power mobility options like the Wizzybug by Designability©, Bugzi by Meru© and Wild Thing by Stealth Products© or pediatric power wheelchairs, can facilitate

early exploration and curiosity in one's world, resulting in positive effects on psychological development from a very early age [20].

Interestingly, however, the practice of identifying, evaluating, training, obtaining funding and ordering power wheelchairs for children and adolescents remains an area in rehabilitation that continues to be slow to progress [1]. For example, power wheelchairs are not commonly prescribed for children younger than 3 years of age [20] despite evidence that children as young as 7 months can drive power devices [23]. In 2017, the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) revised a position paper on the application of power mobility devices for pediatric users which acts as a guideline on clinical and professional practice. The position paper provides a summary of existing scientific literature to assist practitioners in decision-making [24]. Based on existing evidence, their position states that "age, limited vision or cognition, behavioral issues, and the ability to walk or propel a manual wheelchair short distances should not, in and of themselves, be used as discriminatory factors against providing power mobility for children" and it is RESNA's recommendation that "early utilization of power mobility for children with mobility limitations as medically necessary, to promote integration and psycho-social development, reduce passive dependency, and to enhance participation, function, and independence" [24]. RESNA's stance is strong in its' support for power mobility for children and adolescents experiencing mobility restrictions.

Who can Benefit from Power Mobility in the Pediatric Population?

Children who are non-ambulatory, who have inefficient mobility, or who lose the ability to walk or walk effectively, are candidates for power wheelchairs [1, 24]. In addition, children with physical disabilities who cannot use manual wheelchairs efficiently, such as children with cerebral palsy classified as Gross Motor Functional Classification Scale (GMFCS) levels IV and V [25], children with progressive conditions such as spinal muscular atrophy I or II or muscular

dystrophy who lack the muscle strength necessary for walking, children with high level spinal cord injury, and children with certain presentations of osteogenesis imperfecta and arthrogryposis [24] are also frequently prescribed power wheelchairs. Power mobility options for these children is recognized as an important priority for early rehabilitation. Lastly, individuals with secondary orthopedic conditions, chronic fatigue and pain or other conditions that influence physical functioning and subsequently access to community and participation in activities of one's choice, may also be good candidates for power wheelchairs [24].

The Role of Power Mobility in Leisure Activities

It is important to recognize that in Western culture, participation in leisure is a right of children and an important area for development and health [26]. Furthermore, participation in leisure activities can contribute to children's physical, mental, and social well-being [26-28]. Power mobility also can contribute to a child's cognitive, social and physical development, by allowing participation in activities of choice thus contributing to improved quality of life [24]. By allowing access to their community or leisure choice, including unstructured activities like hanging out with friends or structured activities, like dance, drama or sport [26] individuals experience increased independence and choice-making [29]. Power mobility may also positively affect others' attitudes toward children with disabilities in addition to facilitating the development of friendships with their peers since power mobility often enables children to engage in play and social situations independent of adults [29]. It is noteworthy that the alignment of personal interests and preferences and opportunities to participate in ageappropriate activities and leisure activities that are valued, contribute to perceived quality of life, regardless of motor impairment [27]. As well, it is also important to recognize that children who have the ability to engage in activities of choice show more motivation and a higher level of participation and willingness to further engage in other activities [26]. Friendships, gaining

knowledge, learning skills, expressing creativity and determining life's purpose and meaning all occur through social and community participation [30]. Findings from one qualitative study that explored the perspectives of children with disabilities regarding the concept of inclusion in physical activity, reported that feeling like a legitimate participant and having friends are meaningful to them [31]. For some children, power mobility could act as a means for gaining entry to activities by affording independent movement. Rehabilitation professions can promote self-efficacy by ensuring that mobility options align with child and youth priorities for community participation and real-world experiences [30]. Rehabilitation professionals need to prioritize participation in meaningful life activities, including leisure.

The Role of Power Mobility in Sports

A recent systematic review on the benefits of sport participation for children and adolescents [32] revealed psychological and social health benefits of participation including increased self-esteem, social interaction and fewer symptoms of depression. Positive youth development through team sports, in particular, appears to be associated with improved outcomes due to the social nature of participation [32-34]. Participation in sport can also influence life-long physical fitness and health habits, which, in the era of increasing obesity and sedentary behavior in youth, plays a significant role in facilitating long-term cardiovascular health [33, 35].

Children with disabilities consider making new friends, gaining strength, and an ability to assert themselves as benefits to sport participation [36, 37]. Likewise, parents of children with disabilities view their children's participation in sporting programs as affording good health and opportunities to be part of a social group, while gaining knowledge and skills [38]. Parents also regard sport as a means for their children to achieve increased participation in society; important for empowering the children to influence their life situation [38].

Sports primarily or solely comprised of children and adolescents with disabilities, herein after referred to as specialized sport, can enhance the development of meaningful relationships with peers, improve self-esteem, allow for skill development in their sport and may potentially help shape more positive disability identities [39, 40]. Power sports, such as power wheelchair soccer, (known as power football in some countries) can be defined as a specialized sport, as they specifically focus on athletes who use power wheelchairs for mobility.

Power soccer, as played in Canada, is a co-ed game, played in a gymnasium. It involves 4 on 4 play with a 13' soccer ball. Steel or plastic guards are attached to players' chairs and used to strike the ball to score between two goal posts or large pylons. Neither age nor gender is a determining factor for eligibility, with perhaps the exception of major competitive settings. Power soccer is the first team sport developed specifically for power chair users [41].

Well established benefits have been demonstrated in sport for athletes with disabilities using manual wheelchairs [42], and current research citing benefits for sport participation with power wheelchairs, using mainly adult participants [41, 43] suggests that power sport participation is empowering, can improve self-efficacy, and facilitate the development of friendships, relationships and life experiences, thus contributing to improved quality of life [44-47]. Understanding the meaning of power sport participation [32] could assist clinicians in supporting, educating and providing power chairs for children. Ensuring consideration of power mobility and the broad range of contexts in which it could be used, is vitally important to children's development and overall sense of well-being. Power mobility and participation in sport presents an opportunity to explore child and parent experience in a unique context that could affect how therapists consider and present power mobility options. Currently, there is little research in the area of power sport participation with youth; as such, this gap in the literature places a need to broaden our understanding of power wheelchair sport for children, adolescents

and parents, both in its implications and possibilities. This thesis endeavored to determine how experiences shared by young players and their parents related to power sport participation could inform clinical practice in pediatric rehabilitation.

Chapter 2

Wheelchair Physical Activities and Sports for Children and Adolescents: A scoping review

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Abstract

A broad range of outcomes associated with sport participation are highly relevant and important to understand in the pediatric rehabilitation context. Aims- To describe research related to group physical activity and sport participation of children and adolescents who use wheelchairs to participate. Methods- The five-step framework described by Arksey and O'Malley was used to guide the review. Four electronic databases (MEDLINE, CINAHL, SPORTDiscus and SCOPUS) were searched for relevant literature and selected articles were screened and evaluated for inclusion. Basic article information, study objectives, participant information, methodology, outcome measures (quantitative) methods and themes (qualitative) were extracted from the selected articles. Outcome measures and qualitative themes were coded using the conceptual framework of the International Classification of Functioning, Disability and Health. As well, types of sports included in the literature were identified. **Results-** Twenty articles were included in the final review. The quantitative research articles evaluated outcomes related to test/training parameters (n=5), evaluation of tools/models (n=6) and biomechanical/physiological profiles of athlete(s) (n=5). Four qualitative studies explored perceptions and experiences with participation, social supports and identity development. Conclusions- Additional research on the outcomes associated with sport participation specific to wheelchair (and power chair) use is needed to inform clinician perspectives on evaluation and prescription practices.

Introduction

Sports provide children and adolescents with opportunities to belong, achieve fitness goals and compete. Participation in sport can also influence life-long physical fitness and health habits, which, in the era of increasing obesity and sedentary behavior in youth, plays a significant role in facilitating long-term cardiovascular health [33, 35]. A recent systematic review on the benefits of sport participation for children and adolescents [32] also revealed psychosocial benefits including increased self-esteem, social interaction and fewer symptoms of depression. Positive youth development through team sports, in particular, appears to be associated with improved psychosocial outcomes due to the social nature of participation [32-34].

In rehabilitation, interventions to increase physical activity levels and physical fitness are often defined programs that aim to improve physical and physiological outcomes such as aerobic training and muscle strengthening [48]. While rehabilitation has generally focused less on the psychosocial outcomes associated with sport participation, these outcomes are highly relevant in the rehabilitation context since opportunities for participation in preferred activities are associated with increased quality of life [27]. Shikako-Thomas et al. [49] encouraged consideration of leisure participation, including unstructured and structured activities such as sport, as integral to the health and well-being of children and youth with a disability. Since enhanced participation is a widely agreed upon goal of rehabilitation, a broader perspective on the outcomes associated with participation in group physical activity and team sport is necessary to inform practice. Because Physical and Occupational Therapists are often involved in the prescription of manual and power wheelchairs for children and youth, "well-informed decisions regarding each child's participation must consider overall health status, individual activity preferences, safety precautions, and availability of appropriate programs and equipment" [50].

The Canadian Senate Committee on Human Rights, in their document entitled *Leveling the playing field: A natural progression from playground to podium for Canadians with disabilities* [51] examined sport and recreation for individuals with disabilities in relation to Canada's human rights obligations under the United Nations Convention on the Rights of Persons with Disabilities [52]. The committee concluded that "The popularity of sporting activities and the physical, social and economic developmental benefits derived from them make sport an ideal platform and catalyst for fostering the inclusion and well-being of people with disabilities in society…" [51]. Viewing opportunities for sport participation from a human rights perspective further emphasizes the importance of therapists' role in ensuring sport participation is considered when exploring timely wheelchair prescription and features with families.

Previous reviews have explored therapeutic physical activity and exercise interventions to improve health, fitness and well-being of individuals who use wheelchairs [53] and barriers and facilitators of sport participation [54]. However, no reviews have focused specifically on group physical activity or sport participation for children and adolescents with disabilities, who specifically use wheelchairs as their tool to participate. The purpose of this scoping review was to describe research, summarize any gaps and trends in the literature and provide direction for future research. The authors recognize wheelchair users may have alternate access to sport without wheelchairs, however, the intent of this review is to inform clinical practice decision-making related to sport participation and wheelchair prescription. Non-therapeutic group physical activity was included to assist in exploring and evaluating outcomes within the context of a "team dynamic."

Methods

Scoping reviews are conducted to identify gaps in the evidence, clarify key concepts, and summarize evidence that addresses and informs practice in a particular topic area. We used the

five-step framework described by Arksey and O'Malley [55]. 1) identifying the research question, 2) identifying relevant articles, 3) selecting studies for inclusion, 4) charting and collating the data, and 5) summarizing and reporting the results, to conduct the review.

Identifying the research question

Levac et al. [56] recommended a broad approach to developing scoping review questions to ensure all relevant studies are identified. The question that guided this review was: What research has been conducted regarding the outcomes of group physical activity and sport participation for children and adolescents who use wheelchairs?

Identifying relevant studies and study selection

A search was conducted on the following electronic databases (MEDLINE, CINAHL, SCOPUS and SPORTDiscus) using the following search terms: (wheelchair*) AND (sport* or physical activity* or athlete*) AND (child* or toddler* or preschool* or adolescen* or teen* or youth* or school*) AND (disab*). The search strategy was developed in collaboration with a medical librarian. Reference lists of included articles were also searched for relevant literature. Articles were limited to ENGLISH language only and those published between January 1990 and May 2018. Research articles were deemed eligible for inclusion if they met the following two criteria:

- a) research articles focused on evaluating outcomes associated with group physical activity or sport (either non-competitive or competitive) using a wheelchair OR studies that focused on athlete performance in the context of a wheelchair sport, which included reverse integration or inclusive environments.
- a minimum of 50% of the participants were 17 years of age or younger to ensure a focus on children and youth, as registrants 18 years of age or older often move to adult programs.

We defined sport as either a group-based training for individual physical activity (e.g., tennis, track and field) and recreational or competitive team play (e.g. basketball, soccer). Articles were excluded if the physical activity was therapeutic in nature and therefore was not considered to be a group activity or sport (i.e. individualized exercise plan conducted with a physical therapist or isolated physical activity). In cases where it was not possible to determine if at least 50% of the sample met the age criterion, the proportion of the participants under 18 was estimated based on mean and standard deviation of the sample. All research methodologies, quantitative and qualitative, were included; the purpose was to provide a broad perspective on the research that has been conducted to date in this area.

Search and selection strategy

The article selection process is outlined in the PRISMA flowchart (Figure 1). Following the initial database search, the first author excluded duplicates and examined the remaining titles and abstracts for relevance. Full text articles were retrieved for the remaining articles (n=50) and were reviewed independently by both authors. The reviewers met on two occasions to come to consensus on inclusion/exclusion of articles.



Figure 1: Identification and Selection Process

Charting the data, collating, summarizing and reporting the results

Basic information (i.e., author, year, country in which the study was conducted and the journal in which the study was published) was extracted from each of the included articles. In addition, study objectives, participant information (i.e., age, sex, diagnoses), research methodology, outcome measures (quantitative), methods, and themes (qualitative) were extracted (Table 1). Journal titles were mapped to subject areas described in each database to facilitate description of the primary target disciplines (Table 1). Outcomes measures and the focus of qualitative themes were coded by components of the International Classification of Functioning, Disability and Health (ICF) (i.e., body functions/structures, activity, participation, environmental and/or personal contextual factors) (Table 2). Type of sport evaluated (i.e. sport type and whether the sport was competitive or not), was also extracted from the articles (Table 3).

 Table 1: Studies Included in Scoping Review

Author/Year	Journal	Study Aim	Participant	Methodology	Outcome Measures
Country	(Subject Area)		Information		
		QUANT	ITATIVE		
(Müller, Odermatt, & Perret, 2004) Switzerland	Spinal Cord (engineering, health sciences, social sciences)	Assess the reproducibility of test parameters at different intensity levels in wheelchair racing athletes to validate a new w/c racing test	n=11 (8 male, 3 female, \bar{x} =20.5 <u>+</u> 6.4 years); SCI, SB, CP, leg amputee	Psychometric evaluation (test re-test reliability)	Average speed, stroke frequency, heart rate, rate of perceived exertion and concentration of lactic acid
(De Groot, Valent, Fickert, Pluim, & Houdijk, 2016) Netherlands	International Journal of Sports Physiology and Performance (health sciences)	Determine relationship between outcome of the shuttle wheel test and peak O ₂ uptake and whether SWT and VO ₂ peak can discriminate between different skill levels (tennis)	n=15 (male \bar{x} =21.2 \pm 8.4 years); SB, amputee, SCI, bone cancer, caudal regression syndrome, hip dysplasia, spastic tetra & paraparesis	Observational	Peak VO ₂ uptake, shuttle wheel test (SWT), VO ₂ , heart rate, perceived exertion
(Starrs, Chohan, Fewtrell, Richards, & Selfe, 2012)	Prosthetics and Orthotics International (health sciences)	Examine the biomechanical differences between able- bodied and disabled participants during functional activities at a sports club	n=11 (2 male, 9 female, \bar{x} = 9.2 years, 5-15 years); Dx not stated	Cross-sectional	30-second agility test, 1- minute distance test and 10- meter sprint test, upper body kinematics

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(Barfield, Malone, & Coleman, 2009) US	Research Quarterly for Exercise and Sport (arts and humanities, health sciences)	Evaluate the ability of individuals with SCI to reach a training threshold during on-court sport activity; comparison of heart rate response with and without SCI	n=11 with disabilities and n=11 without (8 male, 3 female, \bar{x} = 19.9+10.93 years) (6 under 17 years); paraplegia, below T6	Cross-sectional, cohort	Heart rate
(White and Duda, 1993) US	Adapted Physical Activity Quarterly (arts and humanities, social sciences)	Examine the existence and nature of dispositional goal orientations and perceived reasons for sport success among adolescent disabled athletes	n=59 (52 male \overline{x} =15.5 \pm 3.3, 7 female \overline{x} =16.3 \pm 1.3 years); Dx not stated	Cross-sectional, descriptive	Task and Ego Orientation in Sport questionnaire, 21-item questionnaire concerning beliefs about the cause of sport success
(Knechtle et al., 2003) Switzerland	Spinal Cord (engineering, health sciences, social sciences)	Determine which speed and duration in an exercise protocol is best to test w/c athletes performing track sprint races	n=7, (sex unknown, \bar{x} =18.7 \pm 6.8 years); SB, SCI, poliomyelitis	Cross-sectional, descriptive	Speed, durational tests measuring heart rate and lactic acid concentration
(Kang, Zhu, Ragan, & Frogley, 2007) US	Rehabilitation Psychology (health sciences, social sciences)	Investigate perceived exercise and physical activity barriers of active youth with physical disabilities	n=145 (117 male, 28 female, (12-19 years) Dx not stated.	Cross-sectional, descriptive, (survey)	A 46-item exercise barrier instrument (estimates barrier severity and youth's exercise perception)

(Wilson and Washington, 1993) US	Spinal Cord (engineering, health sciences, social sciences)	Describe training techniques and injury patterns	n=83 (57 males, 26 female, \bar{x} =12.9 years, 6- 18); SB, SCI, poliomyelitis, amputee, CP, other	Cross-sectional, descriptive, (survey)	Survey on training techniques and injury patterns
(Cavedon, Zancanaro, & Milanese, 2015) Italy	PLoS ONE (life sciences)	Assess anthropometry, body composition and performance in sport-specific field tests and evaluate the association of these with variables with functional ability classification and game related stats	n=52 (45 male, 7 female, \bar{x} = 18 \pm 4.6 years); SCI, SB, CP, phocomelia, poliomyelitis & other neurological disorders	Observational (correlational)	Anthropometry, body composition and performance in sport specific field tests
(Brasile and Hedrick, 2004) US	American Journal of Recreation Therapy (health sciences)	Ascertain the determinants of competitive trait anxiety within adolescent w/c basketball players	n=71 (56 male, 15 female, $\bar{x} = 16.2$ years); SCI, SB, Amputee, CP, orthopedic, other	Cross-sectional, descriptive, (survey)	Pre-survey and post tournament survey to measure perceived personal competence, self-esteem and evaluate worry
(Hutzler, Chacham- Guber, & Reiter, 2013a) Israel	PALAESTRA (arts and humanities, health sciences)	Describe the changes in psychological variables of the athletes with disabilities who attended a sports program	n=30 (25 male, 5 female, $\bar{x} = 17.7 \pm 4.3$ years, range 12- 25); CP, SB, Other: (neuromuscular or musculoskeletal)	One group pre- post test	QOL questionnaire, Personal questionnaire, Perceived Social Competence Scale and Perceived Task Success Questionnaire

(Hutzler,	Research in	Examine the impact of	n=90 (57 male,	Prospective,	QOL questionnaire, Personal
Chacham-	Developmental	participation in different	33 female, $\bar{x}=18$	cohort study	questionnaire,
Guber, &	Disabilities	sport modalities on quality of	\pm 3.95 years,		Perceived Social
Reiter,		life and perceived social	range 12-25);		Competence scale and
2013b)	(arts and	competence	CP, SB,		Functional Independence
	humanities, law)		Neuromuscular		Measure
Israel			disease		
(Shapiro	Disability and	Determine if the quality of	n=46 (35 male,	Observational	Evaluated Sport Friendship
and Martin,	Health Journal	friendships, physical self-	11 female,	(correlational)	Quality Scale (SFQS), Self-
2014)		perceptions and general self-	\bar{x} =15.37 +2.45		Perception Profile for
	(law)	worth predicts close	years, range 12-		Adolescents (SPPA) to
US		friendships, loneliness and	21); CP, SB,		evaluate relationships and
		social acceptance among	TBI, SCI, MD,		outcomes and Loneliness
		athletes with disabilities	other (amputee,		Rating Scale
			SMA, scoliosis)		
(Bergamini	BioMed Research	Propose a method to identify	n=12 (10 male,	One group pre-	Biomechanical parameters,
et al., 2015)	International	biomechanical performance	2 female, $\bar{x} =$	post test	progression force,
		indicators of w/c propulsion	17.1 <u>+</u>		propulsion timing and
Italy	(no subject listed)	using an instrumented in field	2.7 years);		coordination using inertial
		test and develop a training	Paraplegia, SB,		sensors with 20-meter sprint
		program	poliomyelitis,		test (pre and post)
			spastic diplegia		
			CP, amputee,		
			arthrogryposis		
(Connor-	Adapted Physical	Investigate physical activity	n=133 (61 male,	Cross-sectional,	Survey-Questionnaire
Kuntz,	Education	participation with respect to	72 female, range	descriptive,	
Dummer, &	Quarterly	age, level of	7-16); SB	(survey)	
Paciorek,		myelomeningocele and			
1995)	(arts and	ambulation			
	humanities, social				
US	sciences)				

(Zwinkels et al., 2018) Netherlands	Frontiers in Pediatrics (no subject listed)	Evaluate the effects of a school-based once-a-week sports program on physical fitness, physical activity, and cardiometabolic health in youth with physical disabilities	n=71 ($\bar{x} = 13.7$ + 2.9 years, range 8–19) 39 male, 32 female; cerebral palsy, other neuromuscular, metabolic, musculoskeletal, cardiovascular disorders	Controlled clinical trial: One control group – (regular curriculum); one sport group (1x/week school activity to include group sports)	Anaerobic performance was assessed by the Muscle Power Sprint Test. Secondary outcome measures included aerobic performance, VO ₂ peak, strength, physical activity, blood pressure, arterial stiffness, body composition, and the metabolic profile.
		QUALI	TATIVE		
Author/Year Country	Journal (Subject area)	Aim of study	Participant Information	Methodology	Themes
(D. M. Anderson, Wozencroft, & Bedini, 2008) US	Journal of Leisure Research (arts and humanities, social sciences)	Examine differences in social support received by girls with disabilities who did and did not participate in organized w/c sport programs and to investigate relationships between social supports and outcomes of w/c sport participation	n=22 (female, 10-18 years); OI, SB, CP, amputee, limited mobility	Generic, non- specified	Role models; reactions; similarity to others; benefits associated with participation; and goals
(D. Anderson, 2009) US	Journal of Sport and Social Issues (arts and humanities, social sciences)	Examine the identity development of adolescent girls with physical disabilities who participate in organized w/c sports with a specific focus on athletic identity development	n=13 (female, age 10-18 years); SB, CP, OI, amputee, limited mobility	Generic non- specified	Opportunities for exploration of emerging interests; Interests are personal and are in line with the individual's values; Action in response to interests: feedback from the environment serves to

					reinforce interests; Degree of competence is achieved which reinforces potential; Degree of commitment to the action and others who are involved; Level of comfort with others in the social world that is created
					around those interests.
(Goodwin,	Adapted Physical	Understand the lived body	n=5 (1 male, 4	Phenomenology	Unconditional acceptance; a
Kronn, &	Education	experience of children who	female, $x = 8.5$,		dream come true; beyond
Kunnie,	Quarterly	were members of a w/c dance	range 6-14		the wheelchair; and a
2004)		program and to give a	years); SB		stronger self
	(arts and	voice to children and parents			
Canada	humanities, social	about the value of movement			
	sciences)	activity in wheelchairs			
(Carter et	Disability and	Explore experiences of	n=63 (8 male,	Appreciative	Realizing potential;
al., 2014)	Society	children, families and	17 female	Inquiry	invisibility of disability;
		stakeholders at a w/c sports	children, and		ambivalence and attraction
	(arts and	club and the benefits of	additional 12		of the chair; fun and
UK	humanities, social	bringing children with	children - sex		fellowship; and thrills and
	sciences, law)	disabilities and children	not reported, 14		skills
		without disabilities together	stakeholders, 10		
			parents, 2 older		
			siblings), Dx not		
			stated		

Abbreviations: w/c: wheelchair, SCI: Spinal Cord Injury, SB: Spina Bifida, WST: Shuttle Wheel Test, V₀₂: Volume of Oxygen, Dx: Diagnosis, btw: Between, CP: Cerebral Palsy, RIBA: Reversed-Integration Basketball Activity, QOL: Quality of Life, TBI: Traumatic Brain Injury, MD: Muscular Dystrophy, SMA: Spinal Muscular Atrophy, OI: Osteogenesis Imperfecta

Table 2: Outcome Measures (Quantitative) and Themes Identified (Qualitative) Categorized by the ICF (World Health, 2001).

Health Condition (ICD)	(n=1)	Wilson et al. (1993)
Body Function/Structure	(n=8)	Müller et al. (2004), De Groot et al. (2016), Starrs et al. (2012), Barfield et al. (2009), Knechtle et al. (2003), Wilson et al. (1993), Cavedon et al. (2015), Zwinkels et al. (2018)
Activity	(n=6)	Carter et al. (2014), Müller et al. (2004), Barfield et al. (2009), Wilson et al. (1993), Cavedon et al. (2015), Bergamini et al. (2015)
Participation	(n=9)	Carter et al. (2014), Anderson et al. (2008), Anderson et al. (2009), Goodwin et al. (2004), Kang et al. (2007), Connor-Kuntz et al. (1995), Hutzler et al. (2013a), Hutzler et al. (2013b), Shapiro et al. (2014)
Environmental Factors	(n=8)	Carter et al. (2014), Anderson et al. (2008), Anderson et al. (2009), Goodwin et al. (2004), Kang et al. (2007), Connor-Kuntz et al. (1995), Hutzler et al. (2013a), Hutzler et al. (2013b)
Personal Factors	(n=10)	Carter et al. (2014), Anderson et al. (2008), Anderson et al. (2009), Goodwin et al. (2004), White et al. (1993), Kang et al. (2007), Brasile et al. (2004), Hutzler et al. (2013a), Hutzler et al. (2013b), Shapiro et al. (2014)
Table 3: Wheelchair sports addressed in the literature

Wheelchair Sport	Community Group Based (informal)	Recreational (organized)	Competitive
Basketball (n=11)	Anderson et al. (2008)	Anderson et al. (2008) Anderson et al. (2009) Hutzler et al. (2013b) Kang et al. (2007)	White et al. (1993) Cavedon et al. (2015) Brasile et al. (2004) Hutzler et al. (2013a) Shapiro et al. (2014) Bergamini et al. (2015)
Tennis (n=2)		Barfield et al. (2009)	De Groot et al. (2016)
Football (n=1)			Shapiro et al. (2014)
Track and Field		Anderson et al. (2008)	Müller et al. (2004)
(n=4)		Anderson et al. (2009)	Knechtle et al. (2003)
Dance (n=1)		Goodwin et al. (2004)	
General w/c activities	Connor-Kuntz	Carter et al. (2014)	
and/or sport (n=4)	et al. (1995)	Starrs et al. (2012)	
		Zwinkels et al. (2018)	
National Tournament			Wilson et al. (1993)
or "competitive			
games" (n=1)			

Results

The initial search identified 929 articles. Following elimination of duplicates (n=43), the first author conducted an initial screen and evaluation of titles and abstracts for relevance. Fifty full-text articles were reviewed for possible inclusion by both authors. Twenty articles met the inclusion criteria and were included in the final review (Table 1). Of the 20 included articles, sixteen were quantitative studies, [57-72] and four were qualitative studies [73-76]. The studies were conducted in United States (n=9), Switzerland (n=2), United Kingdom (n=2), Italy (n=2), Israel (n=2), Canada (n=1) and the Netherlands (n=2). The quantitative research articles evaluated outcomes related to test/training parameters [57, 58, 60, 62, 65] evaluation of

tools/models [61, 63, 66-69] and biomechanical/physiological/participation profiles of athlete(s)/equipment [59, 64, 70-72]. The four qualitative studies focused mainly on exploring perceptions and experiences with participation [75, 76], social supports [73] and identity development [74] (Table 1). Outcome measures (quantitative) and themes (qualitative) represented all components areas of the ICF [6] (Table 2). Most of the studies (n=11) included participants who played wheelchair basketball. Furthermore, eleven of the articles included participants involved in competitive sport, mainly competitive wheelchair basketball (n=6)(Table 3). Some sports were not represented at all, for example, boccia, wheelchair rugby or curling. Inclusion criteria showed no studies that evaluated community or sport participation specifically for children and adolescents who use power wheelchairs. Articles that provided gender demographics showed a lower proportion (34%) of the participants were females. The most common diagnoses were spina bifida (n=14 studies), cerebral palsy (n=11 studies) and spinal cord injury (n=9 studies). Medical diagnoses were not reported in four studies [59, 61, 63, 76]. Two studies described athlete ability using National Wheelchair Basketball Association (NWBA) Classification levels [61, 63]. The majority of articles (n=14) were published in adapted physical education, recreation or sport psychology or disability journals [58, 60, 61, 63, 65-69, 71, 73-76], while less than half (n=9) were determined relevant to Health Sciences [57-60, 62-64, 66, 67] based on journal subject areas listed.

Discussion

Sports play an important role in enhancing physical activity and social opportunities for young athletes with disabilities. Classifying outcome measures (quantitative) and themes identified (qualitative) using the bio-psychosocial framework, like the ICF [77], reinforces consideration of a range of factors including body function/structures, and personal and environmental contextual factors that can influence the ability to participate and engage in sport.

Interestingly, the articles in this review evaluated a broad range of outcomes and themes aligned with all ICF domains. This finding highlights the diversity of outcomes in the recreation/sport or sport psychology or disability journals compared to the traditional focus on body functions and structures found in rehabilitation literature [78]. This ensures a focus on participation as an important outcome and psychosocial and personal factors related to active and meaningful participation need to be considered to a greater extent. For example, team physical activities and sports may be more motivating to children because they assist in the development of one's identity [32, 34, 74] and offer opportunities to develop a sense of community with peers [74]. Sport participation may also increase self-efficacy [44] which, in turn, may result in increased engagement in other physical activities and sports. As such, the need for collaboration between rehabilitation and adapted sports and/or leisure and the importance of rehabilitation professionals' role in facilitating sport participation have been increasingly recognized [49].

While the qualitative literature related to child and adolescent sport was limited (n=4), the existing research does provide rich, in-depth descriptions of lived experience with wheelchair sport participation. For example, Goodwin et al. [75] used a phenomenological approach to evaluate a dance program, and reported that the dancers experienced a sense of belonging they didn't necessarily feel at school. Collectively, they were able to experience dance and express creative freedom from their own perspective, describing 'being one' with the wheelchair instead of viewing the wheelchair as a barrier to dance. In addition, participants in another study [76] reported perceptions of increased physical fitness, empowerment and enjoyment, fun and inclusion at a wheelchair sports club for children. The benefits of engaging in sport with others who share the disability experience was valued by the participants. As well, the concept of reverse integration may be of significant psychosocial benefit with increased perceived ability and enhanced perception of social competence [67, 68]. These studies are particularly important

since athletic competence and self-worth were the most important predictors of close friendships as reported by Shapiro et al. [69]. In addition, Ethnographic studies examining power wheelchair sports explored the culture and lived experience of mainly adult soccer athletes, shared the benefits of belonging to a team, including being part of a team dynamic, travel, and most importantly, the ability to compete and play at a competitive level [44]. Power soccer contributed to the development of their personal identity as a result of unconditional acceptance and recognition as an athlete [79]. This emphasizes the gaps related to child and youth participation in power sport and highlights the potential to learn further about sport culture in child and youth sports in general. In summary, qualitative methods could be used to a greater extent to understand outcomes that children and youth with disabilities associate with sport participation since they aim to provide in-depth understanding of the social world, individual experiences and perspectives and the meanings individuals ascribe to them [80].

Overall, the range of sports evaluated was limited as this review highlighted a focus on competitive wheelchair basketball. It is important to acknowledge that children may enjoy other sports, like boccia and rugby, which were not identified in this review. Additional research to determine the potential benefits and challenges of participation in other sports is needed. Also, children and adolescents, who use power wheelchairs, may be better suited to sports such as power soccer, allowing increased level of participation and the ability to experience both competitive and recreational play. This scoping review revealed interesting gaps in the current research regarding the participation of children and adolescents with disabilities in power sport. The gap in the literature in regards to power sport participation of children and adolescents with disabilities [78] and the literature guiding physical activity for children and adolescents who have more physical involvement, is limited [81]. In addition to providing opportunities for

socialization and competition, research with adults suggests that power wheelchair sport could also provide opportunities to increase physical activity and fitness levels. For example, Barfield et al. [43] evaluated heart rate response during power wheelchair soccer and reported improved cardiorespiratory fitness results. In a second study, Barfield et al. [82] also examined exercise intensity during power wheelchair and reported an increase in sustained exercise expenditures. These two studies suggest that power wheelchair sport may increase cardiorespiratory demands and potentially improve fitness levels for individuals with disabilities who play power sports. It is important, therefore, to consider a broad range of outcomes in future research, including potential for increased cardiovascular fitness in children who use power wheelchairs for sport participation. These social and physical gaps are significant as power wheelchair soccer/football is the fastest growing sport for power wheelchair users [79].

Two studies in this review looked specifically at female athletes with disabilities [73, 74] and the social support mechanisms that have implications for identity development. The high ratio of male to female athletes, even in the pediatric literature, highlights the need to be aware of the potentially different experiences of women and girls related to sport participation. The psychosocial benefits of sport, and the development of social capital and empowerment may be experienced differently by female athletes [44]. Intrapersonal, environmental and policy related psychosocial factors that influence female athlete development, leadership and life-long participation in sport and physical activity are important considerations in either contributing to or hindering engagement and participation [83]. A comprehensive approach to sport and physical activity for girls and women is important for identifying strategies to ensure successful long-term participation. Future work should consider how to provide guidance and encouragement for all athletes, including young females with disabilities and their families.

Previous research has evaluated environmental barriers and facilitators to sport participation [54]. The results of the research included in this review suggest that a lack of fit between the mobility method and the sport may present as a barrier to participation. Connor-Kuntz et al. [71] reported that children with myelomeningocele who did not use wheelchairs in physical education were more likely to be in an adapted physical education class compared to children who used wheelchairs who were more likely to be included in regular physical education classes. Furthermore, children who walked without assistive devices were least likely to participate in sports outside of school. Ensuring the best fit between the mobility method and the activity and environment is a core concept in rehabilitation to facilitate functional mobility and participation. However, children who may be efficient with walking with a walker in the community may prefer a wheelchair (manual or power) for sport participation. This example requires consideration of the ultimate goals of rehabilitation and the need to consider functioning across a broad range of environments, including sport, when exploring assisted mobility options. This example also emphasizes the importance of collaborative goal setting and education between families, the child and/or adolescent and the rehabilitation team to include discussion of sport participation, and the benefits of such, when implementing a best-practice approach to prescribing wheelchairs. This point also highlights policy and funding barriers, as many agencies or government programs have policies related to equipment access and categories that may limit choice, qualification status or the ability to have multiple mobility options, like a walker, manual and power wheelchair that would offer activity options and be participation driven.

Conclusion

We identified and discussed gaps in the literature regarding children and adolescents' participation in group physical activity and sports which included: a lack of qualitative studies, a focus on competitive wheelchair basketball, a higher ratio of male study participants and few

studies pertaining to participants who play other wheelchair sports such as boccia, rugby, curling and others. In addition, there is a lack of research specifically on child and youth participation in power wheelchair sport; a salient gap since the population of children who use power wheelchairs is largely excluded from group activity and sport research to date. In summary, additional research on the outcomes and experiences associated with sport participation for children and adolescents, across a range of health and psychosocial outcomes, is needed.

Limitations

We did not search specific social sciences databases and therefore research that focuses on policy and social aspects of sport participation may not have been included in the review.

Chapter 3: Power Mobility Sport Participation among Children and Adolescents: Player and Parent Experiences

Abstract

Power soccer presents an opportunity for young athletes who use power wheelchairs to experience a team sport that offers independent, competitive play. It is vital that the voices of athletes and their parents are heard, as insight into their experiences could broaden considerations for power wheelchair prescription. **Purpose**- This study aims to provide insight into the experiences of power soccer players and their parents to inform rehabilitation practice. **Method**- Interpretive Description was used to gain insight into the experiences of 5 young athletes, ranging from 11-17 years of age and 3 parents, all involved in the sport of power soccer. **Results**- Data analysis resulted in the development of 5 themes: 1) level playing field, 2) I am an athlete, 3) life lessons are learned by playing team sports, 4) feelings of "belonging" within a community or team, and 5) role of rehabilitation community in supporting power sports. **Implications**- This study's findings demonstrate the benefits of playing power sports and encourage therapists to share information about sport opportunities with families and consider a broader range of contexts when assessing for power mobility.

Keywords. Sport participation, power sports, power wheelchairs, children, adolescents, parents, qualitative research

Background

Sports provide children and adolescents with opportunities to belong, develop social relationships, achieve fitness goals and engage in competitive play. In rehabilitation, interventions to increase physical activity levels and physical fitness, such as aerobic training and muscle strengthening, are often designed to improve physical and physiological outcomes [48]. While rehabilitation has generally focused less on the psychosocial outcomes associated with sport participation, these outcomes are highly relevant in the rehabilitation context since opportunities for participation in preferred activities are associated with increased quality of life [26, 27]. Shikako-Thomas et al., (2009) encouraged consideration of leisure participation, including sports, as integral to the health and well-being of children and youth with disabilities. Since enhanced participation is a widely agreed upon goal of rehabilitation, a broader perspective on the outcomes associated with participation in community physical activity and sport is necessary to inform practice.

A recent scoping review [84] identified gaps in research examining children and adolescents with disabilities, who use wheelchairs to participate in sports or group physical activities. Previous reviews explored therapeutic physical activity and exercise interventions to improve health, fitness and well-being of individuals who use wheelchairs [85] and barriers to and facilitators of participation in sport [54]. This scoping review in particular, examined group physical activity and/or sport participation specific to youth, seventeen and under, who used a wheelchair as their tool to play or participate. It revealed a lack of qualitative literature, a larger number of studies focusing on competitive wheelchair basketball, lack of female participants verses males and the gap whereby some activities or sports were not represented at all. For example, studies focused on wheelchair curling, boccia, wheelchair rugby and power wheelchair soccer were absent in this review [84]. Furthermore, at the time of this study, research focusing

on power wheelchair athletes (of primarily adult players) was noted to also be sparse with only three qualitative studies that explored the experiences of players [44, 45, 47], one qualitative study examining stakeholders views of the sport [86], one mixed methods study [46] and three quantitative articles [43, 82, 87], despite potential for power sport participation to positively influence attributes such as identity development and self-efficacy [79].

Power sport can create valuable opportunities for adolescents and adult power wheelchair users [44] to development strong friendships, hope, a sense of belonging, personal meaning and higher levels of social interaction [44, 47]. Recognizing that qualitative methods could be used to a greater extent to understand the outcomes that children and youth with disabilities associate with their participation in sport may provide a better understanding of their social world, their experiences and the meanings they ascribe to them [80]. While qualitative studies related to child and adolescent wheelchair sports are limited [84], existing research with adults does provide rich, in-depth descriptions of lived experience with wheelchair sport participation. For example, Jeffress [44] used an ethnographic approach to explore the culture and lived experience with a predominately adult power soccer league. The athletes discussed the benefits of belonging to a team, travel, and importantly, the ability to compete and play at a competitive level [44]. Participants also reported that power soccer contributed to the development of their personal identity as a result of unconditional acceptance and recognition as an athlete [79]. Similar research conducted with children and adolescents with disabilities could provide insight into their experiences with power wheelchair sport in these social contexts. To ensure a focus on participation as an important outcome, psychosocial and personal factors related to active and meaningful participation require further exploration. As well, team physical activities and sports may be more motivating to children as research shows that they assist in the development of one's identity [32, 34, 44, 88], and offer opportunities to develop a sense of community and

friendships with peers [31, 88]. Power mobility sport participation may also result in increased engagement in other physical activities and sports and psychosocial benefits such as increased development of self-efficacy, empowerment, social capital and connection with others [44]. These potential benefits make power soccer exciting for so many reasons, not to mention that it is the fastest growing sport for power chair users [41, 79].

In addition to meaningful participation and identified psychosocial benefits, power wheelchair sport may contribute to added physiological outcomes. Research on physical activity intensity during power wheelchair sport indicates that sustained training intensities were associated with fitness improvement [43, 82]. Barfield et al., conducted two studies with older adolescents and adults, which evaluated heart rate response [43] and exercise intensity [82] during power wheelchair soccer. These two studies suggest that power wheelchair sport may increase cardiorespiratory demands and potentially improve increased fitness levels for individuals with disabilities who play power soccer. Research focused on physical activity for children and adolescents who have more physical involvement is limited [81] and therefore power wheelchair sport may represent an opportunity to increase physical fitness in a fun, team environment.

Voices of Young Athletes

Existing research that is limited to older athletes highlights the importance of pursuing qualitative research to understand the experience of power sport participation among younger children. Ensuring the voices of children and adolescents are heard and gaining insight into how participation in power wheelchair sports has impacted their lives could address a crucial gap in the literature [84]. The importance of recognizing child and adolescent agency is crucial in contemporary approaches to childhood sociology that recognize children and adolescents as active social agents in expressing their perspectives [89]. Inclusion within a disability-specific

sport, or specialized sport, like power soccer, could provide unique opportunities for meaningful participation [90]. Children and adolescents with disabilities should be able to choose an activity where they can be physically active with their peers or teammates who have a similar level of functioning [90]. Power soccer, a specialized sport primarily or solely comprised of players with a disability, creates the opportunity for an increased level of participation, the ability to experience competitive and recreational play with knowledgeable instruction and coaching and has shown outcomes such as increased self-esteem and meaningful interactions with peers [36, 39, 40]. It is vital that this group of athletes are heard, by sharing their stories and thus allowing others to learn from their experiences.

Roles of Parents

Since parents play a large role in facilitating their child's engagement in sport, it is also important to understand their perspectives on power wheelchair sport participation. Parental pride is often associated with competitive sports and societal emphasis on sport participation further emphasizes the importance of understanding parents' experiences with power soccer. Participation in physical activity and sport often presents with barriers and limited access for children and adolescents with disabilities and therefore understanding parents experience with power wheelchair soccer will also be vital. Furthermore, research regarding parental perspectives on therapeutic interventions, disability, and movement strategies has direct relevance for practice in pediatric physical therapy [91] since therapists focus on the outcomes and values that are important to families.

Expanding View of Rehabilitation

Power wheelchair sport participation could also potentially influence the clinical understanding of the value of using a power wheelchair as a tool, by shifting the focus from a salient reminder of disability [2] to a facilitator of recreation or competitive sport participation.

Many children with motor disabilities use manual and power wheelchairs for mobility, however using a wheelchair for sport and recreation entry has been less emphasized in rehabilitation. Previous research regarding environmental barriers and facilitators to sport participation [54] also suggests that a lack of fit between the mobility method and the sport may present as a barrier to participation. Ensuring the best fit between the mobility method and the activity and environment at the right time is a core concept in rehabilitation to facilitate functional mobility and participation [1, 2, 24]. For example, children who may be efficient with walking with a walker in their home or community may choose a wheelchair (manual or power) to play sports. However, "despite a developing body of research evidence, power mobility continues to be underutilized even though it is the most effective means of providing independent mobility to children with severe physical disabilities" [1]. Without efficient, independent mobility, young children are at risk of decreased participation and isolation, placing great importance on mobility that allows children and adolescents the opportunity to participate fully in age-appropriate and meaningful activities [1]. Knowledge of the potential benefits of using power wheelchairs for sports could influence the evaluation and prescription process for power wheelchairs among rehabilitation professions. Broadening the focus in rehabilitation to ensure consideration of mobility options across a wide range of environments, including sport, could represent a shift in current practice. These findings may also provide some insight into how rehabilitation and adapted sports and recreation could collaborate to ensure that children and adolescents have the opportunity and supports to participate in activities of choice [26, 92].

A major gap identified in the literature is lack of research, particularly qualitative studies, that describe family experience with power mobility sport participation. By exploring sport participation within the context of current rehabilitation practice, research can facilitate the production of useful knowledge so that therapists and others involved with sport, empower

children and youth as they explore sporting options within their communities. By interacting with players and their parents who play power sports, this qualitative study set out to examine such perspectives and experiences. With power sports becoming a newly identified area of sporting activity and adult literature currently describing benefits to participating in the game, it is vital to learn if similar results can be applied to younger athletes and their families. Second, based on current literature on the importance of early power mobility [24], it is important to establish whether sport participation is an area of rehabilitation worth considering, adding to the discourse of prescription practices.

METHOD

Theoretical Framework and Research Questions

Interpretive Description was used as the methodological approach of this study with the aim to generate knowledge relevant for the clinical context of applied health disciplines [93], particularly power wheelchair prescribers. Overall, the focus of the study was to explore experiences of children and adolescent power soccer players and their parents [94]. The use of a descriptive approach to qualitative inquiry as a methodological tool invited the principal researcher to work within their disciplinary field (Physical Therapy) and to generate credible and defensible new knowledge in a form that would be meaningful to practice [95, 96]. A qualitative approach provides contextual importance of experiences and perspectives of players and parents involved with power soccer [95]. Interpretive Description (ID) was used as the methodological framework and therefore guided data collection and analysis. ID extends beyond description and allows applied disciplines to benefit from understanding meanings and explanations underlying phenomena that may have implications for practice [95]. In addition, ID provides a way for clinicians to understand and interpret the data to help inform best practice and define their potential roles in supporting power mobility and sport participation [24, 95, 97].

A defining characteristic of ID is the intent to ground the research in a disciplinary context and to use the results to inform practice [95]. Sport participation for children and adolescents with disabilities was an area of interest and discovery for the principal investigator having worked within an interdisciplinary assistive technology team assessing, evaluating and prescribing power chairs for children and adolescents. In addition, locating this research within the disciplinary knowledge as a Physical Therapist with clinical experience in prescribing power wheelchairs for children and adolescents, enabled understanding and interpretation of perspectives of the athletes and their parents within the context of pediatric rehabilitation practice. Rooted within the research questions was the curiosity and desire to explore the context and "meaning" of what it is like for children and adolescents, who use a power chair, when moving into a sport "arena." This awareness and motivation for exploring power mobility sport participation was an essential aspect of this research's fore structure and grounding [95]. By acknowledging one's disciplinary stance, implications or recommendations derived from the findings will be used to assist with knowledge translation and education within rehabilitation. It was anticipated that the broader perspective on the outcomes associated with participation in power mobility sport employed in this study could help to inform future rehabilitation practice.

The researcher also used a Social Model of Disability lens which increased awareness of barriers to power wheelchair sport participation. The Social Model of Disability places an emphasis on external barriers to functioning and social relations that produce disability, thereby empowering disabled individuals to identify barriers and co-construct recommendations, helping to direct practice [15]. While there is weak theoretical grounding and lack of recognition of the social and political dimensions of disability in rehabilitation [16], theories and methods from the social sciences and humanities are beginning to inform theory in rehabilitation studies. Increased use of theory is suggestive of a "relational turn in theorizing across disciplinary fields of inquiry"

[16]. Theoretically driven empirical investigations that acknowledge complexity of rehabilitation practices will ultimately improve interventions and service delivery for the children and families who access rehabilitation services [16]. Disability theory can help shape critical enquiry by ensuring a focus on the social and political forces that frame and inform our relationships with each other and the institutions of society that we have created [98]. In addition, it focuses on empowering the individual and viewing them as the expert on their needs and experiences. By using this perspective, voices of children and youth who participate in wheelchair sports need to be understood in a broader societal context. The strength of the Social Model of Disability is that it is socially located in the disabled people's movement, places disabled people in control of their own lives and, as a result, researchers are encouraged to embrace paradigms of participation [99]. This study set out to explore both the individual and collective experiences of young power wheelchair soccer players and their families using an inclusive approach to acquire rich, representative interpretations of their experiences.

In summary, this study aimed to evaluate the experiences of children and adolescent power soccer players and their parents using Social Model of Disability and disciplinary lenses and the Interpretive Descriptive Methodological Framework (Figure 2)



Figure 2: Theoretical Underpinnings

The purpose of this qualitative study was to explore the experiences of children, adolescents and their parents related to power wheelchair soccer. Specifically, we asked the following research questions:

- a. Does power mobility sport provide an opportunity for children and adolescents to develop meaningful relationships?
- b. How does playing a specialized sport contribute to the feeling of inclusion or belonging?
- c. What are the potential benefits/challenges in playing power sports?
- d. Could a tool, like a power chair, used to access sport influence rehabilitation practice and decision-making?

Participant Recruitment

Purposive sampling was used to recruit participants in collaboration with the Alberta Cerebral Palsy Sport Association (ACPSA), the governing body for power soccer in the province of Alberta. The Director of Programs and staff assisted the research process and connection with the participants by sharing research objectives and a call for participants through their newsletter, social media, e-mail and on-site programs and tournament venues. Child and adolescent athletes and parents were invited to participate. Parents of athletes were invited to participate even if their child did not participate in the study. This sampling approach was used to ensure parents, whose children chose not to participate, could still participate in the study. Children and youth aged 17 years of age or younger were eligible to participate if they had participated in a learn-to-play experience, sessional program, belonged to a recreational or competitive team or had participated in a power soccer tournament. Potential participants were eligible if they were able to express their experiences through semi-structured interviews, verbally or through an interpreter, or with an augmentative communication device. Individuals with all medical diagnoses including newly acquired injuries and those with neurodevelopmental disabilities were eligible to participate, as it was important to examine perspectives of individuals with newly acquired and developmental disabilities. Written consent (parent) and assent (children and youth) were obtained.

Data Collection

i) Observations:

The principal researcher observed recreational, learn-to-play and competitive sessions in Edmonton and Calgary, and two tournaments in Grande Prairie and Edmonton (Nationals); all cities in Alberta, Canada. Observations were aimed at documenting general team and player dynamics and any nuances during game play or interactions that were observed during the sport itself with coaches, parents, peers and volunteers. Observation provided opportunities to document individual behaviors and team dynamics, player interactions on and off the court, parent and player relationships and any other subtleties that represented typical or unique athletic behaviour. Individuals were not identified in the field notes.

ii) Interviews:

Players (n=5), three female and two male athletes, and parents (n=3) were interviewed using a semi-structured interview guide. This method of interviewing allowed the researcher to focus on the research questions while also allowing flexibility to explore individual experiences of each participant (Appendix: Interview Guide for Players & Parents). The power soccer organizations advised that only seven players met the player inclusion criteria in the Province of Alberta and subsequently all seven potential participants were invited to participate in the study. Interviews and observations were conducted during program practices, games and tournaments. While participants were given the option of conducting the interviews in their homes, they all chose to be interviewed on-site, in the gymnasium or sporting venue. Limited participant information (age, gender, diagnosis) is included to ensure participant anonymity.

Data Analysis

Interviews were audio recorded and transcribed verbatim to facilitate analysis. The data management strategy described by Knafl and Webster [100] facilitated analysis. That is, inductive reasoning, comprehending, grouping, sorting, and consideration of relationships to present and reflect on the findings and investigation of potential meaning [95] was used. Two researchers read the transcripts, and then engaged in an iterative process of coding and identifying higher-level concepts related to player and parent experiences with power soccer. This process is recommended for interpretive descriptive studies as immersion in the data is required prior to any specific coding to encourage theorizing, synthesizing and recontextualizing [95]. Observations and field notes were used to assist with interpretations of the interview data. The aim of this study was to explicate player and parent experiences with power mobility sport participation, and to determine how their perspectives can inform rehabilitation practice.

Credibility

Reflexivity is the process of being aware of one's own understandings and interpretation and how individual experience, beliefs and perspectives can influence all aspects of the research process. Reflexivity is valuable for examining the impact of a researcher's perspective, their personal or clinical experiences and any interpersonal dynamics they may have by being aware of unconscious motivations and preconceptions [101]. Incorporating reflexivity throughout the entire research process is important to ensure validity in both the theoretical and methodological approach. Tracking of reflections and field notes prior, during, and after data collection was, therefore, incorporated into the analysis process. Documenting subjective impressions and conceptual understandings, within the process of research engagement is crucial for informing the inductive analytic process. For example, theoretical allegiances, expert clinical opinions, other sources of prior knowledge, questions, inspirations and evolving interpretations can affect

how the researcher engages in the research process [95]. The primary researcher is a physical therapist with previous work experience on an assistive technology team assessing and prescribing power wheelchairs. Reflection on how disciplinary knowledge, beliefs and understanding of issues affect data collection and interpretation is a crucial role of reflexivity [95]. In this study, emphasis on the researcher's enthusiasm for the opportunity to learn from data collection and analysis rather than assuming that the researcher's prior knowledge is valid, was an effective way to avoid any inferences that convey there was a "right way" to have experienced the phenomenon [95]. Constraining influence and listening to participants' "voices" was vital to achieving thick, descriptive data.

Findings

Five themes were identified in the data: 1) Level Playing Field, 2) I am an Athlete, 3) Sports Equate to Life – "Life Lessons", 4) Value of belonging to a Community, and 5) Role of Rehabilitation Community in Supporting Power Mobility Sports. Each theme is further described below.

Level Playing Field

All participants shared that playing power soccer provided the opportunity to participate on a level playing field with their fellow athletes. The wheelchair was the "tool" to equalize the game; it gave athletes the opportunity to experience a sport that allowed for fair and equal play and to compete to their capacity during tournaments and showcase what it is to be a competitive player in their sport. There was a sense in the interviews that this equalizing factor, that is all players using a power wheelchair, enabled the play to be competitive, fair, but most of all, fun. All five players used a joystick to drive, although there was variation in access methods with the adult players who were not included in this study; some players used head or chin access to drive

their chair. This equalizing experience was reflected in various ways by the participants and is expressed in the following excerpts:

So, this is more fair, kind of...you don't feel like you're being cheated um, so yeah, it's nice, in that sense...being competitive with other people who are competitive, um, but still being able to have fun with it.

(athlete)

It's fun for me...it feels like I'm in a sport that I could do...like it's with other people that are in chairs.

(athlete)

Even when the potential benefit of playing power soccer were discussed with same aged teammates, age did not appear to be a main focus for the athletes or the parents:

I know having same age groups would be fun, but in the end, I don't think it would matter...the power chairs are all the same.

(athlete)

Players ranged in age from 11 to 17 years. While the participants did not feel that age affected the play, some did, however, reflect on how the idea that playing with same aged peers could be more fun, as they could "goof around" and be together. One athlete stated that although it may be fun playing with same-aged peers, it was more about having the numbers to play the game. Furthermore, the ability to be coached and receive input from older players who mentored them was often expressed as a benefit.

One consistent experience, shared by both parents and players, involved the comparison of play during modified and adapted activities such as a school gym class. Participants discussed and reflected on their experiences with power sport and identified them as very different than 'inclusive' activities. Although very appreciative of inclusive and/or modified sport, power wheelchair soccer enabled them to experience sport as an independent, competitive player which evoked new feelings as an athlete than when participating in inclusive activities. For example, one parent shared:

When he competes in other events with able-bodied children, they – they are able to run faster, they are able to do things a lot better than [son]. So, it's, it's hard for him to compete in any other sport, where this one here – the chairs are limited to a certain speed, and it is everyone being on an equal playing field. So, it is better to have a sport where they're able to compete with people that are in power chairs.

One young athlete discussed how he did not appreciate special accommodations he had

previously experienced in inclusive sports:

In school you're in sports, I guess, uh they worry that if they blow on me too hard, I will shatter. It's like, yeah, my legs don't work, and my arms aren't that strong either, but like do it your all. I remember one time uh we were playing baseball and I had people bat for me and then I'd run the bases and, you know, whatever right. Ah I didn't go much faster than my chair could at that time, as I had a slow little slug. Uh and so I was running home from third and one guy was chasing after me and he pretended to trip just before he got to me. I – I almost killed the guy right there, I was not – not happy, right. Um I sort of went over to the bench and sulked for a bit, cause I was like – I want people to give it their all. Um, and so with power sports I can...**I could never just play and they could never just play**. I get a sense of normal when it comes to power sports. You know that I just, I can't get when I play with able bodied kids. And that's nothing against them, it's just they're sometimes too nice. I want that, you can get me out, you know. In power sports they, they don't give me that sense. I have to work to get it.

In contrast to the many benefits of playing power soccer shared by the participants, off-

court conversations and researcher's field notes also revealed barriers. For example, some

families were required to rent trailers to transport medical equipment, (e.g., hospital beds), to

tournaments. Coaches sometimes fulfilled multiple roles including caregiver and providing

physical management like transfers as a result of lack of accompanied care workers.

I am an Athlete

All participants and parents described how playing power soccer gave them a sporting experience that required teaming, strategizing, sportsmanship and effort, thus legitimizing power soccer as a sport. Their stories revealed that they all felt a certain authenticity, pride and deserving of their athletic accomplishments. The sport also provided an opportunity to demonstrate a level of competitiveness that they were not able to truly experience in other sport. As one participant stated repeatedly, "I'm very, very, very, very competitive". Other athletes described how participating in power soccer made them feel like an athlete.

I think I'm an athlete even though I don't necessarily like, work my body, but I do push myself in different ways like what other athletes do.

I don't view it as a lessor sport. It is no less competitive than another sport. It's just a different sport.

The experience of being an athlete was supported by field observations of the sport, both in practice and tournaments, which revealed that power soccer was a typical sporting event with well-run drills, strategy and coaching, official rules, classification, officiating, and typical scheduling and awards. During the tournament, players were seen hanging and laughing with other players, checking out the medals, having lunch together on-site at the facility, parents with other parents, parents/players connecting with new team members, coaches and more. Various celebrations were observed with the "bumping" of wheelchair guards to acknowledge a goal. Practices were well organized and venue staff were also well versed in the sport, helping to direct new players. Another observation noted was the mentoring and teaching of new or younger players to the sport by the veteran players, as you would see players gather to discuss "game." Often you would see the young players stopping for a drink with a parent but then immediately drive back to their older teammates. Veteran players were also very patient and would often coach or set up younger players to experience the success of a pass or goal opportunity. This also included discussions from older players on how to implement a mounted iPhone to a powerchair to help "coach" a hearing-impaired athlete. This strategy would provide a communication method via text when on the court and in a game situation. Of note, all participants in this study communicated verbally and did not use communication devices.

Sport Equates to Life – "Life Lessons"

Parents expressed how sport was able to bring certain relatable experiences to life in general for their child moving forward. For example, one mother spoke of how her daughter's participation within a team, in her view, has contributed to building life and leadership skills, especially how it may relate to employment skills:

I think there is something that can be said about anyone that can be coached, and I think that translates into being an employee. It's their first kind of exposure to some other parents and peers telling you what to do and guiding you and mentoring them. I think that is important to do, and I think that's what she gets from here –

Another parent of two players, shared a similar observation:

Sport gives an opportunity to develop as a person - to be a leader and develop skills to bring into a person's life moving forward, like employment.

The same mother went on to describe that team sport has also provided an opportunity for her daughter to develop further personality characteristics and personal growth, with being with other players experiencing their own challenges in life through sport, which has given her daughter further insight into how to be a supportive, mindful and patient teammate. This is described as follows:

She talks with her teammates, they do things together. She is super empathetic, and like patient. Sports develops empathy and compassion for her to experience, even though she has a disability, too. She is learning to support others and learning to help others. When she comes here, she deals with kids with all different kinds of situations. She has the opportunity to show her leadership skills and be a really good team player.

Players were able to bring a certain awareness that sport brought a level of insight and learning that was appreciated and could be incorporated into their life in many ways. Sport gave players a sense of accomplishment, not just with the achievement of their first goals, but more importantly, providing a sense of comradery and positive identity. One player made this connection in describing that sport and its participation can be relatable to life in the ebbs and flows, ups and downs, that life at times brings. He shares it like this: Basic relationships for sports and activity, and life, can be the same as your relationship with people. Like your relationship with people, you're going to get hurt, it's going to suck some days. But it is also hard what makes it worthwhile. Soldiering through it makes it worthwhile. Same with sports, some days it sucks...I can't make a save for the life of me...I can't take a pass...and those days I feel totally incompetent, but soldiering through it, just to make it, to be better, to just live life...

Go do something...go have fun...go make mistakes...making mistakes is okay.

Value of belonging to a Community

Players and athletes found value in being able to participate on a team and thus to belong to a greater community. It was evident how much playing power soccer added to their lives, as a family, an individual player and as a parent. Participation in power soccer brought a certain life experience that only participating on a team, one that allowed for an independent, competitive and equal playing opportunity, could give. As a result, the feeling of "belonging" became a consistent part of the dialogue. Players expressed that it was fun to participate in a sport with others who "understand", making them feel like they are a part of a shared activity together. Power sport participation provided a true sense of belonging and an underlying appreciation that everyone belonged, regardless of skill level or cognitive ability. As well, one player described how he had seen players who have been part of the game and who are now into their adult years, have developed a shared bond and friendship, with "decades long relationships" which he credits to their shared sporting experiences of playing on a team sport. The youngest player expressed how power soccer makes him feel like he has found his sport: "It makes me feel like I'm at home. It feels really good. It means a lot".

Parents described the feeling of what it meant to them for their son or daughter to be on a sport team. The pride of watching their child achieve their first goals and achieve success brought tears to all parents that were interviewed as they shared their stories. Quotes like, "We just love it. It's so much fun and she never misses; she refuses to miss…" and "I get why parent's get so excited to watch their kids" were shared during the interview with such pride and

happiness at seeing them be included and involved, not only for them as parents but also from the observation standpoint that they could see that their son/daughter also feel pride in themselves, as being part of the team: "She does feel like this is her crew…she'll say, like "these are my peeps!"

Another important finding from parents was the fact that sport and being part of the game, presented an opportunity to meet other families, share stories and develop relationships with one another; in essence establishing a network for their family that included both social and health support. These relationships place significance on the enjoyment of team sport and the resulting friendships with other parents, players, coaches, and volunteers that develop. In addition, they discussed the value of having contact with other parents who understand the joy of watching their child play and the potential challenges of parenting a child with a disability. Parents shared healthcare experiences and information about supports and resources and they appreciated that others understood their journey. This sentiment was described in the following excerpts:

...gives the opportunity to travel as a family, stay in the same hotel, go have dinner with everyone...I wanted her to always have those experiences with her team...be with tons of different families.

Every single person, whether they are disabled or not, needs that network of people around them. And know we have yet another group of people that we would have never been involved with because of power sports. That is vital for my kids.

When you get questions about health care or have questions about anything. And you are like sitting and talking with a family about things like the good and the bad, surgery, or this or that. It is awesome.

Role of the Rehabilitation Community in Supporting Power Mobility Sports

Suggestions for the role of the rehabilitation community and therapists who order power wheelchairs were clearly articulated and consistent across player and parent interviews.

Recommendations from participants included using sport for wheelchair driver training, the need

to educate and create awareness for children and their families of the sport to allow it to grow, understanding the benefits of engaging in a sport, the need for appropriate equipment and potential implications for policy regarding funding/repairs. Driver training benefits through sport participation was expressed by parents and players. For example, two young players shared playing power soccer enabled them to improve their driving accuracy without the fear or anxiety of "crashing into things". Learning to drive and experience the finer movements of the chair in the context of a fun, meaningful game was a suggestion that they felt therapists should consider for training purposes. One young athlete (age 12), had the insight to suggest creating the opportunity to play power soccer during driver training to then have the child discover if they would like to play the sport:

...if you order chairs, you could probably try and find the power soccer ball. If you could find those and bumpers, then you could try and train kids to play power soccer and see if they like it and they could join the teams.

The potential role for rehabilitation professionals in regard to information sharing was very important to all participants both from the perspective of experiencing the benefits of playing power soccer but also to help grow the sport. A total of only seven players in Alberta were identified to participate in this study, with five agreeing, based on exposure to the sport and age requirements. Interestingly, not one player or parent learned about power soccer through a rehabilitation professional. They did hear about the sport via word of mouth, through contact with other families or self-initiated searches to find activities for their child to participate in. Growth of the sport and the lack of numbers were expressed as challenges. Two fathers described their observations:

Just the fact that sports, like power sports, are not that known at all. Or even found out. Umm, I think little attention is given to having children be able to engage in sports. It's a huge thing. And I mean, yes, all the physio specialists should be involved in this arena...we need equipment...sponsors...or initiatives – that would come out way more – if physios were more involved in the sport.

You guys are a valuable resource. Right, we can – have you guys spread the word more. And really grow the sport. It's scary that their physio doesn't – doesn't suggest it, because they don't know.

The need to grow the sport, or at least present it as an option for families was expressed

by most participants. One player felt that it may not be for all but, at the very least, it should be

presented as an option:

I'd encourage them to look into it, if they so desire and give them enough information to know – for them to know that they can chose this. Um. Don't say oh this will help you get better, I guess. Or this will make, I don't know, you'll be so much happier if you do this. Just picture it as an option, I guess. One they can look into whether in the near or future.

Other parents and a player discussed how knowledge of the sport would encourage

therapists to move away from "fixing" and to focus on activities that are meaningful. One parent

and his son shared their perspectives:

Rehab has to include sport. I think it is vital on so many levels, because it's one thing we can do for their moral...give possibilities...it is important for physiotherapy to integrate sports into therapy...verses silos where lines don't cross. There are benefits of such...it's not about fixing.

Exercise were boring, why do you want me to pick up a weight, right, that's boring. Then she [Physio] started to take a different approach, "okay you are going to play catch with [sister]. Okay, now we're going somewhere. Then in my early teens I discovered badminton, well, that's great...why didn't you tell me about that? Right. I loved it! And it works my triceps in a way more fun way, and biceps - Teach kids the way they want to be taught, through play.

Equipment ordering and prescription practices like wheelchair specifications, repairs,

considerations of environments all need be considered for children and teens who wish to play power sports. Participants stressed the need for therapists to be aware of choices that are more conducive to playing sports and are taking into consideration a broader range of environments of use. An interesting fact that was shared by one player was the fact that he felt he and his therapist could not share with funding sources that he used his power wheelchair to participate in sport, in fear that repairs would not be covered. A parent and player shared this view: The previous chair we had was not sport orientated at all...need to be able to service them. Because that's their legs right...their chairs aren't selected for being able to play sports. There is a huge difference in the kinds of chairs you are going to select if you want to play sports than if you're just going to toodle around the block.

(father)

Actually, from a funding point of view, it's a bit of a nightmare cause we actually can't tell [funding agency] that we play sports. It's like well how did you break that wheel?It's almost like we have to be secretive about it...my biggest hobby.

(player)

Not surprisingly, the integration of sport into therapy, was an idea shared by both parents and players. Only one player expressed having their power chair at a younger age would have been preferred. This finding may have been as a result of the diagnosis of the majority of players shared in the interview process by participants as having neuromuscular conditions, where power mobility was a discussion point early on with their medical team. All parents expressed appreciation of funding support from the provincial governing body, however, this may not be the case in all geographic locations. In addition, this group of participants may have experienced easier access to wheelchair equipment funding based on their medical diagnoses which precluded walking as a form of efficient mobility.

DISCUSSION

This was a novel study since little research has been conducted with this age group and the experiences of parents have not been explored. This study aimed to bridge the gap between what may be fundamentally important to players and their families who play power wheelchair sports and rehabilitation practice regarding power mobility exploration and prescription.

The Essence of Power Soccer:

Athletes and their parents strongly identified the value of sports in their life, both individually and as families. The interviews with the players included rich descriptions of what it

was like to play in a specialized sport, particularly the opportunity to engage in a sport that enabled them to experience equality with their teammates. Specialized sport environments can provide opportunities for meaningful interaction with peers and the development of positive selfesteem by defining their own standard for success in a sport that accommodates individual needs and perceptions of self-efficacy [36]. The results of this study support previous findings, as players considered themselves to be athletes, feeling a true sense of belonging and experiences of competency and pride. Participants shared stories of comparing inclusive verses specialized sporting experience. It is important to note that research has highlighted benefits to inclusive activities, play and sports, including a sense of belonging and skillful participation. However, social isolation, questioned competency and restricted participation can sometimes outweigh benefits of participation in 'inclusive' sport [102]. In this study and others [36, 41] this finding emphasizes the importance of choice.

Players and parents also valued social relationships between teammates and parents with other parents, who they felt understood one another, thus helping to support their journeys together, in sports and life in general. Since sport "enjoyment" is a predictor of sport commitment, this finding indicates a valuable role in helping youth with disabilities maintain their desire to remain in sport [103].

Implications for the Rehabilitation Community

The use of the Social Model of Disability lens ensured a sensitivity to external barriers and social relations to power soccer participation [14]. The Social Model of Disability encourages consideration of all barriers that restrict life choices. By giving the young players and their parents a voice, barriers to access were highlighted that could inform practice in rehabilitation. Of note is that not one family or player learned about power soccer from the

rehabilitation community. This is an interesting finding since all players would have likely had extensive contact with rehabilitation clinicians. The absence of information sharing about power sport opportunities represents a lack of appropriate sport education for families. Availability of participants who met the inclusion criteria were few, suggesting that many families with children under the age of 18, may not know about the sport. The results of this study suggest that therapists may not know of power soccer or be adequately considering the benefits of playing power sports. This lack of information sharing highlights the need to think more broadly and perhaps outside of the realm of current rehabilitation practice.

Participants also highlighted the importance of ensuring that athletes have access to the necessary sporting equipment. Specific chairs for the sport exist, for example, Strikeforce© power wheelchairs. However, it is also important to consider how government funded chairs, also can meet the specifications needed for play. For example, rear wheel chairs, low seat to floor height, avoidance of centre mount footrests to allow for mounting of front steel cage and a sport profile setting with appropriate speed and acceleration parameters are all important considerations. Lastly, therapists can advocate to ensure that players receive funding for repairs. It is important for clinical practice and polices to reflect the knowledge that community participation needs to include opportunities to participate in sport. At minimum, families need be made aware of sporting options and allow for choice, thus ensuring the rights of all people to choose the activities they wish to participate in. The importance of belonging, fun, and control, and choice have implications for clinical practice and should include leisure activity settings [104].

Societal barriers may be significant and should be considered when addressing the capability of disabled children and youth to participate in wheelchair sport. For example, complex travel arrangements, decreased accessibility of venues and hotels, lack of safe

supervision, the need for resources for self-care, lack of funding supports, and the need to transport equipment represent socially constructed barriers that may prevent power soccer participation for children and their families.

There were only seven potential eligible players within the province and five players participated in this study. Therefore, while a large proportion of the provincial population was included, the sample size was relatively small. We were also unable to interview players with acquired injuries. This omission may be significant as their experience may differ from children who have long-term movement disorders.

CONCLUSION

Understanding the importance of sport participation for children and adolescents with disabilities and their families may ensure that therapists consider participation in sports in their interactions with children and families. Participant perspectives on the benefits and challenges of playing power soccer and the potential roles of the rehabilitation community contributed to the development of clinical practice recommendations. In addition, knowledge of the outcomes that were fundamentally important to young athletes and their families demonstrate that future research in the area of power sports is needed.

Chapter 4: General Discussion and Conclusion

Summary of Results

This thesis contained two main parts: 1) a scoping review to describe research related to wheelchair physical activities and sports for children and adolescents and 2) a qualitative study to provide insight into the experiences of power soccer players and their parents helping to inform rehabilitation practice. The scoping review revealed a lack of qualitative literature, a larger number of studies focusing on competitive wheelchair basketball, lack of female participants verses males and the gap whereby some activities or sports were not represented at all, to include power sports. The qualitative study resulted in the development of five themes: 1) Level playing field, 2) I am an athlete, 3) Sports equate to life – "Life Lessons," 4) Value of Belonging in a Community and 5) Role of the Rehabilitation Community in Supporting Power Mobility Sports. This study highlighted the benefits of playing youth power sports, including feeling like a legitimate athlete, a true sense of belonging to a team sport and learning skills that can be brought forward in life beyond sport, for example leadership, all which aligns with findings in the adult literature [41]. Players and families would like to see therapists provide a more supportive and educational role to help grow the sport and provide and advocate for appropriate equipment to play. An interesting finding was that not one of the participants heard about power soccer through the rehabilitation community, suggesting that therapists could be more involved in ensuring families have information about programs in their communities.

Clinical Implications - Significance to the Field of Rehabilitation

The potential role of therapists was highlighted by players and parents as being vitally important to assist in future expansion of power sport. Participants expressed that power sports could present an excellent opportunity for driver training for new drivers. Participants expressed a desire for their sport to be shared with families who may potentially be interested. There were equipment issues raised, mainly, having the right wheelchair specifications that are conducive to playing. In addition, participants identified that, their right to community participation should ensure that playing power sports does not preclude them from having their wheelchairs repaired.

Given the continued challenges with early power wheelchair provision, we anticipated that players and families would have reported they would have wanted a power chair sooner. However, participants did not discuss timing of prescription practices as a barrier. This did not emerge as a finding in this study, perhaps due to the fact that most players were diagnosed with neuromuscular conditions, leaving the prescription and discussion of power wheelchairs as part of an early discussion of their rehabilitation journey. However, this study found power soccer participation, and the benefits of such, are important for therapists to add to their discussion and education with families to assist with helping them to make informed decisions regarding their child's mobility options. In the early phases of power wheelchair chair discussions, power sports can be added to the dialogue of setting independent mobility and community participation goals with families and other health professionals, as sports are an identifiable leisure activity that is relatable on so many levels.

Strengths and Limitations

The strength of this study, and overall thesis, is practice relevant findings. However, it is recognized that there are strengths and challenges to the use of Interpretive Description as described by Hunt (2009) **[93]**, which refers to a potential uncertainty regarding the degree of interpretation to seek in data analysis that is congruent with ID's objectives and boundaries, yet is adequate for exploring the phenomenon under study.

Knowledge Exchange

As the objective of ID is one that relays findings back to clinicians, it will be valuable to disseminate knowledge and any relevant findings that may be of interest to the fields of rehabilitation, recreation and leisure, particularly findings that may influence clinical practice. The aim is for the results of this paper to be accessible to families and professionals so they can consider findings that inform life choices and clinical practice. In-servicing and sharing of the findings will be conducted in conjunction with the Alberta Cerebral Palsy Sport Association (ACPSA), the pediatric community in Alberta, and Nationally.

Future Research

As this study evaluated the voices of children and adolescences who play power soccer along with their parents, with the intent to learn from their experiences and also inform rehabilitation practice, experiences from families and children or adolescents gaining entry to the sport of power soccer with other medical conditions would be valuable to gain any further or new insights. A recommended next step would be to also include therapists who order power wheelchairs (Physical and Occupational Therapists). It would be informative to understand from their perspectives the role power sport participation plays in their own prescription practices. Research aimed at societal relations preventing access to playing power sports is an important area to help identify and expand on barriers and/or policies and recommend ways to eradicate them. Last, collaboration with other disciplines, for example, Recreation and Adapted Physical Activity with Rehabilitation, could add further insight when working with disabled youth athletes and their families, helping to inform practice through interdisciplinary inquiry [92].

> Sport...speaks to youth in a language they understand. ~ Nelson Mandela

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	Players		Parents
1.	Can you share with me when you first started	1.	How was your family first introduced to the
	playing power soccer?		sport of power soccer?
2.	How did you learn about the sport?	2.	What conversations did you have with your
3.	What other sports you have played or		(spouse/partner/family) about your
	currently play?		son/daughter playing this sport?
	a) Are there differences between them?	3.	What did you initially think of the idea of X
	Please explain.		playing soccer?
4.	What is it like playing power soccer?	4.	How do you feel as a parent watching your
	a) Can you share something about power		son/daughter play?
	soccer that you think is cool?	5.	Do you see X as an athlete? Why or why not?
	b) Is there anything that is challenging?	6.	Did you ever see your child as an athlete
	c) Did you know anyone playing before you		before the experience of power soccer?
	joined?	7.	What benefits have you seen from your
	d) Do you have teammates that are now		son/daughter participating?
	your friends outside of the sport?	8.	What has been difficult or challenging about
	e) Does playing bring anything into your		the sport?
	life that you didn't have before?	9.	Do you feel there are enough supports for
5.	Is there anything you do not like about		athletes? Parents? Caregivers? If no, what
	playing?		supports do you think would be beneficial?
6.	What have you learned about yourself?	10.	When did your child/teen receive their power
7.	Do you think of yourself as an athlete?		chair? Was this timely, early or late?
8.	When did you get your first power chair?	11.	What role do you think the rehabilitation
	a) Would you have liked a power chair		community i.e., therapists, physiatrists etc.
	sooner? Why?		could play when it comes to participating in
9.	Do you think having a power chair has		power mobility sport for your child/teen?
	changed the way you feel about sports?	12.	Would you like to add any other thoughts
10.	Can you share an example (or situation) that		about your son/daughter playing power soccer
	shows what power soccer means to you?		that we may not have spoken of?
11.	Is there anything else you would to like to		
	share that we may have not talked about?		

APPENDIX: Interview Guide for Players and Parents