CHARLES UNIVERSITY
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Barriers and facilitators of sports in adults with congenital physical disabilities: A Systematic Review

Master's Thesis

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Declaration

I declare I carried out this thesis independently and I have cited all used information and literary sources. This work or its substantial part has not been submitted for obtaining any other or the same academic degree.

To date:

…… Vít Šašek

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Abstract

Title: Barriers and facilitators of sport activities in adults with congenital physical disabilities: A Systematic Review

Background: Globally, there are over a billion individuals with disabilities in the world. Those individuals may have one or more physical attributes affected by their condition, restricting their access to sports, fitness activities, and physical tasks related to work or household activities. The lack of exercise poses a significant public health concern and may hinder undisputed benefits for physical and psychological of individual well-being.

Objectives: The main objective of this thesis was to systematically review available research sources on sport and physical activity participation among adults with congenital disabilities and to identify the barriers and facilitators for such individuals to participate in physical activities and para sport.

Methods: Four databases – Medline, PubMed, ERIC and Sportsdiscus were searched using terms: exercise; para sport, training, physical activity, continuous exercise, and the range of congenital disabilities. We employed a blend of MeSH terms specific to the database, free-form text, wildcard characters (employing '*' to truncate words), and Boolean operators ('AND', 'OR'). Only papers published from 2003 were included and the search was structured into three stages – evaluation of the title followed by an evaluation of the abstract and finally the evaluation of the full text. All retrieved papers were evaluated by MMAT, version 2018, and combined in a single database. The most recent search date was 26th November 2023.

Results: We identified a total number of 18 barriers and 15 facilitators across 15 included studies and articles. Critical barriers primarily centered around personal physical limitations and psychological barriers, including fear of judgment or lack of motivation. Environmental barriers included insufficient transport, lack of supportive infrastructure and limited access to suitable facilities.

Keywords:

Sports participation, para sport, exercise, cerebral palsy, muscular dystrophy, spina bifida

Abstrakt

Název: Bariéry a facilitátory sportovních aktivit u dospělých s vrozeným tělesným postižením: Systematická rešerše

Teoretická východiska: Na světě žije více než miliarda osob se zdravotním postižením. Tito jedinci mohou mít v důsledku svého zdravotního stavu omezené možnosti sportovat, věnovat se fitness a hýbat se obecně v pracovním i osobním životě. Nedostatek pohybu představuje významný problém pro zdraví populace a může zhoršovat fyzický a psychický stav jednotlivců.

Cíle: Hlavním cílem této práce bylo systematicky prozkoumat dostupné informační zdroje týkající se sportu a pohybových aktivit dospělých jedinců s vrozeným postižením a identifikovat bariéry a facilitátory usnadňující těmto osobám účastnit se pohybových aktivit a zapojit se do odvětví para sportu.

Metody: Byly prohledány celkem čtyři databáze - Medline, PubMed, ERIC a Sportsdiscus s použitím hesel: cvičení; para sport, trénink, fyzická aktivita, kontinuální cvičení společně s vybranými vrozenými tělesnými postiženími. Byla použita kombinace termínů MeSH specifických pro jednotlivé databáze, volného textu, zástupných a logických operátorů. Vyhledávány byly pouze práce publikované od roku 2003 a vyhledávání bylo strukturováno do tří fází – dle názvu, dle abstraktu a nakonec detailní evaluace plného textu. U všech nalezených prácí byla vyhodnocena kvalita pomocí MMAT, verze 2018, a následně byly sloučeny do jedné databáze. Poslední datum vyhledávání bylo 26. listopadu.

Výsledky: V 15 zahrnutých studiích a článcích jsme identifikovali celkem 18 bariér a 15 facilitátorů. Překážky se týkaly především fyzických omezení jedince společně s psychologickými bariérami jako je strach z odsuzování okolím nebo nedostatek motivace. Překážky prostředí pak zahrnovaly nedostatečnou dopravní dostupnost, nedostatek podpůrné infrastruktury a omezený přístup k vhodně bezbariérově přístupným zařízením.

Klíčová slova:

Zapojení do sportu, para sport, cvičení, dětská mozková obrna, svalová dystrofie, rozštěp páteře

List of used abbreviations

BMI – Body Mass Index

CNS – Central nervous system

CP – Cerebral palsy

GMFCS – Gross Motor Function Classification System

ICF – International Classification of Functioning, Disability, and Health

ICIDH – International Classification of Impairments, Disabilities, and Handicaps

MeSH – Medical Subject Headings

MM – Myelomeningocele

MMAT – Mixed Methods Appraisal Tool

NHS – National Health Service

NTD – Neural tube defect

PG – Paralympic Games

PRISMA – Preferred Reporting Items for Systematic Reviews and Meta-Analyses

SB – Spina bifida

SCI – Spinal cord injury

UK – United Kingdom

US – United States

WHO – World Health Organization

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1 INTRODUCTION

In the endeavor to uphold and enhance overall well-being, the integral roles of regular physical activity and sports participation are indisputable. Academic research within this domain stands as an integral part of unraveling the multifaceted benefits. Within this academic discourse, researchers aim to detail the diverse range of such benefits derived from physical activity and sports participation. The thesis extends beyond the commonly acknowledged aspects such as cardiovascular health, weight management, and musculoskeletal strength, to delve into the psychological effects gained by consistent exercise. It briefly touches mentioned impact on health and performance within a specific group of individuals with congenital physical disabilities. The goal is to identify the facilitators and barriers of their sports participation seeking to summarize existing academic research in the field.

The objective is to methodically assess and synthesize available research seeking a comprehensive understanding of the impact that sports participation has on the individuals with disabilities. Health, well-being, and overall quality of life stay in the forefront within this specific demographic group. This review recognizes the complexities of congenital physical disabilities and the potential transformative effects of sports engagement on various facets of the lives of affected adults.

The review also recognizes the diversity within this demographic and aims to acknowledge the various disabilities within the congenital spectrum, encompassing a broad array of conditions such as cerebral palsy, spina bifida, muscular dystrophy, and other congenital conditions that significantly impact physical abilities. Furthermore, it seeks to understand the unique challenges and opportunities faced by individuals within this diverse cohort, acknowledging the variability in their functional abilities, aspirations, and needs regarding physical activities and sport participation. The synthesis of evidence from this systematic review seeks to contribute to an evidence-based understanding of the topic.

The thesis consists of four main parts. The first delves into the theoretical background of several areas regarding the sport participation of adults with congenital physical disabilities. Those include disability types and generally the field of para sport explaining positive effects of physical activities on an individual in the process. The second part is purely methodical aiming to describe the goals, objectives and specific

methodic used in the systematic review. Followed by a third part presenting results of the review. The last part of the thesis discusses the achieved results in comparison with existing research identifying strengths and limitations of the thesis. Finally, this part of the thesis focuses on possibilities of further research and future directions of pursuing academic knowledge in the field of para sport and physical activities of disabled individuals. These are presently recognized as utterly significant topics across academic world. Furthermore, we believe this thesis will help to understand what could be done better in everyday practice of para sport training and how to make physical activities more accessible. That applies not only for the para sport community overall, but also specifically for adult para swimmers, given that this field of work is an integral part of authors life since birth.

2 THEORETICAL BACKGROUND

Understanding the term “physical activity” and its subsequent benefits for health is crucial to see the importance of this research. Together with seeing how physical impairments can influence the individual’s ability to perform physical activities leading to sport participation. The phenomenon of para sport and its peculiarities are also a factor worth considering because it is greatly influenced by sport’s classification. We shall investigate those briefly setting a foundation to methodics of this review.

2.1 Physical activity

Physical activity is defined, for example, by Mužík & Süss (2009) as a type of human movement performed at a higher energy expenditure than the resting metabolic rate of that individual. They include walking as a physical activity, running, swimming and others. However, there are many definitions of physical activity. According to Kelly & Darrah (2005) and Pink (2008) physical activity is characterized by repetitive structured movement patterns that aim to improve physical fitness. McDermott & Mernitz (2006) characterize physical activity as organized, systematic, and recurrent engagement in physical exercises aimed at enhancing overall physical well-being. Physical activities in our daily lives can be classified into various categories, including occupational, sports, conditioning, household, and other activities. Exercise can be defined as activity that person do regulary to advance their physical fitness and wellness (Offiong et al., 2019). Physical fitness encompasses a collection of attributes, which can be health-related or skill-related. Physical activity is a fundamental method for enhancing both physical and mental well-being. Unfortunately, for many individuals, it has been phased out from their daily routines, leading to significant repercussions on their health and overall quality of life. It is estimated that physical inactivity contributes to nearly 600,000 deaths annually within the WHO European Region (Cavill et al, 2006). Addressing this major risk factor would result in a decrease in the chances of developing cardiovascular diseases, non-insulin-dependent diabetes, hypertension, certain types of cancer, musculoskeletal ailments, and psychological disorders. Moreover, promoting physical activity is a crucial element in combating the ongoing global health challenge of overweight and obesity (U.S. Department of Health and Human Services, 2018).

Hardman (2009) counts physical inactivity among smoking and an unhealthy diet as

core cause of approximately one-third of fatalities in developed nations. These risk factors frequently underpin the primary causes of chronic diseases that dominate the health landscape today, including heart disease, cancer, stroke, and diabetes. (Orchard, 2020). Unfortunately, three contemporary trends are poised to amplify the incidence of these ailments in the 21st century. These trends encompass the obesity epidemic, sedentary lifestyles in children, and the growing aging population. Current projections indicate that by 2035, the global incidence of overweight and obesity, defined as a Body Mass Index (BMI) of 25 kg/m² or higher, is expected to impact more than 4 billion individuals, a significant rise from the 2.6 billion affected in 2020. This upward trend signifies a growth from 38% to over 50% of the global population within fifteen years, not counting children below five years of age. Specifically, the rate of obesity (a BMI of 30 kg/m² or more) is predicted to escalate from 14% to 24% during this timeframe, potentially affecting close to 2 billion people, including adults, children, and adolescents (World Obesity Federation, 2023). Nearly one-third of American adults grapple with obesity (National Institute of Diabetes and Digestive and Kidney Disease, 2023). The National Health Service's (NHS) Digital's Health Survey for England offers an overview of obesity trends using body mass index (BMI) statistics from a cross-section of individuals aged 16 and older. The 2021 iteration of this survey utilized adjusted self-reported data for height and weight, a shift from previous years where measurements were taken directly. Findings from the 2021 survey indicate that 25.9% of English adults were classified as obese, and an additional 37.9% fell into the overweight category. This suggests that a combined 63.8% of the adult population in England were either overweight or obese. The survey also revealed a higher prevalence of overweight or obesity in men (68.6%) compared to women (59.0%) (Baker, 2023). Moreover, Baker adds, there are indications that the surge in obesity is often even more rapid in developing countries compared to the developed world. For instance, in South Africa, nearly two thirds of black women have been reported as either obese or overweight. Even in China, where the overall prevalence is below 5%, obesity rates approach one fifth of certain cities' population (Bhurosy, 2014).

There is indisputable evidence indicating that regular physical activity plays a significant role in both the initial and subsequent prevention of numerous chronic diseases, and it is linked to a decreased likelihood of premature mortality. A consistent linear correlation is evident between the amount of physical activity and one's state of health, with the individuals who engage in the highest levels of physical activity experiencing the lowest risk (Warburton et al., 2006). Notably, the most substantial

enhancements in health status are observed when individuals who are least physically fit begin to engage in regular physical activity. Those who surpass the typical exercise recommendations provided in the guidelines are likely to enjoy additional health advantages. It is essential for health promotion initiatives to encompass individuals of all age groups, as the risk of chronic diseases begins during childhood and intensifies with age.

Physical activity stands closely to physical fitness, the first term is associated with the movements individuals perform, whereas physical fitness is a collection of attributes that individuals possess or attain. Physical fitness is often defined as the ability to carry out daily tasks with vigor and alertness, without undue fatigue, and with ample energy to enjoy leisure-time activities and handle unforeseen emergencies (Caspersen et al., 1985). Although this definition has conceptual merit, factors like vigor, alertness, fatigue, and enjoyment are challenging to quantify accurately. Conversely, numerous measurable components contribute to physical fitness. The most frequently cited components can be categorized into two groups: one related to health and the other linked to skill or performance. The health-related components of physical fitness encompass the following:

- Cardiorespiratory endurance,
- muscular endurance,
- muscular strength,
- body composition,
- flexibility (Rieck, 2023).

Physical activity and physical fitness share a close relationship, primarily because physical fitness is predominantly shaped by recent weeks or months of physical activity patterns, although genetics also play a role (Kujala, 2011). While genetic factors are noteworthy contributors to fitness, their influence on fitness variability is typically less significant compared to environmental factors, with physical activity being a key factor. In general, as individuals increase their level of physical activity, there is a corresponding improvement in physical fitness. However, the degree of fitness adaptation to a standard exercise regimen varies considerably among individuals and is influenced by genetic factors (Bouchard, 2011).

The quality of life is intricately linked to one's functional state and their capacity to sustain self-sufficiency. It seems that physical activity plays a pivotal role in ameliorating health-related quality of life, accomplishing this by bolstering psychological well-being and augmenting physical functionality, particularly for individuals grappling with

compromised health (Ruegsegger, 2018). Sedentary habits within the broader population[1] can lead to substantial direct medical expenses, individual handicaps, and an increased societal burden. Approximately 31% of individuals worldwide aged 15 years and older are not getting enough physical activity, and this lack of physical activity is a known factor contributing to the deaths of approximately 3.2 million people annually (Park, 2020). The world is undergoing a demographic shift marked by an enhancement in life expectancy for both men and women. This has resulted in a global rise in the overall population of elderly individuals (Hardman, 2009) so the topic becomes increasingly relevant. The importance of physical activity for the population is even demonstrated by the large number of scientific papers on the subject.

According to Neus & Frömel (2016), ageing of the population is currently one of the most researched topics in the field of kinanthropology and medicine. Examination of physical activity in a population regarding health, culture and sport is supported in a study by Frömel et al. (2006), where highlights the decline in the frequency of physical activity with increasing ageing. Only a fifth of older people exercises sufficiently for gaining health benefits (Lee et al., 2008). At the same time, it is evident that the university educated population is moving less than other groups of less educated people (Feltlová et al., 2011). Furthermore, high scholers and adolescents in the study of Rubin et al. (2018) who did meet recommended criteria for physical activities were more fit than individuals who did not. Children exhibit a higher level of physical activity compared to adults. It's worth noting that boys generally engage in more physical activity than girls, and there is a decline in physical activity as children transition into adolescence, with this decline being more pronounced among girls (Miles, 2007). For both adults and children, those in lower-income groups tend to have notably lower levels of physical activity. Although the levels of physical activity in adults and children have remained relatively steady in recent years, there is some indication of a decrease in occupational activity since the 1990s and a reduction in active transportation to school, as well as a decrease in the time allocated to physical education classes in school. Concurrently, there has been a growing trend in sports participation, such as the increased membership in fitness clubs among adults. On the contrary, after the pandemic of COVID-19 there is slight decrease in the physical activity of children. According to research that was created in the UK in 2021, only 53% of children of age 6 years old met the criteria UK official guidelines. Moreover, the boys were slightly better than girls. Overall, 63% of boys and only 42% of girls has achieved

[1] Jung Ha Park (2020) defines population as people older 15 years old

the criteria (Hesketh, 2022).

Oja & Titze (2011) tackled physical activity guidelines that promote well-being and propose specific activity targets for various demographic groups. According to the guidance provided by the U.S. Department of Health and Human Services (2018) and the World Health Organization (WHO, 2020), children and adolescents are encouraged to engage in a minimum of 1 hour of moderate to vigorous-intensity physical activity daily. For adults and older adults, it is recommended to undertake at least 150 minutes of moderate-intensity or 75 minutes of vigorous-intensity aerobic activity per week, or an equivalent combination of both, along with muscle-strengthening exercises. These physical activity recommendations serve as targeted guidance for populations and primarily focus on the potential for disease prevention. They establish a robust basis for the development of policies, programs, interventions, and counseling aimed at promoting physical activity. While many European countries have incorporated physical activity into their national health and other policies, there remains a necessity to embrace the most current physical activity recommendations at the national level and formulate comprehensive national physical activity strategies. However, the topic of how long the activity should be to gain health benefits has been discussed (Reiner, 2013). NHS (2021) in the official guideline states the adults should have at least of 150 minutes of moderate activity per week. In studies focusing on moderate-to-vigorous physical activity among adolescents, there were notable non-linear relationships observed, particularly in relation to body mass index (BMI) percentile and blood pressure. For female adolescents, significant changes in BMI percentile and systolic blood pressure were noted at around 90 minutes of activity per week. In male adolescents, these changes were seen at about 150 minutes per week, also affecting their cardiorespiratory fitness. Notably, at 150 minutes of weekly activity, both female and male adolescents showed approximately a 7% reduction in BMI percentile compared to no activity (Sriram, 2021).

The positive influence of physical activity on personal well-being is also confirmed by Hošek (2013), who argues that physical activity is the base of well-being and has positive influence manifesting in activities such as yoga or other oriental systems of exercise. Participation in physical activities gives the individuals a sense of accomplishment and joy and is essential for healthy development of children (Bedell et al., 2013).

So, the comprehensive impact of physical activity on overall energy expenditure extends beyond the energy spent during physical activities. It encompasses increases in resting metabolic rate and non-exercise activity thermogenesis. Additionally, physical

activity has the potential to bring about advantageous alterations in body composition, involving the reduction of fat mass and the increase of lean mass. Physical activity can contribute to the reduction of resting blood pressure and enhance the heart's ability to circulate blood through coronary arteries effectively. Favorable changes are also observed in the endothelial lining of blood vessels, which plays a role in directing the proper distribution of blood throughout the body. Regular physical activity can further yield beneficial effects on the body's capacity to form and break down blood clots and promote positive alterations in the plasma lipid profile. Furthermore, physical activity is associated with advantageous changes in the immune system as well as neurological functions (Pesheva, 2023). According to World Health Organization 1.3 billion individuals, constituting about one-sixth of the global population, face significant disabilities. People with disabilities confront premature mortality, poorer overall health, and greater limitations in their daily lives due to health disparities. In comparison to majority people with disability have usually the life span about 20 years shorter. They are challenged with other health disparities as depression, asthma or stroke more often than majority (World Health Organization, 2023).

2.2 Physical disability

The idea of disability is complex, constantly changing, and often debated. Outdated terms like "handicapped worker" have largely been replaced by language that prioritizes the person before the disability. While commonly associated with stereotypes like blind, deaf, or wheelchair users, disabilities cover a wide spectrum of health conditions that can be temporary, recurring, chronic, or progressive. Instead of a simple normal-versus-abnormal classification, disability represents a range, from minor limitations in functioning to complete reliance on others for daily activities. The understanding of disability has shifted from a "medical model," which focused on an individual's impairment, to a "social model" that highlights environmental and societal influences. The preamble to the Convention on the Rights of Persons with Disabilities (United Nations General Assembly, 2006) emphasizes that disability arises from the interaction between individuals with impairments and the attitudinal and environmental barriers preventing their full participation in society. This approach aims to establish disability as a matter of human rights. However, the absence of a universally agreed-upon definition of "disability" has hindered efforts to understand and develop its epidemiology, encompassing health and environmental factors (Burgard, 2014). This lack of standardization also impedes the development of effective interventions to prevent and

alleviate these factors, as well as measures to enhance the functioning and quality of life of individuals with disabilities. Moreover, the ambiguous concept and definition of "disability" make it challenging to compare research findings across interventions, time periods, and regions (O'Young et al., 2019).

2.2.1 Classification of physical disabilities

In 1980, the World Health Organization (WHO) introduced the inaugural International Classification of Impairments, Disabilities, and Handicaps (ICIDH). This framework aimed to conceptually describe and classify the three dimensions of disability—impairment, disability, and handicap—offering an index of severity and prognosis. Following extensive research and assessment of disability models, a revised edition, ICIDH-2, was published in 1997 (Battaglia et al., 2004).

However, many authors expressed issues with the presented terminology across health, disability studies, and rehabilitation fields These labels were seen as inadequate for individuals managing health issues but not restricted in their ability to engage in life due to personal adaptations or environmental accommodations (Yaruss & Quezal, 2004).

Therefore, The International Classification of Functioning, Disability, and Health (ICF) was introduced during the Fifty-fourth World Health Assembly. This updated title signaled a shift away from the conventional "consequence of disease" model, emphasizing functioning as integral to health. Upon unanimous endorsement in May 2001, member states were advised to integrate the ICF into their research, surveillance, and reporting endeavors. The ICF-2 joined the WHO Family of International Classifications, complementing the ICD-10, which focuses on mortality and morbidity coding. While ICD-10 covers fatal and non-fatal conditions, the ICF codes represent a broad spectrum of health states and health experiences. Encouraging the simultaneous use of both ICD-10 and ICF, the World Health Organization (WHO) aims to offer a more comprehensive understanding of individual or population health (Üstün et al., 2003).

We can divide physical disabilities according to the time of onset into congenital and acquired. We will dive further into the former in following chapter.

2.3 Congenital disabilities

According to Sissons (2020) scope of congenital disabilities' medical conditions varies from mild to severe, impacting organs or specific body parts, and in some cases, influencing overall development, bodily functions, or sensory abilities. The causes of most congenital anomalies are not readily apparent. While some are linked to genetics,

others may be associated with the mother's health during pregnancy. Environmental factors could also contribute to the severity of these conditions.

The author further states congenital disabilities can be caused by either structural anomalies or developmental issues and classifies hearth defects as one of the common causes of disabilities. Parker et al. (2010) names the example of such heart defect. The tetralogy of Fallot can result in decreased oxygen in the blood circulating to the body. Newborns with this condition might display a bluish skin color known as cyanosis due to insufficient oxygen in their blood. While not initially apparent at birth, infants may later experience sudden instances of bluish skin during activities such as crying or feeding, termed tet spells. Infants diagnosed with tetralogy of Fallot or similar conditions leading to cyanosis may encounter various issues including a heightened risk of heart infection (endocarditis), an increased likelihood of irregular heart rhythms (arrhythmia), as well as symptoms like dizziness, fainting, or seizures due to low levels of oxygen in their blood. Moreover, delayed growth and developmental concerns can be observed in affected individuals. Mentioned symptoms can affect physical activity participation of diagnosed individual.

Limb deficiencies as another type of congenital disability mentioned in the work of Gold, Westgate & Holmes (2011) is described encompassing the congenital absence or underdevelopment of long bones and/or digits, exhibit significant variability in both their anatomy and underlying causes. The authors introduce a novel classification system that comprehensively aims to name all potential phenotypes of limb deficiencies on the selected sample of infants. They found longitudinal defects to be more prevalent than terminal transverse defects, while intercalary defects were identified as infrequent occurrences. Longitudinal defects predominantly manifested on the preaxial side of the limb. Nearly half of the affected infants displayed deficiencies in digits, despite possessing normal long bones. Vascular disruption defects, such as amniotic band-related limb deficiencies, were recognized as the most prevalent apparent cause (0.22 per 1,000) among the various types of limb deficiencies. Ten years prior Giele et al. (2001) conducted a comprehensive population study over an 11-year period in Western Australia, focusing on the prevalence and epidemiology of congenital upper limb anomalies. All identified anomalies were categorized in accordance with the International Federation of Surgical Societies of the Hand classification. The study revealed that the prevalence of newborns born with upper limb anomalies was approximately 1 in 506.

Neural tube defects are another significant group of structural anomalies causing

physical disabilities. Au, Ashley-Koch & Northrup (2010) state that neural tube defect (NTD) is a congenital malformation affecting the central nervous system (CNS) due to the incomplete closure of the neural tube, with a global incidence varying between 1.0 to 10.0 per 1,000 births. Most cases fall into two main categories: anencephaly, involving a lack of closure in the head region, and spina bifida (SB), characterized by the lack of closure below the head. Both types occur in approximately equal frequencies at birth. Infants with anencephaly typically survive only a few days after birth. Medical advancements since the 1960s have significantly increased the survival rate of individuals affected by SB, which encompasses various subgroups of defects, including myelomeningocele (MM), meningocele, and lip meningocele. Among these, MM, accounting for over 90% of SB cases, involves the protrusion of nervous tissue and its covering through a defect in the vertebrae.

Mitchell et al. (2004) highlights improved survival rate of individuals diagnosed with SB due to recent advancements in medical and surgical care. Population-based data suggests approximately 87% survival at one year, with approximately 78% of individuals with spina bifida reaching the age of 17 years. However, despite these improved survival rates, individuals with spina bifida still face increased health complications and mortality persisting from early years into adulthood.

Among strongly represented developmental issues in population causing physical disabilities and impaired movement abilities is muscular dystrophy. Pandey et al. (2015) counts gradual weakening and breakdown of skeletal muscles caused by genetic modifications into the etiology of muscular dystrophy. This condition is observed globally. The incidence of muscular dystrophy differs among its various forms, with some being more prevalent than others. It's important to note that not all muscle loss and weakness is solely attributed to genetic alterations. Factors such as skeletal muscle disuse, nerve disconnection, cancer-related muscle wasting, and the body's responses to fasting or insufficient nutrition also contribute to the reduction in skeletal muscle mass by disrupting the balance between protein synthesis and breakdown. Numerous genes have been identified, directly or indirectly implicated in different forms of muscle wasting. Research conducted in both human subjects and animal models has significantly enhanced our understanding of the molecular mechanisms behind muscle degeneration. Despite these advancements, the current knowledge remains insufficient to develop truly effective therapies. Thus, a more detailed examination of the intricate molecular mechanisms holds the key to developing therapeutic strategies not only for muscular

dystrophies but also for combating skeletal muscle loss. Butterfield (2019) mentions congenital myopathies as similarly projected diseases in comparison to muscular dystrophy.

In the list of developmental issues causing disabilities cerebral palsy (CP) cannot be overlooked. McPhee et al. (2022) characterize CP as a persistent condition that limits an individual's daily activities, potentially leading to an elevated risk of various health issues, such as an increased susceptibility to fractures (Whitney et al., 2019). They further note an improvement in life expectancy for those with CP due to medical advancements in recent decades. Graham et al. (2016) corroborate this trend, emphasizing that nearly all individuals affected by the disease survive into adulthood. Professional delineations and descriptions of the manifestations of this disease may vary, but all definitions share four common attributes. CP is identified as a neurological musculoskeletal disorder that detrimentally impacts motor function. Typically emerging by the age of two, the disorder is deemed non-progressive and enduring. Nevertheless, this permanence doesn't preclude changes in the limitations it imposes; rather, limitations generally intensify due to the natural course of development and growth (Panteliadis, 2018).

Craven (2008) categorizes cerebral palsy into different forms based on the specific area of the underdeveloped brain affected, influencing the nature of the condition and the ensuing limitations. Those forms are a spastic type, characterized by heightened muscle tension, severely restricting movement in non-exertional locomotion patterns. Attempting movement results in a notable increase in muscle tone within the affected area, at times completely hindering movement. This restriction arises from damage to the cerebral cortex. In contrast, the athetotic type manifests as continual, involuntary, and uncontrolled muscle movements, with fluctuating degrees of muscle tension between extremes. This form results from damage to the basal ganglia. The atactic type features persistent muscle tremors, and affected individuals continually strive to manage these tremors during movement. Damage to the cerebellum is responsible for this form. On the other hand, the hypotonic type, being the opposite of the spastic form, exhibits extremely low muscle tension, leading to nearly constant muscle relaxation. As per Senst (2014) the spastic form represents the most prevalent type within the population, accounting for approximately 85% of confirmed cases.

2.4 Benefits of physical activies in disabled individuals

Research indicates that engagement in physical activity, exercise, or sports is associated with a decrease in depressive symptoms within the general population

(Wanjau, 2023). Nevertheless, there is limited understanding regarding its impact on individuals with disabilities (Jacinto et al., 2023). The findings of Hutzler et al. (2013) suggested positive effects of an exercise training program on hand and wrist strength and function in individuals with cerebral palsy. Significant data exists regarding the adverse physiological consequences of extended bed rest and limited physical activity on overall health and physical functioning. Individuals with chronic diseases or disabilities typically experience a decline in physical activity, initiating a cycle of deconditioning that negatively affects various physiological systems. This cycle contributes to physical deterioration, leading to a subsequent reduction in physical activity. The well-documented effects of bed rest and inactivity further underscore the importance of maintaining an active lifestyle in individuals with disabilities (Durstine et al. 2000). Other authors therefore highlight the benefits of physical activities for disabled. Wilhite & Shank (2009) highlight the advantages of engaging in sports encompassing improved functional capacity, health promotion, the development of relationships, heightened optimism, and inclusion in meaningful life activities and roles. Health professionals play a crucial role in introducing and motivating individuals with disabilities to participate in sports. According to the authors sport serves as a valuable and promising avenue for enhancing both physical and emotional well-being, as well as establishing meaningful social connections. Health professionals, collaborating with individuals, families, and community members, can utilize the ICF framework to inform their clinical and educational strategies aimed at promoting sports participation among individuals with disabilities.

Martin Ginis et al. (2021) state that physical activity yields positive effects on cardiovascular fitness, musculoskeletal fitness, and cardiometabolic risk factors. Moreover, authors suggest that health benefits can be attained with less than 150 minutes of physical activity per week, emphasizing the notion that any amount of physical activity is superior to none. This applies not only for the individuals with congenital disabilities. Halabchi et al. (2017) consider exercise as a safe and effective rehabilitation tool for individuals with Multiple Sclerosis and state supervised and personalized exercise programs have demonstrated the potential to enhance fitness, functional capacity, and overall quality of life, while also addressing modifiable impairments in those individuals.

Benefits of staying active are not just physical but also psychological. People who lead an active lifestyle are likely to encounter improved mood states, reduced stress, increased strength and functional capacity, and possibly more fulfilling social relationships when

compared to individuals who are less active (Giacobbi et al., 2008). This applies even for individuals with intellectual impairments. Özdemir, Ilkım, and Tanır (2018) discovered a statistically significant difference in both total scores and subscales of the Social Skills and Compliance Scale between pre-test and post-test assessments for both the experimental and control groups of intellectually impaired children participating in a 12-week sports program.

Hicks et al. (2003) researched long terms effects of physical activities in individuals with spinal cord injuries. In their study, the exercise group exhibited substantial increases in submaximal arm ergometry power output and upper body muscle strength, whereas the control group showed no significant changes. Following training, the exercise group reported reduced levels of pain, stress, and depression, surpassing the control group in satisfaction with physical function, perceived health, and overall quality of life. The exercise adherence for those who completed the 9-month training was noteworthy.

2.5 Para sport

Parasport, also known as disability sport, includes athletic activities for individuals with physical, visual, and intellectual impairments. It has significant impact on psychological aspects of sport participation and physical activities performance among disabled (Afacan & Afacan, 2021; de Groot et al., 2020; Purdue & Hoe, 2012). While often used interchangeably, parasport specifically refers to athletes participating in the Paralympic Games (PG). Not all disability sports fall under the Paralympic category. The first PG took place in Rome in 1960, marking the genesis of parasport. Over time, participation has grown significantly, positioning the PG as the second-largest multisport event globally. Despite recent recognition, there's a limited development in optimizing opportunities for para-athletes. A knowledge gap exists in understanding pathways for para-athlete success, and there's a need to explore tailored sport policies for parasport (Patatas, De Bosscher & Legg, 2018). A parasport system requires specific programs and policies distinct from those of an able-bodied sports system. What may be effective in the context of able-bodied sports might not necessarily be applicable in parasport, especially concerning elite sport operations. For example, athletes in parasport may encounter different requirements and operate within distinct contexts. The unique complexities of parasport, including the classification system, set it apart from other sports. Additionally, studies have underscored the importance of social aspects in understanding disability and delved into the intricate relationships between individuals with disabilities and their social environments (Patatas et al., 2021).

Most sports employ a form of classification, with age, gender, and body weight being the predominant units. The primary objective of such classifications is to reduce the influence of extraneous factors on competition outcomes (Vanlandewijck et al., 2011). In para sports, classification stands out as a crucial distinction between the Olympics and Paralympics (Burkett et al., 2018), ensuring fair competition for athletes with diverse physical disabilities (Oh et al., 2013). This approach establishes an equitable starting point by minimizing the impact of impairments on event outcomes (Payton et al., 2020), albeit presenting one of the most complex challenges in Paralympic sports (Jaecken, 2020). Para-sport classification systems not only determine eligibility but also establish a competition structure to mitigate impairment effects on outcomes (Tweedy et al., 2018). Essentially, these systems aim to prevent the dominance of athletes with minimal impairments and prioritize athletic excellence as the primary determinant of success (Ungerer, 2018).

Across sports, there is a prevailing trend toward evidence-based classification, given its critical role in Paralympic sports. As awareness of the Paralympic movement grows in the public and media spheres, the significance of classification decisions governing athlete eligibility and allocation into classes amplifies. It is widely acknowledged that the assigned classification significantly influences an athlete's potential success level. Therefore, advocating for individual classification systems based not solely on classifier judgment but also on evidence-based and validated studies is increasingly emphasized (Vanlandewijck et al., 2011).

The classification assigned to an athlete significantly influences their level of success, highlighting the need for individual classification systems not solely reliant on classifier judgment but supported by evidence and validated studies (Tweedy et al., 2009). As emphasized by Tweedy et al. (2014), classification plays a critical role in Paralympic sports, determining eligibility for competition. With the increasing awareness of Paralympic sports in the public and media, the significance of classification decisions governing participation in these sports grows. Moreover, legitimacy in Paralympic sports hinges on classification. If stakeholders, including athletes, media, and the public, perceive success as merely a result of having a lesser degree of impairment than competitors, the value of achievements in Paralympic sports diminishes. The complexity of classification systems presents a barrier to broader awareness and acceptance of Paralympic sports among the general public. The primary goal of classification should be to establish categories where individuals with similar impairments can compete equitably.

This approach aims to minimize the influence of the degree of disability, prioritizing factors such as physical ability, sports preparation, and actual performance. While scientifically valid methods are crucial for assessing the degree of disability, they should not be the sole criteria for classification. Certain impairments, though permanent, can be influenced by exercise and training to varying degrees.

For instance, individuals with partial spinal cord injury and spastic hypertonia may have permanently limited muscle strength influenced by exercise and training. To ensure that well-trained athletes are not unfairly disadvantaged, classifiers need methods to distinguish them from untrained athletes. Implementing a battery of reliable tests that identify limitations based on the consequence of the disability level provides classifiers with a means to differentiate between athletes (Reina, 2014).

The current Paralympic Movement recognizes 10 eligible areas of disability, with eight pertaining to physical disabilities, the ninth being visual impairment, and the tenth involving intellectual impairment. These physical disability categories include:

1. Reduced Muscle Strength: Athletes with limited ability to consciously contract muscles due to central or peripheral paresis to plegia (e.g., spinal cord lesions, cerebral palsy (CP), muscular dystrophy, etc.).
2. Limited Passive Range of Motion: Reduction in passive movement in one or more joints, such as that caused by arthrogryposis or chronic immobilization.
3. Limb Loss: Athletes with complete or partial absence of bone or joints due to trauma, disease (e.g., amputation due to bone cancer), or congenital causes (e.g., dysmelia).
4. Differences in Lower Limb Length: Discrepancies caused by congenital defects, growth defects, or trauma.
5. Stature Disorder: Limited length of the trunk, lower or upper limbs, which can result from conditions like arthrogryposis.

   Additionally, there are categories for neurological impairments, including:
6. Hypertonia: Increased muscle tone and reduced ability to relax muscles caused by central nervous system damage (e.g., cerebral palsy, traumatic brain injury, stroke).
7. Ataxia: Central nervous system disorder characterized by uncoordinated movements.
8. Athetosis: Central motor disability characterized by constant slow, wavy/thread-like movements resulting from brain damage (e.g., CP, stroke, trauma).

   The remaining two categories are:
9. Visual Impairment: Manifested by damage to the eye structure, optic nerves, optic pathways, or the visual center. This category has three classes (B1-B3) based on the

degree of impairment.

10. Intellectual Impairment: Athletes with intellectual disabilities (IQ 75 and below) affecting conceptual, social, and practical adaptive skills. The impairment must be present before the age of 18.

An athlete must have at least one of the listed qualifying disabilities to participate in para sport. Any further expansions would need approval (International Paralympic Committee, 2023).

2.6 Barriers in para sport and physical activities

Globally, there are over a billion individuals with disabilities, who may have one or more physical attributes affected by their condition, restricting their access to sports, fitness activities, and physical tasks related to work or household activities. they face a notably higher risk of severe health issues linked to physical inactivity (Rimmer and Marques, 2012). Kehn and Kroll (2009) focus on this general idea and highlight motivation as the key factor influencing the initiation and maintenance of an active lifestyle among individuals with spinal cord injuries while the main barriers were identified as the unbeneficial energy spent vs results achieved ratio and insufficient available personnel to help the individuals with spinal cord injuries (SCI) to exercise. This issue is further confirmed by Jaarsma et al. (2014) who identified impossibility to exercise alone without help of someone else as the main problem in sport participation among more than the fifth of evaluated paralympic athletes in their study. While the authors recognised several other obstacles for physical activities and sport participation in individuals with different disabilities such as the lack of nearby accesible sport facilities or facing discrimination, there were singnificant differences between groups of wheelchair users and those able to move without it especially when it comes to transportation possibilities to sport locations.

The importance of wheelchair itself when identifying barriers of sport participation among disabled is well showcased in the study of Martin (2013) as the author highlights the wheelchair can be perceived as a barrier because of its width or weight but simultaneously can be a tool for wheelchair-bound individuals to facilitate physical activity pointing out the enviromental obstacles (ramp, narrow doors) or the atributes of the individuals themselves (low strenght) are the bigger barriers. Concluding the complexity of the issue DeFazio and Porter (2016) break down the barriers to participation in sport and physical activities for disabled individuals and especially children into following two cathegories:

- Personal barriers,
    - physiological factors such as lack of energy, pain, loss of strenght or skills, lack of motivation, needing more time to exercise than nondisabled peers, fear of injury, physical limitations of disabilities and more,
    - psychological factors such as disliking the exercise or competetivness of the sport, vulnerability and fear of embarrassment and exclusion etc.,
- enviromental barriers,
    - sport opportunities (limited activity choices or too distant sport possibilities),
    - feasibility (financial and time limitations mainly),
    - social factors (fear of being bullied or rejected)
    - parental factors (as barriers among children).

On the other hand authors also show facilitators in every mentioned aspect such as positive physical changes to the body, overal enjoyment, sense of belonging to a group, boost in confidence or reaching personal goals.

The thesis emphasizes the significance of researching adults with congenital physical disabilities, a topic that has been notably overlooked in previous studies and is therefore crucial for several reasons. Firstly, adults with congenital physical disabilities constitute a population that has not been extensively studied. This lack of research highlights a significant gap in our understanding of their unique needs and challenges. Secondly, these individuals often fall through the healthcare system's cracks. While they receive care from pediatricians or specialists in developmental motor disorders during childhood, there's a noticeable void in specialized care once they reach adulthood. This transition period is critical, and the absence of tailored healthcare services can lead to inadequate support for their specific needs.

The situation of adults with congenital physical disabilities is contrasted with other impairment groups, for example spinal cord injury patients, who have access to specialized care. This comparison underscores the disparity in healthcare and support services available to different groups, highlighting the need for more inclusive healthcare practices.

3 RESEARCH QUESTION AND OBJECTIVES

3.1 Objectives

The goal of this thesis is to systematically review the literature on participation of adults with congenital disabilities in para sport and to identify the studies and scientific works aiming to explore the barriers and facilitators for adult individuals to participate in physical activities and para sport.

A systematic review is set to answer a research question by reviewing available sources, looking into the works regarding stated topic. The systematic review provides search, evaluate, and integrate information on a particular topic. It combines findings from various related primary studies, employing methods designed to minimize biases and random errors (Gopalakrishnan, 2013).

A systematic review must be methodically planned and executed to minimize biases and exclude low-quality or irrelevant studies. The process involves four key steps: formulating a precise clinical question, developing a protocol with specific inclusion and exclusion criteria, conducting an extensive literature search, and then screening the search results, first at the abstract level and then the full texts (PRISMA). After selecting the relevant studies, the next steps include extracting vital data according to the pre-designed protocol, evaluating each study's biases to determine the quality of evidence, and then creating tables and text to summarize the findings effectively (Linares-Espinós, 2018).

The objective is to create structured overview of available research information.

3.2 Research Question

What are the known barriers and facilitators of participation in sports for adults with congenital physical disabilities?

3.3 Methods

Four databases – Medline, PubMed, ERIC and Sportsdiscus were searched using following terms: exercise; para sport, training, physical activity, continuous exercise, cerebral palsy, neural tube defect, spina bifida, tetralogy of Fallot, limb deficiency, anencephaly. muscular dystrophy.

The thesis is about a range of congenital disabilities, encompassing cerebral palsy, neural tube defects (including spina bifida), tetralogy of Fallot, limb deficiency, anencephaly, and muscular dystrophy. This selection is strategically diverse, covering

various aspects of congenital disorders, from neurological and cardiac anomalies to musculoskeletal and developmental issues. Such diversity allows for an extensive exploration of congenital anomalies, enhancing understanding of their impact on human development and health. the thesis tackles a crucial array of congenital disabilities, poised to make significant contributions to medical research, public health policy, and the understanding of these complex conditions.

The search approach employed involved utilizing a blend of MeSH terms specific to the database, free-form text, wildcard characters (employing '*' to truncate words), and Boolean operators ('AND', 'OR'). The time restrictions were used including only papers published from 2003 and the search was structured into three stages – evaluation of the title followed by an evaluation of the abstract and finally the evaluation of the full text. All retrieved papers were combined in a single database and duplicates were removed. The most recent search date was 26th November. Detailed search strategy is described in the "Screening and Selection" chapter of the thesis due to significant differences among available filters and search tools for each of the individual databases.

Each assessment was performed by three independent observers. One of the observers is an expert in the field of adapted physical activities, the other two have lifelong experiences in the field of para sport. If the observer was not fluent in the language of the paper, the other two reviewers made decision with joint consent whether to include said paper into this review.

3.4 Inclusion and Exclusion Criteria

Cross-sectional studies, mixed-methods studies, longitudinal studies, observational studies and other works were included if they were written in English or German, included a population with an age of 18 years or older and the research topic was sports or physical activity and a minimum of five individuals with either cerebral palsy, limb deficiencies, neural tube defect, heart defect or muscular dystrophy were part of the study population.

The papers were excluded if they were case studies or reviews, were written in other languages, published before 2003, tackled irrelevant topics or had unsufficient population. Both inclusion and exclusion criteria are detailed in Table 1 below.

Criteria	Inclusion	Exclusion
Population	✓ 18+ years old ✓ 5+ participants ✓ Cerebral palsy ✓ Limb deficiency ✓ Neural tube defect ✓ Hearth defect ✓ Muscular dystrophy	× Younger than 18 years × 4 or less participants × Other impairments × Diagnosis combined with an intellectual impairment
Language	✓ English ✓ German	× Other languages
Publication date	✓ 2003 - 2023	× Earlier than 2003
Study design	✓ Cross-sectional studies ✓ Mixed-methods studies ✓ Longitudinal studies ✓ Observational studies	× Review × Case studies × Case reports
Topic	✓ Sport ✓ Physical activities	× Other

Table 1 Inclusion and Exclusion Criteria

3.5 Screening and Selection

The Medline database was searched using the following query with the Boolean operators AND, OR: (“training” OR “physical activity” OR “para sport” OR “exercise” OR "continuous exercise") AND (“muscular dystrophy” OR "tetralogy of fallot" OR "limb deficiency" OR "cerebral palsy" OR "neural tube defect" OR "spina bifida") combined with using published date filter from 2013–2023, no language filters were used. The search led to 1339 results in the Medline database of which 842 tackled irrelevant topics for the systematic review. 138 results delt with other types of disabilities and 178 consisted of participants aged below 19 years old. There were also 44 different reviews and 39 other study types considered non eligible for this review. The total number of 98 results were considered for the second stage of screening. Through the second screening stage 90 results were eliminated leaving 8 articles for the full text review.

The PubMed search was initiated with the same search query as in the Medline database with following active filters: Language - English, German; Age - Adult: 19+ years, Young Adult: 19-24 years, Adult: 19-44 years, Middle Aged + Aged: 45+ years, Middle Aged: 45-64 years, Aged: 65+ years, 80 and over: 80+ years. This resulted in 3 662 hits followed by narrowing the search using publishing date filter as specified above and checking the “Free full text” box for all the results to be considered for the next stage of screening. The search then let to 1000 results. 82 articles and studies incorporated children and 21 studied different disabilities. Furthermore 24 results were excluded due to being different study types or reviews and 858 articles were either irrelevant to the topic or duplicates. Only 15 results were considered for the second stage of screening. We assume this considerably low number of studies is caused by the fact Medline database was searched first so most of the content of PubMed was already investigated resulting in a very high number of duplicates. After the second screening stage 13 results were excluded leaving 2 articles for the full text review.

ERIC database was the third one examined. There were no other filters used and previously functioning advanced queries with Boolean operators did not yield any results so after several attempts a simplified version of the search query was used. “physical activities disability sport” resulted in 4 144 hits further narrowed down by checking the full text availability to 1 105 results. However only 234 sources focused on individuals with disabilities and only 91 of those were published after 2003 being eligible for the review. Among 91 sources, 61 were irrelevant to this review’s topic, 8 focused on wrong diagnosis, 6 researched non adult participants and 6 were reviews or manuals. For the

second stage of screening 10 articles were chosen and 8 were finally excluded for the 2 remaining in the last full text stage of screening and selection.

The fourth searched database Sportsdiscus was examined similarly to Medline and PubMed using Boolean operators „AND“ and „OR“ combined with previously mentioned keywords and their combinations. Published date filter from 2003 to 2023 was used in conjunction with available “full text” box and “apply equivalent subjects” filter. This led to a total number of 1425 results. 469 articles were excluded due to the age limit, 156 results were reviews. We have also eliminated 8 results based on the language of the publications. After cutting out articles with irrelevant topic to this review a total of 51 results were considered for the second stage of screening process. 44 articles were eliminated in the second stage having 7 results for the final full text screening.

One article was added to the evaluation by a hand search so a total number of 20 articles across all the searched databases were considered for the third and final stage of the screening process by a full text evaluation. After carefully examining all the results according to relevance and usability to the topic of this review 15 articles were included in the review as seen in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram (Figure 1 below). PRISMA represents an evidence-driven, essential set of elements for reporting in systematic reviews and meta-analyses. We decided to use PRISMA due to its versatility and easy-to-work-with framework for introducing detailed steps of our systematic review screening and selection process in all four databases.

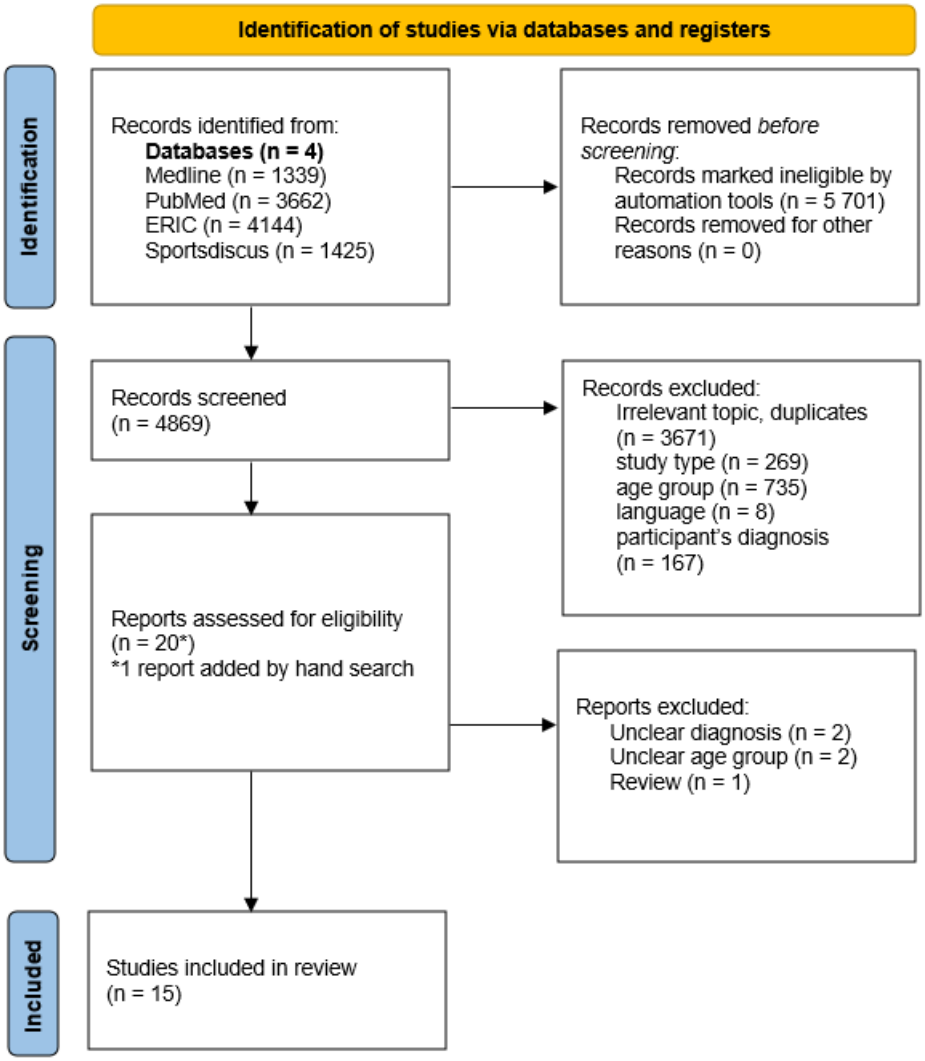


Figure 1 PRISMA flow diagram (Page et al., 2021)

3.6 Data Extraction and Critical Appraisal

We used a customized extraction form (detailed in Appendix 8.1). The form was specifically focused on the enrolled population characteristics regarding its total number, age and medical diagnosis of the participants. Most importantly, through this extraction form we identified barriers and facilitators in accordance with the main aim of the review.

To evaluate the quality of the 15 identified studies from the screening process, the Mixed Methods Appraisal Tool (MMAT) was employed (Hong et al., 2018). It is designed as a checklist for simultaneously assessing studies of different types therefore we decided to use MMAT, version 2018 for this systematic review. The assesment itself is done by answering „Yes“, „No“ or „Can't tell“ to predetermined question regarding each study types in conjuntion with two baseline screening questions - S1. Are there clear research questions? S2. Do the collected data allow to address the research questions? If

either of those two basic screening questions is answered “No”, that study lacks the sufficient quality to be included in the review.

We present the assesment in the Table 2 below, the „1“ stands for „Yes“, the „0“ stand for „No“. When the square is empty, the aswer is either „Can’t tell“ or is irrelevant to the assesed study. For detailed MMAT description see the Appendix 8.2. Calculating an overall score based on individual criterion ratings is not recommended (Hong et al., 2018).

Author	Screen		Qualitative					Quantitative RCT					Quantitative NR					Quantitative D					Mixed methods				
Publication date	S1	S2	1.1	1.2	1.3	1.4	1.5	2.1	2.2	2.3	2.4	2.5	3.1	3.2	3.3	3.4	3.5	4.1	4.2	4.3	4.4	4.5	5.1	5.2	5.3	5.4	5.5
Reina; 2019	1	1																1	1	1	1	1					
Jensen; 2006	1	1											1	1	1	1	1										
Roselien; 2012	1	1											1	1	0	1	1										
Ballas; 2020	1	1	1	1	1	1	1																				
Maltais; 2010	1	1																1	1	1	1	1					
Dysterheft; 2011	1	1																					1	1	1	1	1
Iedynak. 2017	1	1											1	1	0												
Aviram; 2021	1	1	1	1	1	1	1																				
Buffart; 2009	1	1	1	1	1	1	1																				
Barfield; 2013	1	1																					1	1	1	1	1
Gaskin; 2008	1	1																1	1	1	1	1					
Nieuwenhuijsen; 2011	1	1																1	1	1	0	1					
Sandström; 2009	1	1	1	1	1	1	1																				
Buffart; 2008	1	1																					1	1	1	1	1
Allen; 2009	1	1											1	1	0												

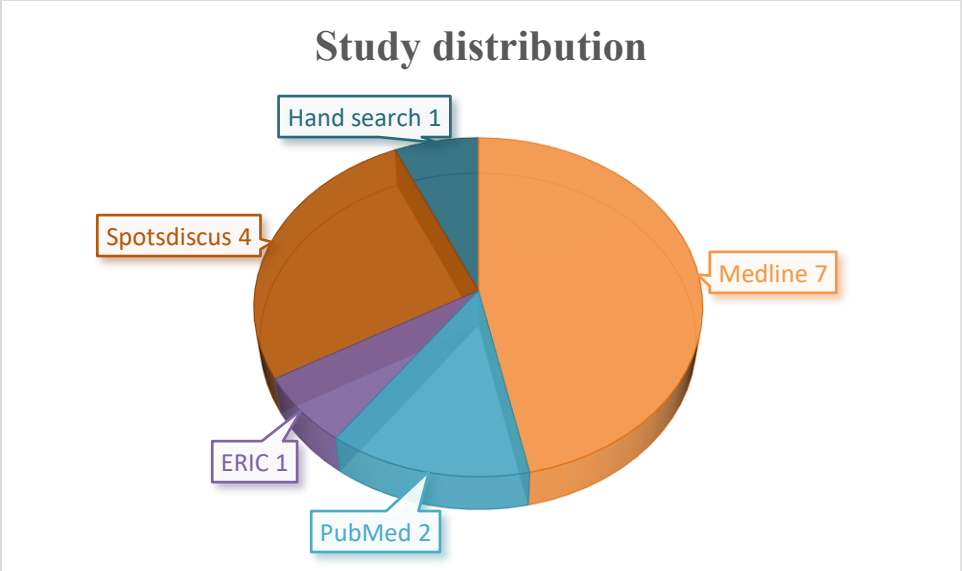
Table 2 Mixed Methods Appraisal Tool (MMAT), version 2018 (Hong et al., 2018)

4 RESULTS

The results of this systematic review are presented visually in graphs and tables with explanatory comments to help further understand the gained data. At first, we investigate the study composition regarding the source database and time period of publication. Then we aim to differentiate between participation group of each study and finally we present the identified barriers and facilitators to physical activity and sport among adults with physical congenital disabilities.

4.1 Study composition

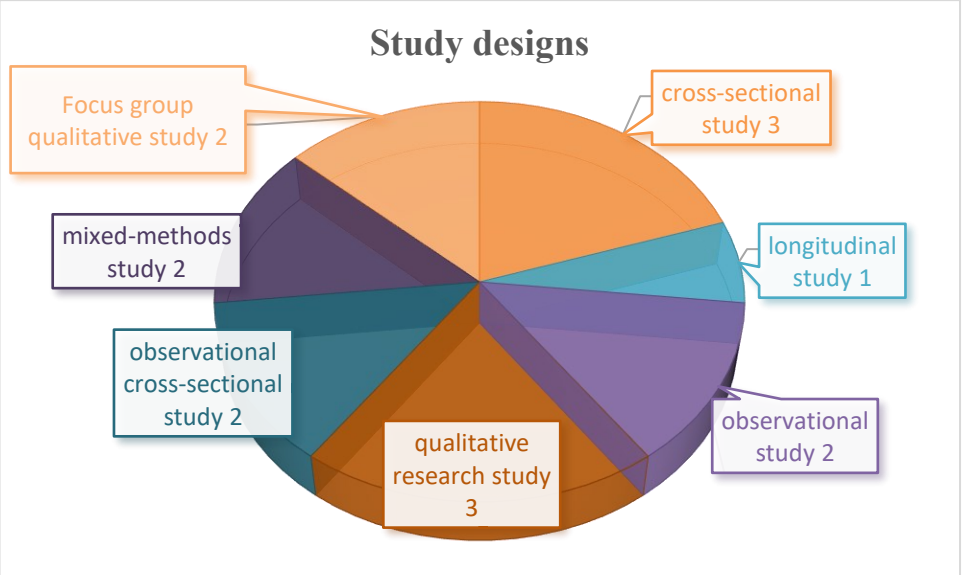
Graph 1 delves into number of studies and articles gathered across all 4 searched databases including the 1 hand-searched article. Publication date range from 2006 to 2021 encompassing almost the entire twenty-year inclusion period. It should be noted 11 out of 15 included articles were published in the first decade of studied time period, furthermore there is a visible gap in the number of articles published after 2020. Notably, we have been able to extract at least one study from each of the source databases.



Graph 1 – Source databases and hand search study distribution

The highest number of retrieved studies and articles comes from the Medline database which corresponds with the medically focus topic of this review. Additionally, the Medline database was searched through first, so the total distribution is affected by high number of duplicates regardless of their inclusion or exclusion from the review in the end. Representation of several study designs is shown in Graph 2. The most frequent

study designs were cross-sectional study and general qualitative research study. However, due to the differences between data collection and data analysis in several studies, we found it quite complex to clearly identify the exact design of individual studies retriever for this systematic review, therefore we left observational studies with aspects from cross-sectional studies in separate group. Otherwise observational studies would be mostly represented in the graph below.



Graph 2 –Study designs of retrieved articles

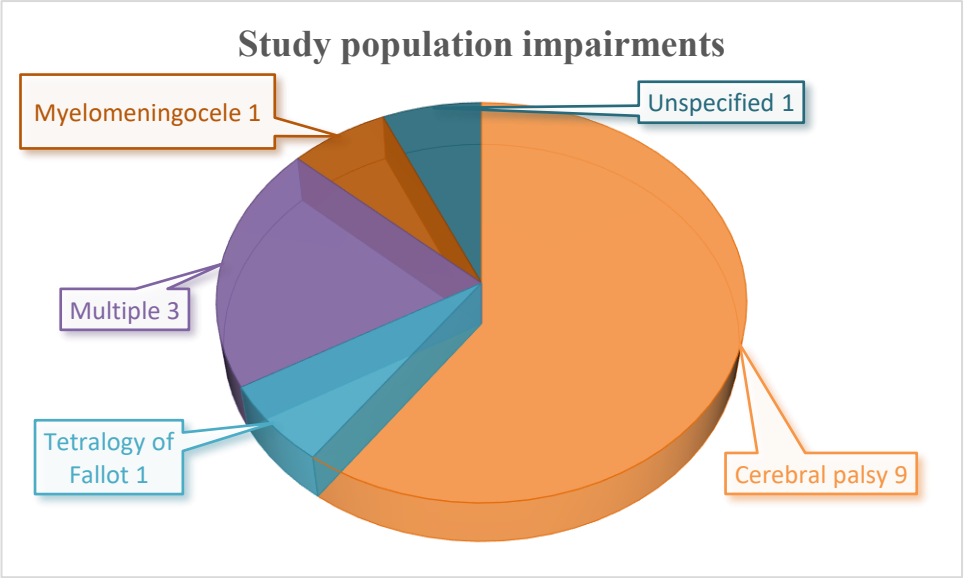
4.2 Study population

The pool of participants of each retrieved study was diverse and Table 3 showcases number of participants, median age and gender. However, in 3 studies (Ballas et al., 2020; Aviram et al., 2021; Bafield et al., 2013) a total number of participants was higher than presented below. This is caused by uneligibility of some participants due to age or medical diagnosis/impairment type. Only the number of eligible participants is presented in the Table 3 and is accounted for in the results. If there were no clear separation lanes between eligible and uneligible part of study population, the study was excluded in the last phase of screning and evaluation as detailed in Chapter 3. Mentioned 3 articles clearly differentiate between population groups in methods and results, thus being evaluated as eligible for this review. Furthermore, Ballas et al. (2020) only described the age of population in range 18–35 years old, so the average value of those two numbers is stated as study population age. Additionally, Iedynak et al. (2017) stated the study population age as 24.4 years with one exception from that value being a female participant aged 40.2 years.

Author	**Study population**		
Publication date	Number	Age	Male/Female
Reina; 2019	48	23	48/0
Jensen; 2006	48	40.1	24/24
Roselien; 2012	74	27.3	53/21
Ballas; 2020	7	21.5	4/3
Maltais; 2010	132	29/27	66/66
Dysterheft; 2011	6	20	1/5
Iedynak. 2017	9	24.4	0/9
Aviram; 2021	13	18.9	7/6
Buffart; 2009	16	22.4	12/4
Barfield; 2013	18	28.8	unspecified
Gaskin; 2008	51	38.2	32/19
Nieuwenhuijsen; 2011	42	36.4	29/13
Sandström; 2009	22	42	12/10
Buffart; 2008	51	21.1	26/25
Allen; 2009	10	45.8	6/4

Table 3 Age and Gender Population Characteristics

It is crutial to investigate the type of impairment of study participants as it serves as not only the key inclusion factor for this review but also as a significant determinant to relationship between an indivudial and his/her physical activity and sport participation. For this purpose, Graph 3 presents study population impairment type.



Graph 3 –Study population impairment types

The 80% of retrieved studies and articles focused on single impairment type. Barfield et al. (2013) worked with adults diagnosed with unspecified physical congenital impairment, thus this study being eligible for selection and use in the systematic review.

It is worth noticing clear overal research focus on individuals with cerebral palsy. Even in the studies population marked as „Multiple“ where several congenital impairments were present among participants (Dysterheft et al., 2011; Buffart et al., 2009; Barfield et al., 2013), cerebral palsy was also among those making it by far the most researched type of impairment in this review with four fifths of available sources investigating cerebral palsy adults. However, this trend is present among children too as disccused in Chapter 5 of the thesis.

4.3 Identified themes

We succesfully identified 21 different themes about barriers among adults with physical congenital disabilities. Since only 5 of included studies (Aviram et al., 2021; Buffart et al., 2009; Barfield et al., 2013) tackled the topic of barriers and facilitators of physical acitivity and sport directly, the most themes were marked indirectly by investigating the full text of each study. Therefore in 2 studies (Iedynak et al., 2017; Sandström et al., 2009) none of the barrier themes were identified and only facilitators were evident. Similarly so, 19 themes about facilitators of physical activity and sport participation were named among the study population with 3 studies (Reina et al., 2019; Jensen et al., 2006; Roselien et al., 2012) presenting no such themes and introducing only barriers into this review. Generally, we could divide identified themes into 3 major subgroups of factors:

- Personal physical,
- personal psychological,
- enviromental.

The layout of different factors among different studies divided into barriers and facilitators can be seen in Table 4 and Table 5, marking „1“ for the factors present in the study and „0“ for the absence of such.

Author	**Barrier Themes Presented**		
Publication date	Personal physical	Personal psychological	Enviromental
Reina; 2019	1	0	0
Jensen; 2006	1	0	0
Roselien; 2012	1	0	0
Ballas; 2020	1	1	1
Maltais; 2010	1	0	0
Dysterheft; 2011	1	0	0
Iedynak. 2017	0	0	0
Aviram; 2021	1	1	1
Buffart; 2009	1	1	1
Barfield; 2013	1	0	1
Gaskin; 2008	1	0	0
Nieuwenhuijsen; 2011	1	0	0
Sandström; 2009	0	0	0
Buffart; 2008	1	1	1
Allen; 2009	1	1	0

Table 4 Overwiev of barrier themes identified

Notably if there were barrier themes present, personal physical factors prevailed in the studies over personal psychological and enviromental factors.

Author	**Facilitator Themes Presented**		
Publication date	Personal physical	Personal psychological	Enviromental
Reina; 2019	0	0	0
Jensen; 2006	0	0	0
Roselien; 2012	0	0	0
Ballas; 2020	0	1	1
Maltais; 2010	0	1	0
Dysterheft; 2011	0	1	1
Iedynak. 2017	0	1	0
Aviram; 2021	0	0	1
Buffart; 2009	1	1	1
Barfield; 2013	1	1	1
Gaskin; 2008	0	0	1
Nieuwenhuijsen; 2011	1	0	0
Sandström; 2009	1	1	1
Buffart; 2008	1	0	1
Allen; 2009	1	1	1

Table 5 Overwiev of facilitator themes identified

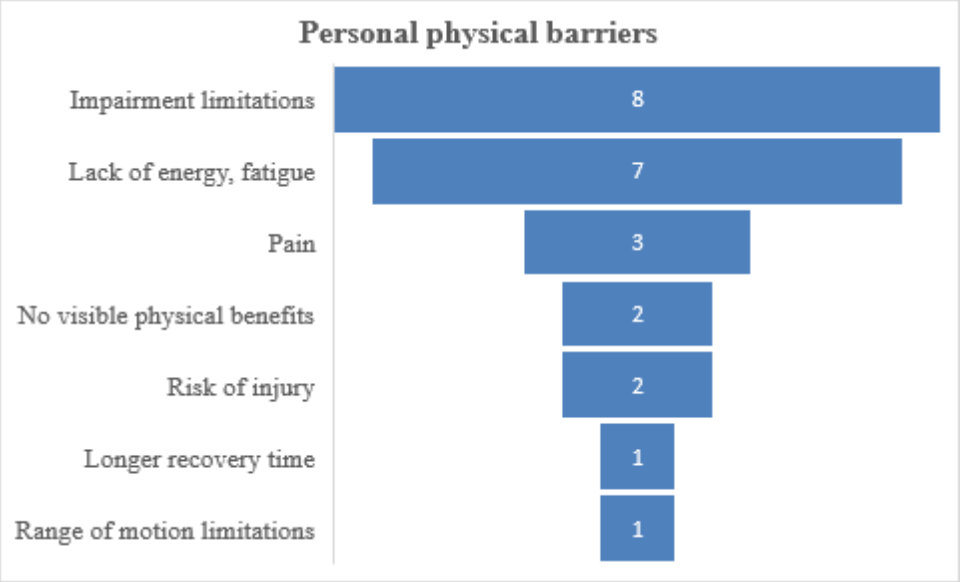
In the contrast from marked barrier themes, enviromental factors made the majority of identified themes among included studies in the review. Similarly to the previous barrier themes, authors who did not investigate the topic of barriers and facilitators directly often did not include one or more subgroups of themes in their study.

4.4 Barriers of sport participation

Coming from the uniqe themes described in the previous subchapter, in the subgroup of personal physical barriers to physical activity and sport participation we identified a total of 7 barriers:

- Lack of energy, fatigue
- general impairment limitations,
- pain. chronic pain,
- range of motion limitations,
- risk of injury,
- long recovery time,
- no visible physical benefits.

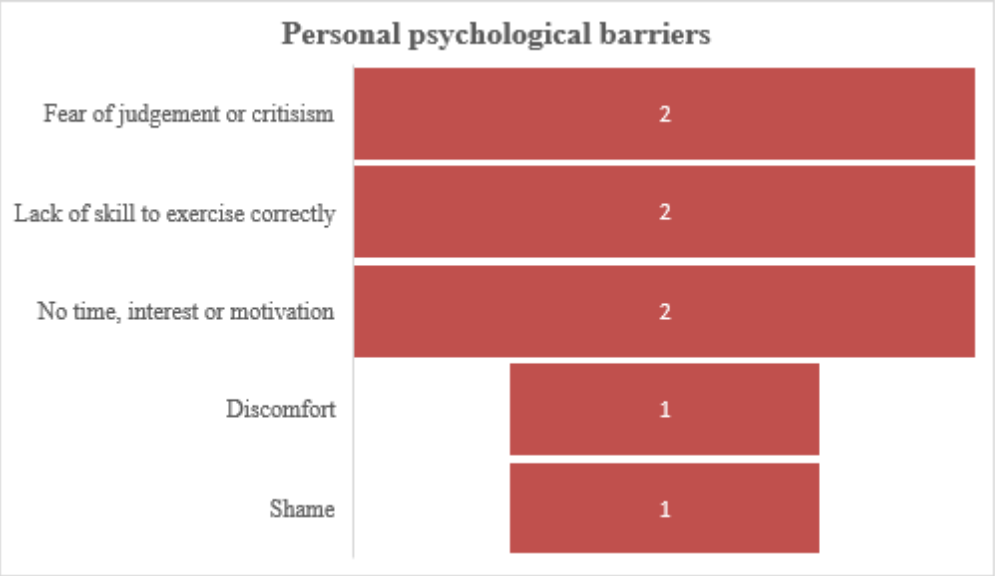
Graph 4 showcases all mentioned barriers as we identified them throughout all the included articles and studies.



Graph 4 – Personal physical barriers identified

The second subgroup of identified barrier are personal psychological factor. We marked a total of 5 psychological barriers as shown in Graph 5:

- Fear of judgement or critisism,
- lack of skill to exercise correctly,
- no time, interest or motivation,
- discomfort,
- shame.

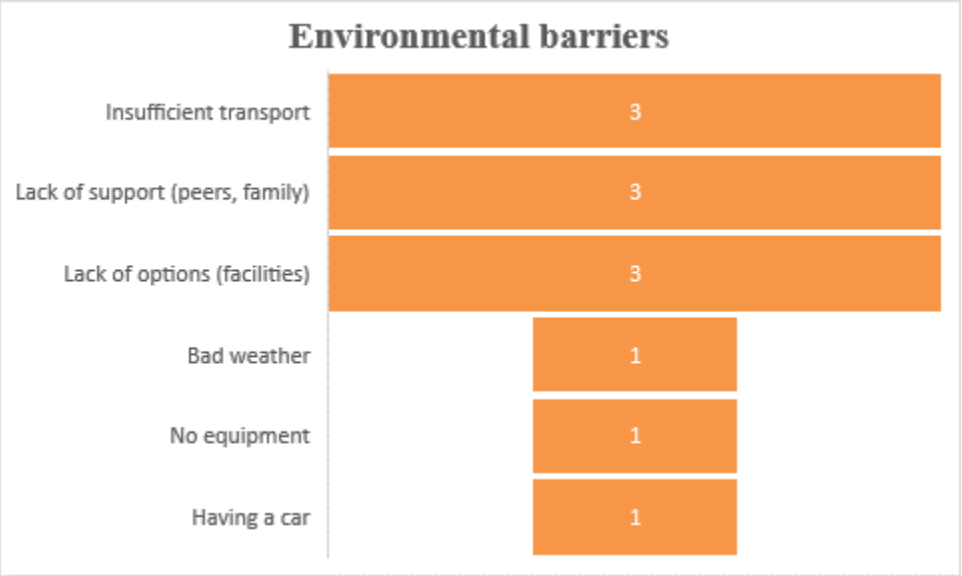


Graph 5 – Personal psychological barriers identified

Psychological barriers were smaller in numbers compared to physical barriers with 3 factors being the most visible – Fear of judgement or critisism, Lack of skill to exercise correctly without high risk of injury and No time, interest or motivation.

In the last subgroup of enviromental barriers we managed to identify 6 factors hindering physical activity and sport participation in adults with congenital physical disabilities (see also Graph 6 below):

- Insufficient transport,
- lack of support (peers, family, personnel),
- lack of options (facilities),
- bad weather,
- no equipment,
- having a car.



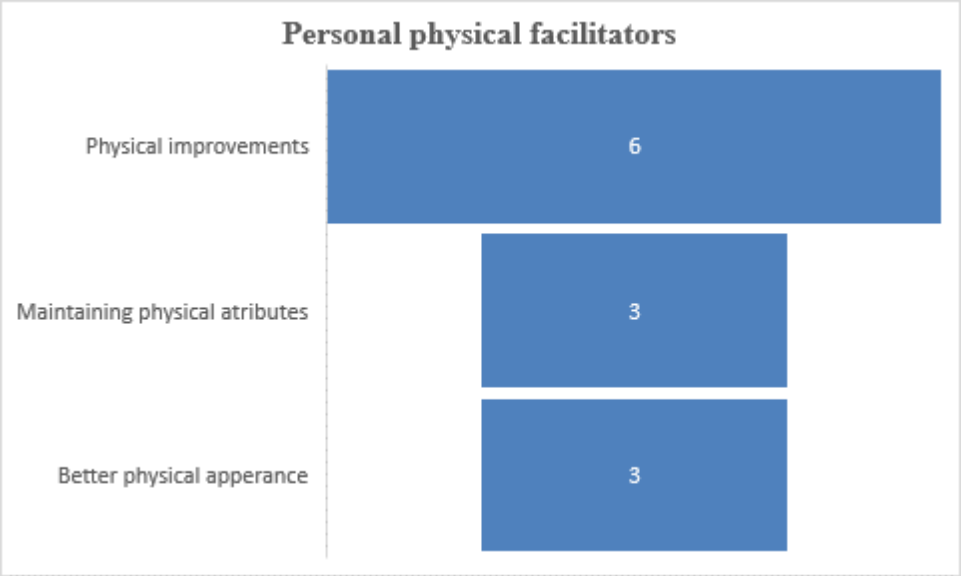
Graph 6 – Environmental barriers identified

Insufficient transport options to the facilities which tend to be far away from individual's home seems to be the main issue when it comes to enviromental barriers of sport participation. The lack of support from family, peers or even uneducated facilities' personnel further decreasing availability of performing physical activities or sport for this review's study population. Interestingly, having a car was mentioned as both the barrier (rather driving then walking, thus not exercising) and the facilitator (by driving, more distant facilities become available) in the study of Buffart et al. (2009).

4.5 Facilitators of sport participation

In this subchapter we summarised all identified facilitators from all 3 subgroups of personal physical, personal psychological and environmental factors of sport and physical activity participation in adults with congenital physical disabilities. In the first mentioned category we marked 3 main contributors to higher physical aktivity engagement:

- Physical improvements (muscle growth, fitness, endurance),
- maintaining physical atributes,
- better physical apperance.



Graph 7 – Personal physical facilitators identified

As Graph 7 above suggests physical improvement are considered the biggest drive towards physical activity and sport participation. Those improvement include faster muscle growth, overall better fitness and higher physical endurace. In conjunction maintaining those benefits and keeping in shape follows second tied with better looks. These facilitators are closely linked to personal psychological factors listed below and shown in the Graph 8:

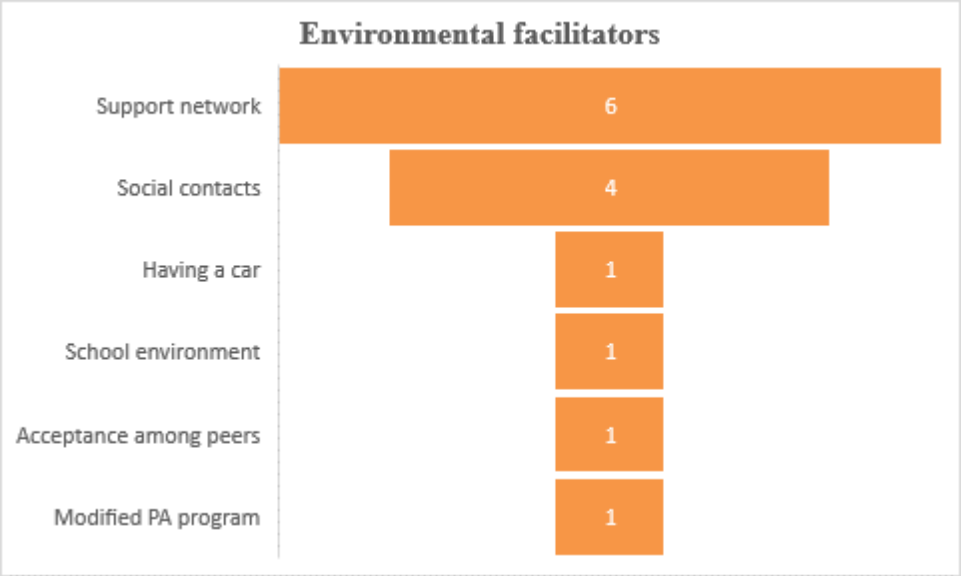
- Enjoyment,
- motivation,
- achieving goals,
- well-being,
- better skills,
- independence from parents.

Graph 8 – Personal psychological facilitators identified

Enjoyment and fun seem to be the main psychological facilitators of physical activities and sport participation closely connected with motivation and mental health well-being among others.

Similarly to barriers the third subgroup consists of the enviromental factors facilitating physical activities. Across all 15 examined studies we have found 6 environmental factor supporting sport participation as shown also in the Graph 9:

- Support network (family, personnel),
- social contacts,
- having a car,
- school environment,
- acceptance among peers,
- modified physical activity program.



Graph 9 – Environmental facilitators identified

The greatest environmental facilitator is good support network. The network consists of family members, friends and trained professionals who all contribute to succesfull physical activity and sport participation of the individual. This is closely accompanied by a theme of finding new friends via sport and exercise which is often the case in para sport social environments.

5 DISCUSSION

We aimed to systematically review available research sources on sport and physical activity participation among adults with congenital disabilities and to identify the barriers and facilitators for such individuals to participate in physical activities and para sport. In our systematic review we identified a total number of 18 barriers and 15 facilitators across 3 subgroups - physical, psychological, and environmental.

Personal physical barriers made the majority of identified barrier themes. We consider this to be a results of indirect identification of several themes and lack of specific aiming to target other than purely physical themes in work not directly linked to the topic of barriers and facilitators of physical activity and sport participation. Note that several factors are repeated across different studies with general impairment limitations being the most prevalent personal physical barrier for physical activity and sport participation. Impairment limitations overall hinder individuals and turn them away from active lifestyle. Aviram et al. (2021) even suggest a correlation between GMFCS classification of an individual and his engagement in physical activities pointing out the higher the classification level is (scale ranges from I – lightly impaired often able to walk freely to V – severely impaired often bound to wheelchair having issues maintaining posture) the more of a barrier logically the impairment is.

The number of barriers and facilitators seems to align with the results of similarly focused studies in different population groups. The study of Shields & Synnot (2014) revealed that participants identified a total of 20 barriers influencing the participation of children with disabilities in physical activity and community sports. These factors were categorized into program, social, environmental, personal, and policy domains. Similarly, to our review with the theme of "having a car", the environmental category included two interconnected concepts, transport, and accessibility of facilities, which were perceived as both barriers and facilitators depending on their availability. In the review of Williams, Smith & Papathomas (2014) aimed at individuals with spinal cord injury, 8 interconnected concepts emerged – well-being, environment, physical body, body–self relationship, physically active identity, knowledge, restitution narrative, and perceived absences. The similarly focused study on individuals with spinal cord injury Stephens, Neil, & Smith (2012) explores the advantages and obstacles associated with engaging in organized sports. Through semi-structured interviews with seven diverse SCI athletes, the research identified 20 benefits and 18 individual barriers. Benefits were classified into

sub-themes like socialization, self-worth, physical challenge, and emotional well-being, while barriers included organizational, medical, emotional, lack of information, and societal views. Notable barriers involve financial constraints, limited information on medical aspects and sports opportunities, and the need for able-bodied support. Mulligan et al. (2012) identified impaired body structure or function as a major barrier to participation in physical activity in individuals with several different impairment including multiple sclerosis, stroke, traumatic brain injury or spinal cord injury. The authors reported multiple environmental barriers as well. Survivors of stroke in the study of Damush et al. (2007) noted that physical impairments, such as vision and walking difficulties arising post-stroke, hindered their involvement in physical activity. Additionally, a lack of motivation, desire, or energy was also reported together with limited exercise options. The same issues can be seen among people with spinal cord injury (Scelza et al., 2005) or adults with Down syndrome (Heller, Hsieh and Rimmer, 2003). On the other hand, discovering motivation for physical activity, receiving social support for exercise, and regarding exercise as a dedicated task or duty were listed as facilitators. Similar benefits associated with enhancements in physical performance and health, along with a sense of personal achievement are reported among people with multiple sclerosis (Strout, Minahan and Sabapathy, 2009). The signifficance of enviromental barriers to physical activity participation among wheelchair users was fully fleshed out more than twenty years ago by Meyers et al. (2002) stating that narrow aisles, absence of ramps, adverse weather conditions, inaccessible bathrooms, insufficient parking, or challenging surfaces may all stop wheelchair using individuals from participating in sport or physical activity. However, those obstacles were deemed surmountable in comparison with more personal ones such as illness, limited physical strength or fitness. Similar enviromental issues were experienced among individuals with limb amputations (Gallagher et al., 2011). The second research area in the field of barriers and facilitators of sports participation among disabled individuals is strongly focused on disabled children. Children living nearby sport facilities for disabled seem to participate in sports easier calling for suitable transportation and the wheelchair accesible buildings (Welsh et al., 2006). The primary hurdles for youth with physical disabilities encompassed constraints in time, experiences of pain or discomfort, a lack of suitable exercise spaces for socializing, weather-related challenges, and misconceptions about the individual's physical condition or abilities held by others (Kang et al., 2007). The key role of people around young disabled individuals supporting their physical activity

participation is further strengthened by Wright et al. (2019) focusing on the point of view of clinicians and their task to determine both parent and child commitment to a physical activity which if not high enough, can be perceived as a barrier to physical activity or sport participation. So, in conclusion it seems the topic of barriers and facilitators of sport activities itself is well researched among several population groups. However, there is a lack of structural overview of available material regarding adults with congenital disabilities and their participation in physical activities and sport. We could categorize available research papers into two main subgroups. Researchers of physical activity barriers and facilitators either focus on wide range of disability types or their work is aimed on youth and children. Therefore, we believe a more could be done for adults with disabilities generally because across the spectrum of medical professionals and academic researchers alike there is a strong prevalent theme of focusing on the children with disabilities rather than adult patients. In this review the thematically relevant studies excluded due to being focused on children despite having eligible medical diagnoses and enough participants comprised the largest subgroup of eliminated material throughout the screening process (n = 735). That said there is still room to explore more material in the future research efforts.

We investigated 4 databases – Medline, PubMed, ERIC and Sportsdiscus screening 4869 articles, but selected other reviews explored more databases in comparison such as AMED, PsychINFO, CINAHL or Australian Education Index (Shields, Synnot & Barr, 2012), The Cochrane Library, EMBASE, PEDro and ProQuest (Carlon et al., 2013), Web of science, OTseeker and REHABDATA (Shikako-Thomas et al., 2008). However, despite a higher number of investigated databases the amount of included articles ranges roughly in the middle when compared to similarly focused reviews with comparable population and inclusion criteria (Carlon et al., 2013, n = 6; Shields, Synnot & Barr, 2012, n = 14; Shikako-Thomas et al., 2008, n = 10; Butler, Scianni, & Ada, 2010, n = 3; Anttila et al., 2008, n = 24; Moreau et al., 2016, n = 24).

5.1 Strengths and Limitations

We feel investigating more databases and gathering more studies eligible for the review would greatly help to uplift the thesis core findings. That inevitably leads to more whole understanding of the effects, benefits, and lifestyle of researched population. Since there was a notable number of studies aiming to identify barriers and facilitators to physical activity and sport in adolescents in our target group of individuals with

congenital disabilities, we therefore recommend widening the population group. This expansion to adolescents together with adults would multiply the number of included studies. For future research direction we would consider adding multiple languages to the inclusion criteria since it is evident German language studies are scares and maybe Spanish written research would bring more relevant material to the review.

We see the major strenght in included population of the thesis encompassing wide range of congenital disability types from cerebral palsy throught hearth defects to other genetic disorders.

6 CONCLUSION

We successfully identified 18 core barriers and 15 facilitators to physical activity and sport participaton in adults with congenital disabilities. Critical barriers primarily centered around personal physical limitations, such as impairment-related restrictions, pain, and fatigue. Psychological barriers, including fear of judgment, lack of motivation, and skill deficiencies, also emerged as significant deterrents. Environmental barriers, including insufficient transport, lack of supportive infrastructure, and limited access to suitable facilities, further compounded these challenges.

This thesis presents a comprehensive systematic review of the barriers and facilitators affecting sports participation among adults with congenital physical disabilities. The findings highlight the complex interplay of personal, psychological, and environmental factors that influence engagement in physical activities and para sport.

Conversely, the facilitators identified in this review provide valuable insights for enhancing participation in sports and physical activities. Personal physical improvements, such as increased fitness and muscle growth, were significant motivators. Psychological factors like enjoyment, motivation, and goal achievement played pivotal roles in encouraging engagement. Crucially, supportive environments, characterized by strong support networks, accessible facilities, and inclusive programs, were identified as vital in facilitating participation. The findings from this review underscore the necessity of a holistic approach to promoting sports participation among adults with congenital physical disabilities. Interventions should be multi-faceted, addressing physical, psychological, and environmental barriers while simultaneously leveraging identified facilitators. Importantly, the study reveals a research gap in direct investigations into these barriers and facilitators, highlighting an opportunity for future studies to delve deeper into specific aspects of these elements.

Future research should aim to explore the complex relationships between these factors in more detail, particularly focusing on how psychological and environmental elements interact with personal physical barriers and facilitators. Additionally, longitudinal studies could provide insights into how these factors evolve over time and the impact of interventions aimed at reducing barriers and enhancing facilitators. Further exploration into the unique experiences of different congenital disabilities could also yield more tailored strategies for promoting sports participation.

In conclusion, this thesis contributes understanding of the factors influencing sports participation among adults with congenital physical disabilities. By identifying key barriers and facilitators, it lays a foundation for developing more effective strategies to encourage involvement in physical activities, ultimately enhancing the quality of life for this population. The study's findings serve as a call to action for researchers, policymakers, and practitioners to collaborate in creating inclusive, supportive environments that enable all individuals, regardless of physical ability, to participate in sports and physical activities.

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8 APPENDICES

8.1 Data Extraction Form

1. Study title

2. Authors

3. Method
    a. Participant recruitment
    b. Participant characteristics
        i. Number
        ii. Age
        iii. Inclusion/exclusion details
        iv. diagnosis

4. Barriers identified

5. Facilitators identified

6. Results

7. Discussion

8. Additional info

9. Comments

8.2 Mixed Methods Appraisal Tool (MMAT), version 2018

Category of study designs	Methodological quality criteria	Yes	No	Can't tell
Screening questions	S1. Are there clear research questions?			
	S2. Do the collected data allow to address the research questions?			
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?			
	1.2. Are the qualitative data collection methods adequate to address the research question?			
	1.3. Are the findings adequately derived from the data?			
	1.4. Is the interpretation of results sufficiently substantiated by data?			
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?			
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?			
	2.2. Are the groups comparable at baseline?			
	2.3. Are there complete outcome data?			
	2.4. Are outcome assessors blinded to the intervention provided?			
	2.5 Did the participants adhere to the assigned intervention?			
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?			
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?			
	3.3. Are there complete outcome data?			
	3.4. Are the confounders accounted for in the design and analysis?			
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?			
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?			
	4.2. Is the sample representative of the target population?			
	4.3. Are the measurements appropriate?			
	4.4. Is the risk of nonresponse bias low?			
	4.5. Is the statistical analysis appropriate to answer the research question?			
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?			
	5.2. Are the different components of the study effectively integrated to answer the research question?			
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?			
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?			
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?			