

**TOWARDS TRUE INCLUSION:
DEVELOPING A PHENOMENOLOGY OF
PHYSICAL ACTIVITY WITH CEREBRAL PALSY**

A Thesis By

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Abstract:

This thesis investigates the lived experiences of individuals with Cerebral Palsy (CP) engaging in physical activity (PA), employing Maurice Merleau-Ponty's phenomenology to explore subjective experiences beyond mere physical limitations. The research is rooted in understanding CP, a common motor disability in childhood, and its impact on PA participation, addressing the historical neglect of adapted PA for this group. By examining CP through the lens of phenomenology, the thesis delves into how individuals with CP perceive their bodies and movement, offering a fresh perspective on "normality" and the concept of "adapted" PA. The methodology incorporates phenomenological analysis, analyzing existing literature to conceptualize the bodily experiences of people with CP, particularly focusing on feelings of alienation from their bodies. Through the theoretical framework of Merleau-Ponty, the study highlights the intertwined nature of body and world, proposing a reimagined understanding of movement that transcends traditional notions of physicality. This work aims to contribute to a more inclusive and diverse PA setting, advocating for the integration of individuals with disabilities into mainstream physical education. The thesis also discusses the limitations, including the diversity of CP experiences and the lack of specificity in phenomenological research, and suggests future directions focusing on the practical application of inclusive PA practices.

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CHAPTER 1

INTRODUCTION

Physical activity (PA) is defined as “any bodily movement produced by skeletal muscles that requires energy expenditure” (World Health Organization [WHO], 2022). PA includes, but are not limited to, recreational or leisure-time physical activity, transportation such as walking or cycling, occupational or work related activities, household chores, play, games, sports, or planned exercise, in the context of daily, family, and community activities. PA is recognized as a mean to health and wellness which offers a multitude of benefits that span physiological, psychological, and sociological dimensions. According to Warburton et al. (2006), PA significantly reduces the risk of over 25 chronic conditions, including coronary heart disease, stroke, diabetes, and several forms of cancer, establishing PA as a cornerstone of preventive medicine. Beyond the reduction of chronic conditions, PA also plays a crucial role in improving muscular strength and mitigating the adverse effects of aging. According to the American College of Sports Medicine (ACSM), regular engagement in resistance training enhances muscular strength and endurance, contributes to better body composition, and improves physical function in individuals across all age groups (Garber et al., 2011). Additionally, PA’s role in aging is highlighted through its association with improved cognitive function and a reduced risk of falls in older adults, suggesting a direct link between regular physical engagement and prolonged independent living (Paterson & Warburton, 2010). These benefits illustrate the extensive physiological advantages of regular PA, reinforcing its necessity for health maintenance, the promotion of functional independence, and the enhancement of life quality in the aging population.

Psychologically, PA has been linked to improved mental health, with benefits including reduced symptoms of depression and anxiety, improved mood, and enhanced cognitive function. According to Mammen and Faulkner (2013), even modest levels of PA can prevent future depressive episodes, positioning PA as a significant factor in mental health promotion and mental disorder prevention. This relationship underscores the importance of integrating PA into routine healthcare and public health

strategies to improve mental health outcomes across populations. The positive impact of regular exercise extends beyond the prevention of depressive episodes, contributing to overall psychological resilience. As Sharma et al. (2006) note, physical exercise can improve self-esteem and cognitive functions while reducing levels of anxiety, stress, and depression, thereby acting as a natural anti-anxiety treatment and mood enhancer. This body of evidence supports the integration of PA into comprehensive mental health strategies, highlighting its role not only in the prevention but also in the management of mental health disorders.

On the sociological front, the benefits of PA encompass far-reaching implications for social integration and community development. Engaging in sports and recreational activities has been shown to enhance social skills, promote diversity and inclusion, and facilitate community engagement. Eime et al. (2013) highlight the positive relationship between community-based sports participation and social health outcomes, including increased social cohesion and connectedness. This research suggests that sports and PA can act as vehicles for social change, encouraging community involvement and fostering a sense of belonging among participants. By offering opportunities for interaction and engagement, PA plays a critical role in strengthening community ties and supporting the development of healthy, vibrant communities.

Given the numerous benefits which PA poses, the WHO (2022) recommends that adults aged 18–64 should engage in at least 150–300 minutes of moderate-intensity aerobic physical activity, or 75–150 minutes of vigorous-intensity aerobic physical activity, as well as two or more days of muscle-strengthening activities throughout the week. However, the reality does not always align with recommendations as WHO (2022) reports that over a quarter of the global adult population, amounting to 1.4 billion adults, does not engage in enough PA. This issue is even more pronounced among individuals with disabilities.

A disability refers to any physical or mental condition (impairment) that complicates an individual's ability to perform certain tasks (activity limitation) and engage with their surroundings

(participation restrictions) (CDC, 2024). The impairment spans from mild to severe and can impact various domains of life, affecting mobility, cognition, sensory abilities, and emotional well-being. Disabilities can be congenital, arising before birth, or acquired due to injury or illness later in life. In the United States, more than 1 in 4 adults between age 18–64 possesses a disability (CDC, 2021). Specifically, mobility disability is the most prevalent disability type accounting for 13.7% of people with disabilities (Okoro, 2018). And less than half (45.2%) of this population participate in aerobic PA, and only 39.5% met one or both components of the PA guidelines provided by WHO (Hollis et al., 2020). This significant disparity highlights the numerous barriers that individuals with disabilities face, including limited access to suitable facilities, social stigma, and a lack of tailored programs that meet their needs (Rimmer et al., 2018). As such, challenges related to accessibility and inclusion persist, reflecting broader societal attitudes towards disability (Misener & Darcy, 2014).

So, the big question is: “how can we make PA more inclusive?” To explore answers to this question, I chose to use Cerebral Palsy (CP), the most common type of mobility disability as a framework. CP is a very unique disorder because it is congenital, meaning that the disability exists at birth and neither progresses nor diminishes over time. Such congenital nature gives individuals with CP a distinctive view of what constitutes a “normal” body and movement. While body is usually a reliable source of movement and action for people with non-disability, body often appears as a “foreign” or “alien” object for people with CP due to uncontrollability of their limbs. Yet, this sense of alienation is paradoxically normal for them, as they have never experienced their bodies differently. And this perspective challenges our traditional views of mobility and ability, which potentially helps us develop a new perspective towards human movements and physical activity. Thus, in this thesis, I investigate how people with CP perceive their bodies within PA settings and what PA means to them by listening to the voices of people with CP.

Cerebral Palsy

Cerebral palsy (CP) is a non-progressive neurological disorder that affects movement, posture, and coordination, and is caused by damage to the developing brain (Centers for Disease Control and Prevention, 2023). CP is the most common childhood disability, with a prevalence of 1 in 345 children in the United States (CDC, 2021). The severity and pattern of movement impairments can vary widely depending on the type, timing, and location of the brain injury (Novak et al., 2017). The most common types of CP are spastic CP (characterized by stiff, tight muscles), dyskinetic CP (characterized by uncontrolled, writhing movements), and ataxic CP (characterized by problems with balance and coordination) (Novak et al., 2017). Within each type of CP, there can be further subtypes based on the distribution of motor impairments (e.g., hemiplegia, diplegia, quadriplegia) (CDC, 2023). CP can also cause other impairments, such as sensory deficits, intellectual disability, communication difficulties, and epilepsy (Novak et al., 2017). Although CP cannot be cured, early diagnosis and appropriate management can improve outcomes and quality of life for individuals with CP (CDC, 2023).

To systematically categorize the functional capabilities of individuals with CP, the Gross Motor Function Classification System (GMFCS) is employed. Developed by CanChild in Canada, GMFCS distinguishes five levels of motor function based on self-initiated movement abilities, particularly with respect to sitting, walking, and wheeled mobility (Cerebral Palsy Alliance Research Foundation, n.d.; Palisano et al., 1997). At one end of this spectrum, Level I captures those with minimal impairments, who demonstrate the ability to engage in a wide array of physical activities with little to no need for modifications or assistance. At the opposite end, Level V is characterized by profound motor function impairments, with individuals requiring extensive support for basic mobility and daily tasks, underscoring the system's role in guiding therapeutic goals and interventions tailored to the specific needs and potential of each person with CP (Palisano et al., 2008). This gradation from Level I to Level V facilitates a nuanced understanding of motor function in CP, enabling healthcare providers to more

accurately predict mobility outcomes, customize care plans, and communicate effectively about an individual's abilities and challenges.

By centering on lived experiences of people with CP as the framework for this exploration, this research leverages CP's widespread prevalence and its distinct congenital nature as a pivotal opportunity to challenge and expand our conventional understanding of "normality" in body and movement. For individuals with CP, the daily experience of their own bodies fundamentally differs from those without this condition due to the uncontrollability of their limbs. This often results in their bodies feeling foreign or alienated, a phenomenon I refer to as "alienation of the body." The unpredictable nature of their movements means that simple tasks such as walking or picking up objects require meticulous planning and adjustment. This constant need to manage their physical selves imposes a relentless awareness that those without disabilities seldom encounter. This profound disconnect not only affects their physical interactions but also deeply influences their psychological and emotional realms, fostering a unique perspective on what constitutes normalcy in physical ability.

My personal motivation for selecting this focus is deeply rooted in my journey of growing up with my brother, whose experiences with CP have deeply enriched my understanding of the diverse and unconventional concepts of human movement. The rich, lived experiences of individuals with CP offer profound insights, presenting an alternative perspective on the significance of body and movement, thereby broadening our comprehension and appreciation of physicality in diverse forms. Engaging with the existing literature reveals a dialogue about individuals' perceptions and relationships with their bodies and movements, a conversation that is ripe for deeper exploration. To delve into these nuanced understandings, I will utilize a phenomenological approach in my research. This method will not only allow us to explore the subjective experiences of people with CP but also provide a richer, more empathetic comprehension of physicality from a spectrum of lived realities, setting the stage for a discussion on the philosophical underpinnings of phenomenology and its application to understanding human movement in the context of CP.

Phenomenological Approach

Phenomenological analysis, rooted in the exploration of subjective experiences, offers a profound avenue for understanding the lived realities of individuals with Cerebral Palsy (CP). This approach, as highlighted by Denzin and Lincoln (2011), delves into the personal narratives of individuals, aiming to unearth the meanings embedded within their experiences. By adopting the phenomenological lens, we direct our focus towards the individual's perspective, shedding light on the distinctive challenges and barriers faced by those with CP in their everyday lives, alongside the strategies they employ to navigate these obstacles. Such an approach has illuminated the complexities faced by individuals with CP within PA settings, underscoring the imperative for more inclusive and diverse PA programs (Martiny, 2015a). It enables us to grasp the nuanced ways in which CP affects their participation and enjoyment in physical activities, compelling us to rethink how these activities are structured and delivered. Ultimately, this insight advocates for adjustments in PA programs that are truly accommodating of all abilities, promoting equal access and engagement. Through phenomenological inquiry, I aim to deepen our understanding of CP individuals' perspectives, fostering more effective and empathetic support for their engagement in PA. This paper sets out to explore the nexus between CP and PA from a phenomenological standpoint, drawing inspiration from the philosophical insights of Maurice Merleau-Ponty among others. I endeavor to conceptualize the distinct bodily experiences of individuals with CP in PA contexts, with a particular focus on their experiences of bodily alienation. This exploratory research eschews a hypothesis in favor of a broad, investigative approach.

Incorporating the profound insights of an influential French Philosopher, Maurice Merleau-Ponty, I explore the movement as phenomenon and how it occurs in people with CP. In his foundational text, *Phenomenology of Perception*, found within *Basic Writings* (edited by Baldwin, 2004), Merleau-Ponty asserts the human body as the core of our experiential reality. He wrote:

The body is the vehicle of being in the world, and having a body is, for a living creature, to be interwoven in a definite environment, to identify oneself with certain projects and be continually committed to them. (Merleau-Ponty, 2004, p. 93)

From this quote, we are reminded of the intrinsic link between our physical existence and our engagement with the world around us. Furthermore, Merleau-Ponty's observation that "my body is the pivot of the world: I know that objects have several facets because I could make a tour of inspection of them, and in that sense I am conscious of the world through the medium of my body" underscores the body's centrality in shaping our perception and interaction with our environment (p. 93). These philosophical tenets guide this research's approach to reviewing existing literature that applies Merleau-Ponty's philosophy to the context of CP and PA. By applying his phenomenology to analyze dialogues from individuals with CP, this study aims to bridge the gap between phenomenological theory and the lived experiences of those with CP, particularly in how they navigate and perceive PA spaces.

Thus, this thesis is not merely an academic endeavor but a journey towards reimagining inclusivity in PA through the lens of phenomenology and the embodied experiences of individuals with CP. It seeks to transcend traditional notions of physicality, advocating for a PA domain where everyone, regardless of their bodily conditions, can find belonging, engagement, and fulfillment. In the end, I will provide a practical suggestion to possibly realize true inclusivity in PA culture, that is, to incorporate individuals with disability in mainstream physical education (PE) classes. While recognizing the challenges inherent in accommodating a wide range of abilities, introducing children to the concept of bodily diversity from an early age fosters a more inclusive and empathetic understanding, laying the groundwork for a more diverse and accepting society.

CHAPTER 2

LITERATURE REVIEW

In this section, the literature on physical activity (PA) and physical disability will be reviewed first to understand the current situation in regard to participation and benefits of PA for individual with physical disability. After examining the general population with physical disability, the literature review delves into more specific population: individuals with cerebral palsy (CP). The literature on CP and PA will be reviewed in relation to three topics: 1) barriers and facilitators, 2) peers, and 3) self. The first topic will examine the barriers and facilitators that affect the participation of individuals with CP in physical activity. The second topic will specifically explore the role of peer communities in promoting physical activity among individuals with CP. Finally, the impact of individual factors such as physical limitation and other psychological factors (e.g., self-efficacy and motivation) on the engagement of individuals with CP in physical activity will be investigated. By examining these three topics, I will identify the gap in the literature, which is a need for a further investigation on the lived experience of individuals with CP to better understand how it is like to be in their shoes not objectively but from inside.

Reality of PA and Physical Disability

Physical activity (PA) is essential for the health of individuals with physical disabilities, yet their participation rates are significantly lower than those of the general population (de Hollander & Proper, 2018). In a study utilizing healthcare registration data, de Hollander and Proper (2018) found that individuals with physical disabilities engaged in significantly less moderate-to-vigorous intensity physical activity, demonstrated by a difference ranging from -691 to -200 minutes per week ($p < 0.01$). This issue is not confined to any single region but is a widespread concern on a global scale (Ginis et al., 2021). Therefore, Ginis et al. (2021) call for international efforts to improve accessibility and inclusivity in PA opportunities for people with disabilities. But the reason for the lower participation of individual

with physical disabilities in PA is multifaceted such as physical limitations, inaccessible facilities, and societal understandings.

One of the primary reasons for lower participation rates among individuals with physical disabilities is the physical limitations inherent to their conditions. Martin Ginis et al. (2016) discuss how these physical challenges make engagement in traditional forms of physical activity more difficult. For instance, limited mobility can restrict participation in activities that require a certain level of physical prowess, thereby reducing the opportunities for individuals with disabilities to engage in PA. This is further supported by de Hollander and Proper (2018) noting that the type and severity of disability can significantly impact the level of physical activity, with some disabilities presenting more substantial barriers to participation. For example, people with sensory disabilities were less active among people with physical disabilities due to greater challenges in their body orientation.

Environmental factors, such as inaccessible physical environments and inadequate fitness equipment, also play a critical role in the lower participation rates of individuals with physical disabilities in PA. These environmental factors include inaccessible facilities and lack of inclusive opportunities that are specifically designed to accommodate the needs of those with physical disabilities (Rimmer et al., 2004). Corresponding to this point, Rimmer and Marques (2012) also point out the systemic challenges faced by this population, including the lack of adequately trained staff and specialized programs in fitness centers. These factors highlight the need for more accessible facilities and inclusive opportunities that cater specifically to the needs of those with physical disabilities.

Furthermore, the participation rates in PA among individuals with physical disabilities, particularly children, are influenced by a lack of understanding and support from peers and educators. Youth with physical and sensory disabilities face unique challenges, including societal misconceptions and stereotypes about their capabilities in terms of physical activity (Longmuir & Bar-Or, 2000). Blande and McCallister (1998) highlight the voices of students with physical disabilities, revealing feelings of marginalization in physical education settings due to these societal attitudes. Students with disabilities

frequently encounter negative experiences in physical education, largely due to a lack of understanding and accommodation of their needs (Haegele & Sutherland, 2015). These experiences can significantly deter their participation in physical activities. Moreover, Rekaa et al. (2019) discuss the critical role of teacher attitudes in facilitating or hindering inclusion in physical education. Their systematic review indicates that while some teachers strive for inclusivity, others lack the necessary training or mindset, thereby perpetuating the challenges faced by students with disabilities.

As such, the low participation rates in PA among individuals with physical disabilities result from a complex interplay of factors, including physical limitations, environmental barriers, and a lack of understanding and support from peers and educators. Addressing these challenges requires a comprehensive approach that encompasses improving facility accessibility, increasing awareness and information about PA opportunities, and fostering more inclusive attitudes in physical education and broader society.

Benefits of PA on Physical Disability

Despite the challenges towards participation, there is a growing recognition of the importance of PA for people with disabilities due to various benefits extend across physiological, psychological, and social dimensions, each playing a crucial role in enhancing overall well-being. Washburn et al. (2002) developed the Physical Activity Scale for Individuals with Physical Disabilities, a tool designed to assess and promote activity in this group. This scale is a crucial step towards understanding and measuring the physical activity levels of people with disabilities, thereby aiding in the development of targeted interventions. In the following section, literatures addressing physiological, psychological, and social benefits of PA participation for individuals with physical disabilities are reviewed.

Physiological Benefits

PA plays a pivotal role in enhancing the physical health and independence of individuals with physical disabilities. Research consistently shows that increased PA results in notable improvements in muscle strength, coordination, and overall physical functioning (Bloemen et al., 2017; Dykens et al.,

1998). These improvements are particularly important as they directly contribute to greater autonomy, enabling individuals to perform daily tasks more easily and reducing their dependence on caregivers. Moreover, Malone et al. (2012) highlight the significant perceived benefits of regular exercise, particularly in areas like muscle strength and conditioning. These benefits not only improve physical condition but also act as powerful motivators for ongoing participation in physical activities, underscoring the importance of PA for those with physical disabilities or chronic health conditions.

Beyond the immediate positive effects on physical health, continued participation in PA also serves as prevention of secondary health conditions associated with a sedentary lifestyle, which is prevalent among individuals with physical disabilities. Regular physical activity helps in maintaining a healthy weight, bolstering cardiovascular health, and improving metabolic function. Murphy et al. (2008) stress the impact of PA in reducing the risk of chronic diseases such as obesity, heart disease, and certain types of diabetes, which are more common in individuals with limited mobility. Cooper and Quatrano (1999), further reinforce the long-term health benefits of PA, particularly in reducing the risks associated with chronic diseases. Incorporating regular exercise into daily routines can markedly enhance the long-term health outlook for individuals with physical disabilities, emphasizing the need for PA programs that are both accessible and tailored to meet their varied needs.

Psychological Benefits

The psychological benefits of physical activity (PA) for individuals with physical disabilities are as significant as the physiological ones, profoundly impacting their mental health and overall quality of life. Engaging in PA has been shown to significantly improve mood among individuals with physical disabilities. Hutzler and Bar-Eli (1993) highlight that participation in sports and physical activities leads to positive mood changes, reducing feelings of depression and anxiety. This improvement in mood is attributed to the endorphin release during exercise, as well as the sense of achievement and social interaction that comes with participation in PA.

PA also plays a crucial role in enhancing self-esteem and self-efficacy. Goodwin and Watkinson (2000) emphasize that inclusive physical education and sports participation boost self-esteem in students with physical disabilities. This is echoed by Giacobbi et al. (2008) who note that regular engagement in PA leads to a stronger sense of self-efficacy and personal empowerment. These psychological benefits arise from the mastery of new skills, overcoming physical challenges, and the positive feedback received from peers and coaches during sports and exercise. Such improvements are particularly crucial given the additional mental and emotional challenges often faced by this population.

Furthermore, PA significantly enhances the quality of life and overall life satisfaction for individuals with physical disabilities. Dykens et al. (1998) demonstrate that children and adolescents with developmental disabilities participating in exercise and sports experience improvements in their quality of life. Similarly, Martin (2013) further explores these benefits, emphasizing the positive impact of PA on self-perception and social identity among individuals with disabilities. Engaging in physical activities helps break down societal barriers and stereotypes associated with disability, fostering a more positive self-image and a stronger sense of belonging. This shift in self-perception and social identity is critical, as it can lead to increased confidence and a more active engagement in various aspects of life.

Social Benefits

In addition to physiological and psychological benefits, PA offers significant social benefits for individuals with physical disabilities, enhancing their social interactions, relationships, and overall integration into society. One of the key social benefits of PA is the enhancement of social ties and the normalization of experiences for children and adolescents with physical disabilities. Taub and Greer (2000) discuss how participation in PA serve as a normalizing experience for school-age children with physical disabilities, enhancing their social identity and relationships. Through sports and physical activities, children with disabilities find opportunities for interaction and connection with peers, which are crucial for their social development and sense of belonging.

Inclusive physical education especially plays a vital role in promoting social integration (Goodwin & Watkinson, 2000). When students with physical disabilities are included in physical education and sports, not only does it improve their social skills but also fosters a sense of equality and acceptance within the school environment. This inclusion is essential for breaking down barriers and stereotypes, allowing students with disabilities to form meaningful relationships with their peers. Grenier (2006) takes a social constructionist perspective—“reality” is shaped through social interactions, language, and shared cultural understandings—on teaching and learning in inclusive physical education, emphasizing that such environments promote understanding and respect among all students, regardless of their abilities. Grenier (2006) highlights that students learned to accept and respect the differences through interaction in the inclusive classroom, which reshaped the prejudice towards people with disability and the whole dynamics of the classroom. This understanding is crucial for creating a more inclusive society where individuals with disabilities are valued and respected.

Furthermore, the social benefits of PA extend beyond educational settings, impacting broader societal inclusion for individuals with physical disabilities. Participation in community sports, recreational activities, and organized physical events provides a platform for these individuals to engage with a wider community, fostering social connections and networks beyond their immediate circles. Murphy et al. (2008) highlight the importance of such community-based activities in promoting the social and emotional development of children with disabilities. These activities not only offer a sense of community and belonging but also help in challenging and changing societal perceptions about disability.

Benefits of PA on Cerebral Palsy (CP)

Transitioning from the general benefits of physical activity (PA) for those with physical disabilities, we now hone in on the unique benefits for individuals with Cerebral Palsy (CP). CP presents distinct challenges, making it crucial to tailor PA to meet specific needs. This next section will detail

how PA can positively influence the physiological and psychological facets of life for those with CP, highlighting the vital role that customized PA interventions play in enhancing their quality of life.

Physiological Benefits

The physiological benefits of PA for individuals with CP are multifaceted, with increased muscle strength and endurance serving as a foundational element. The systematic review by Dodd et al. (2002) provides a thorough assessment of strength-training programs, revealing their effectiveness in substantially enhancing muscle capacity for this population. The significance of this enhancement cannot be overstated, as it directly translates into functional benefits, enabling those with CP to engage with their environment more autonomously. Complementing this, the work of Verschuren et al. (2007) demonstrates that tailored exercise regimens lead to improvements in muscular strength among children and adolescents with CP. This increased muscular strength is not merely a reflection of improved physical capacity but is instrumental in enhancing the functional abilities of individuals with CP, thereby fostering greater independence and improving their quality of life.

Building upon enhanced muscular strength, PA also contributes to enhanced motor skills in individuals with CP. Capio et al. (2012) found that physical engagement is closely linked with the enhancement of essential motor abilities, which are foundational to the autonomy and daily functioning of individuals with CP. Concurrently, the systematic review by Dodd et al. (2002) demonstrated that children with CP engaging in regular, structured physical activities exhibited notable improvements in both gross and fine motor skills. These activities, ranging from basic exercises to play-based therapy, can lead to increased motor control, which is essential for performing daily activities.

In addition to muscle strength and motor skills, PA plays a pivotal role in improving postural control and balance for individuals with CP. Verschuren et al. (2014) emphasize that exercise is a key in improving postural stability, which is essential for reducing the risk of falls—a common concern for those with CP. Bjornson et al. (2008) extend this discussion by linking regular PA with improved health status and quality of life due to the benefits of enhanced postural control. The ability to maintain balance

and control posture not only promotes physical safety but also encourages participation in social activities and community life, which are vital for the holistic well-being of individuals with CP.

Psychological Benefits

Engaging in PA is not only beneficial for the physiological aspects of individuals with CP but also positively associated with mental health and emotional well-being, which are crucial components of overall quality of life. Starowicz et al. (2022) conducted a scoping review that highlighted the positive impact of PA on various aspects of mental health among youth with CP, including reductions in symptoms of depression and anxiety, and improvements in self-esteem and overall mood. The psychological uplift associated with regular physical engagement is partly due to the release of endorphins during exercise, but also from the sense of accomplishment, increased agency, and the positive social interactions that PA often entails. These findings parallel to the psychological benefits for more general population of people with physical disability.

Additionally, quality of life and happiness in children and adolescents with CP have been directly linked to their levels of physical activity. The research by Maher et al. (2016) indicates that PA is a strong predictor of enhanced life satisfaction and happiness in this demographic. Specifically, children with CP who participate regularly in PA exhibit more positive moods and report a higher sense of well-being than those who are less active. This link underscores the importance of PA not only as a means of physical rehabilitation but also as an essential element of comprehensive care for those with CP. By promoting PA, caregivers and healthcare providers offer these young individuals a pathway that leads to a more rewarding and enjoyable life, underscoring the holistic benefits of PA that go beyond physical health to include emotional and social fulfillment.

Furthermore, participation in leisure activities, including PA, contributes significantly to the enjoyment and life satisfaction of school-aged children with CP. Majnemer et al. (2008) found that participation in such activities was not only enjoyable for these children but also facilitated social inclusion and fostered a sense of normalcy. Adapted PA, such as dynamic cycling discussed by

Pickering et al. (2013), provides opportunities for socialization and engagement in communal activities, which can be particularly empowering for young individuals with CP, promoting their integration into social networks and enhancing their social identity.

CP and PA—Barriers and Facilitators for Participation

While people with CP receive a lot of benefits (e.g., improved mobility, strength, cardiovascular health, mental health, etc.) from physical activity, they have many obstacles to overcome to participate. Those obstacles are often neglected or simply unnoticeable by people without disability. This section of the literature review explored the barriers and facilitators to physical activity and leisure participation among children with CP from the perspective of children, parents, and caregivers. Below, I will first introduce the barriers that people with CP face, and later discuss how those barriers could, in turn, be facilitators.

Barriers

Individuals with CP face several barriers to participation in physical activity and leisure activities. Lack of accessible facilities, including recreational areas, parks, and gyms, is a common barrier reported in the literature (Conchar et al., 2014; Earde et al., 2018; Longo et al., 2020; Steinhardt et al., 2021). In addition, lack of transportation to and from activities can limit participation (Conchar et al., 2014; Earde et al., 2018; Steinhardt et al., 2021). Lack of adaptive equipment, such as specialized wheelchairs and braces, can also restrict physical activity and leisure participation (Longo et al., 2020; Steinhardt et al., 2021). Furthermore, individuals with CP may experience barriers related to the knowledge and skills of their caregivers and healthcare providers, such as lack of information about accessible activities and appropriate exercises (Earde et al., 2018; Longo et al., 2020; Steinhardt et al., 2021). Besides those external factors, lack of motivation and fear of injury are other common barriers reported in the literature (Conchar et al., 2014). Yet, it is important to note that those internal barriers are highly affected by the environmental factors that are listed above.

Facilitators

Despite the barriers, several facilitators to participation in physical activity and leisure activities have been identified in the literature. Access to adaptive equipment and facilities, such as adapted bicycles and wheelchair-accessible parks, can promote physical activity and leisure participation among individuals with CP (Conchar et al., 2014; Earde et al., 2018; Longo et al., 2020; Steinhardt et al., 2021). Supportive friends and family members can also provide motivation and encouragement to participate in physical activity and leisure activities (Conchar et al., 2014; Earde et al., 2018; Longo et al., 2020; Steinhardt et al., 2021). Knowledgeable and supportive healthcare providers, including physical therapists and physicians, can offer guidance and recommendations for accessible activities and exercises (Earde et al., 2018; Longo et al., 2020; Steinhardt et al., 2021).

As seen, identified barriers including limited access to appropriate equipment and facilities, lack of social support, and negative attitudes towards disability will in turn become facilitators once the problems are cleared. Supportive social networks, accessible and inclusive environments, and easier access to adapted equipment and activities are the key components to promote physical activity among children with CP. Especially, peer support seems to have bigger impact on PA participation for individuals with CP, so in the next section, I will more specifically focus on the effect of peers on participation in PA.

CP and Others—Impact of Peers on Participation

Peer support from family members, caregivers, and other participants has been identified as a potential facilitator for individuals with CP to engage in physical activity and further form a new identity beyond their physical characteristics (Aggerholm & Moltke Martiny, 2017; Pack et al., 2017; Steinhardt et al., 2021). In this section, I will examine the role of peer support in promoting physical activity among individuals with CP as well as its effect on their psychology. By understanding the importance of peer support in promoting physical activity for individuals with CP, we can better design interventions to facilitate participation and improve outcomes for this population.

Family support has been identified as a critical facilitator for participation in physical activity for individuals with CP (Steinhardt et al., 2021). Family members play a crucial role in providing time and financial commitment to ensure the individual with CP can participate in physical activity. However, family members may also be overprotective and limit opportunities for the individual to explore physical activity independently. Steinhardt et al. (2021) found that family members often perceived a lack of accessible and appropriate physical activity options for individuals with CP, which can further limit their participation. It is also financially difficult to sustain participation when the child requires a full support system like one-to-one support. To promote physical activity among individuals with CP, it is important to consider and address the role of family support and the need for accessible and appropriate physical activity options.

The attitudes and knowledge of caregivers towards CP are also critical aspects in promoting participation in physical activity for individuals with CP. Longo et al. (2020) found that children with CP often face barriers to participation due to negative attitudes and misconceptions about their abilities. For example, one child stated, “During physical education class at school, our teacher only cares about what the other kids can do, it seems that she doesn’t see my condition, then she says: ‘You, sit down here! ... because you can’t do that!’” (Longo et al., 2020, p. 196). Caregivers who lack knowledge about CP may unintentionally contribute to these negative attitudes and misconceptions. On the other hand, caregivers who have a positive attitude towards CP and a good understanding of the condition can advocate for their loved ones and help create a supportive environment that promotes participation in physical activity (Longo et al., 2020).

Though family members and caregivers play an important role in the participation of physical activity for children with CP, fellow participants in the activity may have an even bigger impact on their psychology. According to research by Longo et al. (2020) and Earde et al. (2018), the attitudes and behaviors of friends can significantly affect the psychological well-being of individuals with CP, as well as their participation in physical activity. In the study by Longo et al. (2020), children with CP reported

feeling excluded from leisure activities due to negative attitudes from their peers. Fear of failure or shame for being different may also prevent children with CP to join the other kids' play. However, when children with CP had positive social interactions with their peers during physical activity, they reported higher levels of enjoyment and a greater desire to participate (Earde et al., 2018). Therefore, creating inclusive environments that promote positive social interactions among all participants can be a key factor in promoting physical activity participation and overall well-being for individuals with CP.

Studies by Aggerholm and Moltke Martiny (2017) and Andersen and Winther (2023) ensure the positive psychological effects of participating in a physical activity with fellow participants who possess the same disability. Aggerholm and Moltke Martiny (2017) conducted a phenomenological study on a sports camp for young people with CP. The study found that the camp provided a safe and inclusive environment where participants could engage in physical activities without feeling self-conscious or limited by their impairments. The camp also provided opportunities for participants to socialize and form meaningful connections with other individuals with CP. Similarly, Andersen and Winther (2023) conducted a qualitative study on the experiences of young people and adults with CP participating in adapted physical activity interventions with peer communities. The study found that peer communities provided a sense of belonging and support that was essential for the participants' engagement and persistence in physical activity. The participants felt that their peers understood their experiences and challenges and provided motivation and accountability for their participation. These studies suggest that inclusive sports settings and peer communities can effectively promote physical activity among individuals with CP by providing supportive environments and social support that encourage participation and enhance the effectiveness of physical activity interventions.

CP and Self—Embodiment and Lived Experience of CP

While there is a growing body of literature on cerebral palsy (CP) and physical activity (PA), research on the lived experience of individuals with CP is scarce. To date, most studies have focused on the physical limitations associated with CP and the barriers and facilitators that impact participation in

PA. However, the lived experience of individuals with CP encompasses much more than just physical limitations. It includes a complex interplay of psychosocial factors such as self-efficacy, body image, and social support, all of which can influence an individual's engagement in PA.

The way people with CP perceive themselves plays a significant role in their physical activity participation. Hammar et al. (2009) studied adolescents with CP and found that they had a poorer body image than their able-bodied counterparts. As a result, they faced difficulties in self-expression and social interaction, which limited their participation in physical activities. In a study conducted by Hanes et al. (2019), young Canadians with CP felt self-conscious and stigmatized because of their physical appearance and limitations, which negatively impacted their self-esteem and participation in physical activities.

However, involvement in physical activity has been shown to improve self-perception and self-efficacy among individuals with CP. A study by Aggerholm and Moltke Martiny (2017) on a sports camp for young people with CP suggests that participation in the camp improved their self-perception towards their physical abilities and limitations. The participants also reported an increased sense of self-efficacy, which led to a more positive attitude towards physical activity participation. Pack et al. (2017) similarly demonstrated that involvement in Paralympic sports can have a positive impact on the self-perception and identity development of athletes with disabilities. Paralympic athletes viewed themselves primarily as athletes, rather than individuals with disabilities. This shift in identity helped improve their self-image and confidence, and they also felt a sense of belonging within the sports community, which increased their physical activity participation.

As seen, lived experience of people with CP in physical activity is rather dynamic and fluid from person to person depending on their ability. Yet, little attention has been paid to this aspect of the field. Further investigation of the lived experience of individuals with CP is essential to gain a deeper understanding of the unique challenges they face and the potential interventions that can promote PA in this population. By examining the lived experience of individuals with CP, we can develop a more

holistic understanding of their needs and identify the factors that can facilitate or hinder their engagement in PA. Therefore, this paper seeks to develop a conceptual understanding of how individuals with CP experience their bodies in physical activity settings, with a specific focus on the feeling of “alienation” from their bodies that many individuals with CP encounter.

CHAPTER 3

PHILOSOPHICAL ANALYSIS

In this study, philosophical analysis will be used to explore the unique bodily experiences of individuals with CP in physical activity settings, with a particular focus on their self-perception and sense of alienation from their bodies. Philosophical analysis involves the interpretation, clarification, and critical analysis of concepts, ideas, theories, and arguments, so it allows us to gain a deeper understanding of the phenomena (Holowchak & Education, 2002). One type of philosophical analysis is phenomenology. Phenomenology as a method of analysis involves a disciplined and systematic approach to understanding human experience. As explained more fully below, phenomenology attends closely to phenomena as they appear in consciousness while seeking to uncover the underlying structures that shape our understanding of the world. This approach is well-suited to this research question, as it allows for a nuanced and holistic understanding of the lived experiences of individuals with CP. Through philosophical analysis, this research aims to provide a deeper and more comprehensive understanding of the bodily experiences of individuals with CP and their impact on physical activity participation, which can inform the development of more inclusive and effective physical activity interventions.

Introduction to Phenomenology

As a conceptual framework, I will employ phenomenology, or “philosophy of experience.” Phenomenology emphasizes the importance of examining subjective experiences as they are perceived by individuals, rather than focusing solely on objective reality (Husserl, 2012). A simple example to explain this concept is the perception of time. For instance, the duration of a day remains the same whether you are a child or an adult. However, as we grow up, we often feel that time seems to pass more quickly. This is because our subjective experience of time changes, even though the objective reality of time remains constant. Husserl would argue that the essence of our experience of time is related to our consciousness and our perception of the world around us.

Maurice Merleau-Ponty, an influential phenomenologist, emphasized the embodied nature of perception, where the body and the world are intertwined and cannot be separated (Merleau-Ponty, 2004). Merleau-Ponty's *Phenomenology of Perception* underscores that human beings are not simply thinking things that operate independently of the world; instead, we exist as embodied beings that are fully engaged with the world. The body's typical mode of existence is "being-toward-the-world" which always acts against the world as the body perceives the surroundings. And he argued that the basic level of perception is the gestalt, where a meaningful whole emerges as a figure against a backdrop, or the world. In other words, if my body does not exist, I cannot perceive the world so that the world would not exist to me; yet without the world, my body cannot exist either. So, the body and the world are not distinct entities, but rather they are intertwined in such a way that the body serves as the vehicle through which we interact with and experience the world. Thus, our bodily experiences play a critical role in shaping how we perceive and interact with the world around us. As such, Merleau-Ponty calls human beings "body-subject" since our body is the source of experience (Merleau-Ponty, 2004).

The body's engagement with the world forms the core context for how we experience everything around us, but perception of our body itself is unique compared to other entities. The body persistently exists within our perceptual domain, although not all of it can be directly sensed. For example, we cannot entirely perceive our back without aid like someone touching it. Merleau-Ponty explains this unique nature of the body as phenomenon of "double sensations," where touching one hand with the other creates a reflexive interaction between being the toucher and the touched (Merleau-Ponty, 2004). So, the body appears to us both as a subject which perceives the world and as an object which is perceived. And this bodily experiences encompass affective dimensions that go beyond simple cognitive representations—they are felt and lived through. The kinesthetic awareness of our movements provides us with a direct, intuitive sense of motion and position, unmediated by explicit thought. This direct bodily knowledge and its inherent reflexivity highlight

the body's distinct role in our interactions with the world, offering a complex blend of sensations and perceptions that fundamentally shape our engagement with reality.

Merleau-Ponty's phenomenology and the notion of "body-subject" are particularly influential in the field of kinesiology, where the primary focus is on human body and movement. Initial stage of modern Western philosophical thinking was largely influenced by a French Philosopher, René Descartes, and his Cartesian mind-body dualism. The Cartesian dualism believed in the separation of mind and body, placing mind over body as mind controls bodily movement. Kinesiologists' view of the human body and movement at that time was also shaped by this historical thinking of dualism, leading to the mechanistic view of the body which treated the body like a machine. Later on, materialistic view of human body guided by an idea of a German Philosopher, Immanuel Kant, further shifted the attention more towards physiology of exercise and human body. Here, focus of kinesiology research was mostly on the objective view of human body.

However, apart from Cartesian mind-body dualism and Kantian ethics, Merleau-Ponty's notion of "body-subject" brought an attention towards subjective experience of human body again. He notes that "we are the body" and argues that what matters is how we experience the world from our body. His phenomenology not only reassured the importance of kinesiology and human body, but also gave a new scope into the research in kinesiology, where the full attention had been paid merely on the physiological aspects of human body. Phenomenology caused a paradigm shift in the field of kinesiology, as it increased the attention towards the inner, subject experience of athletes, performers, and people who engage in PA. As a result, researchers' interest has shifted towards more holistic approach towards human body and movements. In the next section, some examples of how phenomenology is employed in the kinesiology research will be presented.

Phenomenology in Kinesiology Research

Phenomenology is used in the field of kinesiology to explore and understand the lived experiences related to physical activities, exercise, and body movement. This approach allows

researchers to delve into the personal, lived experiences of individuals, offering insights that might not be captured through more traditional, quantitative methods. By focusing on personal narratives and perceptions, phenomenology enriches our understanding of the human aspects of physical activity and sports.

One of the most prevalent ways of using phenomenology in kinesiology is a qualitative interview to understand the psychological flow state of performance, or the phenomenon of “being in the zone.” Sport psychologists often utilize phenomenology to grasp the essence of this state, which is characterized by a deep immersion and focus in an activity, leading to a heightened state of performance and enjoyment. Hefferon and Ollis (2006) provide a compelling study on professional dancers’ experiences of flow, illustrating how these moments are not just about optimal performance, but also about a profound connection with the activity that transcends ordinary experience. This approach sheds light on how athletes achieve and experience this state, guiding coaches and trainers in fostering environments conducive to flow.

Phenomenology is also utilized to investigate the experience of participating in extreme and dangerous sports such as BASE jumping (Buildings, Antennae, Span, Earth), extreme skiing, waterfall kayaking, big wave surfing and high-level mountaineering. In this realm, phenomenology reveals the intricate relationship between fear, thrill, and personal growth as well as the reason to why athletes engage in extreme sports regardless of risks. Brymer and Schweitzer (2013) shows that extreme sports athletes often engage in these activities not merely for the thrill but for the profound sense of accomplishment and self-awareness that comes from overcoming fear and perceived limitations. Wiersma (2014), in his study on big-wave surfers at Maverick’s, expands on this by showing how these athletes seek experiences of awe and a deep connection with nature, as well as a strong sense of community and belonging with fellow surfers. These insights challenge the traditional view that sees risk-taking in sports merely as thrill-seeking behavior, highlighting the deep, personal growth experiences these athletes undergo.

Phenomenology has also emerged as a powerful methodological approach in sports sociology, particularly in exploring the nuanced experiences of gender through the embodied experiences of athletes. This approach focuses on the subjective, lived experiences of individuals, bringing to light the intricate ways in which the body interprets and interacts with the world of sports. For instance, Allen-Collinson and Owton (2015) explore the intense embodiment of women in physically demanding sports like running and boxing, illustrating how heat and exertion intersect with gendered identities. These sensory experiences contribute significantly to the construction and negotiation of femininity in sports, providing a deeper understanding of the physicality involved. Similarly, studies like those by Berry et al. (2010) and Dimler et al. (2017) focus on young women's experiences in fitness activities, showing how phenomenology can illuminate aspects of self-compassion and body image. These studies collectively highlight the profound impact that phenomenological insights can have on understanding gender through the body in sports, advocating for more inclusive and empathetic approaches to studying PA and its diverse effects on participants.

In the realm of pedagogy and skill acquisition, phenomenology helps in understanding how individuals learn and experience physical movements. Brown and Payne (2009) conceptualize the phenomenology of movement in physical education, emphasizing the importance of experiential learning and the subjective experience of the learner. This perspective is crucial in designing teaching methods and curriculums that are more aligned with the learner's experience, thereby enhancing the effectiveness of physical education. Standal (2016) furthers this discourse by examining how phenomenology can inform pedagogical practices, focusing on the lived body as the primary site of learning and interaction with the world. Standal (2016) argues that the embodiment of skills is deeply influenced by the learners' perceptions, motivations, and interactions, suggesting that educators should consider these factors to facilitate a more profound and holistic learning experience. This approach ensures that the teaching of physical movements is not just a transmission of techniques but an integrated process of personal and embodied discovery.

The phenomenological approach also offers significant insights into the experiences of injury, rehabilitation, and retirement among athletes. Grindstaff et al. (2010) investigate into athletes' experiences of sport injuries and reveal how these events are not just physical setbacks but also deeply emotional and existential challenges that can redefine an athlete's identity and relationship with their sport. This holistic perspective is crucial for developing empathetic and effective rehabilitation programs that address the complete spectrum of recovery. Similarly, the work of Brown et al. (2018) underscores the psychological and emotional challenges athletes face during the transition out of elite sport, offering a deeper understanding of the support systems necessary for successful transition. Their findings highlight the essential role of support systems, including family, coaches, and peer networks, in facilitating a successful and healthy transition, ensuring athletes redefine their self-concept and life direction post-retirement.

Lastly, phenomenology offers profound insights into the experiences of those surrounding athletes, including coaches, family, and peers, and how they contribute to the athlete's journey. Cronin and Armour (2015) delve into community sport coaching, using a phenomenological approach to reveal how a coach's experiences and perceptions directly influence their coaching styles and strategies. This understanding is pivotal in fostering coaching practices that are attuned to the athletes' emotional and psychological dimensions. Building on this, Callary et al. (2015) provide a detailed look into the methodological process of interpretive phenomenological analysis within sport coaching research, highlighting the value of understanding the subjective experiences of coaches. Their work suggests that by engaging deeply with coaches' personal narratives and reflections, researchers and practitioners can gain a richer appreciation of the coaching philosophy and practice, which in turn can inform the development of more personalized and impactful coaching interventions that resonate with both the athlete and the coach's experiences.

As seen, employing phenomenology in kinesiology research provides valuable insights into the lived experiences of athletes, informing more empathetic approaches in sports science. It has deepened

understanding of the psychological states in performance, the transformative nature of extreme sports, and the emotional journeys through injury and retirement. It also offers perspectives on the influence of coaches, peers, and families. This nuanced understanding sets the stage for applying phenomenological methods to investigate the unique experiences of individuals with CP in PA settings.

How to Understand CP Using Phenomenology

Before diving into the analysis, it is important to clarify how phenomenology is used in this research. To understand cerebral palsy (CP) through phenomenology, this research heavily focuses on the deep understanding of the source, *Basic Writings* by Merleau-Ponty (2004), and applying the concept to the existing literature on CP and PA. Literature from other phenomenologists such as Martin Heidegger, Edmund Husserl, and Jean-Paul Sartre, as well as contemporary scholars using their ideas, will also be analyzed as a reference. Unlike traditional empirical research papers which use phenomenology as a qualitative data collection method, this research integrates it as a core conceptual framework to interpret lived experience of people with CP. Below are some example studies conducted in a similar manner.

First, Martiny and Aggerholm (2016) used phenomenology as a conceptual framework to explore the lived experiences of people with CP in relation to self-control in physical activity. They conducted a series of interviews with individuals with CP, focusing on their subjective experiences and how they perceived their own bodies in the context of physical activity. Following their interview, they analyzed the quotes from the participants applying phenomenological lens mainly relying on Merleau-Ponty's *Phenomenology of Perception*. By using a phenomenological approach, they aimed to gain a deeper understanding of the ways in which individuals with CP experience their bodies and how this impacts their ability to engage in physical activity.

Similarly, Sorensen (2005) used phenomenology as a conceptual framework to investigate the phenomenon of the "alien-hand" in individuals with neurological disorders. He used a phenomenological approach to examine the subjective experiences of individuals with the condition,

focusing on how they perceived their own body and the movements of their hand. By using phenomenology as a conceptual framework, he was able to gain a deeper understanding of the subjective experiences of individuals with the condition and how they perceived their own bodies in relation to the movements of their hands.

Following their practice, I will employ phenomenology, specifically Merleau-Ponty's embodied perception, as a conceptual framework to investigate the lived experience of people with CP in physical activity settings upon reading existing literature. Embodied perception emphasizes the role of the body not just as a biological entity but as a fundamental medium through which we perceive and interact with the world. For people with CP, their bodily experiences may differ from those without this condition as their legs and arms are unreliable when it comes to PA. Aggerholm and Moltke Martiny (2017) found that in their study with people with CP at winter sports camp, participants often "talked to" or "yelled at" their legs on the slope. In other words, body parts can be "foreign objects" to individuals with CP. I define this phenomenon as "alienation from the body" and examine throughout this research. By drawing upon Merleau-Ponty's insights into the inseparable nature of the body and the world, I aim to explore the unique bodily experiences of people with CP and how it influences their engagement in physical activities. Through the detailed examination and description of subjective experiences, I hope to gain a deeper understanding of the sense of alienation from the body experienced by many people with CP and how it impacts their participation in physical activities.

CHAPTER 4

PHENOMENOLOGY AND CEREBRAL PALSY

In this section, the lived-experience of individuals with cerebral palsy (CP) will be analyzed by drawing upon Merleau-Ponty's *Phenomenology of Perception*, more specifically, relating to two examples that Merleau-Ponty attempts to unravel, which are: phantom limb and Schneider's case. Existing literature with quotes from individuals with CP was collected and analyzed paralleling to the phenomena observed in the two conditions above. Comparing to the two phenomena which will be discussed later in details—phantom limb and Schneider's case—CP is a unique condition in which patients' limbs appear to them as semi-functioning in a traditional bodily notion yet fully functioning in a different way than those of people without physical disabilities. The uniqueness derives from the nature of CP as a chronic, congenital condition. In other words, unlike the cases of patients with phantom limbs or Schneider, individuals with CP does not think their limbs are malfunctioning—for them, “it is what it is,” and therefore, natural to them as much as our limbs are for us. Thus, by understanding their perception towards their own body and movement, I aim to realize a new possibility of physical activity that is not constrained by a stereotype, and ultimately, fill the gap between the understanding of people without physical disability towards people with CP and the reality that people with CP is experiencing. Merleau-Ponty's notion of “freedom,” which he states as “the choice which we make of our life is always based on a certain givenness” (Merleau-Ponty, 2004) will at the end open up the conversation towards this goal.

Merleau-Ponty's *Phenomenology of Perception*

In *The Phenomenology of Perception*, a key work by Maurice Merleau-Ponty included in his *Basic Writings* (edited by Baldwin, 2004), Merleau-Ponty presents a detailed exploration of human perception and experience and how these reveal our existence in the world, or “being-in-the-world”. This work is particularly influential in the field of phenomenology, as Merleau-Ponty challenges traditional Cartesian dualism, which separates the mind and body, or psychic and physiological in his

words, and instead posits the concept of humans as “body-subjects,” which exist in the world through our movement.

Merleau-Ponty’s argument centers around the discussion towards human “existence” in the world. He refutes both the Kantian ethics of human beings as mere objects in the world (physiological) and Cartesian philosophy which puts mind over body (psychic), and claims that “they are no longer distinguishable respectively as the order of the in-itself, and that of the for-itself, and that they are both directed towards an intentional pole or towards a world” (Merleau-Ponty, 2004, p. 98). That is, to exist is to act towards the world, or have a relationship with the world with one’s action. The body is a “frontier” of this phenomenon which creates our relationship to the world through movement since we only can exist *in* and *from* our body. To support his argument, he employs two concrete examples: the phantom limb and anosognosia. The phantom limb is a phenomenon where an amputee still feels the existence of his/her amputated limb through pain and discomfort regardless of its absence. On the other hand, patients with anosognosia fail to receive the signal or sensations on their limbs despite its actual existence due to neurological deficiency or brain dysfunction. If human body is either physiological or psychic, neither of the phenomena of phantom limb nor anosognosia can be explained.

According to Merleau-Ponty (2004), “Anosognosia and the phantom limb lend themselves neither to a physiological nor to a psychological explanation, nor yet to a mixture of the two, though they can be related to the two sets of conditions” (p. 91). In case of anosognosia, the corresponding limb physically exists in the world, but the subject fails to recognize it as a functioning limb due to lack of sensation. The patient describes their paralyzed arm as “a long, cold snake,” which is detached from their body (Merleau-Ponty, 2004). It is physiologically existing “in-itself” yet psychologically absence for the patient. Similarly, phantom limb shows an opposite phenomenon, where the limb physically does not exist in the world but perceived as though it exists to the subject. The patient, in a sense, refuses the absence of their missing limb. However, relying on psychoanalysis, Merleau-Ponty points that we only can refuse the absence by fully accepting the absence. It is impossible to avoid the painful reality

without knowing what one wants to avoid. In case of phantom arm, the patient does not want to face the reality of not having a right arm, and the previous knowledge of having it allows the subject to reconstitute the sensation of having it. As such, “phantom arm is not a representation of the arm, but the ambivalent presence of an arm” (Merleau-Ponty, 2004, p. 92). Although neither of the physiological nor psychological explanation succeed to demonstrate human existence in the world, these two phenomena lead us to a new realization: our existence is in the action that relates to the world. In other words, we are “body-subjects” that realize our existence with bodily movement acted towards the pre-existing objective world.

To explain the importance of movement, Merleau-Ponty introduces the case of Schneider, a German World War I veteran who acquired apraxia, a neurological disorder which incapacitates the patient from planning or explaining an “abstract” movement despite his ability to perform a “concrete” movement represented by the same motor control. For instance, Schneider had no problem with performing a “concrete” movement such as swatting a mosquito on his skin. However, he was unable to perform “abstract” movement involved in the same motion such as “raising a right arm above his head” before hitting a mosquito, or pointing the spot in his skin where he was touched with a ruler by the doctor. As an explanation, Schneider comments that

I experience the movements as being a result of the situation, of the sequence of events themselves; myself and my movements are, so to speak, merely a link in the whole process and I am scarcely aware of any voluntary initiative... It all happens independently of me. (Merleau-Ponty, 2004, p. 108)

The performance of “concrete” movement can partially be explained as a reflex; pre-established motor circuit was fired by the need of swatting the mosquito without cognitive intervention. However, there is no significant physical difference in the two motions of pointing the spot on the skin touched with a ruler and scratching the spot stung by the mosquito. Why is “pointing” not possible while “scratching” is possible? The simple explanation is that the action of pointing is a movement merely for itself while

scratching is for a phenomenal purpose, which is to relieve an itch. This phenomenal action creates a relationship with the world, and ultimately, grants the existence to our body in this physical world.

The notion that further helps explain the importance of movement is “intentional arc,” which is metaphorically described as “a searchlight” that directs our attention towards our future or past, physical or ideological situation. Merleau-Ponty (2004) insists that motility is the most basic intentionality because it allows us to enter into a relationship with objects. For example, when hairs touch our skin, that movement directs our intentional arc towards the spot being touched. In the same way, when we attempt to swat a mosquito, we are acting towards an object—mosquito—and having a relationship with the outer world existing around us. Motility is specifically important as Merleau-Ponty (2004) suggests that

We perform our movements in a space which is not ‘empty’ or unrelated to them, but which on the contrary, bears a highly determinate relation to them: movement and background are, in fact, only artificially separated stages of a unique totality. (p. 122)

Furthermore, movement is particularly significant as he mentions that “even in the normal person the perception of the body and of objects in contact with the body is vague when there is no movement” (Merleau-Ponty, 2004, p. 111). When hair touches our skin, first we can feel the sensation of being touched, but as hair and the skin remain in contact, we lose the sense of “being touched”. In short, “the body is our general medium for having a world,” and movement is what creates the world for us by dictating the direction of our intentional arc (Merleau-Ponty, 2004, p. 123).

As much as Merleau-Ponty insists the significance of our body and movement, he also emphasizes the existence of the physical world before us. The world does not exist to a subject without the subject existing, but the subject also cannot exist in the nothingness. Merleau-Ponty (2004) puts this as “To be born is both to be born of the world and to be born into the world” (p. 230). It is a collision of two worlds, and as such, the subject and the world are complexly interdependent. However, Merleau-Ponty still overweigh the premise of having the physical world beforehand. He claims that “We can achieve freedom only when we understand the world in which we have been living and from which we

can never completely escape” (Merleau-Ponty, 2004, p. 209). There need to be a “field” for one to exist, and there need to be a “constraint” for one to be free. Therefore, our freedom is premised on the precondition that is given to our birth, such as being a male or having a physical disability.

These concepts explained so far—body-subject and movement, phantom limb and anosognosia, Schneider’s case, intentional arc, and freedom preconditioned by a givenness—are specifically relevant to unpack the lived-experience of individuals with CP. Phantom limb and anosognosia present an interesting comparison with CP as the experience of having CP indicates a kind of middle ground between phantom limb and anosognosia. For people with CP, their limbs are physically there and sensible, yet not fully manipulatable. Their intentional arc and the phenomenal function trigger their movement and action towards the world, yet their limbs are not fully responsive as they do not move accordingly with their will. Similarly, Schneider’s case may help explain the emergence of their other body parts as alternatives of their affected limbs. That is, to respond to the situation and need of action, people with CP often use other body parts to accomplish the phenomenon. For example, my brother who possesses CP regards his arms as his “front legs” and crawls around instead of walking because his legs are not fully functional as traditional notion of legs. Yet, his body as a whole completes the movement and acts towards the world in the same way as people with no disability do. The most interesting part is what occurs when they turn their intentional arc towards their own body; does it feel more like a part of their body or feel more alienated? Due to its congenital nature, people with CP perceive their body as both alienated and integrated. The body may appear as non-manipuletable and foreign to them, but that whole experience is integrated because they are experiencing it for their life time. CP as a congenital preconditioned disability helps us realize a new way of movement as their freedom of movement and existence is premised with the existence of their disability. They have no other alternative reality, which is, freely using their limbs without difficulties. Still, they can freely choose to move in their own ways that satisfy the same phenomenological purpose such as getting to a destination or grabbing an object. Their invention of their accommodated movement is a hint to realize a new possibility of human

movement and physical activity. Therefore, to fully understand their experience, unique bodily experiences of individual with CP will be analyzed in comparison to phantom limb and anosognosia, and Schneider's experience in the following sections. Simultaneously, this analysis opens up the limitations and the possibility of this application.

Bodily Perceptions in Cerebral Palsy: The Alienation and Integration of the Body

Two conditions that troubled the traditional mind-body relationship: phantom limb and anosognosia give us an interesting departure to understand the experiences of individuals with CP. While patients of both phantom limb and anosognosia either experience false sensation of missing limb despite its absence or fail to receive somatic sensation of their limb despite its presence, an individual with CP has the experience between them. Unlike people with anosognosia, people with CP sense and acknowledge the existence of their limbs and regard as somewhat manipulatable. They do have their limbs physically attached to their body, yet do not have the sensation or connection to it as vividly as people with phantom limbs do. Then, what are limbs to people with CP? Using Heideggerian term, are they "ready-to-hand" or "present-at-hand"?

In his seminal work *Being and Time*, Martin Heidegger delves into the concept of *Dasein's* (human being's) engagement with the world through three modalities: ready-to-hand, unready-to-hand, and present-at-hand (Heidegger, 2010). Ready-to-hand describes our primary mode of encountering tools and equipment, where they recede into the background as we focus on the action at hand. A hammer, for instance, fades into the activity of hammering. Unready-to-hand arises when equipment malfunctions or disrupts our activity, forcing us to attend to its material properties (e.g., the broken hammer as an object with weight and shape). Finally, present-at-hand describes a detached, theoretical observation of entities independent of their practical use (e.g., studying the hammer's composition in a lab). For individuals with CP, their own arms and legs often impede their activity. Heidegger premised

that our body is always “ready” to use tools for our activity. However, what if our body itself is not available to use the equipment, or even to freely move?

Interestingly, for individuals with CP, their own arms or legs could appear as all three modes of existence. For example, their legs generally exist as ready-to-hand for the purpose of walking. However, their legs would not completely disappear in the background; they require a constant monitoring and adjustment otherwise they will turn into unready-to-hand state. HJ, a participant of the research conducted by Martiny (2015a) calls his experience with his limbs as “reaction” as he needs to react against unexpected movement that his own body produces (p. 558). LJ, another participant of his research, also comments that “The expression ‘walking with your head’ fits nicely with the fact that, if I’m just walking and you were to say my name or something, then I’d almost fall” (p. 563). A participant of his different research, NJ uses the word “uncertainty” and “disbelief” when describing his experience with performing an action since there is a “divergence between what he wants to do, what he can do, and what he does” (Martiny, 2015b, p. 129). As such, the relationship between individuals with CP and their own body is dynamically changing between ready-to-hand and unready-to-hand. At the same time, some body parts could also appear as present-at-hand. HJ, a participant of the research by Martiny (2015b) reveals that there are certain movements that he does not know how to make, such as moving his foot upwards (p. 127). In this case, it is plausible to say that his foot is alienated from his body and existing present-at-hand since he has no control over it. For some patients with severe CP, their limbs generally exist as present-at-hand since they do not have control over their affected body parts.

Although there are individual differences based on the severity of their disability, it is commonly identified that the people with CP feel that their limbs are uncontrollable. Our traditional notion of limbs as people without disability is fully controllable to accomplish our phenomenological purpose. In fact, limbs are the main tools that we use daily to accomplish our tasks. However, for people with CP, the limbs are not reliable source of movement. Rather, their limbs could be a source of frustration because

they prevent them from accomplishing the daily tasks. More than how I get frustrated by my car not starting its engine when I decide to leave for work, people with CP are always frustrated with their own limbs not coordinating with their will. Their limbs are part of their body, but not perfectly manipulatable as our body parts should be. So, individuals with CP feel a bit of emotional distance to their limbs as if they are not their own. I call this “alienation of the body” and try to understand the phenomenon throughout this essay using the comparison to phantom limb and anosognosia.

CP surely presents similarity with both anosognosia and phantom limb at a certain degree—vagueness of the connection—but it is significantly different from them due to chronic pain associated with their muscle stiffness and movement limitation. Despite the weak sense of ownership towards their limbs due to lack of control, functional unreliability, and neurological disengagement, pain is always existent to people with CP. Because of its congenital existence, they even normalize the pain and discomfort. In a sense, the pain is what connects individuals with their limbs by assuring their presence with unpleasant sensation. Even though they are not controllable, they assure that they possess their limbs with their sensation of pain stemming from their relationship with their arms and legs. Yet, as existing literature suggests, lack of controllability and constant pain steer away individuals with CP from physical activity and movement itself. So, in this section, I will investigate what body means to individuals with CP using comparison with anosognosia and phantom limb while paying special attention to the phenomenon of alienation of the body and normalization of pain. Various phenomenological concepts such as phantom limbs, phenomenology of pain, and sense of agency (SoA) reveals that individuals with CP perceive their body both as alienated and integrated.

Alienation of the Body

The sense of alienation from the body stems from three reasons: 1) lack of control, 2) functional unreliability, and 3) neurological disengagement. When things are not manipulatable, they feel much more foreign to us. Having a control over our limbs is an important premise to act towards the world outside. Yet, individuals with CP often express the inability to control their limbs according to their will

due to their disability. This lack of control leads to unreliability towards their own body to perform a movement. Since they do not have a full control over their body, they often hesitate to engage in the movement such as walking for a long distance in case their body gives up all of sudden in the middle and causes them to fall to the ground. Such relationship with their body is a result of neurological disengagement caused by their unique disorder, CP. Individuals with CP are unable to establish the neurological circuit to control their posture, balance, and coordination, and therefore, have difficulty managing their bodily movement.

Based on the types of CP—spastic, dyskinetic, and ataxic—individuals with CP suffer from different types of uncontrollability of their body and movement, which leads to the detachment from their limbs. Spastic CP makes it harder for patients to contract their muscles and initiate the movement due to stiffness and tightness of their muscles. People with dyskinetic CP experience unintended jerky movements suddenly occurs out of their control while individuals with ataxic CP struggles to balance and coordinate their body in general. Although each type of CP causes frustration in different ways, it is prominent that all types of CP prevent patients from taking full control over their bodily movement as many patients with CP express their wish to have ability to control their limbs. For instance, participants of study conducted by Longo et al. (2020) identified their structure and functionality of their upper and lower extremity as the biggest barrier towards PA participation and showed a desire to have a “new legs and hands” to engage in more physical activity.

When individuals with CP reveal their relationship with their limbs, they emphasize the unpredictability of their movement and bodily capacity. Particularly, individuals with dyskinetic CP who experience sudden jerky movement use words like “contrary arm,” “blender body,” “jumpy movements,” “tricky body day” to describe their bodily experience (McKinnon et al., 2020). Participants of research by Brunton and Bartlett (2013) also indicated that it is impossible to predict their own behavior of muscles and body in general. Travis, one of the participants of their research expressed like this:

I don't know when my balance is going to go—let's say if I'm on a walk and it's been long, I can tell that my balance is going to take a swing, because after a long period of time my legs get tired and that's usually when...I either have to hold on to a tree or I have to just tell my family that I need to sit down because I'm going to lose my balance. (p.25)

They also experience the difference in their condition and capacity day to day and within a day. Even on a good day where they can control their body well and participate in PA, they often experience the sudden loss of control over their body.

Due to the unpredictability, individuals with CP often regard their body parts as foreign objects apart from themselves. Patients with CP, in the research of Aggerholm and Moltke Martiny (2017) “talked to” or “yelled at” their own limbs to control them. Signe, a participant of their research described her relationship with her legs as follows:

Many times I also spoke to my legs, because my legs don't really want to do what I want... and I think that when you say it out loud, it helps your body to obey... It wasn't always that they [her legs] would obey. (p.368)

When we intend to accomplish a task—for example, picking up a coffee cup—we generally do not talk to our arm because it is totally under our control most of the time. Even before thinking of lifting the right arm off the table, my arm is already trying to reach the cup. However, in case of CP as we can analyze from the patients' comments, their limbs act like a mediator to accomplish a task. It might be much like using a controller to move a claw crane to pick up the object; they enter the command to lift the right arm, reach the coffee cup, and close their fingers to grab the cup. Their movement is not as precise as they wish to be and often hinders their performance. As we all experience, it is much harder to grab objects using a claw grabber than using our own arms. This experience of being unable to freely control their limbs creates a detached feeling of their body from themselves and leads them to regard their limbs as foreign objects. Because they cannot control their movement, they do not trust their body as a vehicle to carry out the movement. Such distrust creates a psychological distance between their limbs and themselves. Limbs are “theirs, but not theirs” so that they dissociate themselves.

However, although they sometimes objectify their limbs, they do not regard them as completely foreign. They still recognize that their limbs are attached to them and consider them as parts of their body. This account is significantly different from the experience of patients with anosognosia who completely loses the sensation of their paralyzed limb and ignores the existence of it. Merleau-Ponty (2004) claims that patients with anosognosia not only fail to perceive the sense of being touched, but also completely disregard their existence of their paralyzed limb in a refusal to recognize their disablement. For instance, when a patient was asked to raise her paralyzed right hand, she held out her left hand instead because she cannot feel her right hand. On the other hand, individuals with CP still have a sensation of their limbs and at least try to manipulate them. There are also certain levels of numbness on their limbs which makes it harder for them to recognize the contact with the foreign objects. For example, my brother who possesses CP struggled to identify where I touched on his feet because, as he says, “my feet are kind of numb.” Yet, he was still able to tell that his feet were being touched. Although they are bit distanced from them, their limbs are still there with them. In this sense, it is plausible to say that limbs for people with CP are part of their body regardless of its occasional alienation.

Then, how is it compared to phantom limbs? The phenomenon of phantom limb occurs when the patients expect the movement or sensation on their missing limbs because their nerve system gets activated. When the patient with an amputated right arm decides to grab a coffee cup on her right side, her brain sends the signal to her neurological path to the missing arm so that she feels the existence of it even though her right arm is not physically there. Merleau-Ponty (2004) describes this phenomenon as a sort of “memory.” He mentions that “To have a phantom arm is to remain open to all the actions of which the arm alone is capable; it is to retain the practical field which one enjoyed before mutilation” (p.93). It only occurs because she has a memory of having her right arm and remembers how it feels like when moving it or it being touched and what it was capable of doing. Now, even though their sensation of having their amputated limb is as vivid as they used to be, of course they cannot manipulate them

since there are no physical existence. CP is unique in this account because the condition exists from their birth. Because they have been dealing with their condition since the beginning of their lives, they do not have an alternative experience of moving their limbs as freely as they wish. Although the factual uncontrollability is similar, their sensation of it is different. They might have an objective idealistic image of how their limbs should function, but their limbs are functioning as they ought to be per their lived-experience.

Limbs to individuals with CP is, then, a dynamic relationship of being foreign and internalized. For someone with CP, the limbs often do not act as mere extensions of the will but rather as independent entities with their own unpredictabilities. They can obstruct movement, resembling foreign objects that need to be consciously managed or manipulated, similar to operating a claw crane where precise control is necessary but often elusive. This aspect of their experience highlights the limbs' role as both tools and obstacles, demanding a constant negotiation between intention and action. However, this very experience of struggle and negotiation with one's own body parts is normalized and internalized by individuals with CP. Through phenomenological analysis, it became evident that this normalization arises not from a resolution of the difficulty but from its constant presence. There are no alternative experiences for comparison; the continuous interaction with uncooperative limbs is a fundamental part of their being. Thus, phenomenology allowed me to see how this persistent challenge becomes an accepted, even owned, aspect of their identity.

Now, besides the consistency of uncontrollability, there is another life-long burden that people CP continue to face throughout their lifetime, which is pain associated with their disability. Though such pain and discomfort surely annoy individuals with CP, that annoyance also becomes "normal" due to its persistency. The experience of pain is also unique compared to anosognosia and phantom limb as it is absent to these two conditions. Thus, in the next section, I will examine the experience of people with CP in terms of constant pain to unpack how those pain alter their relationship with their body and attitude toward movement and physical activity.

Chronic Pain

Chronic pain is common for individuals with CP. Systemic review by Mckinnon et al. (2019) revealed that between 14% and 76% of children and young adults with CP suffer from long-term or chronic pain occurring on a daily basis. Such pain is a result of spasticity, a main issue with CP which causes increase in muscle tone, twitching, and resistance to stretching due to descending of motor pathways (McKearnan et al., 2004). Schwartz et al. (1999) reported that two thirds of their research participants complained about chronic pain, and most of them were coming from lower extremities or lower back. About 53% of their participants also expressed that the intensity of pain is moderate to severe, and it is impossible to ignore. Participants say that they have done and are willing to do everything to relieve the pain, but as represented in Matt's word, "sometimes it won't go away, it will just stay there" (Castle et al., 2007, p. 447). While patients are constantly fighting against the pain, they also often normalize the pain. CJ, a participant of research by Castle et al. (2007) commented that "my body got used to the pain being there all the time. It just felt normal" (p. 447). McKinnon et al. (2020) also discovered that pain and discomfort has been persistent for children throughout their life, as a comment from Child C reads as "oh a long time, I can't remember how long" (p. 8). The congenital nature of CP and pain associated with their disability poses an interesting relationship between the subjects and their body. But before diving into the analysis of their lived-experience with congenital pain, it is worth reviewing the phenomenological account of illness by a French phenomenologist, Jean-Paul Sartre as it is frequently quoted when analyzing pain through phenomenological lens.

Sartre (1956), in his *Being and Nothingness*, presents the first-person experience of pain and illness with different phases: 1) pre-reflective "lived pain," 2) descriptive "suffered illness," 3) "disease" constituted with knowledge and perspective of others, and 4) "disease state" where the symptom is diagnosed as a medical fact. In the pre-reflective state of lived pain, for example, the action of reading a book is disturbed by headache. The pain is not a sensation in the head, but an inseparable quality disrupting our focus and engagement with the text. But when we reflect on this pain, it transforms into

an object of our attention—*psychic object* of “illness” in Sartre’s term, which is an entity with its own history and potential trajectory. Now, if we are to describe the intensity or sensation of this headache to a third person, we constitute the experience with the “disease” by including knowledge and perspectives of others. Often, this third person is medical personnel who provides diagnosis and prescription, which adds a label to the phenomenon of headache and escalates the status into a “disease states.”

Nevertheless, this discomfort—illness or pain—is what brings our body to the front of our conscious awareness. Experiencing pain initiates a process where the body becomes increasingly unfamiliar and difficult to manage. This sense of “alienation” stems from the body’s display of uncontrollable and foreign aspects, undermining the individual’s sense of control over their physical self. Juggling Sartre’s *psychic object* and Merleau-Ponty’s *body-subject*, Svenaeus (2015) puts this way:

Illness makes us feel our own bodies: it reveals the body to us in different painful ways, through making it heavy, stiff, hot, nauseated, plagued by pain, twists, jerks, shivers, etc. This facticity of the body is the result neither of the gaze of the other person, nor of a “reflection” adopting the outer perspective of the other person in an indirect way, but a result of the very otherness of one’s own body which “makes itself known” to us as an experience of suffering. (p. 114)

This notion of body alienation corresponds to the previous section of this essay: individuals with CP experience the body parts as foreign objects due to their uncontrollability. However, pain also brings us back into our body through the experience of suffering. In case of chronic pain, as Svenaeus (2015) suggests, the lived body actively searches for ways to escape its ongoing suffering; yet, these attempts to find new meaning and relief are continuously unsuccessful, forcing the body back into a confrontation with its own pain. Pain is what brings us out of thrownness of having the body, but also puts us back into the thrownness of having pain, all through the bodily experience. However, is it still true for the case of congenital pain like CP’s? When pain has always been existent, can’t it be normalized?

The notion of normalization of pain (exemplified in the comments from CJ and Child C above) is worth reviewing because there is a dilemma between unavoidable chronic stress that bothers them vs. acceptance of pain existing all the time. Due to the consistency of the pain, it became “normal” for them

to have pain as much as it is for them not being able to move their limbs freely. TV, in the interview with Martiny (2015a), commented “[l]iving with CP...that’s difficult to describe, because I’ve never tried anything else. In other words, what I experience I’ve always experienced” (p. 557). Likewise, pain has always been there for them as far as the spasticity exists. Additionally, individuals with CP often seem to be giving up for fighting against the pain because there is not much that they can do about it. Castle et al. (2007) points that all participants of their research showed despair and frustration because no treatment has worked to reduce their pain and it only gave them temporary relief. However, despite that they are used to having pain on their body, there is an unchangeable truth: it hurts and bothers. Child C from the research by McKinnon et al. (2020) described her experience with pain like a “crash with [a] rubbish truck” while Child A dealing with his back pain states as “bones were breaking” (p. 9). Danielle, a participant of the research by Brunton and Bartlett (2013) illustrated the pain as if the shoelace is getting tighter and tighter and aches muscles. Chronic pain is even a bigger issue for the aging population. Tom, a participant in the research by Horsman et al. (2010) acknowledged that increase in muscle pain and stiffness as well as the magnitude of such change is greater because of CP. Another participant described that she feels like a 65-years-old while only being 37. Even though the chronic pain associated with CP is “normal” to them, it is not something that they can easily ignore. Rather, it would occupy their thoughts and intervene their everyday life.

Now, let us compare the pain in CP with the experience of anosognosia and phantom limb. There is a significant difference between CP and anosognosia because patients with anosognosia do not perceive pain as they have no sensation on their paralyzed limb. People with phantom limb, however, do feel the pain when they perceive the sensation of being hit on their phantom limb. Yet, it only occurs when they have a stimulus registered into their brain. Without the movement or action of someone hitting their phantom limb, or unless the subject perceives that way, patients with phantom limb do not feel the pain on their missing limb. They may also experience pain by remembering the moment of amputation or previous injury on their missing limb, but again, their pain is fully conditional. On the

other hand, pain in people with CP is unconditional. They are always experiencing the pain as such they feel normal to have the pain. Some patients do not even remember their life without pain on their body. In other words, the pain is fully internalized as it is always with them.

This notion of chronic pain somewhat contradicts the sense of alienation. Legs, for example, feel alienated from individuals with CP because they are non-manipulatable when they walk. When their legs do not obey their will, they appear as unready-to-hand in Heideggerian term since they do not function as walking tools, and thus, become foreign to them. However, such non-manipulatable legs give them a constant, vivid pain. Merleau-Ponty argued that human body-subjects experience the world through movement in a way which phantom limb becomes prominent with the intention of using it, but pain for individuals with CP does not accompany with action. Regardless of movement, people with CP constantly feel the pain always existent to them. Then, are their legs alienated or internalized?

For people with CP, both the experience of alienated limbs and internalized pain in total is their lived experience and form of life. That is, having legs non-manipulatable is how their legs are. Perhaps, they are not alienated but “seem” alienated from other perspectives because they are talking to their own legs. But this action of talking is just another form of people without CP sending unconscious neurological signals to their legs to move. It is simply a different mode of input, and response is not as efficient as it should be. Similarly, constant pain perceived on their corresponding muscles or joints objectifies the body presenting it as a source of unpleasant bodily experience. While the consistency of this experience throws the experience of having pain itself into a background, the suffering from the pain also strengthens the connection with the body. The notions of alienation of the body and chronic pain combined, the body is foreign object that is non-manipulatable (not moving well and causing pain), yet the whole experience of having such trouble is normal and internalized. In such situation, the bothersome pain strengthens the connection to the body and awareness towards its existence.

Yet, one thing that is consistent to them is that they are unable to control. They are unable to control their body to create the movement that they imagine and unable to remove their pain from their

limb. Such uncontrollability would cast a question of one's "sense of agency" which Gallagher (2006) defines as "a sense of being the initiator or source of a movement, action, or thoughts" (p. 173). When their body is not under their control, how does it affect their sense of agency towards their movement and body? The answer to this question will help us understand what the body is to people with CP, so it will be pursued in the next section.

Uncontrollability and Sense of Agency

One theme that arises as common experience in individuals with CP is sense of uncontrollability. Alienation of the body occurs because patients feel unable to control their own body as their own. Similarly, even though the chronic pain is present all the time, the intensity fluctuates throughout the day without their control. Such unavoidable pain also makes them feel powerless as they have no solution to relieve their pain. Yet, controllability is an important premise to feel the Sense of Agency (SoA). SoA can be simply described as the feeling of being the originator and controller of one's own actions (Gallagher, 2000). It involves the experience of oneself as the causal force behind choices and movements. And Gallagher (2006), using the examples of patients with schizophrenia and phenomenon of reflex, claims that SoA is absent when experiencing movement without initiating the movement. This description fits well in case of CP: unexpected movement caused by their muscle spasticity is experienced without their intention, or at least outside the degree of their intention to move (e.g., speed, force, direction, etc.). Contrary though, their SoA also can be disrupted from the absence of actual movement or the response to the signal. For instance, even when the subject attempts to move their toe upwards, their corresponding body parts do not respond to create the movement. How, does such uncontrollability and unreliability of the body affect their SoA?

SoA is often explained by using the comparator model (Martiny & Christensen, 2015). This model posits two internal representations within the motor system, likely located in the cerebellum: the inverse model and the forward model. The inverse model acts as the motor output mechanism, transforming intentions into executable commands. For example, when trying to reach a cup of coffee

on the table to take a sip, the inverse model within the brain acts as a translator, converting the desired outcome (grasp the cup and bring it to my mouth) into a meticulously orchestrated sequence of neural signals. These signals govern the path of our arm, the shaping of our hand to match the handle, and the precise force required for lifting. Conversely, the forward model anticipates future motor states using an efference copy of the motor command. Consider reaching for a coffee cup: before your hand even makes contact, the forward model generates a prediction based on the planned movement. This predictive signal, termed the “corollary discharge,” facilitates the motor system’s capacity to differentiate self-generated (re-afferent) sensory consequences from those initiated externally (ex-afferent). For instance, the feeling of the cup’s warmth against your skin is expected (re-afferent), unlike an unexpected bump from someone else that might shift your arm (ex-afferent). When the forward model’s prediction aligns with the actual sensory data, this agreement reinforces the feeling that the action is your own, contributing to the experience of the SoA (Gallagher, 2000).

However, as Martiny and Christensen (2015) suggest, there is no motor comparison in the movement of individuals with CP. Spasticity, a hallmark of most cerebral palsy cases, occurs when damage to specific brain cells disrupts the signals controlling muscle movement. This disruption leads to excessive muscle activity, noticeable as overly strong reflexes and increased muscle stiffness (Dietz & Sinkjaer, 2007; Sheean & McGuire, 2009). At the same time, based on the location, size, and timing of the brain damage, individuals with CP might experience difficulties with proprioception (sensing their body’s position and movement), coordinating perception and action, accurately integrating vision and body-awareness information, discerning fine details through touch, and sensing their overall joint position and bodily movement. Thus, according to Martiny and Christensen (2015) “both the efferent and afferent signals and the processing of these signals seem to be disturbed in CP, and spasticity can generally be seen as one characteristic feature of this disturbance (p. 98).”

To understand SoA in more concrete sense, the comparison between individuals without disabilities and individuals with CP would help. Individuals without disabilities typically experience a

seamless integration between their intended actions and their bodily execution. When initiating a movement, such as reaching for a cup, their body follows through smoothly, providing the expected sensory feedback. This congruence between intention, action, and feedback reinforces their SoA, fostering a feeling of being in control and capable of influencing the world around them. This experience aligns with Merleau-Ponty's notion of the "transparent" body, where the body acts as a reliable tool for engagement with the world, receding into the background as we focus on our actions and their outcomes. In contrast, unpredictability of body and movement take the SoA away from individuals with CP. MS, in the interview with Martiny and Christensen (2015), used the word "involuntary" when describing his uncontrollable intensity of his action (p. 100). Martiny and Christensen (2015) analyze the responses from the other participants and claim that "they experience 'a resistance in their movements', they 'have stiffness in their movements', their 'body is weighing them down' or their 'body is working against them'" (p. 100). It is difficult to have SoA when their own movement is not performed according to their will. And this disruption in SoA can lead to a phenomenological shift characterized by feelings of frustration, helplessness, and even alienation from their own bodies. The body, instead of being a transparent tool, becomes an uncertain and unreliable source of experience, hindering their ability to confidently engage with the world.

However, the uniqueness of CP is, again, its congenital nature. Even the experience of the unpredictable movement is also, in a sense, premised for individuals with CP. JN, a participant of the research by Martiny and Christensen (2015) comments that

I have gotten used to my body being uncertain, so, by contrast, I would say that I experience being in full control of both my body and thoughts in the way that I have become more aware of how my body works. (p. 102)

HJ, another participant also refused to use the word "uncertain" because he does "not know what is certain" since having unexpected movement is a default for him. He has his "own parameter" which allows him to approximately predict the degree of differences that his movement creates from his imagination (Martiny & Christensen, 2015, p. 103).

Furthermore, this “parameter” is trainable up to a certain point. When learning a new bodily movement such as hitting a tennis ball with a racket, the subject is yet to know the feeling of hitting at the sweet spot, thus, does not possess “correct” efferent signal. As we practice the movement and learn the proper technique through afferent feedback, the brain constructs the correct efferent signal so that makes it possible to create a more suitable copy to project the proper movement. In the same way, individuals with CP also can attain fluency in their movement through practice. It might take higher number of practice and longer time to acquire skills, but they will learn their own way of action. MP, a participant of the research by Martiny and Christensen (2015), comments as below:

I’ve trained a lot in both occupational therapy and things like that. Precisely in order to be able to [tie my shoes], to do actions like that. But now it’s not something I think about, because I can do it and I uphold it by putting on a shirt and stuff like that. Now it has just become automatic, but I know that an enormous amount of practice is necessary for being able to perform fine motor control things. (p. 101)

Yet, they may also not experience the fluency of the action where the body recedes into the background, and the movement becomes “automatic.” In fact, Martiny and Christensen (2015) found out that individuals with CP control their movement by using cognitive strategies. JN, for instance, reveals that “I’m not good at having deep conversations when I walk and that’s an expression for the fact that sure I can walk and I don’t really think about it, but I think about it more than others” (p. 102). Sometimes, the lack of afferent sensation or spasticity of muscles even prevent them from learning a specific skill. Without feedback, it is impossible to reflect whether the movement was correct or incorrect. They may receive a visual or auditory feedback, but without proprioceptive feedback, it is quite difficult to finetune the accuracy of the movement. Still, all those experiences afford them a profound SoA over their movements. Regardless of the uncertainties they face, whether grappling with the unpredictability of movement output, dedicating themselves to extensive practice to master a skill, or even confronting the possibility of never achieving fluency in certain movements, the individual is in the center of the whole experience. This centrality of the person within their movement journey helps us understand how

individuals with CP navigates their physical reality on their own terms and opens up the possibility of having SoA without full control over the body, which I will discuss in the next section of this thesis.

So far, I delved into the complexities of defining “body” for individuals with CP. By contrasting CP with phantom limb and anosognosia, I argued that the body for people with CP exists in a dynamic state between foreign and internalized. While lack of control, functional unreliability, and neurological disengagement can lead to alienation from their limbs, individuals with CP also internalize this experience due to its lifelong presence. Chronic pain strengthens the connection to their limbs while the existence of the pain is normalized due to its constant presence. This unique combination of alienated and internalized body was further examined through their SoA as their bodies often feel unpredictable and outside of their full control. CP’s congenital nature, however, normalizes the experience of the body not coordinating with their will and provides with the new perspective of having SoA without a full control. Specifically, the experience of unable to perform a certain movement often opens a possibility of new compensated movement to achieve the same phenomenal goal. So, in the next section, paralleled to Schneider’s case, I will examine the different ways for a body to exist through various movement as a phenomenon triggered by a situation. Through this perspective, I would challenge the notion of “normality” in PA as being able to correctly mimick an ideal movement and introduce a new approach to PA as an opportunity to explore the body to find the movement style matches the subject’s unique situation.

Redefining “Adapted” Physical Activity with Cerebral Palsy

As I have explored in the literature review section, people with disability face various challenges for their PA participation, including their own physical and psychological limitations, lack of accessible facility and adaptive sporting opportunity, and inadequate understanding and support from the peer. Additionally, “ableism” —a belief in the superiority of being non-disabled—and societal biases within sports culture lead to underestimation of abilities and limitations on opportunities for people with disabilities (Weeber, 1999). These factors all contribute to an environment where individuals with

disabilities are not fully integrated and may feel marginalized within a space designed for movement and connection. As such, sport and PA culture largely remains centered on the idealized abled body.

The abled body centered movement culture is clearly represented in the language exemplified in *Paralympics* as Olympic sports and *adapted physical activity* as PA for individuals with disability. Deriving from the Greek preposition “para” (besides or alongside) and the word “Olympic”, the name means that “Paralympics are the parallel Games to the Olympics and illustrates how the two movements exist side-by-side” (International Paralympic Committee, n.d.). Similarly, the term *adapted physical activity* was first introduced by the founders of the Federation Internationale de l’ Activite Physique Adaptee in 1973 and has been used to describe “the practice of physical activity in persons with disability and/or under challenging physical or mental conditions” (Hutzler & Hellerstein, 2016, p. 109; Hutzler & Sherrill, 2007). The International Federation of Adapted Physical Activity (2014) promotes an inclusive view of adapted PA, extending beyond individuals with disabilities to anyone requiring modifications for full participation in PA. This includes those who are obese, aged, young, or have any unique circumstances that may limit their involvement in traditional PA. While the intention of creating sports and PA opportunities for all ability levels through modification is remarkable, these languages such as “para” or “adapted” emphasize the separation from “normal” sports and PA and strengthen the ideology of ableism in movement culture.

During the last decade, a newer term *adaptive physical activity* emerged by chance of translating non-English language or misinterpretation of the original term *adapted physical activity*. Yet, the term was used more purposefully in one article by Standal and Rugseth (2016) with the connotation of “*adaptive* to mean physical activity that causes change in those engaging in it and with one another” (Hutzler & Hellerstein, 2016, p. 110). While *adapted* focuses on modifications to accommodate existing activities, *adaptive* suggests a dynamic process of mutual transformation between participants and the activity itself (Standal & Rugseth, 2016). In other words, *adaptive* PA is an ongoing process of both redesigning activities based on experiences of individuals with special needs, peers, and educators

altogether and reframing our perspectives towards differences in ability. Drawing upon the two principles in the educational theory of experience by Dewey (1986), namely, *continuum* and *interaction*, Standal and Rugseth (2016) contend that “the meaning of Adaptive PA is created through a complexity of individual and shared meaning making processes, based on all the participants’ earlier experiences, their engagement here-and-now, and their investments toward the future” (p. 38-39). Hutzler and Hellerstein (2016) praise their intentional use of the term *adaptive* yet raise the caution to the risk of a thematic fragmentation and confusion. Thus, they suggest using the term “*adapted* PA to refer to physical activity provided within the field of practice that has been modified to meet the needs of its participants, with the intention of eventually having a positive *adaptive* effect on them” (Hutzler & Hellerstein, 2016, p. 111).

While I agree with Hutzler and Hellerstein (2016), I also believe that *adaptive* needs of PA should be more emphasized and widely recognized. The term *adapted*, with the suffix *-ed*, suggests a completed action or adds descriptive notion that has already been constructed. As such, *adapted* PA is used to clearly distinguish “special” PA from “regular” PA to pronounce that the activity is modified to meet the special needs of individuals. On the contrary, *adaptive*, with the suffix *-ive*, means “to cause or to make” so that *adaptive* PA attempts to expand the notion of “regular” PA to make it more inclusive. (Hutzler & Hellerstein, 2016). The former amplifies the separation whereas the latter promotes the variation. Ultimately, all PA are *adapted* with specific artificial constraints to create challenges (e.g., use feet to play soccer), and all participants are required to be *adaptive* to overcome such hindrances (e.g., practice to control the ball with feet). Yet, all PA should also be *adaptive* to include individuals with special needs because, as Bouffard and Streat (2003) states, there is no one method that satisfies all individual needs in APA. So, it is important to respect the voices of individuals with special needs in the PA settings and continuously search for the possible adaptations.

In the previous section of this thesis, I specifically delved deep into how individuals with Cerebral Palsy (CP) interact with their own body and regard their movement. Their lived experience is

valuable to realize more inclusive PA culture not just because CP is the most common disorder, but also their experience is well-transferrable to other populations such as elderlies or people with different physical disabilities. As Eichberg (2015) insists, abled time is a limited phase of human's life which starts with disability and ends with disability. Sports and PA are the artificial obstacles that humans create during the abled period to test our physical and intellectual abilities. By making PA more inclusive to people with CP, we can create more inclusive movement culture to everyone. So, the aim of this essay is to explore the possibility of PA's adaptability by drawing upon Merleau-Ponty's phenomenological work, specifically Schneider's case and his take about the concept of freedom. I argue that PA is not constrained to a certain movement but rather should be freely created because movement is created by situation, and listening to the lived experiences of people with CP will play a pivotal role in making PA more adaptive.

Is There a “Correct” Movement?

Traditional notions of physical ability rely on a concept of “correct” movement. Whether in competitive sports or PA settings, there is often an ideal form or technique to strive for. However, for individuals with CP, the very concept of a single “correct” way to move is challenged. Due to neurological differences, people with CP often develop alternative movement strategies that allow them to accomplish goals despite the limitations of their bodies. These strategies may not resemble what is considered “correct” in mainstream PA, but they allow them to accomplish goals and embody the world around them in their own unique way. Such creation of unique alternative movements resonates with Merleau-Ponty's argument about the phenomenal body of which “the whole operation takes place in the domain of the phenomenal” rather than a mere result of motor control (Merleau-Ponty, 2004, p. 109).

In order to explain the notion of phenomenal body, Merleau-Ponty (2004) employs the case of Schneider, a World War I veteran whose neurological disorder (*apraxia*) prevented him from intentionally planning or explaining abstract movements, even though he still had the physical capacity to carry them out in certain concrete contexts. Schneider's case illustrates the flaw of the idea of

mechanistic body, which merely obeys our intention, and suggests that movement is a complex phenomenon resulting from the interaction of the human body-subject and the world around him. For example, Schneider could easily perform a concrete movement like swatting a mosquito or scratching the bitten spot on his skin to relieve an itch. However, he struggled with abstract tasks like raising his arm or pointing to a spot that was touched by a ruler. Schneider explains that concrete movements feel disconnected from his will, as if they happen on their own (Merleau-Ponty, 2004, p. 108).

The key difference between the very similar physical acts of pointing and scratching is the phenomenal purpose. Scratching has a specific goal (relieving an itch), creating a connection between the action and the body's experience in the world. This purposeful connection is what grants a sense of agency and embodiment, allowing us to feel truly in control of our bodies. Yet, such phenomenal purpose is given to us by the situation, or the world, as Merleau-Ponty (2004) emphasizes that

the space is given to him in the form of the world at this moment; it is the piece of leather 'to be cut up'; it is the lining 'to be sewn'. The bench, scissors, pieces of leather offer themselves to the subject as poles of action; through their combined values they delimit a certain situation, an open situation moreover, which calls for a certain mode of resolution, a certain kind of work. (p. 110)

In the case of Schneider, the situation given to him was the itch "to be relieved" or the mosquito "to be swatted." Schneider's case suggests that reflexive movements, triggered by external stimuli, operate somewhat independently of conscious thought.

Merleau-Ponty (2004) further supports this phenomenal and temporal aspect of bodily movement by introducing the "intentional arc," a metaphorical "searchlight" that directs our attention. Whether that focus is on an external goal (e.g., swatting a mosquito) or even on internal sensations (e.g., where an itch is), "it is this intentional arc which brings about the unity of the senses, of intelligence, of sensibility and motility," thus allows us to perceive and act towards the world (Merleau-Ponty, 2004, pp. 120-121). So, a specific situation such as a mosquito coming to me directs my intentional arc towards the mosquito and triggers an action of swatting it. As such, it is plausible to say that the situation creates a movement.

This notion of phenomenal movement which is created by situation casts doubt on the idea of “correct” movement. Schneider is, according to Merleau-Ponty (2004), “incapable of play-acting” so that “he is ‘tied’ to actuality, he ‘lacks liberty”, that concrete liberty which comprises the general power of putting oneself into a situation” (p. 120). More specifically, he is capable of swatting a mosquito but incapable of rehearsing or recreating the movement by imagining the same situation. The phenomenal movement of swatting occurs right at the moment in the certain way that is dictated by the situation. In a hypothetical case, if Schneider were placed in a PA setting such as batting in baseball, he would be able to perform the movement yet unable to correct his movement based on cues from a third person like “rotate your body when you swing”. Schneider would simply react to the situation of the ball thrown towards him by swinging his bat on his own way.

The case of Schneider opens up the possibility of freedom in movement and PA. Whether aiming for a mosquito or the ball in a baseball game, the “correctness” of the movement lies in its effectiveness within that situation. For individuals with CP, this becomes even clearer. Their alternative movement strategies often emerge as adaptive solutions within the context of their unique bodily experiences. Palisano et al. (2009), in their research about mobility experiences of adolescents with CP, found that they are constantly making choices in mobility and use of assistive device based on the task and environmental factors. In the context of the most basic form of PA, walking, one of their participants (participant 10) commented that “when I am home, just because it’s my house and I’m used to it, I walk around and hold onto the furniture and the wall or something. If I am inside, I will walk on my hands and knees” (p. 145). Individuals with CP navigate their environments in ways that work for them, as my brother also crawls on his hands and knees as his preferred style of moving. However, his crawling is a bit different from “regular” crawling. He says, “it is difficult for me to move forward with right hand and left leg together, then switch to the other side” so that he moves in an almost galloping motion, hopping forward with his arms and tucking his feet together. As discussed in the previous section, they have been living with CP through their lifetime so that they have their own ways of overcoming

situations. Participant 5 of the research by Sandström (2007) assured that “when people have said to me ‘you can’t do that’ ... you shouldn’t say that to me because then by golly, I’m going to make it work” (p. 437).

As seen from the lived experience of people with CP, what might seem like an “incorrect” or limited movement from the perspective of people without disability could be the most effective or expressive means for an individual with CP to engage with the world. Resonating with Kumagaya’s (2009) experience in rehabilitation of CP, Kawai (2014) notes that harder he tries to follow the “correct” movement directed by a therapist, the tenser and the more awkward his body and movement becomes (p. 33). From such experience, he concludes that rehabilitation should not be a training to “correct” the movement, but rather be an opportunity to communicate with his body to find his own style of movement. This notion of movement coincide with the following texts by Merleau-Ponty (2004):

A movement is learned when the body has understood it, that is, when it has incorporated it into its ‘world’, and to move one’s body is to aim at things through it; it is to allow oneself to respond to their call, which is made upon it independently of any representation. (p. 123)

Recognizing the validity of alternative movement strategies invites us to rethink traditional notions of “correct” movement within physical activity settings. Rather than focusing solely on achieving a predetermined ideal, PA settings can become spaces where a wide variety of embodied experiences are celebrated and supported. This does not imply abandoning technique entirely, but rather shifting the goalposts. Instead of prioritizing how closely someone mimics a standard, the focus shifts to how effectively and expressively an individual engages with an activity within their unique capabilities. In doing so, PA becomes more inclusive and empowering.

Freedom: Movement Beyond Disability

The congenital nature of CP invites us to reframe our understanding of movement and, by extension, physical ability. Their unique experiences lend us an opportunity to discard the notion of “normality” and freely re-think of movements. As represented in the Schneider’s case, movement is

created by a situation rather than mere motor control. Similarly, CP's limitation shaped their unique and creative movements to adapt to the world. Merleau-Ponty (2004) also emphasizes such thrownness and situatedness of human beings, claiming that freedom cannot exist without limitation. We are "thrown" into the world with certain bodily experiences and environmental constraints. True freedom lies not in escaping these limitations, but in actively and creatively engaging with them. Merleau-Ponty (2004) put it perfectly:

If freedom is to have room in which to move, if it is to be describable as freedom, there must be something to hold it away from its objectives, it must have a field, which means that there must be for it special possibilities, or realities which tend to cling to being. (p. 214)

Limitation is, in other words, the source of creativity and freedom.

This idea is echoed in the words of legendary Japanese swordsman Musashi Miyamoto, who likened the mind to water: "Water adopts the shape of its receptacle, it is sometimes a trickle and sometimes a wild sea" (Miyamoto, 1974, p. 43). Like water, our movement potential is always situated—shaped by our unique bodies, our environments, and the goals we pursue. The beauty of movement lies in this constant adaptation and transformation within the constraints we encounter. Through his "Attitude No-Attitude Teaching" in using a long sword, Miyamoto wrote that "However you hold the sword it must be in such a way that it is easy to cut the enemy well, in accordance with the situation, the place, and your relation to the enemy" (Miyamoto, 1974, pp. 58-59). The "correct" movement is determined by the unique situatedness of the body in this world, therefore, it is completely up to the person right in that movement.

Individuals with CP exemplify this beautifully. Their movement strategies are born from a lifelong dialogue with their unique relationship with body. They do not see their differences as deficits but as starting points for exploration and adaptive problem-solving. Gary, a participant of research by Horsman et al. (2010) commented that "I tell people when people are born with cerebral palsy, they're born completely normal [for them] because they're never going to be able to change it" (p. 300). He

acknowledged that while his disability was an essential part of him, it does not define his entire identity. McKinnon et al. (2020) similarly reported that “the physical presence of the movement disorder had become a normal part of their everyday lives and they perceived little impact, even feeling ‘comfortable [accepting of it]’” (p. 5). Child G from their research even said that “I would say nothing, I don’t notice them [dyskinetic movements]” because their experience is so integrated into their life (p. 5). Another participant in the research by Horsman et al. (2010), a bit negatively expressed that “‘all the therapy in the world’ would not change that fact that a person has CP” (p. 298). Yet, Aggerholm and Moltke Martiny (2017), in their ski camp for individuals with CP, found that participants have learned “the bodily experience of being able to modify what they can and cannot do by practicing” (p. 374). Particularly, as Ditte, one of their participants, gained better control of her body, she felt a sense of “I can” and the ability to relax rather than constantly trying to consciously direct her movements. This sense of freedom and liberation resulted from shifting their focus on the external challenge of the ski slope, rather than their own physical sensations. This allowed them to trust their bodies, be present in the moment, and respond intuitively to the environment. As Aggerholm and Moltke Martiny (2017) contend, “control does not always mean explicitly or consciously controlling your body and the situation” (p. 371). Instead, it is to let the situation and our body condition freely shape the most natural form in that moment.

This freedom and creativity of movement is not confined to the case of CP as similar examples can be found across disability communities. For instance, the fastest man on Earth, Usain Bolt revealed that he has *scoliosis*—a sideways curvature of the spine causing asymmetric body balance (Bolt, 2016). Yet, this condition likely contributed to his distinctive running style, giving him an advantage over his competitors (Allen, 2017). A Paralympic wheelchair racer, Tatyana McFadden was born with *spina bifida* (a defect in spine) but become one of the most successful Paralympic athletes of all time with her adaptive approach (McFadden, 2020). Non-athletes with various physical and cognitive differences also find creative ways to navigate everyday tasks. This might include a person with limited mobility

developing their own techniques for getting dressed, or someone with a visual impairment adapting their cooking methods by using touch and sound cues. These examples, from top athletes to everyday individuals, defy the notion that there is only one “correct” way to move. They reveal the unbounded potential of the human body when limitations are met with ingenuity and a refusal to be confined by external definitions of ability.

So far, by drawing upon Merleau-Ponty’s phenomenological work and lived experiences of people with CP, I have explored the philosophical ideas that movement is not a mere product of cognitive intention but rather triggered by a situation as a phenomenon. Not only the artificial restriction in sports and PA settings but also a person’s physical limitation like disability will create the new possibility of the movement. While such analysis gives us a deep insight into the possibility of PA, it does not suffice to nudge a societal change to create more inclusive culture in sports and PA. So, to bring about a positive change to the society, I will conclude this chapter by discussing possible ways to realize true inclusivity in sports and PA culture. More specifically, my goal is to reimagine the concept of inclusion by respecting different kinds of “normality” experienced by people with CP, and place all human beings in the spectrum of abilities instead of distinguishing people with disability by labeling them “special.”

Reimagining True Inclusion

Not just people with disability but everyone is different, so it is questionable to define the “normal.” Eichberg (2011) pointing the case of the shaman of Mentawai people posits that “normalization is a cultural construction” and related to power (p. 8-9). In current society, people with disability are an oppressed group and considered as “others.” However, Eichberg (2015) maintains that “the human being is born disabled and dies disabled” so that abled body is temporary (p. 19). In other words, all human beings exist on the spectrum of different abilities instead of a clear distinction of abled vs. disabled. Despite the medical categorization, people with disability are just people with different characteristics, just like someone is good at running or mathematics. So, true inclusion is not merely

adapting “regular” PA to the needs of people with disability, but rather, to dispute the notion of “special” people and normalize their PA participation.

Voices of people with disability suggest that their disability is just one aspect of who they are, not the whole identity. Rather, sports and PA participation as well as other life activities have much more significant influence on the construction of self-image. Hanes et al. (2019) point that “only two participants (out of sixteen) immediately identified their cerebral palsy as a part of their introduction” (p. 618). Instead, “most participants chose to introduce themselves with the different activities in which they participate—including work, school, and recreational opportunities (as opposed to introductions based on diagnosis)” (p. 616). Vince and Tony in the research of Pack et al. (2017) emphasize their desire and pride of being recognized for their swimming abilities as athletes, not for their disabilities. Perrier et al. (2014), also recognize that their research participants with disability who identify themselves as athletes did not see themselves as different from athletes in the general population (p. 117). Rather, their commitment and sacrifice towards their sports are what define them as athletes, regardless of disability status. As such, viewing disability at the forefront of their whole personhood conflicts to their desire to “normalize” disability or physical differences.

However, social unacceptance towards physical differences of people with disability is still broadly existent as an issue. As Weeber (1999) claims that ableism ideology shapes a misleading statement that non-disabled people “should feel sorry” for disabled ones and creates tension or mood in which makes one feel that disability should not be talked about. (p. 20). Eichberg (2015) warns that “ableism implies a negative view on the assumed ‘lack of ability’ and is not so far from discrimination based on ability or disability” (p. 16). In fact, Huang et al. (2010) based on their interviews with Chinese mothers after learning their child’s diagnosis of Cerebral Palsy reveals that “some mothers felt hopeless because the diagnosis of CP felt like ‘the end of the world’” (p. 1216). This is not specific to CP or Chinese households as Ho and Keiley (2003) analyze by citing Rolland (1994) that family members experience profound shame and are more likely to deny the too devastating fact—their child was born

with disability (p. 240). Anne, a participant of research of Pack et al. (2017), also revealed that she kept wearing a prosthetic arm at school to hide her disability to fit in. Profound insecurity of “being different” is deeply implanted by the social image and unacceptance towards physical differences of people with disability.

To challenge this social norm, Niko von Glasow, a film director of *My Way to Olympia* (2013) featured Paralympic athletes’ voices indicating their indifference from non-disabled people. It is one of the very few sports films about people with disability directed by a person with disability, and those athletes’ dialogue gives us another realm of phenomenological study. Moreover, as Smith (2001) contends, “all cultural products carry cultural meaning,” and therefore, “examining a film can give us clues about the meanings and assumptions shared by the members of a culture” so that it is worth reviewing (p. 132). First, Christiane Reppe, a German single-legged Paralympic swimmer answers to the question “what do you think is your problem?” as follows:

I don’t really have any problems. Despite my disability, I could always do everything...there are moments when I think: “shit, I only have one leg!” But everyone gets that. Everyone with a disability, and then everyone who is fat or has a big butt. Usually, I am quite content.

Grigorios Polychronidis, a Greek boccia player with spinal muscular atrophy, expresses his view towards his life with disability as follows:

You may be the coolest or the most disabled or something, but if you can find something makes you happy, you may be happier than anyone else...that’s one of the most difficult questions for everyone: to find what makes you happy.

These athletes reveal much more positive views of their life with disability than public stereotypes.

Their lived experiences show that life is not so different in spite of their physical difficulty. When life is tough, it is tough for everyone, but so is worth living in the same way. Finally, the comment from the coach of Rwanda national sitting volleyball team represents the attitude of those Paralympians: “we look forward.” Instead of complaining their past—traumatic war experience, unfortunate disease, or inevitable fate with disability—they embrace it and live through with what they are given or taken. This

mindset corresponds with all the research presented so far, especially the perspective of individuals with CP who accept their disability as a part of their everyday reality and regard their body as normal. The choice is ours, as a society, as to whether we create a truly inclusive PA culture. Inclusion means embracing physical differences as natural variations within the human experience, and respecting individuals with disabilities as whole persons, not simply as “special cases.”

One possible way to encourage this perspective is to include children with disability into “regular” Physical Education (PE) classes. While challenges exist, such as safety concerns, the need for extra support, and potential disruption to class flow, the social benefits for all students significantly outweigh these difficulties. Inclusion of children with disabilities in mainstream PE settings promotes diversity, empathy, and understanding among all students. As a result of a qualitative case study of including children with severe CP and visual impairment in a mainstream PE class, Grenier (2006) insisted that such inclusion not only benefits children with disabilities by providing them with a sense of belonging but also fosters awareness and a supportive environment among their peers. Similarly, Hilderley and Rhind (2012) observed that inclusive PE benefits children with CP and positively shapes the attitudes of their non-disabled classmates, who develop greater patience and understanding. Vogler et al. (2000) further highlighted that the inclusion of a child with severe CP in PE contributed to a more empathetic and cooperative classroom environment where all students learned the value of adaptability and teamwork. Exposure to physical differences at a young age is crucial in shaping attitudes toward inclusivity and can reduce the likelihood of prejudice and discrimination. This approach helps break down barriers and misconceptions about disabilities, fostering a more inclusive and understanding community. Including children with CP in mainstream classes benefits everyone—it supports those with disabilities while enriching the social and emotional learning of their peers, ultimately preparing them for a diverse and inclusive society.

Conclusion

This section attempted to emphasize more “adaptive” aspects of PA rather than “adapted” with an overarching goal of making PA culture more inclusive. The case of Schneider, analyzed in Merleau-Ponty’s *Phenomenology of Perception*, highlighted the importance of understanding movement as a phenomenon. Just as Schneider’s ability to move depended on the context giving a reason for that movement, individuals with CP create their own contexts within which their movements make sense. Their alternative ways of using their bodies are not errors in execution, but rather adaptive solutions within a unique physical reality. Drawing on Merleau-Ponty’s philosophy, I have also argued that our unique bodies and environments shape how we move, emphasizing the adaptive, situated nature of movement. It contrasts with the concept of a single “correct” form, using examples like Musashi Miyamoto’s water analogy and the lived experiences of people with CP. Such freedom of movement transcends CP and further challenges the notion of traditional PA and movement.

Building upon a new “normality” reimagined with the lived experience of individuals with CP in comparison with Schneider’s case, I have later argued for a paradigm shift towards a holistic and inclusive perspective in physical activity, one that challenges the traditional notions of ability and normalcy. If the “correct” movement is what the subject feels right according to their unique situation, there is no single “norm” that they need to strive for. Rather, embracing the full spectrum of human diversity, this essay posits that inclusion should be about more than adapting programs for those deemed “different”; it should be about transforming our understanding of participation itself. By integrating individuals with disabilities into mainstream PE, we not only enrich the lives of those with cerebral palsy but also foster a more empathetic and diverse society. True inclusion means creating a culture where every individual’s unique contributions are valued and where participation in PA is a shared, equitable experience.

CHAPTER 5

CONCLUSION

The main question of this thesis was: *how can we make sports and physical activity (PA) more inclusive?* Throughout human history, sports and PA have been an integral part of cultures around the world. From their origins in ancient civilizations, they have evolved and transformed over time. Yet, despite these advancements, the quest for inclusivity in sports and PA remains an ongoing challenge—a space where discrimination persists, especially towards those with disabilities. This necessitates a nuanced understanding of the barriers and challenges that marginalized populations, particularly those with disabilities, face in their pursuit of active participation. Among these, individuals with cerebral palsy (CP) represent a significant group whose experiences and needs offer profound insights into the broader dialogue of accessibility and accommodation in sports and PA.

CP stands as the most common motor disability in childhood, affecting an individual's ability to move and maintain balance and posture. It is not a disease with a progression; it is a congenital condition that affects individuals differently, presenting a unique spectrum of challenges that require equally unique solutions. The choice to focus on CP within the scope of this thesis stems from a recognition of its prevalence and the distinct set of challenges it presents in the context of PA participation, which I have observed firsthand growing up with my brother with CP. Moreover, the congenital nature of CP offers a vantage point from which to explore the depths of physical inclusivity. By understanding and addressing the needs of those with CP, I attempted to uncover principles and practices that extend inclusivity to a wider demographic, potentially revolutionizing how society approaches PA for individuals with various disabilities.

Through literature review (Chapter 2), I identified various benefits of PA on people with disability, and more specifically, on people with CP. These benefits span physiological, psychological, and sociological aspects, offering a comprehensive view of the positive impacts of PA beyond mere physical health improvements. Physiologically, PA has been shown to enhance muscle strength,

coordination, and overall physical functioning, directly contributing to greater autonomy and the ability to perform daily tasks more efficiently. This is particularly critical for individuals with CP, for whom physical limitations often pose significant challenges to independence. The psychological benefits of PA, including improvements in mood, self-esteem, and self-efficacy, are equally significant. Regular engagement in PA leads to positive mood changes, reduces feelings of depression and anxiety, and boosts self-esteem, all of which are essential for the mental health and overall well-being of individuals with CP. Sociologically, PA serves as a powerful vehicle for enhancing social interactions, relationships, and integration into society. Participation in sports and PA fosters social connections and breaks down societal barriers and stereotypes associated with disability, promoting a more inclusive environment. Crucially, integrating individuals with CP into these activities also enriches the experiences of those without disabilities, fostering a mutual understanding and acceptance, and strengthening community ties, thus promoting a comprehensive societal integration.

Although the benefits of PA participation for these populations are remarkable, it also became clear that they face significant barriers to participation. These include inaccessible facilities, transportation challenges, a scarcity of adaptive equipment and programs tailored to their needs, and pervasive societal misconceptions regarding their capabilities. Additionally, the limited knowledge and skills of educators, caregivers, and program administrators, coupled with a lack of support and understanding from peers, significantly hinder their ability to engage in PA. These very barriers, however, highlight areas where targeted efforts can act as facilitators, transforming obstacles into opportunities for enhancing PA participation among individuals with CP. In fact, the presence of a supportive peer group not only boosted their motivation to engage in PA but also reinforced their social integration. Thus, by addressing these challenges directly, we can begin to dismantle the barriers, paving the way for more inclusive and accessible PA opportunities.

However, addressing the question of inclusivity takes more than just providing resources according to their needs; it requires a radical change in the societal view towards PA and disability. For

that purpose, this thesis proposed a deep dive into the lived experiences of individuals with CP employing phenomenology, or “philosophy of experience.” Phenomenology, as explored in Chapter 3, is fundamentally the study of structures of experience, or the study of phenomena as they present themselves to consciousness, from the first-person point of view. This philosophical approach, deeply rooted in the work of Maurice Merleau-Ponty, seeks to uncover the essence of experience by examining how individuals perceive and interact with the world around them. In the context of this thesis, phenomenology presents a particularly suitable framework for investigating the lived experiences of individuals with CP engaging in PA. The emphasis on the embodied nature of human experience, which is central to phenomenology, allows for a deeper exploration of how people with CP experience their bodies and movements in ways that traditional research methodologies might overlook.

Merleau-Ponty’s assertion that the body is not just an object in the world but a fundamental aspect of our being-in-the-world provides a critical lens through which to view the unique physicality of individuals with CP. It challenges the conventional medical model of disability, which often focuses on physical limitations as obstacles to be overcome, and instead invites a more nuanced understanding of these individuals’ bodily experiences. Phenomenology allows us to see beyond the generic modifications and accommodations typically associated with “inclusive” PA, urging a reevaluation of what it means to move and participate in PA from the perspective of those whose bodily experiences diverge from the norm. Thus, heavily drawing upon the influential work by Maurice Merleau-Ponty, *Phenomenology of Perception*, this thesis sought to conceptualize the voices of individuals with CP, understand their challenges, and envisage the world of PA through their perspectives. This approach acknowledges that true inclusivity cannot be achieved through surface-level adjustments or one-size-fits-all solutions. Therefore, I challenged the notion of “normality” and advocated for a reevaluation of “dis-ability” and concept of “adapted” PA, emphasizing the diversity of abilities and the inherent adaptability of all PA. I did so by first carefully analyzing the complex interplay of alienation and integration of the body parts for people with CP in comparison to phantom limbs and anosognosia, and

later examining the notion of “freedom” relying on Merleau-Ponty’s “phenomenal body” situated in the world.

In Chapter 4, titled *Bodily Perceptions in Cerebral Palsy: The Alienation and Integration of the Body*, I investigated the complex bodily experiences of individuals with CP engaging in PA. Merleau-Ponty’s phenomenology, emphasizing the embodied nature of human experience, provided a rich framework for examining how individuals with CP perceive and experience their bodies and movements. By placing the body at the center of the interaction with the world, phenomenology shifts our understanding from a traditional Cartesian dualism, which separates mind and body, to a more integrated view. However, Merleau-Ponty premised that the body is a reliable source to experience the world. In comparison, individuals with CP experience the body in a complex negotiation between alienation and integration. Uncontrollable limbs and persistent pain without a cure defy conventional functionality and present the body as a foreign object. Yet, the chronic pain actually strengthens the connection with their limbs and reminds them that the body is theirs. Similarly, the congenital nature of CP allows them to take full sense of agency—the feeling of being the controller of the movement. Even though the body is not fully controllable, such uncontrollability as a whole is their bodily experience. In fact, the parameter of the uncontrollability is somewhat trainable, according to individuals with CP, as much as we train for a certain movement in sports and PA settings. These findings, revealing a robust sense of agency amidst the intricate duality of bodily experiences inherent in the congenital nature of CP, transcends mere adaptation to physical limitations. Instead, they signify a profound acceptance and integration of their bodies in their entirety and offer a new perspective on “normality” and the freedom of movement.

Following the exploration of bodily perceptions in CP, the second essay within Chapter 4, *Redefining “Adapted” Physical Activity with Cerebral Palsy*, ventures into a philosophical discourse that moves beyond the simple adaptation of activities for individuals with CP. In this discourse, I leverage Schneider’s lived experience, as interpreted by Merleau-Ponty, to underscore movement not as

a mere mechanical reaction but as a meaningful engagement with the world. This interpretation serves to highlight the body's inherent capacity for adaptability and creativity in the face of physical constraints, thus, challenges the limiting frameworks of "adapted" PA which often marginalize or devalue the expressive capabilities of individuals with disabilities. Schneider's scenario, analyzed by Merleau-Ponty, exemplifies movement as a "phenomenon" born from the body's profound interaction with its surroundings. Schneider's difficulty in conceptualizing or articulating abstract movements, despite his ability to perform targeted actions like scratching an itch, exemplifies the body's natural propensity for adaptability and ingenuity in navigating its limitations. This type of movement emerges when the phenomenal body encounters a specific situation, directing itself towards an intended purpose. This idea aligns with the philosophy of the Japanese swordsman, Musashi Miyamoto, who likened adaptability and purpose to the fluidity of "water." His "Attitude No-Attitude Teaching" emphasizes that "correct" movement is inherently dependent on the body's specific context within the world, thus, it entirely rests on the individual in that moment of movement.

This reevaluation of movement underscores the philosophical concept of freedom in physical activity—not as the absence of limitation but as the embodiment of possibility and engagement within one's circumstances. Such a view of freedom advocates for a paradigm shift in how society perceives and facilitates PA for individuals with CP, suggesting that true inclusivity in sports and physical activities must recognize and embrace the diverse and dynamic ways individuals interact with their environments. By integrating Merleau-Ponty's insights on the phenomenological nature of movement and freedom, in the end, this thesis calls for a broader, more inclusive definition of PA that honors the unique ways in which people with CP, and indeed all individuals, experience and engage in movement. It urges a departure from standardized notions of physical ability and "adapted" activities, advocating instead for a more flexible and responsive approach to PA that validates and supports the varied expressions of bodily engagement. This philosophical and practical reimagining aims to foster a more inclusive realm of PA, where the richness of human movement is celebrated as a fundamental

expression of our engagement with the world, moving beyond adaptation to embrace the full spectrum of human capability and interaction.

Limitations

One limitation of this research is inherent in the phenomenological approach itself, which, while powerful for understanding personal experiences, may not capture the full diversity of experiences among individuals with CP. Phenomenology focuses on the depth of individual experiences but can sometimes miss the broader variability across a population. Given the wide spectrum of CP manifestations, from mild to severe with different personal background such as age, gender and ethnicity, the insights gained may not fully represent the entire CP community. Additionally, phenomenology's emphasis on subjective experience can lead to challenges in generalizing findings, as the interpretation of experiences is deeply personal and may not be universally applicable.

Moreover, the focus on CP, while providing a detailed framework for exploring the challenges in PA, means that the findings may lack specificity to other disabilities. The unique congenital nature of CP offers invaluable insights into the embodiment and physicality within PA settings; however, this specificity might limit the applicability of findings to individuals with other types of disabilities who encounter different barriers to PA.

Lastly, another significant limitation is the potential lack of direct practical application of the findings. While phenomenological research enriches our understanding of lived experiences, translating these insights into concrete, actionable strategies for improving inclusivity in PA settings can be challenging. The abstract and theoretical nature of phenomenological insights might not immediately inform the development of practical interventions or policies to enhance PA accessibility for individuals with CP.

Future Directions

Future research should aim to address these limitations by incorporating a wider range of experiences from individuals across the entire spectrum of CP, as well as from those with other

disabilities. Expanding the scope to include quantitative methodologies alongside phenomenological analysis could also provide a more comprehensive understanding of the barriers to PA and the effectiveness of different inclusive strategies. This dual approach could offer a more nuanced view of how physicality and movement are experienced across diverse conditions and how inclusive practices can be optimized for various needs.

Exploring the diversity of CP experiences more comprehensively could lead to the development of more targeted and effective interventions for increasing PA participation. Additionally, integrating insights from other philosophical frameworks alongside phenomenology could enrich the analysis, offering new angles from which to understand and address the challenges faced by individuals with disabilities in accessing PA. Integrating the phenomenological insights with practical, evidence-based approaches could bridge the gap between understanding and application, leading to more tangible improvements in PA inclusivity.

In conclusion, while this thesis makes significant strides toward understanding the lived experiences of individuals with CP in relation to PA through a phenomenological lens, the path forward calls for broader and more inclusive research efforts. By embracing the complexity and diversity of experiences among individuals with disabilities and striving to translate theoretical insights into practical applications, future research can continue to advance the goal of truly inclusive PA environments where everyone can find their place and way to participate, enhancing both individual well-being and societal cohesion.

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