Walking and rolling: Evaluating technology to support multimodal mobility for individuals with disabilities

Nicole L. Zaino

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Reading Committee:
Katherine Steele, Co-Chair
Heather Feldner, Co-Chair
Patrick Aubin, Member

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Abstract

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Nicole L Zaino

Co-Chairs of the Supervisory Committee:

Katherine M. Steele
Department of Mechanical Engineering

Heather A. Feldner
Department of Rehabilitation Medicine

Mobility is considered a human right and enables freedom. Self-initiated mobility is imperative for development of physical, cognitive, visual, and sensory abilities, and independence. Engineers design technology to support humans' many modes of mobility; whether that be walking, biking, crawling, or rolling (e.g., propelling a manual wheelchair, car, or powered wheelchair). For people with disabilities, technology that supports mobility includes surgical interventions, therapies, and mobility aids which facilitate independence and participation. This dissertation investigates the impact of a multitude of strategies designed to support mobility for individuals with disabilities.

One large population within the disability community are individuals with cerebral palsy (CP). CP is the result of a brain injury at or near the time of birth and impacts mobility. Due to the

unique nature of brain injuries, individuals with CP have heterogeneous disabilities that limit mobility and function. Elevated energy consumption during walking is a leading complaint of children and adults with CP that impacts endurance and community involvement. The causal mechanisms underlying elevated energy consumption for individuals with CP is unknown. One proposed cause of elevated energy consumption is muscle spasticity: velocity dependent resistance to stretch. We found that while a surgical intervention -- selective dorsal rhizotomy (SDR) -- did reduce spasticity, it did not reduce energy consumption during walking. These results not only demonstrates that spasticity is not a cause of elevated energy in CP, but also have large clinical implications as elevated energy consumption is commonly used as a selection criterion for SDR and "more efficient" walking and greater endurance are advertised as benefits of SDR.

Despite advances in technology and design of many mainstream mobility devices (e.g., cars or bikes) over the past century, devices designed for individuals with disabilities have not seen this same level of innovation. This is due to a dearth of research in the field of mobility aid design. For example, despite ankle foot orthoses (AFOs) being the most ubiquitous mobility aid for individuals with CP, the basic design has not significantly changed and there are still many opportunities for improvement to support mobility. Using focus groups with individuals with CP and their caregivers who had experience with AFOs, we investigated the lived experiences of AFO provision, use, and impact. We found that AFOs can benefit mobility and independence. However, many challenges still exist that hinder AFO provision, including the confusing and lengthy provision process, the need for more education and information during provision, and AFO discomfort.

"Early" or on-time mobility aid provision for infants and toddlers with disabilities is quite variable and there is no consensus of what is best with two different camps: (1) wait and see and

(2) support mobility with technology as soon as possible. For young children with CP, orthoses and walking aids are the two most common types of devices they receive first. Yet, we do not know when or how most children first get these devices or the developmental impacts for this specific age group. We used surveys and interviews with caregivers and clinicians about the provision process of first mobility aids for young children with CP. We found that there are specific challenges for the provision and use of first mobility aids including, 1) requiring an agreement among clinicians on the provision timing, 2) which devices to use first, and 3) providing more enriched education and training for families.

One under-explored but promising mode of first mobility for toddlers is powered mobility. Experiencing different postures is important for development in early years. Additionally, it has been proposed that using powered mobility in a standing posture can allow the child to have dual progression in mobility and body structure goals. However, the impacts of posture while engaging with and learning how to use powered mobility is unknown. Through an experimental study, we investigated how children with disabilities under the age of three engage with and learn to explore with powered mobility over four play visits in both seated and standing postures. We found that toddlers with a variety of disabilities or mobility delays were able to engage with the joystick and explore their environment in both postures. Each posture (seated and standing) had its own positive and negative impacts on joystick control, distance traveled, bodyweight support, and muscle activity. Specifically, in the standing posture participants had more joystick activations, traveled a shorter distance, loaded a similar amount of weight through their legs, and had greater muscle activity especially when driving (vs. stationary play). Our findings can motivate future investigations and device design to optimize posture and access to device control. Additionally,

our results can guide how to best implement on-time powered mobility in clinical care, even as an intervention in a therapy setting.

The work in this dissertation contributes to the fields of mechanical engineering and rehabilitation engineering through a comprehensive investigation of different technologies that individuals use to support and enhance their mobility. I employ methods from engineering, biomechanics, rehabilitation science, and disability studies fields to holistically answer these questions to better understand and support mobility for individuals with disabilities. This work will enable improved mobility aid design, provision, and use for individuals with disabilities.

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TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

Chapter 1

INTRODUCTION

Mobility enables independence and is considered a fundamental human right [1, 2]. Access to self-initiated mobility, independent of the mode (i.e., crawling, walking, manual or powered wheelchair driving), is critical for the development of physical, cognitive, visual, and sensory abilities while also providing independence for all people, including individuals with disabilities. Humans move in a wide variety of ways and use technology that engineers design to support this movement. Surgical interventions, therapies, and mobility aids all are approaches that may help support independent mobility for individuals with disabilities. Mobility aids are used by individuals with disabilities to support mobility and facilitate participation in family and community life. For example, children with cerebral palsy (CP), which is caused by a brain injury at or near the time of birth and is one of the most common pediatric motor disabilities in the United States affecting over 3 per 1000 live births, may use multiple modes of mobility throughout their lifespan and in different settings [3]. Because of the heterogenous impacts of brain injuries, children with CP have heterogenous motor capabilities. Thus individuals with CP utilize a range of technologies to support their mobility and these modes can range from walking independently, walking with a mobility aid, using a manual wheelchair, and/or using a powered wheelchair, all of which may be essential in supporting participation [4–7]. Despite advances in technology and design of many mainstream mobility devices (i.e., cars or bikes) over the past decades, those designated for individuals with disabilities have not seen this same level of innovation. Minimal innovation stems from the little research that has been conducted to understand and improve design, provision, and use of mobility aids which is needed to understand how these technologies impact function and participation at various stages across the lifespan.

Advancing the development of interventions and technology to support mobility, *e.g.*, powered mobility for toddlers or surgical interventions, is imperative to enhance mobility opportunities for children with disabilities. To do so, we need to understand the complex impacts (potential) each aid has on improving mobility and incorporate the perspectives of individuals with lived experiences (*i.e.*, human centered design). This dissertation harnesses engineering, biomechanics, disabilities studies, and rehabilitation medicine lenses to address the impact of technology of mobility for individuals with disabilities. We do this via computational, qualitative, and experimental methods which allows us to investigate energy consumption during walking, perceptions of the provision and use of mobility aids, and postural impact on powered mobility use to improve our ability to most effectively improve mobility.

1.1 FOCUS OF THE DISSERTATION

This dissertation takes a mixed-methods approach and perspective to understand the impact of surgical interventions and the design and use of mobility devices on mobility for individuals with disabilities. We started with current surgical interventions and how they impact mobility, specifically energy consumption, during walking for children with cerebral palsy (CP). We retrospectively quantified energy consumption during walking and spasticity changes after selective dorsal rhizotomy (SDR) in children with CP (Chapter 3). We found that although SDR significantly reduced spasticity, there was no significant change in energy consumption during walking between the SDR and no-SDR groups. These results highlighted the challenges of understanding and effectively targeting factors that are thought to limit mobility and hinder participation, even for well-established surgical interventions. Beyond surgical interventions, there are a wide range of mobility aids that are used by individuals with disabilities across their lifespan. Next, we turned to qualitative methods to understand more about lived experiences of mobility aid provision and use (Chapter 4). We found that AFOs can benefit mobility and independence despite the many challenges with AFO provision, including the confusing and lengthy process, the need for more education and information during provision, and AFO discomfort. While Chapter 4 considered the full lifespan perspective, we then aimed to better understand the current process and norms for first mobility aid provision for infants and toddlers with CP where there is little experience or knowledge (Chapter 5). To address this, we conducted a mixed-methods study of parents and clinicians on the provision of a child's first orthoses or hand-held mobility aids (Chapter 5). We found the prescription patterns of first mobility aids vary based on clinician perspectives, and that there are mixed impacts, use patterns, and varied educational and training opportunities for both parents and clinicians. While we know that access to mobility aids to allow for self-initiated mobility is critical for development, we do not quantitatively know how toddlers interact and use a device when learning to move and how the device set-up impacts the toddlers interaction and use. So, to determine the impact of on-time powered mobility, specifically navigation and neuromechanical impacts of powered mobility use in toddlers with disabilities, we experimentally evaluated device control, navigation, and muscle activity in two driving postures (Chapter 6). We found that all children were able to interact and control the joystick and that on average they had more activations, drove a shorter distance, loaded less bodyweight through their feet, and had more muscle activity in their legs during the standing posture compared to the seated posture.

1.2 SIGNIFICANCE

This dissertation employs a unique perspective, drawn from the fields of mechanical engineering, biomechanics, rehabilitation, and disability studies to improve our understanding of the impacts of different treatments or mobility aids on function, mobility, and participation for individuals with disabilities. A wide array of tools are used to improve and support mobility for individuals with physical disabilities. This includes both invasive treatments, such as surgical intervention, and noninvasive methods, such as mobility aids. The research conducted in this dissertation contributes to the fields of mechanical engineering, biomechanics, rehabilitation medicine, and assistive technology by advancing the understanding the impacts of surgical interventions and mobility aid on many different modes of mobility. It also takes a human-centered design approach and amplifies the voices and lived experiences of individuals with disabilities and their families, which to date have not been prominently included in research and design. It is critical to include these voices in all aspects of the research process to build off of their lived-experiences, perspectives, and priorities. The following sections gives an overview of each chapter and their contributions:

1.2.1 Chapter 3: Surgical intervention for mobility improvement

Spasticity has long been proposed to be a large contributor to elevated energy consumption during walking in individuals with CP and is often used by hospitals as a motivating decision point to parents for recommending interventions that reduce spasticity, e.g., SDR, for their children with CP. SDR is an invasive surgery with a very long required in-patient recovery process of 6 weeks with additional rigorous out-patient therapy afterwards for months. Prior studies have also suggested that SDR may reduce energy consumption, however these studies lacked a proper control group of children with CP to account for covariate factors such as speed, age, and general development for children with CP [8, 9]. By using an age, energy consumption, and spasticity matched group of children with CP who did not undergo an SDR, we were able to eliminate covariates impacting energy consumption reduction over time, likely age and development that previous publications missed by not having a proper control group. We concluded that SDR does not reduce energy consumption.

1.2.2 Chapter 4: Ankle foot orthoses provision and perceptions from lived experiences

We must guide our research and device design by listening to individuals with lived experiences. To bolster and learn from individuals with lived experiences we had participants outline areas of improvement and their priorities for the design and provision of AFOs. Prior work did not include individuals with CP, but rather only clinicians or caregivers. By including individuals with CP, we were able to note the differences in experiences. For proposed ideas to improve AFOs (design, prescription, use) caregivers and individuals with CP focused on two different areas: (1) process and fabrication and (2) ease of use and comfort.

1.2.3 Chapter 5: First mobility aid provision and impacts

Early mobility is critical for cognitive, visual, and physical development, thus early and effective provision of mobility aids for infants and toddlers with disabilities is pivotal to access to self-initiated movement and development. Research supporting the provision and use of first and early mobility aids is extremely important. The purpose of this chapter was to establish what the current standard of care is for first mobility aid provision for toddlers with CP in the United States. We conducted surveys and semi-structured interviews with clinicians and caregivers to understand the current norms of provision timing, device type, and training, in addition to the provision process and ways to improve early provision of first mobility aids. There are challenges that are specific to the provision of mobility aids, specifically in the need for agreement among clinicians on the provision timing, which devices to use, and often requiring more enriched education and training for families.

1.2.4 Chapter 6: On-time powered mobility

Another way to support early mobility for toddlers with disabilities is powered mobility. Children who will be wheelchair users, who are delayed in walking, or have inefficient mobility can all benefit from power mobility [10]. New technology to enable early mobility has recently become available and cleared by the US Food & Drug Administration. The Permobil Explorer Mini is specifically designed for toddlers ages 1 to 3 years old. This device has a midline joystick, 360 degree turning radius, 5 speed options, and is height adjustable. One exciting design component of the Explorer Mini is that it allows for the child to be in an upright position in both a "seated" and "standing" posture which researchers have suggested may support postural control, muscle strength, or bone strength [11]. This study is one of the first studies with the Explorer Mini and a quantitative analysis of how toddlers use powered mobility by using wheelchair-based sensors to accurately quantify joystick and device movement and muscle activity and bodyweight support during powered mobility device use.

1.3 DISSERTATION OVERVIEW

This dissertation includes one retrospective study, two qualitative studies, and one experimental study. Each of the four studies are presented as a self-contained article. Chapter 2 serves as an overview of all related and relevant background material. Chapter 3 examines the impact of spasticity reduction via selective dorsal rhizotomy on energy consumption during walking (Zaino, et al., *DMCN*, 2020). Chapter 4 summarizes the lived experiences of individuals with CP and their caregivers on AFO provision and impacts (Zaino, et al., *POI*, 2022). Chapter 5 highlights the provision process, impacts, and use of first mobility aids for children with CP from both a caregiver and clinician perspective along with proposed improvement points to provide better care (Zaino et al., *Disabil. rehabilitation. Assist. Technol., in review*). Chapter 6 quantifies the navigation and neuromechanical differences in toddler powered mobility exploration in two different postures. (Zaino et al., *Assist Technol, in preparation*). Finally, Chapter 7 summarizes the important findings throughout the entire dissertation and provides directions for future research.

Chapter 2

BACKGROUND

Engineers design technology that allows us to move and enhance our mobility. This dissertation investigates the impact of such technologies designed for individuals with disabilities. Rehabilitation engineering is a unique field at the cross-section of engineering, biomechanics, and rehabilitation science. While each chapter in this dissertation includes the necessary background, this chapter seeks to provide an overview of the methods drawn from multimodal mobility (using several methods for mobility) and early mobility literature to frame rehabilitation engineering research.

2.1 ON-TIME MOBILITY

Mobility, specifically self-initiated mobility, at an early age is critical for young children because it allows the individual to initiate and control their movement. For young children with disabilities who either have delayed walking or will become wheelchair users, the default mode of mobility is being pushed in a stroller or manual wheelchair. This removes the opportunity for exploration, socialization, and cognitive, physical, and visual development. Self-initiated mobility strongly correlates with overall development and is linked to the development and acquisition of visual, cognitive, social, and perceptual skills [12, 13]. Thus, children with mobility disabilities and delays have fewer opportunities to engage in age-appropriate self-initiated exploration and play, which may decrease motivation and cause passive peer interactions [12]. There is an extensive understanding of how non-disabled children learn to crawl, walk, and explore their environment [14–19], but this does not include disabled toddlers or extend to disabled toddlers learning how to move with the support of a variety of mobility aids.

Mobility aids are an important technology to enable on-time development and improve peer engagement for children with disabilities and mobility delays. For example, recent research suggests that access to "on-time" powered mobility at an age when non-disabled peers start self-initiated movement may be critical for development [10, 20]. On-time mobility is a theory proposed by Sabet A. and colleagues that "*all children have the right to be mobile throughout their development to explore, engage in relationships, and develop agency to cocreate their lives*" [21]. This means providing access to supportive mobility aids for children with disabilities concurrently with when their non-disabled peers start self-initiating their mobility (i.e., at the time of typical crawling). Mobility aids can support mobility sooner at this critical age, as delays in self-initiated mobility can have trickle down effects on cognitive, spatial, and physical development. Some examples of assisted on-time mobility for toddlers with disabilities include orthoses, walkers and gait trainers [22], bodyweight support systems (PUMA) [23], adapted ride-on cars (GoBabyGo) [24, 25], and powered mobility including Wizzybug [26], Bugzi [26], and Explorer Mini [11, 20, 27]. For example, the positive effects of powered mobility use on behavior and development have been well documented for children under 3 years of age [28, 29], including improved social skills [30, 31], independence [32], communication [33], mobility skills [33, 34], and self-care skills [33]. These positive effects can also be seen for other modes of supported self-initiated mobility.

While there is a rich base of evidence of the benefits of on-time mobility, there is inadequate knowledge regarding the prescriptive process of assistive devices to support on-time mobility for children with disabilities. There are many different types of assistive technology that can help support mobility for infants and toddlers. However, implementation of this technology is not always implemented by clinicians for this specific age group [35–37]. Further, there is little known how children with disabilities learn to use mobility aids and interact with their devices to explore their environment [38]. Prior work on on-time powered mobility for toddlers with disabilities focused on community implementation and observational outcomes [11, 39–41], while prior work on the use and biomechanics of walking with mobility aids such as walker does not include this young age group [42, 43].

2.2 MULTIMODAL MOBILITY

We all use technology to support our mobility; ranging from sizable technology that is used outside such as bikes, trains, or cars to smaller technology used in many environments like hiking poles, walkers, and wheelchairs. We use many different modes of mobility that are supported by technology because they are context specific. The same is true for people with disabilities, however their modes of mobility consider more than just distance and the environment. For people with disabilities other factors considered include pain, endurance, accessibility of the specific location, fear of falling, location, inside/outside, terrain surface, and distance.

Multimodal mobility is the use of different mobility aids to support play, function, life, work, and socialization for individuals with disabilities based on different environments and needs. The use of mobility aids and assistive technology influences the interaction between a person with a disability and their environment and allows for independence, employment, and a better quality of life [44]. The World Health Organization's International Classification of Functioning, Disability, and Health (ICF) framework is commonly used in the rehabilitation field [45]. The ICF framework focuses on the fact that a disability is a dynamic relationship between a person, technology, and the environment [46]. Thus, one's choice of mobility aid is influenced by an individual's environment, their needs, and their goals. So, mobility aids need to be as unique as the individual who uses them.

A few different categories of mobility aids that are commonly used and discussed in this dissertation: (1) orthoses, (2) handheld mobility aids, (2) hands-free mobility aids, and (4) wheeled mobility, among others. Orthoses (supportive braces for limbs) used to support walking mobility include supra-malleolar orthoses (SMO), ankle foot orthoses (AFO), and knee ankle foot orthoses (KAFO). Handheld mobility aids include walkers (anterior and posterior), forearm crutches, and canes. Hands-free mobility aids include gait trainers and dynamic standers. Wheeled mobility includes manual wheelchairs, powered wheelchairs, standing powered wheelchairs, and scooters. New devices are also constantly being developed and tested [47], such as innovations in powered exoskeletons [46], devices to support crawling [48], and functional electrical stimulation systems [46].

2.3 CEREBRAL PALSY

Cerebral palsy (CP) is one example of a pediatric onset condition for which individuals utilize many different modes of mobility throughout their life and even different modes depending on their environment. CP is caused by a brain injury at or near the time of birth. It is a lifespan disorder and affects roughly 3 per every 1000 children in the United States, making it among the most common pediatric motor disabilities [49, 50]. In this dissertation, most of my work specifically focuses on individuals with CP. However, many of the multimodal mobility strategies presented are used by a wide range of individuals with disabilities; therefore, the results and implications of this work can be applied and translated to other groups like individuals with spina bifida, incomplete spinal cord injuries, stroke, multiple sclerosis, down syndrome, and any mobility disability with a childhood onset.

CP has a highly heterogenous presentation, thus individuals with CP require a wide variety of modes of mobility – participation and function throughout the lifespan are enhanced by a multimodal view of mobility. While CP is a non-progressive brain injury, secondary musculoskeletal impairments, pain, increased body mass, and physical fatigue further impact mobility, participation, and quality of life for individuals with CP. This can change over time as they grow throughout their childhood and into adulthood [5]. Approximately 33% of people with CP use wheeled mobility, such as manual or powered wheelchairs, as their primary mode of mobility [5, 51]. Rodby-Bousquet et al. (n=563, ages 3-18 years) reported that 29% of children with CP used a wheelchair indoors and 41% outdoors. Additionally, it is important to note that prior research has shown that 86% of children using a powered wheelchair had independent mobility compared to only 14% of children using manual wheelchairs [52]. A recent publication out of Norway using their national registry of children with CP, found that children with CP use 0-12 assistive devices (median: 2.5) [53]. 60% of the children used mobility aids which align with GMFCS level classification abilities. Understanding and supporting mobility in all of its forms is critical to further research, training of, and development of supportive mobility technology for individuals with disabilities to facilitate efficient movement for their life. This includes including individuals with lived-experiences in the research process to include their perspectives and ideas to drive innovation in mobility aids as well as quantifying and understanding the user-device-environment interaction and relationship for mobility aids. This dissertation evaluates mobility across the spectrum to support and enhance mobility, independence, and engagement for individuals with disabilities.

2.4 MIXED-METHODS APPROACHES

Scientists use a variety of research methods to holistically answer complex questions. In this dissertation, computational, qualitative, and experimental approaches are all used to provide a holistic view of the gaps and opportunities for multimodal mobility.

One unique aspect of this dissertation is the integration of lived experiences with laboratory-based experiments of mobility. There are a few different research methods that can be used to include lived experiences (an individual's experiences, perceptions, and behavior) in research. This includes focus groups, Delphi process, surveys, and interviews. Each of these methods has additional categories. For example, interviews can be structured, open, or semi-structured to allow for more or less freedom in the discussion [54]. Structured interviews are a questionnaire with no back-and-forth discussion. A semi-structured interview has a pre-set list of questions and topics; however, the list of open-ended questions, topics, sub-topics, and sub-questions are intended to *guide* but not *restrict* the conversation. Open interviews are free conversation. Another example is the Delphi process: a structured method for consensus building among experts using multiple rounds of anonymous questionnaires and discussion [55] and has been used in clinical research to understand end-user perspectives [56, 57]. Focus groups are moderated by a researcher(s) with a small group of participants to discuss both between the researcher and participants and between participants to discuss a specified topic [58]. Finally, surveys can capture both quantitative and qualitative results either in a paper or digital format [[59].

Experimental research studies in biomechanics often include in-lab experiments in a controlled environment. A few specific methodologies within biomechanics include electromyography (EMG) and motion capture. There are a few different ways to measure and quantify 3D movement. The most common in clinical and biomechanics research is a camera-based motion capture system that tracks retro-reflective markers placed on specific bony landmarks or objects. EMG measures the electrical activity that is produced during the activation of muscles and is commonly used in experimental experiments and clinically in gait evaluations to quantify the timing and activity of muscles. Surface EMG (sEMG) and fine-wire EMG are two different types with the prior being non-invasive and the latter being invasive [60]. For this reason, sEMG is most commonly used. sEMG is measured using a pair of electrodes placed on the skin over the muscle belly and in line with the muscle fibers, according to placement guidelines [61, 62]. Prospective experimental studies allow for specific questions to be asked in a controlled environment to help isolate out the secondary parameters that could impact the research question outcome.

Computational methods are critical to support rigorous scientific research and can leverage and use the experimental data collected such as kinematics and EMG. Clinicians and hospitals collect a large amount of data, such as in clinical gait analyses to assess mobility, these databases can be leveraged for understanding and improving outcomes. The deluge of data generated by clinics can be leveraged for modeling purposes of treatment efficacy, mobility trajectory, and many other important research questions that can impact clinical care through both retrospective studies and modeling.

In this dissertation, we leverage this retrospective clinical data to probe and evaluate current and future mobility options. Especially, when conducting research on a population with a disability and investigating the effectiveness or efficacy of a treatment it is critical to have the control group to have the same disability rather than a non-disabled cohort to reduce the covariates of aging and development. Without a proper control group within the same population, prior researchers committed a Type 1 error to falsely conclude that the intervention alone caused the changes with no way to control for the natural changes over time, especially in a pediatric population [63]. There are many ways to select a control group for a retrospective analysis. Poor selection of a control group in a retrospective analysis can have significant impact on the evaluation of the results due to selection bias.

As an example, in this dissertation we used k-nearest neighbor matching. K-nearest neighbor matching (k-NN) is a matching method that selects the closest neighbor for each data point [64]. In rehabilitation research this assists with selecting a true control group, retrospectively, which is pivotal for eliminating as many co-variates as possible.

There are a few different methods within nearest neighbor-based control group selection [65]. One calculates the distance for each pair of individuals from the case group and the candidate group and then selects the nearest neighbor from the candidate group. However, this approach allows for one participant in the control group to be the control for multiple participants. A more rigorous version of the nearest neighbor-based control group selection prevents this problem by removing the nearest neighbor from the candidate population after they are matched to a participant in the case group. This iterative nature allows for two distinct groups without any one specific participant in the control group weighing the results and minimizing error.

Proper control group selection allows for more impactful and accurate retrospective research which can take advantage of the deluge of data that clinics collect in repeated gait analyses. This reduces the burden on the individuals with disabilities to participate in experimental studies, since the data collected from their regular gait analyses can be used to gain valuable insight from clinical databases retrospectively about interventions and treatment.

The following chapters employ a collection of research methods within experimental, qualitative, and computational realm to understand, quantify, and summarize the impact and use of technology to support multimodal mobility for individuals with disabilities.

Chapter 3

ENERGY CONSUMPTION DOES NOT CHANGE AFTER SELECTIVE DORSAL RHIZOTOMY IN CHILDREN WITH SPASTIC CEREBRAL PALSY

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Nicole L. Zaino

Katherine M. Steele

J. Maxwell Donelan

Michael H. Schwartz

ABSTRACT

Aim: To determine whether energy consumption changes after selective dorsal rhizotomy (SDR) among children with cerebral palsy (CP).

Method: We retrospectively evaluated net nondimensional energy consumption during walking among 101 children with bilateral spastic CP who underwent SDR (59 males, 42 females; median age [5th centile, 95th centile] 5y 8mo [4y 2mo, 9y 4mo]) compared to a control group of children with CP who did not undergo SDR. The control group was matched by baseline age, spasticity, and energy consumption (56 males, 45 females; median age [5th centile, 95th centile] 5y 8mo [4y 1mo, 9y 6mo]). Outcomes were compared at baseline and follow-up (SDR: mean [SD] 1y 7mo [6mo], control: 1y 8mo [8mo]).

Results: The SDR group had significantly greater decreases in spasticity compared to matched controls (–42% SDR vs –20% control, p<0.001). While both groups had a modest reduction in energy consumption between visits (–12% SDR, –7% control), there was no difference in change in energy consumption (p=0.11) or walking speed (p=0.56) between groups.

Interpretation: The SDR group did not exhibit greater reductions in energy consumption compared to controls. The SDR group had significantly greater spasticity reduction, suggesting that spasticity had minimal impact on energy consumption during walking in CP. These results support prior findings that spasticity and energy consumption decrease with age in CP. Identifying matched control groups is critical for outcomes research involving children with CP to account for developmental changes.

3.1 INTRODUCTION

Cerebral palsy (CP) is a neuromuscular disorder caused by a brain injury at or near the time of birth, and is the most common pediatric disability in the US, affecting over 3 per 1000 live births [49, 50]. Fatigue is one of the top complaints of children with CP and their families [66]. A likely contributor to fatigue is the amount of energy children with CP consume during daily activities, such as walking. There are many different metrics used to evaluate energy during walking. Clinically, the volume of oxygen consumed per unit time, often called 'energy consumption', is a widely used indicator of exertion [67]. The energy consumption during walking for children with CP has been estimated to be two to three times that of typically developing peers [68–72]. The cause of increased energy consumption is unclear.

Spasticity, defined as a velocity-dependent resistance to stretch, [73] has been theorized as a cause of the observed increase in energy consumption in CP. Spasticity can cause an increase in overall muscle activity, which is thought to directly contribute to elevated energy consumption. Spasticity is observed in up to 80% of children with CP [49] and is also common in other neurological disorders such as multiple sclerosis and spinal cord injury. Prior research has found that individuals with multiple sclerosis and spasticity also have energy costs two times that of typically developing peers, suggesting that spasticity may be an important determinant of high energy during walking. [74]

Selective dorsal rhizotomy (SDR) is a neurosurgical procedure where afferent nerve fibers in dorsal rootlets are cut in order to reduce efferent excitations. [75] SDR has been shown to significantly reduce spasticity. [76–78] Prior outcome studies have also suggested that SDR may reduce energy consumption. [8, 9] For example, Carraro et al. found that energy consumption was significantly reduced across multiple walking speeds after SDR for nine children with CP. [8]

While these studies seem to indicate that spasticity can be a contributor to elevated energy consumption in CP, there are several critical limitations to drawing causal conclusions from these prior studies. There are numerous other factors that could contribute to changes in energy consumption after surgery. For example, changes in walking patterns and speed [79] after SDR could change joint moments and muscle demands. [69] Energy consumption [68] and spasticity [80] are also known to decrease with age among children with CP. Evaluating energy consumption before and after procedures thus requires that covariate factors, such as speed and age, be considered. Identifying appropriate control groups of peers with CP provides one method to address these challenges.

The purpose of this study was to determine if spasticity is a significant contributor to elevated energy consumption among children with CP by investigating if reducing spasticity after SDR leads to lower energy consumption. We hypothesized that if spasticity contributes to energy consumption for children with CP, then an SDR should result in greater changes in energy consumption compared to matched controls with CP who did not undergo an SDR. Understanding the role of spasticity on energy consumption is important to inform treatments that aim to lower energy consumption, reduce fatigue, and increase quality of life for children with CP.

3.2 METHODS

3.2.1 Participants

We retrospectively identified individuals with bilateral spastic CP who underwent gait analysis at Gillette Children’s Specialty Healthcare (St. Paul, MN, USA) between 1994 and 2018. Inclusion criteria for this study were individuals younger than 18 years old who: (1) had a primary diagnosis of bilateral spastic CP; (2) underwent a bilateral SDR before the age of 12 years; (3) had at least one gait analysis before (baseline) and after (follow-up) SDR that included both energy consumption and Ashworth scores.

We also identified a control group of peers with CP that met the above inclusion criteria but did not undergo an SDR. This group was matched to the treatment cohort by baseline levels of age, energy consumption, and spasticity (Fig. 1). To identify matching peers between the control and SDR cohort we transformed all matching variables for each participant into a single summary score using an autoencoder. [81] An autoencoder is a neural network that can be used for dimensionality reduction of complex data. [82] For this research, the autoencoder was defined using age, energy consumption, and spasticity across all children with bilateral spastic CP who had previously received a gait analysis at Gillette Children’s Specialty Healthcare to define a summary metric of the variations in these dimensions across the population. The summary scores were then calculated for each child in the SDR group and a k-nearest-neighbors search algorithm was used to identify the closest matching peer with CP. If two children in the SDR group matched to the same nearest neighbor peer, we checked to determine if the second-nearest neighbor was an acceptable match. To be acceptable, the distance to the second-nearest neighbor had to be within the 95th centile of the distances between the SDR group and their first nearest neighbors.

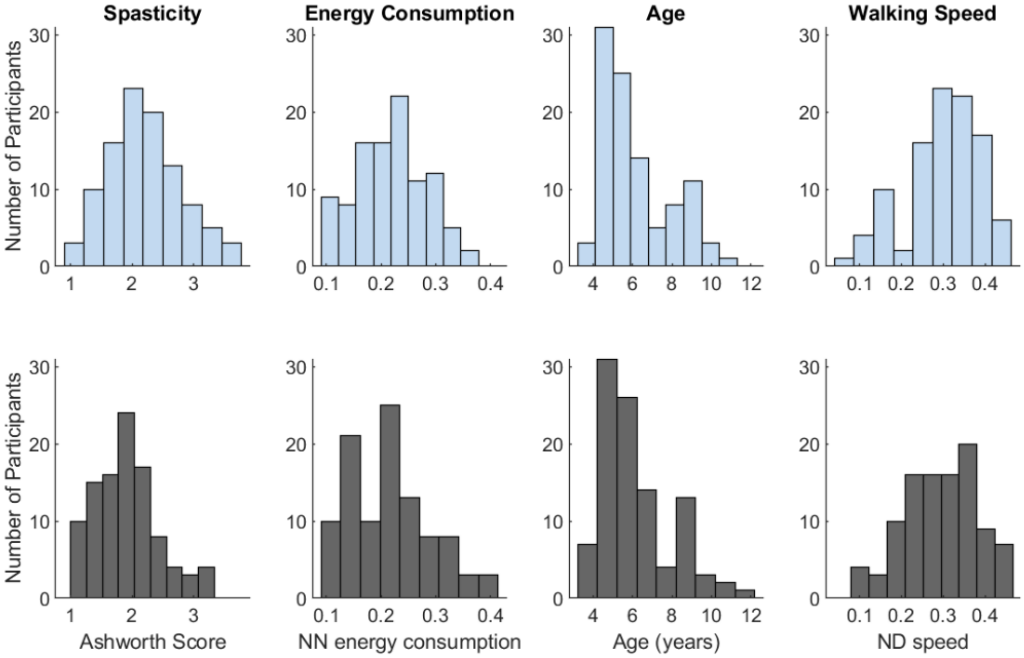

Figure 3.1 Baseline age, net-nondimensionalized (NN) energy consumption, summary spasticity score, and nondimensionalized walking speed for (top row) children who underwent a selective dorsal rhizotomy and (bottom row) matched peers with cerebral palsy. Participants were actively matched for age, NN energy consumption, and summary spasticity score. While not actively matched, speed was passively matched between groups.

This method was used to actively match participants based on age, walking speed, and spasticity. To avoid over-constraining the matching algorithm, we evaluated whether other important variables were passively matched. In this context, 'passively matched' means the baseline values of variables were matched between groups despite not being included in the active matching. Additionally, the resulting groups were constrained after active matching in order to limit the difference in follow-up time between matched pairs to less than 18 months. All matching variables were compared between groups to evaluate the similarity of the cohorts using Wilcoxon rank-sum tests.

3.2.2 Spasticity

To evaluate spasticity, we calculated a summary spasticity score for each individual. The score was derived from the Ashworth Scale of six right limb muscle groups using principle component analysis. [83] The six muscle groups were hip adductors, hip flexors, hamstrings, rectus femoris, plantarflexors, and posterior tibialis. The Ashworth Scale is a discrete scale with five levels used to categorize spasticity. [84] At Gillette Children's Specialty Healthcare, the following Ashworth Scale definitions are used: (1) no increase in tone, (2) slight increase in tone, (3) more marked increase in tone, (4) considerable increase in tone, and (5) rigidity. This spasticity summary score is a weighted average and can be interpreted as an Ashworth score on a continuous 1 to 5 scale.

3.2.3 Energy

Energy during walking was assessed by converting the time rate of breath-by-breath oxygen consumption ($\dot{O}_2^{gross}$) to energy consumption (E^{gross}) using the conversion rate of 21 Joules/ml. [85] Both $\dot{O}_2^{gross}$ and $\dot{O}_2^{rest}$ were converted to gas volume expressed under standard conditions of temperature, pressure, and dry from testing conditions. The testing protocol consisted of a 6-minute over-ground barefoot walking trial preceded by a 3 to 10 minute rest period. [67] Resting energy consumption (E^{rest}) was assessed during supine or sitting. [67] We calculated net-nondimensionalized energy consumption as:

$$\text{net} - \text{nondimensionalized energy consumption} = (E^{gross} - E^{rest}) \times \left(\frac{1}{mg\sqrt{gL_{leg}}}\right)$$

where m is body mass, L_{leg} is the length of the leg, and g is acceleration because of gravity.

3.2.4 Strength

Strength was also collected during the physical exam using a manual muscle test (MMT) for hip extensors, hip flexors, knee extensors, knee flexors, and plantarflexors. Like the method used for the summary spasticity score, an individual strength score was calculated for each individual for both the baseline and follow-up visits using principal component analysis. This MMT summary score is a weighted average and can be interpreted as an MMT score on a continuous 1 to 5 scale, where 1 is defined as ‘visible or palpable contraction (no range of motion)’ and 5 is defined as ‘full range of motion against gravity’.

3.2.5 Walking speed

Walking speed was measured during the 6-minute over-ground barefoot walking trial. We computed nondimensionalized walking speed as: [86]

$$nondimensionalized\ speed = speed \times \left(\frac{1}{\sqrt{gL_{leg}}}\right)$$

3.2.6 Statistical analysis

We used Wilcoxon signed-rank tests (α<0.05) to compare changes in net-nondimensionalized energy consumption, spasticity, and walking speed between baseline and follow-up within each group (SDR and control). We then used Wilcoxon rank-sum tests (α≤0.05) to compare change in net-nondimensionalized energy consumption, spasticity, and walking speed between the groups (SDR vs control). All values are reported as a median [5th centile, 95th centile], unless otherwise noted. All analyses were done using Matlab (MathWorks Inc., Natick, MA, USA).

3.3 RESULTS

3.3.1 Baseline comparison of groups

We identified 101 individuals with CP (59 males, 42 females) who met the inclusion criteria for the SDR group (age 5y 8mo [4y 2mo, 9y 4mo]; height 107cm [96.5, 133.2cm]; weight 17.7kg [14.1, 27.3kg]). Our control group consisted of 101 individuals with CP (56 males, 45 females) who did not undergo an SDR (age 5y 8mo [4y 1mo, 9y 6mo]; height 110cm [96.5, 131.3cm]; weight 18.8kg [13.8, 33.6kg]). The distributions for age, walking speed, net-nondimensionalized energy consumption, and spasticity at baseline were well matched between groups (Table 3.1, Fig. 3.1). There were no significant differences between groups for baseline net-nondimensionalized energy consumption (p=0.6) and baseline age (p=0.8, Table 3.2). There was a small difference between groups for baseline spasticity (SDR 2.2 [1.4, 3.3] and control 1.9 [1.2, 3.0]; p<0.001), with an effect size of 0.8. This difference in spasticity corresponds to less than half of an Ashworth level, below the threshold for clinical significance. The time between visits was similar between groups (SDR 1y 6mo [1y 1mo, 2y 8mo] and control 1y 6mo [0y 11mo, 2y 11mo]; p=0.7).

Table 3.1 Summary of demographics and outcome measures for both cohorts. Data are median (5th centile, 95th centile). SDR, selective dorsal rhizotomy; NN, net-nondimensionalized.

	Baseline		**Follow-up**		**Change**	
	SDR	Control	SDR	Control	SDR	Control
Age (y:mo)	5:8 (4:2, 9:4)	5:8 (4:1, 9:6)	7:6 (5:6, 11:1)	7:6 (5:6, 11:10)	1:6 (1:1, 2:8)	1:6 (0:11, 2:11)
Height (cm)	107.0 (96.5, 133.4)	110.0 (96.5, 131.3)	118.4 (104.1, 146.5)	120.7 (106.3, 142.6)	8.5 (2.8, 18.5)	9.0 (0.9, 20.8)
Weight (kg)	17.7 (14.1, 27.3)	18.8 (13.8, 33.6)	21.7 (16.4, 36.1)	22.9 (17.1, 40.2)	3.60 (1.2, 9.8)	3.70 (0.9, 13.7)
Leg length (cm)	53.5 (47.0, 69.2)	55.0 (47.0, 70.5)	60.0 (52.3, 77.0)	61.5 (51.8, 77.0)	5.5 (2.0, 11.5)	6.0 (2.0, 13.0)
NN energy consumption	0.22 (0.12, 0.32)	0.21 (0.11, 0.36)	0.17 (0.11, 0.27)	0.19 (0.09, 0.30)	–0.04 (–0.15, 0.07)	–0.01 (–0.14, 0.08)
Spasticity	2.20 (1.4, 3.3)	1.90 (1.2, 3.0)	1.20 (1.0, 1.7)	1.40 (1.0, 2.6)	–0.9 (–2.2, –0.2)	–0.4 (–1.3, 0.5)
NN walking speed	0.32 (0.14, 0.42)	0.30 (0.13, 0.42)	0.32 (0.12, 0.40)	0.32 (0.13, 0.41)	0.00 (–0.11, 0.11)	0.01 (–0.11, 0.11)

Table 3.2 P-values comparing cohorts. NN, net-nondimensionalized.

	Baseline	**Follow-up**	**Change**
Age	0.8	0.7	0.7
NN energy consumption	0.6	0.2	0.1
Spasticity	<0.001	<0.001	<0.001
NN walking speed	0.7	0.9	0.6

3.3.2 Spasticity

Children who underwent SDR exhibited greater reductions in spasticity at follow-up compared to matched peers with CP (p<0.001; Table 3.1 and Fig. 3.2). The baseline summary spasticity score was 2.2 (1.4, 3.3) for the SDR group and 1.9 (1.2, 3.0) for the control group. The SDR group exhibited a large decrease in spasticity after surgery, with a follow-up summary spasticity score of 1.2 (1.0, 1.7; p<0.001). The change in spasticity after SDR varied from –2.7 to 0 (–0.9 [–2.2, –0.02; p<0.001]). The control group exhibited a small decrease in spasticity at follow-up, with a summary spasticity score of 1.4 (1.0, 2.6; p<0.001). The change in spasticity in the control group varied from –2.3 to 0.7 (–0.4 [–1.3, 0.05; p<0.001]). The change in spasticity for the SDR group was more than twice that of the control group (p<0.001).

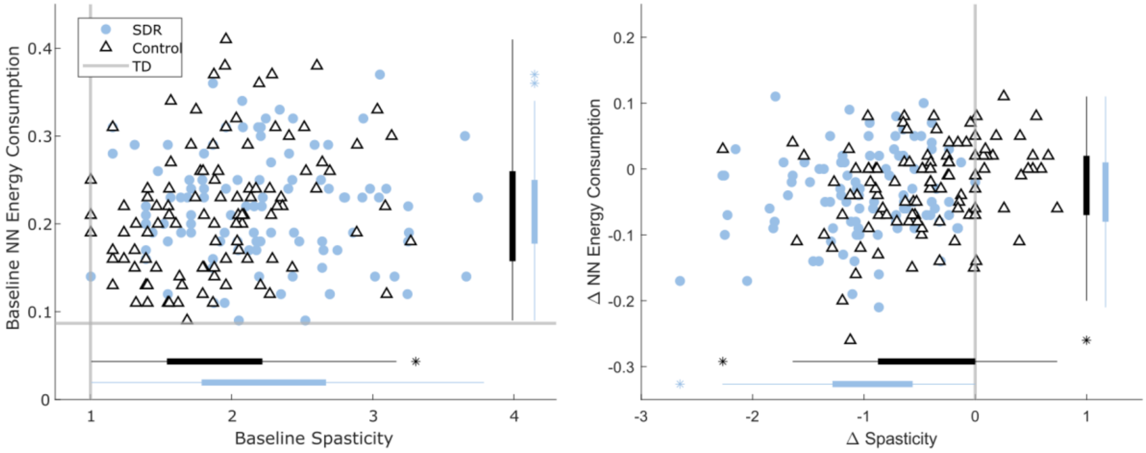

Figure 3.2 Spasticity and net-nondimensionalized (NN) energy consumption for children with cerebral palsy (CP) who underwent a selective dorsal rhizotomy (SDR) and matched peers with CP who did not undergo SDR (control). (a) Baseline spasticity and NN energy consumption were similar between groups. Gray lines show normative values for typically developing (TD) peers from Gillette Children's Specialty Healthcare. (b) Spasticity and NN energy consumption decreased significantly at follow-up for both groups. The SDR cohort had a significantly greater decrease in spasticity compared to the no-SDR group, but a similar decrease in NN energy consumption. Bars represent distributions for each group including outliers (*).

3.3.3 Energy consumption

An SDR did not result in a greater reduction in net-nondimensionalized energy consumption compared to the control group (p=0.11; Fig. 3.2). The baseline net-nondimensionalized energy consumption was 0.22 (0.12, 0.32) for the SDR group and 0.21 (0.11, 0.36) for the control group. The net-nondimensionalized energy consumption remained similar between groups at follow-up, 0.17 (0.11, 0.27) and 0.19 (0.09, 0.30) for the SDR and control groups respectively. The net-nondimensionalized energy consumption decreased significantly for both groups between visits (SDR, –0.04 [–0.15, 0.07; p<0.001], no-SDR, –0.01 [–0.12, 0.08, p<0.001]).

3.3.4 Strength

Strength was not actively matched for in the matching algorithm, but baseline strength (MMT summary score) was similar between groups: 3.4 (2.4, 4.2) for the SDR group and 3.4 (2.3, 4.0) for the control group. The follow-up strength was 3.5 (2.6, 4.3) and 3.4 (2.4, 4.5) for the SDR and control groups respectively. There was no significant difference in strength between groups at baseline (p=0.4), follow-up (p=0.09), or change in strength (p=0.3).

3.3.5 Walking speed

Walking speed was not actively included in the matching algorithm but can influence energy consumption. Therefore, we also evaluated changes in walking speed between visits. The baseline nondimensional walking speed was 0.32 (0.14, 0.42) and 0.30 (0.13, 0.42) for the SDR and control groups respectively. The follow-up nondimensional walking speed was 0.32 (0.12, 0.40) and 0.32 (0.13, 0.41) for the SDR and control groups respectively. There was no significant difference in walking speeds between groups at baseline (p=0.7) or follow-up (p=0.9). There was no significant change in walking speed for either group (SDR p=0.9, control p=0.5).

3.4 DISCUSSION

While SDR was effective at reducing spasticity, there was no associated decrease in energy consumption compared to matched peers with CP who did not undergo an SDR. We had hypothesized that if spasticity contributes to high energy consumption, then an SDR would result in lower post-treatment energy consumption compared to matched controls with CP who did not undergo an SDR. However, the change of energy consumption for the children with CP who underwent SDR was not significantly different from the change in energy consumption for the matched controls with CP. This indicates that spasticity is not a primary factor contributing to elevated walking energy in children with CP when compared to typically developing peers. The energy reduction at follow-up observed in both groups was consistent with the idea that energy consumption decreases with age among children with CP, independent of treatment. [87]

Prior studies have reported reductions in energy consumption after an SDR. However, these studies used either a typically developing control or no control group at all. [8, 76, 78] For example, Trost et al. reported a 22% reduction in energetic cost after SDR. [77] In their study, the average age (SD) before and after SDR was 7 years 3 months (2y 1mo) and 8 years 9 months (4mo). This is an age span during which we would expect energy to decrease substantially among children with CP regardless of treatment. To our knowledge, no studies have included a control group of peers with CP when looking at the impact of SDR on energy consumption. Our results demonstrate the critical importance of identifying and comparing to a cohort of peers with CP when evaluating treatments to differentiate whether observed changes are due to the treatment or natural development. [88]

There are a few possible explanations for why spasticity does not affect energy consumption: (1) the additional muscle activity from spasticity does not increase energy consumption; (2) the additional muscle activity from spasticity is not large enough to have a large effect; (3) the spasticity measured by the Ashworth score does not reflect the muscle activity during gait; or (4) other factors beyond spasticity are the primary contributors to the elevated energy consumption in individuals with CP. Other possible contributors to elevated energy consumption in children with CP include poor selective motor control, [89] excessive cocontraction for stabilization, [90] and altered muscle properties. [91] While SDR provides a platform to evaluate the impacts of spasticity, other strategies will be necessary to evaluate the relative importance of these other factors and to identify optimal strategies for reducing energy consumption for children with CP. This is critical, as physical fatigue is prevalent and hinders participation and quality of life among individuals with CP throughout their lifespan. [66, 92]

This study analyzed retrospective data from clinical gait analysis, which, like any retrospective study, has certain limitations. Energy consumption in these analyses is measured from a 6-minute walk test that does not control walking speed, mood, or other possible confounding factors. These analyses are conduced barefoot, which may not represent energy consumption during activities of daily living. Previous research has shown no significant difference in oxygen consumption between walking barefoot or with shoes. [93] We matched our groups by baseline spasticity, age, and energy consumption. Walking speed was not actively matched, but we found no significant difference in speed between groups at baseline or follow-up. We limited the difference in time between visits for matched pairs to a maximum of 18 months. This resulted in a similar time between visits for both groups, and we found the results were insensitive to the selected threshold. We did not control for other surgeries that occurred between visits. Post hoc examination showed that 9% of the SDR group and 36% of the controls had orthopaedic surgery. Additionally, 7% of the SDR group and 29% of the controls received botulinum neurotoxin A (BoNT-A) injections. While BoNT-A may also impact spasticity, prior research has demonstrated that BoNT-A injections result in small and transient effects on spasticity. In a placebo controlled trial, BoNT-A provided minimal advantage compared to placebo at 4 and 6 weeks as measured by the Ashworth Scale (~0.25 reduction lower than placebo), and no advantage at 2, 4, 6, 8, or 12 weeks as measured by the Tardieu scale. [94] A recent systematic review of long-term effects of SDR also showed the long-term effect of SDR on spasticity is unclear, with many studies reporting additional spasticity treatment. [95] Results were similar between cohorts that either received or did not receive orthopaedic surgery or BoNT-A injections. There are concerns that SDR may cause weakness, and that this weakness may lead to increases in energy that could offset decreases from spasticity reduction. However, prior research has documented either no change or an increase in strength after SDR. [96–99] We similarly found no significant changes in strength between visits for either group using values from MMT during the physical exam. MMT provides limited precision for strength measurements but is the most common strength measurement used in the clinic.

3.5 CONCLUSION

Spasticity was significantly reduced for individuals with CP who underwent an SDR compared to matched peers with CP, but energy consumption was not different between groups. These results demonstrate that spasticity has minimal impact on the high energy consumption observed among children with CP. Both groups demonstrated a reduction in spasticity and energy consumption between visits, likely reflecting changes due to development. Selecting appropriate control groups is critical for research involving children with CP to account for changes in function due to age, development, and other factors. While SDR is often suggested to reduce spasticity and improve energy, clinicians and families should understand that this procedure does not improve energy consumption during walking.

3.6 ACKNOWLEDGMENTS

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Chapter 4

“THAT’S FRUSTRATING”: PERCEPTIONS OF ANKLE FOOT ORTHOSIS PROVISION, USE, AND NEEDS AMONG PEOPLE WITH CEREBRAL PALSY AND CAREGIVERS

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Authors

Nicole L. Zaino

Momona Yamagami

Deborah J. Gaebler-Spira

Katherine M. Steele

Kristie F. Bjornson

Heather A. Feldner

ABSTRACT

Background: Cerebral palsy (CP) affects roughly 3 per 1000 births in the United States and is the most common pediatric developmental motor disability. Ankle foot orthoses (AFOs) are commonly prescribed to provide support and improve function for individuals with CP.

Objectives: The study objective was to evaluate the lived experiences of individuals with CP and their caregivers regarding AFO access, use, and priorities. We examined experiences around the perceived purpose of AFOs, provision process, current barriers to use, and ideas for future AFO design.

Study design: Secondary qualitative data analysis.

Methods: Secondary data analysis was performed on semi-structured focus groups that included 68 individuals with CP and 74 caregivers. Of the focus group participants, 66 mentioned AFOs (16 individuals with CP and 50 caregivers). Deidentified transcripts were analyzed using inductive coding, and the codes were consolidated into themes.

Results: Four themes emerged: 1) AFO provision is a confusing and lengthy process, 2) participants want more information during AFO provision, 3) AFOs are uncomfortable and difficult to use, and 4) AFOs can benefit mobility and independence. Caregivers and individuals with CP recommended ideas such as 3D printing orthoses and education for caregivers on design choices to improve AFO design and provision.

Conclusions: Individuals with CP and their caregivers found the AFO provision process frustrating but highlight that AFOs support mobility and participation. Further opportunities exist to support function and participation of people with CP by streamlining AFO provision processes, creating educational materials, and improving AFO design for comfort and ease of use.

4.1 INTRODUCTION

Ankle foot orthoses (AFOs) are a mobility aid commonly prescribed to provide support and improve function for individuals with cerebral palsy (CP) [100]. CP represents a heterogenous group of movement disorders that is caused by a brain injury at or near the time of birth. It is a lifespan disorder and affects roughly 3 per every 1000 children in the United States, making it among the most common pediatric motor disabilities [49, 50]. Although there are many mobility aids available to support function for people with CP, AFOs are the most common aid used across all Gross Motor Functional Classification Scale (GMFCS) Levels [101].

Ankle foot orthoses can affect walking function and joint alignment for individuals with CP. Previous research has shown that AFOs can improve walking speed, energy consumption, gait kinematics, step length, and standing postural control for individuals with CP [100, 102, 103]. However, the type and fit of AFO varies widely, as well as the process used to prescribe and adjust the AFO for each individual. When a device is properly optimized for each individual, AFOs have been shown to support more consistent improvements of gait and functional metrics across individuals [100, 104, 105]. For example, AFOs where the shank-to-vertical angle has been optimized to an individual's standing and walking patterns have been shown to improve standing balance, gait, activity, and participation [105]. However, how to optimize AFOs to each individual is unclear and AFO responses are generally more variable [106]. In a retrospective analysis of more than 400 children with CP who wore bilateral AFOs, only 37% produced a clinically significant improvement in gait (Gait Deviation Index) compared with barefoot walking [107]. Ankle foot orthoses are also used by individuals who are nonambulatory to correct and prevent musculoskeletal deformities, provide joint alignment, and maintain foot and ankle positions [108–

110]. Unfortunately, there is little to no evidence regarding the extent or consistency of the benefits in these cases [111].

Although these previous studies have examined the functional impacts of AFOs, the perspective of AFO users is limited in the scientific literature. Some previous work has examined caregiver and clinician perspectives on AFO prescription and use. For example, Kane et al evaluated perspectives among therapists, orthotists, and physiatrists and identified challenges in the current prescription process including funding, communication, and technology to enhance clinical evaluation. Clinicians emphasized the desire for the prescription process to be a collaborative, iterative, and individualized process [112]. Caregivers have voiced some similar perspectives. Lana et al reported that mothers of children with CP expressed that AFOs improved their child's mobility but wanted more personalization and increased comfort [113]. Ankle foot orthoses are commonly used for other disabilities, such as Charcot–Marie–Tooth disease. Individuals with Charcot– Marie–Tooth voiced concerns about functional mobility, pain/ discomfort, choice of AFOs and associated footwear, custom design, and use in practical situations. Orthotists have shared similar perspectives, additionally emphasizing the need to prevent future complications and provide education regarding device limitations [114]. Holtkamp et al used a questionnaire to examine AFO satisfaction among a broad spectrum of AFO users (n=211), which included individuals with CP (n=20) and stroke (n=49). They found high levels of satisfaction, with 62% of users reporting that they use their AFO regularly and are satisfied with its function. However, 35% of respondents still reported that they were dissatisfied with their AFO [115].

The needs and perspectives of AFO users are important when prioritizing future research and improvements for AFO provision and use. For example, in 2018, a stakeholder engagement group that included people with CP, caregivers, and healthcare providers documented a list of the top 16 research priority areas, one of which was determining key family-centered interventions (including orthotics) that are associated with optimal functional outcomes [92]. Another priority research area, aging with CP, was identified to better understand treatment considerations for adults and also to update therapeutic intervention protocols for children with CP to prevent common secondary impairments such as pain, fatigue, and functional loss. Focusing on AFO experiences across the lifespan is important to understand the priorities and challenges that individuals with CP and their families experience to drive future strategies to improve AFO acquisition, use, and satisfaction. Thus, the purpose of this study was to evaluate the lived experiences of people with CP and their parents/ caregivers specifically regarding AFO access, use, and priorities. We were particularly interested in examining experiences around the perceived purpose and benefits of the AFO, the provision process, the current barriers to use, and ideas for future AFO design.

4.2 METHODS

This study is a secondary, qualitative analysis of a larger mixed methods study in which the overarching goals were to 1) understand the mobility experiences, supportive mobility device use, and desired participation outcomes of children, youth, and adults with CP and 2) describe how perspectives of rehabilitation care providers (therapists, physicians, and durable medical equipment vendors) and professional resources (time, knowledge, etc.) may influence mobility decision-making processes and outcomes in people with CP and their caregivers (https://onlinelibrary. wiley.com/doi/10.1111/dmcn.15243, Seattle, WA). The overarching study consisted of 2 parts, a Delphi study with a group of 9 stakeholders from the CP community, and a series of 24 focus groups including people with CP, their caregivers, and healthcare professionals across 4 large metropolitan regions in the United States: Boston, MA; Chicago, IL; Los Angeles, CA; and Seattle, WA. All procedures in this study were approved by the authors' institutional review board, and written consent and verbal assent were obtained from all participants before initiation of study procedures.

The Delphi process, a structured method for consensus building among experts using multiple rounds of anonymous questionnaires and discussion, was facilitated by HF and KB and conducted with 9 paid stakeholders from the CP community. Three Delphi rounds were conducted to codevelop and prioritize study topic areas and specific questions that were implemented in the subsequent focus groups (https://www.medrxiv.org/content/10. 1101/2022.01.26.22269919v1).

Focus groups were then conducted by HF, DG, and KB with 1–2 facilitators in each focus group. Overall, 68 people with CP and 74 parents/caregivers (Figure 4.1) were recruited through local regional care facilities and community groups from May 2019—December 2019. Focus groups were stratified by age and GMFCS level, including individuals with CP and their caregivers, when applicable. Inclusion criteria were as follows: 1) a person with CP of any age and with functional skills consistent with GMFCS levels I–V and 2) individuals 18 years of age and older who identify as family members or caregivers of individuals with CP.

This article describes a secondary analysis of a subset of responses from 19 focus groups that contained discussions related to AFO use and provision. We identified 66 participants (16 individuals with CP and 50 caregivers) who specifically discussed having previous or current experience using AFOs (Figure 4.1).

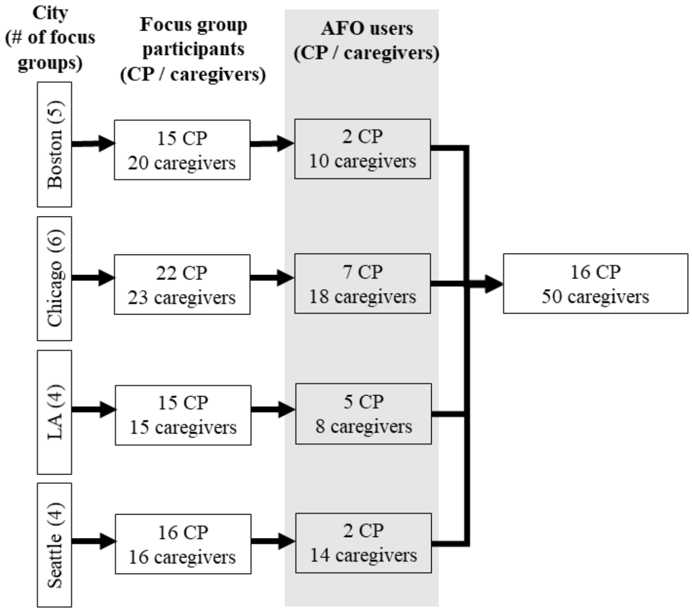

Figure 4.1 Number of participants who participated in each focus group and the subset of participants who discussed having previous or current experience using AFOs.

All focus groups were audio-recorded, transcribed verbatim, and deidentified, and the quotes specific to discussions of braces/AFOs were separated for analysis. We completed reflexive thematic analysis using inductive coding [116, 117]. Reflexive thematic analysis enables researchers to interpret participants' stories "through the lens of their own cultural membership and social positionings, their theoretical assumptions and ideological commitments, as well as their scholarly knowledge" [118]. Because our interpretation of our coded data was influenced by our backgrounds, reflexive thematic analysis enables the interpretation of our data through the lens of our own backgrounds. One author (NZ) reviewed all the interviews to take notes and develop the coding structure. Another author (MY) also took notes and developed codes for one focus group to compare results and check for the level of agreement, gaps, or biases. The final 87 codes were discussed and applied by NZ and MY to all transcripts. Differences in interpretation between NZ and MY were resolved through discussion until a 100% consensus was reached. Codes and associated quotes were then discussed among all authors until themes emerged and 100% consensus was reached (see Table 4.1 for example flow).

Table 4.1 Qualitative coding structure

Example Quotes	**Applied Codes**	**Themes**
"If there weren't such a hassle bias to driving downtown, getting him out of the wheelchair, getting him into the clinic, getting him plaster casted, getting him back in the wheelchair, getting him back in the car, that's an entire day of school that he misses. Talk about the social interactions and social impact piece, that's a huge component of the hassle bias. But if there weren't such hassle biases to getting new, something as simple and basic as AFOs, we would be doing that every three months so that they actually fit him better." – caregiver	Length of time to obtain AFO; casting process; social interactions, outgrowing AFO	AFO Provision is a Confusing and Lengthy Process
"I don't know why [they don't] inform the parent...There're other options to always just getting the same [AFO]." – caregiver	Education needed	Participants Want More Information During AFO Provision
"When I did wear the AFOs, I'm a warm, sweaty person to begin with. And so that was a huge part of the reason why I stopped [wearing AFOs]. And even when I did wear them I would, I didn't wear them in the summer, especially because it was like come summer, oh I would either get like the worst breakout, like skin rashes or I would get the worst puddles of sweat." – AFO user	Hot to wear; skin issues; uncomfortable; not used during summer; stopped use	AFOs are Uncomfortable and Difficult to Use
"I like that it makes [the AFO user] feel independent. You know, he can feel close to his friends without having me around. So, he uses his walker at school and he walks to the bus and then from the bus into class. I think he really enjoys feeling like he's included, even though he's still in the back. But he likes the challenge of trying to stay up." – caregiver	Independence; interact with peers	AFOs Can Benefit Mobility and Independence

4.2.1 Reflexivity statement

We acknowledge that, during our analyses, our backgrounds shaped our findings. This research was conducted by a group of clinicians and engineers, White and Asian, disabled and non-disabled, and parent and nonparent scholars who work in US institutions. All primarily do work in improving rehabilitation outcomes for pediatric and nonpediatric populations. To mitigate biases that might have arisen from our positionality, we ensured review and analysis by multiple researchers, included rich, thick description and verbatim quotes, and in the initial development of the qualitative questions for the focus group, convened a nine member stakeholder advisory panel to ensure that individuals with lived experience of CP were represented in the focus group study co-development.

4.3 RESULTS

Four major themes emerged from the data: 1) AFO provision is a confusing and lengthy process; 2) participants want more information during AFO provision; 3) AFOs are uncomfortable and difficult to use; and 4) despite challenges, AFOs can benefit mobility and independence (Table 4.2). These themes highlight how AFOs can be a useful tool for mobility and independence, but that there are also significant challenges in AFO provision and use. The following sections outline the quotes and insights that informed each theme.

4.3.1 AFO provision is a confusing and lengthy process

Twenty-two focus group participants (4 users and 18 caregivers) discussed challenges and opportunities specific to the AFO provision process, from prescription to fabrication to fitting the AFO. The first step of the AFO provision process—getting a prescription and finding the right orthotist—was a major hurdle for eight participants (2 users and 6 caregivers). One AFO user discussed that “one of the hard things is finding [a prescription for] new braces,” and one caregiver discussed that “finding somebody that can do really good AFO work [is hard] … we’ve been through a lot of providers before we got our orthotist.” One caregiver of an AFO user who recently aged out of the pediatric care system described additional challenges of finding an orthotist: “I can’t find anybody to make these orthotics. I have a prescription, insurance is paid for and I keep hearing ‘we only do children, we only do children, we only do children.’ So, he’s aged out of them.” One caregiver discussed how using “word of mouth” to find a suitable orthotist is a way that they overcome this hurdle. Once caregivers and AFO users found an orthotist, they “stuck with [the orthotist] forever” (2 caregivers) as a way to alleviate the challenge of finding new orthotists.

Once AFO users and caregivers obtained a prescription and found an orthotist, the next challenge was the process length because of the need for multiple appointments, frequent delays, and adjustment issues (1 user and 6 caregivers). One caregiver discussed that “[you] have to show up in the clinic 17 times before you can get your AFOs,” and one AFO user discussed that their AFOs “are custom made. They take weeks [to make] because [the orthotists] have to send them out.” One caregiver discussed how the lengthy process caused their child (the AFO user) to miss “an entire day of school,” leading the AFO user to miss “social interactions” at school, and how they would get new AFOs more often that fit better if the process took less time. However, one caregiver noted that “we’ve gotten orthotics in shorter time frames,” suggesting that not all participants had challenges with obtaining their AFOs in a timely manner. Three participants (1 user and 2 caregivers) suggested that AFOs should be more adaptable and grow with the user, so they would not have to go through the AFO provision process as often. In addition, to decrease the provision length, two caregivers suggested 3D Just list as 3D printing in all places in the publication (no three-dimensional printing) printing as an alternative, quicker manufacturing method.

Finally, insurance coverage and the cost of AFOs was an aspect of the AFO provision process that caused frustration for 11 participants (2 users and 9 caregivers). One caregiver discussed the challenge of obtaining a prescription for an orthotist that was covered by their insurance: “[the AFO user] needs new AFOs… [but] we can’t get those scripts. Everything’s got to have a prescription or…a referral.” Eight caregivers mentioned the challenge of getting insurance to cover new AFOs during growth spurts. One caregiver discussed how insurance would deny coverage when their son had “growth spurts…and his feet are hanging over” because “he hasn’t used [the AFOs] long enough to do another [set].”

4.3.2 Participants want more information during AFO provision

Twelve caregivers discussed wanting more information when obtaining an AFO or made comments that suggested that they would have benefitted from further knowledge about how an AFO helps a user with mobility and stability. Ten caregivers discussed wanting more information or expressed confusion about the different types of AFOs that are available and the reasons for a certain type being chosen during AFO prescription. One caregiver expressed frustration at not being given information about different AFOs and always being given the same AFO: “I don’t know why [the orthotists] don’t inform the parent…there’s other options to always just getting the same [AFO].” Two caregivers expressed the opposite frustration, where they were not informed of why the AFO kept changing over time: “I felt like they experimented on [the AFO user] in using all these different braces and things…[eventually] I came to a point [where] I said enough is enough…we’re done.” In this narrative, it seems that the caregiver was not provided information on the reasoning behind how each change to the AFO would improve the AFO user’s experience, leading to the caregiver refusing to let the orthotist make additional changes. People's experiences with AFO provision significantly improved when they were able to find supportive clinicians who carefully explained the reasoning for suggesting certain assistive devices. For example, one caregiver discussed how "our physiatrist, he tracks our care within [our] clinic, has been more proactive in suggesting equipment that might be helpful to [the AFO user] whether that's a DMO [Dynamic Movement Orthosis] suit, which worked for a while for him and was helpful, or modification to his AFOs or whatever."

Table 4.2 Exemplary quotes for each theme.

Theme	**Sub-Theme/Topic**	**Sample Quote**
AFO provision is a confusing and lengthy process	Orthotist quality, finding orthotist, AFO modifications, AFO experimentation, casting, process length, prescription process, insurance	*"What was hard for us was finding a person who could make [the AFOs], because [AFO user] has with her feet some bones structure issues...we've been through a lot of providers before we got to our orthotist" - parent*
Participants want more information during AFO provision	Received education, wanted education	*"I think the education was lost, yeah we didn't get education [to make an informed decision]. They just give [the AFO] to us." - parent*
AFOs are uncomfortable and difficult to use	Comfort, ease of use, aesthetics, stopped use	*"I just wish the braces weren't so heavy" – AFO user*
AFOs can benefit mobility and independence	Mobility, positioning, independence, useful device, timing of use	*"As difficult as [the AFO] is to get and as expensive as it is to get, as cumbersome as it is, if all that stuff disappeared, [the AFO user] couldn't participate to the extent that he does. He couldn't experience life as he does, so there's lots to be critical of but it's also enabled a lot." - parent*

Another point of confusion was how AFOs supported mobility and stability. One caregiver discussed how "sometimes [the AFO] helps [the AFO user] manage the spasticity…I don't know why.” Other participants made AFO modifications that indicated that they might not have understood how the AFO was designed to support the user. One caregiver discussed taking the hard part of the AFO out and keeping only the soft insert to avoid wounds on the AFO user’s foot. However, the hard part of the AFO is what enables the AFO to support mobility or positioning. Providing caregivers with information on how an AFO works could avoid frustration on the caregiver’s part because they discuss how AFOs should be modified with the orthotist. For example, one caregiver expressed frustration that the orthotist would not listen to their suggestion to slice the hard part of the AFO to provide room for the AFO user’s feet.

4.3.3 AFO are uncomfortable and difficult to use

Focus group participants discussed that AFOs were uncomfortable and difficult to use because AFOs were hot and heavy, difficult to find shoes for the AFOs, difficult to put on or take off (independently or with assistance), and not aesthetically pleasing.

Four participants said that discomfort was the reason for discontinued use, because of temperature, skin irritation, pain, and weight. A total of 13 participants (3 users and 10 caregivers) mentioned that the AFOs were hot, and five participants (2 users and 3 caregivers) noted that they did not use AFOs in the summer because of the heat and skin irritation: “In the summer, at home, I don’t wear my braces because it gets too hot” (AFO user). One AFO user discussed how when they wore AFOs in the summer, “I would either get the worst breakout, like skin rashes or I would get the worst puddles of sweat.” We observed participants sharing information to alleviate heat and skin irritation issues during the focus group sessions. Participants suggested adding vents inside the AFOs, using spray deodorant on the feet, using moisture wicking socks, and having the AFOs checked monthly to see whether there is rubbing or skin irritation. Other AFO users discussed how AFOs were uncomfortable for them because “they’re totally painful” and “I just wish the [AFOs] weren't so heavy." Although many participants described challenges, three AFO users discussed their AFOs being comfortable, especially "if you get the right orthotist" (AFO user). In addition, one AFO user and one caregiver discussed how the AFO user did not experience pain when using the AFO.

A total of 10 participants (1 user and 9 caregivers) expressed their frustration with AFOs not fitting in shoes. Seven participants (1 user and 6 caregivers) mentioned the difficulty of finding shoes that accommodate AFOs, especially shoes other than sneakers. One caregiver discussed:

> *"I had to buy special shoes. It took me so long to find a shoe that fit [the AFO], and we had the means for it, so I drove around, and I ordered the special shoe." An additional four caregivers discussed challenges with finding shoes that were durable enough to not "tear up the insides of your shoes."*

One caregiver discussed that "for [the shoes] to last longer, you have to pay for more expensive ones that actually fit the AFOs as well… they don't make shoes durable." It was also challenging for participants to find "stylish shoes" (caregiver) or "dress up shoes" (caregiver) that were not sneakers. To alleviate challenges with finding shoes that fit AFOs, we observed participants sharing information during the focus group sessions: "[the AFO user] just recently got the [BILLY Footwear], and they're not badly priced…I didn't even have to take the sole out" (caregiver) with another caregiver affirming "I like those a lot."

Six focus group participants (1 user and 5 caregivers) also highlighted that putting on and taking off AFOs is difficult and time-consuming. One caregiver discussed that "these things [referencing to AFOs] are a monster to put on and take off by yourself," making it difficult or impossible for AFO users to eventually "put shoes on independently" (caregiver). One caregiver discussed how they plan to "get some new AFOs which are going to be rear entry, so it might be easier [to put on and take off].” One proposed solution to this problem was to have a brace and shoe open together for easier donning of the AFOs and shoes.

Finally, 6 participants (3 users and 3 caregivers) discussed how AFOs were not aesthetically pleasing or not minimalistic enough. One AFO user discussed how they stopped wearing their AFO in high school because of “the stigma of having a brace, and high school is a brutal place for a person with a disability.” When asked why they do not like their brace, an AFO user discussed: “[AFOs] used to look weird on me.” However, one caregiver discussed how their child gets to express themselves through their AFO through customization: “[The current AFO] is the Chicago skyline. The ones she had before were leopard color and then all the ones before that was blue jean,” and another caregiver discussed how their child’s AFO is orange because “he loves orange.” Three participants (1 user and 2 caregivers) discussed how they wished that the AFOs would be more aesthetically pleasing. One AFO user discussed: “if I have to have AFOs for the rest of my life, I would like maybe one for each outfit like shoes, I have my AFOs,” and a caregiver mentioned that AFOs should be “customizable, both in terms of fit and in terms of appearance.”

4.3.4 Despite challenges, AFOs can benefit mobility and independence

Despite these challenges, obtaining an AFO was an exciting experience for one AFO user: “I can remember coming home one time. Wow, I’ve got new braces. And you think about it now, you think, are you nuts? You’re crazy. You’re happy because you got brand new braces? But it was like getting new shoes, they were all nice.”

Participants of the focus groups discussed the beneficial impacts of AFOs in facilitating meaningful participation across environments and contexts. A total of 8 participants (2 users and 6 caregivers) said that AFOs were the most useful and beneficial of their supportive mobility devices, providing support (11 participants: one user and 10 caregivers) and improving walking ability (10 participants: 2 users and 8 caregivers). For example, one caregiver mentioned: "[the AFO user] doesn't walk very well and she has got weak ankles and stuff so the AFOs have been really instrumental in helping her to walk at least a particular distance." However, four participants (2 users and 2 caregivers) also said that AFOs were the least useful and beneficial device that they had. Ankle foot orthoses could negatively affect function: "if I fall, I can't get back up because my braces are so rigid" (AFO user).

The use of AFOs also affected psychosocial factors. Four participants (1 user and 3 caregivers) said that AFOs improved their (or their child's) independence and interaction with their peers. For example, one caregiver mentioned: "He can feel close to his friends without having me around. I think he really enjoys feeling like he's included."

4.4 Discussion

Previous research has demonstrated that AFOs can be a useful mobility aid for improving gait and function. However, AFO abandonment is a common and persistent issue [115, 119]. Considering AFO user and caregiver perspectives is important to improve the provision process and inform the development of the next generation of AFOs. Previous work established that five factors contributed to child user and caregiver satisfaction with AFOs: materials, structure, aesthetics, service, and impact [119]. Our results align with these results, in particular, heat/breathability, aesthetics, and fitting of shoes with AFOs; structure impacts on skin irritation/ pain; service limitations and inconsistency in practitioners; and impacts on functional mobility and emotional health were mentioned by focus group participants. These perceptions highlight opportunities for improving AFO design, provision, and use that can support mobility and participation among people with CP. It is important for orthotists, families, and therapists to co-create solutions. This may include joint appointments with therapists and orthotists, orthotists going into the community to broaden access, new fabrication techniques, and further research with clinicians and insurance companies to improve provision access.

Individuals with CP who use AFOs and their caregivers experience many challenges including difficulty in obtaining AFOs, confusion in the acquisition process, and poor comfort and ease of use. However, AFO users and their caregivers expressed that there are benefits of AFOs, including improved mobility and independence. These results are not surprising to any AFO user, parent, or orthotist within the CP community, but it is important to capture these perspectives to improve AFOs and the provision process. Similar to previous research with mothers of children with CP, our participants felt that although AFOs are useful for mobility and positioning, AFOs could benefit from improved aesthetics and comfort [113]. A key difference between the study by Lana et al. and our study is the strong focus in our study on the AFO provision process, possibly suggesting that the ease or difficulty of obtaining AFOs may be a location-specific challenge. Our study focused on AFO users and their caregivers in the United States, whereas Lana et al. sampled mothers of AFO users in Brazil. In addition, a previous study in Canada on the perspectives of physical therapists, orthotists, and physiatrists focused on the prescription of AFOs for individuals with CP [112]. Kane et al discussed how AFO prescription should be an iterative, collaborative, and individualized process.

The suggestions made by AFO users and caregivers offer numerous ideas to improve and inform AFO design and fabrication. Typical fabrication of a custom AFO involves creating a plaster cast of the limb, which is modified by an orthotist and used to create a custom AFO from vacuum thermoforming [120]. This is a lengthy process with many visits and time between visits, which is confounded by children outgrowing their AFOs quickly. This is an issue with both service and the device itself. As highlighted by the participants, advances in 3D scanning and printing offer opportunities to improve this process. 3D scanning is a promising alternative to the lengthy and messy casting process, which has been used with amputees and other types of orthoses such as cranial, wrist, and spinal orthoses [121–123]. However, there are still variable results on the accuracy and reliability of 3D scanning to capture foot and ankle morphology [124]. In addition, 3D scanning limits the amount of corrective positioning that the orthotist can do during the casting process to make sure that the foot is in the intended position for the AFO. Most studies of the accuracy and feasibility of 3D scanning have been conducted with non-disabled adult participants, which do not reflect current AFO users [124]. Roberts et al. found that the time spent in the rectification and molding of a scanned AFO was around 50% less than a cast AFO; however, the time to delivery increased by 9 days and had a higher incidence of problems in a randomized controlled trial [125]. Although 3D printing is in its infancy for orthoses, there have been initial studies on the effectiveness and feasibility of 3D-printed AFOs [126, 127]. These suggestions highlight how technology may further improve AFO acquisition and fit [128].

Many of the challenges brought up by AFO users and their caregivers can be addressed by improving the devices themselves and the provision process. Some of the participants' confusion and frustration with the process highlighted a knowledge gap. Participants noted that they did not understand why they were prescribed a specific type of AFO or why designs changed over time. Participants also mentioned attempting to modify the AFOs themselves, which can have significant implications for safety and long-term use. Providing additional education and clear communication to caregivers and AFO users and involving the caregiver and AFO user in shared decision-making can be a simple and effective way to address these concerns. This could include enhancing education about AFO selection, how an AFO will support function and participation goals, or how to address common challenges such as pain or hot areas. Simple and clear standards for sharing information may not only address many of the frustrations expressed by the participants in this study but may also decrease rates of abandonment and support improved communication between often complex care teams. Additional solutions to improve family knowledge and understanding may include the following: 1) joint decision-making with the family regarding the short-term and long-term goals for a device, 2) reducing "information silos" between practitioners and industry, and 3) creating more opportunities for parent or peer support groups to share personal experiences and solutions.

The benefits of AFOs regarding function and mobility were highlighted by participants of the focus groups, from both AFO users and their caregivers. Families were resilient and clever in coming up with solutions and navigating the process despite the frustrations that they expressed. This highlights the nuances of experiences with AFOs because participants had both positive and negative comments on the provision and use of AFOs. In addition, most of the participants still noted benefits from their AFOs, even if the process was frustrating. There is no information linking these qualitative and quantitative assessments. Although previous studies have evaluated functional impacts and variable responses, it is unclear whether people who had better experiences had better responses. A compelling area of future research is to link biomechanical outcomes and community-based functional outcomes (i.e. walking activity, standing, and improved joint alignment) with user experiences.

4.4.1 Limitations

Our study had several limitations that affect generalizability to a broader population. First, our participants all lived in or near large metropolitan areas in the United States. These perspectives may not be able to translate to individuals who live in rural regions where access to orthotists may be much further, which could amplify the frustrations on the lengthy process of multiple appointments to obtain and modify an AFO. Second, a small number of individuals with CP were represented in this subset of the focus group data relative to caregivers. It is important to acknowledge the difference in perspective from the lived experience of an individual with CP compared with a parent/caregiver. One area where this difference was most visible was in the proposed ideas to improve AFOs in the future—caregivers in our study focused on ways to improve the process and fabrication of AFOs and ease of use, whereas AFO users focused on ways to improve ease of use and comfort. Finally, other stakeholders such as orthotists and clinician perspectives were not involved in the focus groups and may offer unique perspectives in collaboration and conversation with the families they serve.

4.5 CONCLUSIONS

This research provides insights into the lived experiences of individuals with CP and their caregivers regarding the process of obtaining and using an AFO. Individuals with CP and their caregivers emphasized that AFO provision is frustrating and that current AFOs are often uncomfortable and difficult to use. The number of design ideas mentioned by participants highlights both current limitations and opportunities for design and innovation. Future research should focus on collaborative design and engagement with individuals with CP across the lifespan and clinical teams to establish educational and functional processes and products that can support care, function, and participation. Although there were many challenges with AFO design and use, participants still highlighted the benefits of AFOs in daily life and participation. As one caregiver underscored: “As difficult as it is to get and as expensive as it is to get, as cumbersome as it is, if all that stuff disappeared, he couldn’t participate to the extent that he does. He couldn’t experience life as he does, so there’s lots to be critical of but it’s also enabled a lot.”

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Chapter 5

PERCEPTIONS AND EXPERIENCES OF FIRST MOBILITY AID PROVISION AND USE FOR YOUNG CHILDREN WITH CEREBRAL PALSY

Submitted to Disability & Rehabilitation: Assistive Technology

Nicole L. Zaino

Zahra McKee

Charlotte D. Caskey

Katherine M. Steele

Heather A. Feldner

ABSTRACT

Purpose: The purpose of this study was to establish and understand the provision process and impacts of first mobility aids for children with cerebral palsy (CP) in the United States - specifically orthoses, walkers, and gait-trainers.

Methods: We performed a mixed-methods study including surveys and semi-structured interviews of caregivers of young children with CP and clinicians who work with young children with CP. We used content analysis for the surveys and inductive coding for the interviews.

Results: Four themes emerged: 1) first mobility aids have mixed impacts and use patterns, 2) there is varied caregiver education and understanding about mobility aids, 3) clinician knowledge, consistency, and connection impact care, and 4) numerous access barriers exist for families, but there are still opportunities for improvement across all domains.

Conclusions: This research provides insights into the lived experiences of clinicians and caregivers of young children with CP regarding the prescription, provision, use, and impact of first mobility aids, specifically AFOs and walkers/gait trainers. This study not only provides researchers and clinicians with an understanding of the current status of the prescription and provision process in the United States, but also offers suggestions for improvements of the process and devices themselves. These results have implications for future research, device, design, and the provision process of first mobility aids.

5.1 INTRODUCTION

Cerebral Palsy (CP) is one of the most common pediatric motor disabilities in the United States, affecting over 2 per 1000 live births [3]. CP is a group of non-progressive neuromuscular disorders caused by injury to the developing brain and can be detected early in an individual's life [49]. The average age of diagnosis has been reported as between 8 and 24 months old [129].

There is extensive research describing how non-disabled children learn to walk, with non-disabled infants and toddlers starting to walk around 12 months [14–16, 130]. For ambulatory children with CP, walking is often delayed, with an average age of walking between 3 and 5 years [131]. Evidence also suggests that limited experiences with self-initiated mobility for children with CP may cause long-term functional and participation challenges [132, 133]. Self-initiated mobility is defined as any movement that lets an individual initiate and control their movement through space, including crawling, walking with or without support, and wheeled mobility [2]. Self-initiated mobility is essential to a child's development of not only motor skills, but for social, cognitive, and sensory development [5, 134]. Since the ability to move and explore has been shown to be important for development, children with disabilities such as CP risk secondary cognitive, sensory, and motor delays, due in part to their limited ability to explore through traditional locomotor activities like crawling or walking [20].

Despite documented positive effects of early access to self-initiated mobility, young children (i.e., less than 3 years old) with CP and other disabilities continue to have limited access to self-initiated mobility. Early self-initiated mobility for young children with CP can be supported with a variety of mobility aids. Early mobility aid literature includes adaptive ride-on-cars (ROC) [25], partial body weight support systems [135–140], walkers or gait-trainers [141], orthoses [142], crawl assist devices [48, 143, 144], and powered mobility devices, like the FDA-approved Explorer Mini [20].

Mobility aids are commonly prescribed for children with CP, with the first mobility aid often being prescribed prior to two years of age. Common mobility aids include walkers, gait trainers, wheelchairs, crutches, and orthoses such as ankle foot orthoses (AFOs) and supra-malleolar orthoses (SMOs) [145, 146]. The probability of use for different mobility types for individuals with CP varies with Gross Motor Function Classification System (GMFCS) Level. Tieman et al. reported that in a school setting, 81% of children GMFCS Level II walk independently, 14% walk with a mobility aid, and 4% use a different mode of mobility. For children with GMFCS Level III, 26% walk independently, 35% walk with a mobility aid, 19% self-propel a manual wheelchair, 10% use a power wheelchair, and 8% are pushed in a manual wheelchair. For children with GMFCS Level IV, 15% walk with a mobility aid, 10% self-propel a manual wheelchair, 30% use a power wheelchair, 44% are pushed in a manual wheelchair, and 1% use a different mode of mobility [7]. Despite the prevalence of mobility aids, there is limited literature on the provision process or use of mobility aids for young children with CP. The provision process starts when a clinician first brings up a mobility aid, through prescription, and delivery of said device. Understanding the provision process for first mobility aids would help to understand when and how children are getting access to devices to support early self-initiated mobility.

To guide future research, device design, and improvements in the provision process of and initial experiences with first mobility aids for young children with CP, we must first understand this process. With limited literature on the provision of mobility aids at this critical young age; the timing, processes, and perceptions of mobility aid use for young children is not well understood.

The aim of this study was to capture the experiences of early mobility aid use and provision for young children with CP based on caregiver and clinician perspectives. Specifically, we examined the prescription process, expectations, initial use, and impacts of first mobility aids. We included both caregiver and clinician experiences in order to get a full picture of the process from multiple stakeholders.

5.2 METHODS

We performed a mixed-methods study that consisted of surveys and semi-structured interviews of clinicians and parents/caregivers of children with CP. Surveys and interviews focused on the following most common mobility aids among children with CP: hinged or solid ankle foot orthoses (AFOs), supra-malleolar orthoses (SMOs), anterior or posterior walkers, and gait trainers. A mixed methods structure was used to fully capture complementary data regarding provision and use of these mobility aids.

All procedures in this study were approved by the authors' institutional review board, and informed consent was obtained from everyone who participated in the study.

5.2.1 Participants

We completed this study virtually with individuals in the United States, recruited via convenience sampling through known networks, including local clinics and clinicians, internet groups for caregivers with CP, etc. Inclusion criteria for the caregiver group was that they were a caregiver of child with CP who was 8 years of age or younger who uses or used a mobility aid by the age of 5. Inclusion criteria for the clinician group was that they were a licensed clinician, including physical therapists, occupational therapists, orthotists, and physicians, who have experience working with children with CP who are under 5 years of age. The age restrictions of the children with CP were because we specifically wanted recent experiences of first mobility aid provision.

Survey participants included 29 clinicians (21 physical therapists (PT), 4 orthotists, and 4 physicians) and 10 caregivers. Caregiver participants were caregivers who had children across all GMFCS levels who received their first mobility aid under the age of 5 years old (child's current age: 5.9±2 years). A summary of the participant characteristics is available in Tables 5.1 and 5.2.

Table 5.1 Participant characteristics for clinicians

Years of experience	<5	2
	6-10	6
	10-20	8
	20+	13
Type of setting worked in	Outpatient clinic	14
	In-patient hospital	2
	Birth-to-three center	8
	School	4
	Private practice	1
Profession	Pediatric Physical Therapist	21
	Orthotist	4
	Physical Medicine and Rehabilitation Physician	3
	Developmental Medicine Physician	1
Devices Experienced	Gait trainer	27
	Walker	27
	AFO	29
	SMO	28
Devices trained on	AFO	27
	Walker/Gait trainer	22
	SMO	26

Table 5.2 Participant characteristics for parents and their children. Note some children received an AFO and walker at about the same time and are listed in both groups.

First mobility device(s)	Orthosis	6
	Walker	1
	Orthosis and Walker	3
First orthosis	Hinged AFO	1
	Solid AFO	8
First walker	Rear walker	2
	Walker with support (gait trainer)	2
Child's age	Diagnosed with CP age (years)	1.3±0.9
	Age at time of survey (years)	5.9±2.0
Impacted limbs	Diplegia	4

	Hemiplegia	2
	Triplegia	2
	Quadriplegia	2
GMFCS level	I	2
	II	1
	III	1
	IV	5
	V	1
Type of area lived in	Urban	1
	Rural	2
	Suburban	7

A subset of survey participants (7 clinicians and 5 caregivers) completed semi-structured interviews about their experiences with first prescribed mobility aids, as well (Figure 5.1).

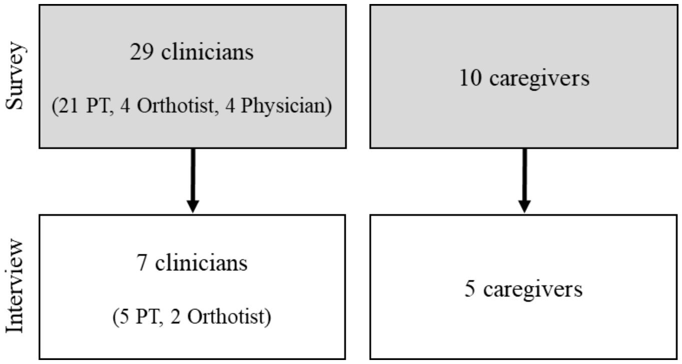

Figure 5.1 Survey and Interview Participants

5.2.2 Procedure

Surveys were distributed via REDCap (Vanderbilt University, Nashville, TN) and consisted of multiple choice, Likert scale ranking, and short answer questions. Questions were focused on the devices that a clinician had experience with or that a caregiver's child was first prescribed.

Two authors conducted the clinician semi-structured clinician interviews (NZ & CC) and the caregiver interviews (NZ & ZM). The interview questions (Table 5.3) focused on process perceptions and expectations, initial device use, and device impacts (see Interview Guide in Appendix A.1 and A.2) of the devices clinicians and caregivers had experience with. In addition to scripted questions that all clinicians and caregivers were asked, the interviewers asked additional questions for clarification and interviewees were encouraged to discuss anything else about their experiences relevant to the study.

Table 5.3 Example semi-structured interview questions

General Topic	**Participant Type**	**Questions**
Process	Clinician	• What is the current process at your clinic for a child receiving their first [device]? • What do you think works well with the current process? • What do you think can be improved in this process and do you have any proposed solutions?
Training	Clinician	• What type of training have you received on the [devices]? • What type of training is provided to the family for [device]
Process & child	Caregiver	• Can you walk us through the process of getting your child's first [device]? • What kinds of motor skills was your child working on when they received their first [device]?
Training	Caregiver	• What type of training did you and your child receive on how to use the [device]?
Expectations	Caregiver	• What were your initial expectations or assumptions about your child's use of the [device]? • What were the first weeks of using the [device] like?

5.2.3 Study Analysis

The quantitative survey results were numerically analyzed using Microsoft Excel. The open-ended short-answer survey questions were qualitatively coded using inductive coding [117]. The responses were consistently brief, so the fill in components of the survey were analyzed using content analysis. The qualitative coding for the short answer questions in the surveys was first done independently by two authors (NZ & ZM) and then compared and discussed until full consensus was reached.

The interviews were audio recorded, transcribed verbatim, and de-identified. We completed reflexive thematic analysis using inductive coding [116, 117]. To create a codebook, one author (NZ) reviewed all the interviews to take notes and develop the coding structure. Another author (ZM) also took notes and developed codes for a single interview to compare results and check for the level of agreement, gaps, or biases. After discussion a code book was developed that was subsequently applied to the remaining transcripts. The final 87 codes were discussed and applied by NZ and ZM to all transcripts. The codes were then discussed among all authors until the themes presented in this paper emerged and 100% consensus was reached (see Table 5.4 for example flow).

Table 5.4 Inductive coding structure

Example quotes	Applied codes	Themes
"He cried a lot he didn't like them, but he got used to it and because we use them as intensely as we did, we were able to hold off on botox treatments for a good year okay." – Parent (P5)	Child emotions toward device, device use resulted in prevention, device use impacts musculoskeletal parameters, AFO	Impacts of first mobility aids
"It's necessary to reach your social and participation, as well as your strengthening and your bone health. But we should be lending those because they're only going to use it for a year or so and then they're going to be good to go and I don't think the family should have to buy those." – PT (C21)	Walker, social impact, device use impacts bone/joint health, access to lending closet/trials, family burden	Barriers to care
"Their diagnosis, their moving disorder, the GMFCS level - if it can be estimated, and the parent goals, the child's risk or long term musculoskeletal/bony issues and problems." –PT (C9)	Type of orthoses, consideration of diagnosis, long term impact, family goals, bone development	Provider knowledge
"Yeah, I just didn't know so I don't know what went well or what didn't go well, because I was so new. I just didn't understand the process. I didn't understand." – Parent (P3)	AFO, family understanding, family expectations	Caregiver education and training

5.2.4 Positionality Statement

The team included individuals in mechanical engineering and rehabilitation science across multiple levels of experience. The lead author is a researcher with experience in mobility aids, orthotic fabrication, and rehabilitation engineering. One of the authors is a mobility aid researcher and a pediatric physical therapist with more than 20 years of experience. One of the authors is an engineering faculty member with a rehabilitation research focus.

5.3 RESULTS

Four major themes emerged from the surveys and interviews: 1) first mobility aids have mixed impacts and use patterns, 2) there is varied caregiver education and understanding about mobility aids, 3) clinician knowledge, consistency, and connection impact care, and 4) numerous access barriers exist for families. There are still opportunities for improvement across all domains. These themes highlight that the provision process is complex and multifactorial and involves an interplay between education, training, provision, and impacts for both clinicians and caregivers. The following sections outline the quotes and insights that informed each theme. Given the nature of responses provided, the results for theme one primarily reflects survey responses, while the remaining themes are balanced between survey and interview responses. AFOs, walkers, and gait-trainers were the primary mobility aids used by the children of the caregivers in this study.

5.3.1 Theme 1: Mixed impacts

In survey responses, participants shared both the positive and negative impacts of first mobility aids for children with CP (Figure 5.2). For example, from a caregiver perspective, AFOs were perceived as having a positive effect on walking and standing, with limited impact on jumping, climbing, and/or stair climbing. The most notable positive impacts of AFOs from caregivers included improved standing or walking posture and positioning, as well as “stretching” tight lower extremity muscles. While not specifically asked, many caregivers mentioned “stretching” as a positive impact of AFOs in an open-ended question. The primary negative impact of AFOs mentioned by caregivers was decreased floor mobility – caregivers indicated that their child would not crawl or move when they wore their first AFOs. Caregivers also reported that AFOs were often painful for their children. For walkers and gait-trainers, the primary positive impacts reported by caregivers were increased time in upright postures, increased independence, and taking steps. The most significant negative impacts were poor body alignment and gait and damage to walls and door frames caused by equipment.

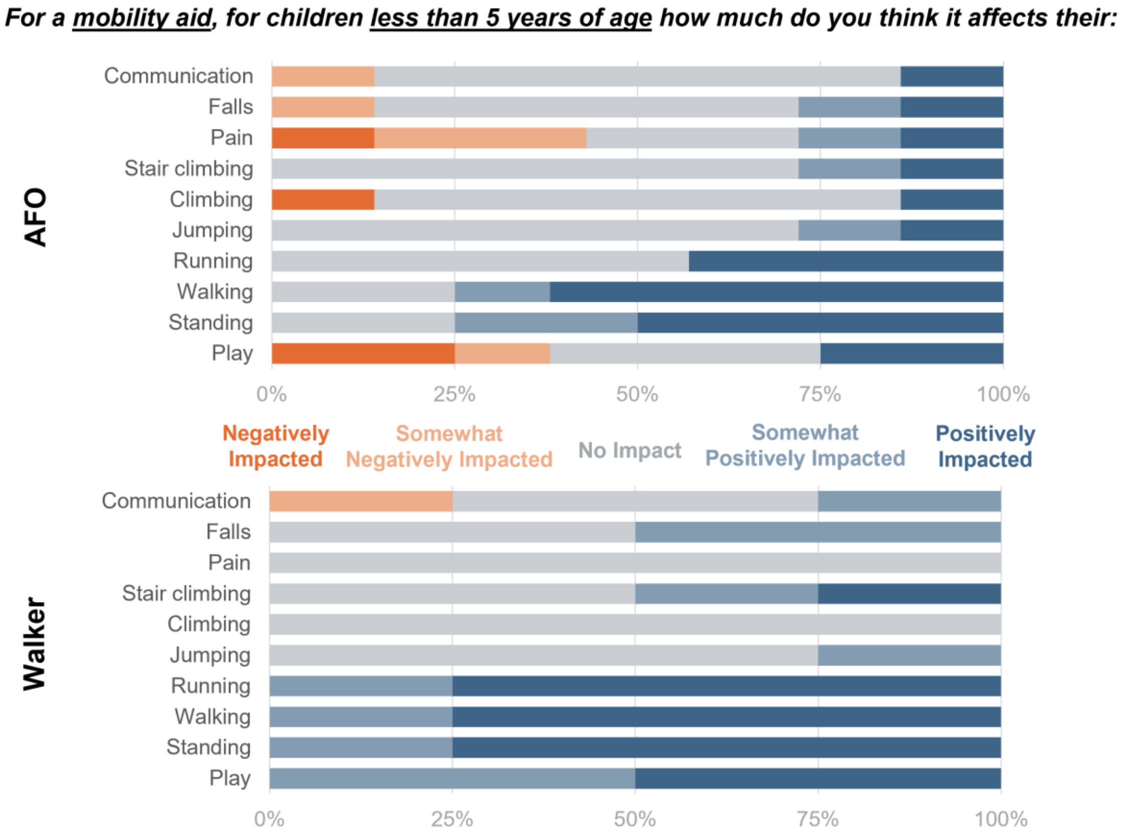

Figure 5.2 Caregiver views of impact of first orthoses (n=8) and walkers (n=4).

Clinicians shared similar, mixed perceptions as caregivers of early mobility aids. Clinicians reported the primary positive impacts of AFOs as improved gait, improved standing alignment and endurance, and stability (Figure 5.3). The most common negative impacts of AFOs were inhibiting transitions for floor to standing, skin problems and discomfort, and limitations in floor mobility (i.e. crawling). The primary positive impacts of walkers/gait trainers included their support of upright mobility, independence to move and explore, and opportunities to socialize with peers. The primary negative impacts of walkers/gait trainers were a lack of accessibility and physical barriers in the community, transportation challenges, device size and weight, contributions to poor postural habits, and lack of acceptance from families.

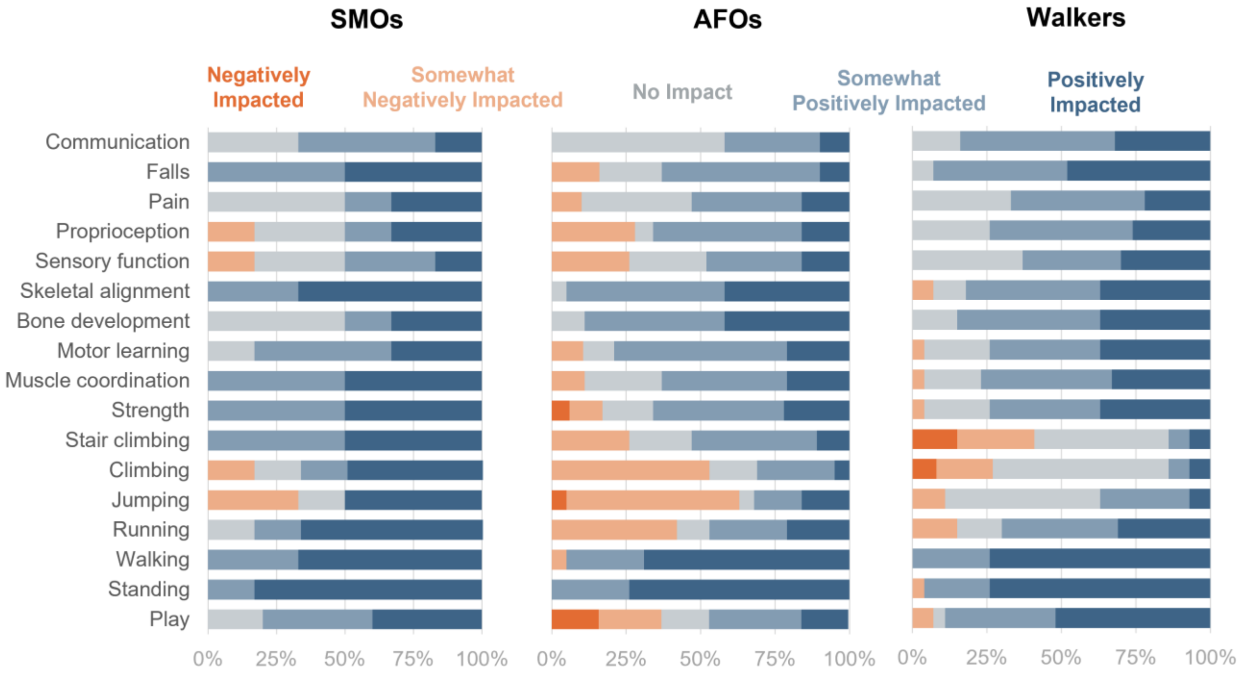

Figure 5.3 Clinician views of impact of first SMOs (n=6), AFOs (n=19), and walkers (n=27).

5.3.2 *Theme 2: Caregiver education & training*

The education and training reported by both families and clinicians when receiving or providing a device varied greatly. Here, it is important to distinguish between education and training. Education about devices was before device prescription and included discussion about why a device was being prescribed and the potential impacts and benefits. Training was provided after device provision and focused on instructions for proper use of the device, including device setup and use, adjustment and maintenance, and safety information.

Survey data indicated that for the children who received an orthosis as their first mobility aid, more than half (55%) of the caregivers reported having received training on how to best use and care for the orthosis, but only a third (33%) reported that their child received similar training themselves. For the children who received a walker as their first mobility aid, three quarters (75%)

of caregivers reported receiving training, with half (50%) reporting that their child also received training. In the survey, in regard to education caregivers reported having varying levels of understanding of why their child was prescribed their mobility aids, with some caregivers reporting adequate understanding and others reported having no understanding. On average, families had some, but incomplete knowledge of donning/doffing, use, care, adjustments, and impacts of the devices.

Survey results indicated that clinicians who provided training for new mobility aids included orthotists, therapists, physicians, and durable medical equipment (DME) providers. Training information was typically shared either verbally and/or in writing. Clinicians reported that training was provided by themselves, another clinician, or not at all. Multiple clinicians were reported being responsible for training to a family. Training for orthoses was provided by a broader spectrum of disciplines including PTs (90%), OTs (3%), orthotists (59%), and/or physicians (17%). For walkers/gait trainers, the training was typically provided by PTs (100%) and/or DME providers (10%). For both orthoses and walkers, types of training provided to families by clinicians included safety (79%), how to use (37%), donning/doffing (37%), adjustments (21%), day to day use (37%), and guidance on shoes for orthoses (11%). Dialogue from the interviews with clinicians regarding training focuses on safety, such as looking for hot spots or rubbing in the case of orthoses and proper alignment and negotiating slopes or obstacles in the case of walkers/gait trainers.

In the caregiver interviews, many families reported that they felt like they were following along and just doing what the clinicians were telling them, rather than understanding and becoming educated and/or trained. One caregiver stated,

> *“I had no idea what we're doing, I’m just following along. Until I finally understood once I moved, and more explanation came, this is why we're doing what we're doing. Okay, now*

> *I understand but there's not a whole lot of information that I had at the time."* – Caregiver (P3)

One caregiver highlighted how important education was to her when selecting and staying with a specific clinician,

> *"I did get very good education, I feel like with the first one, [she was] just reading the book to me. Basically, here's the steps to do, here's how to do it, here's what to look for and so I liked that orthotist, and she was very educational, that's why we've stayed with her."* – Caregiver (P5)

The final aspect of varying family/caregiver education and understanding that emerged related to varying expectations of what function the mobility equipment would perform. This included varied expectations of duration of use. As one caregiver explained, *"I had no idea we were in this for the long haul. And I mean indefinitely… for a long time there was no indication at all or no education on it"* – Caregiver (P3). Additionally, caregiver understanding of device impacts varied. Two caregivers reported they did not know what to look for as far as changes or impacts of a device. Relatedly, many clinicians noted, unprompted during their interviews, that families were often challenged by the need for simultaneous use of multiple mobility aids. For example, families were perceived by clinicians as more likely to accept a walker over orthoses, potentially due to their misunderstanding of the purpose and impacts. As one clinician stated,

> *"I think parents are a little bit more comfortable with a walker because they're really focused on just getting their kid on their feet/moving and they don't always understand the need for an orthotic and a walker. They don't think they need both of them, so a walker is kind of a no brainer because that gets them up on their feet."* – PT (C9)

These perceptions can be an important factor influencing mobility, impact, and acceptance. Survey responses corroborated these qualitative clinician perceptions, as caregivers generally had more positive views of walkers compared to AFOs.

5.3.3 Theme 3: Clinician knowledge and availability

According to the caregiver survey, their child's orthosis was prescribed by a PT (6/9), physical medicine and rehabilitation physician (2/9), or a pediatrician (1/9). The walkers were prescribed by PT (2/4) or pediatricians (2/4). Clinicians considered a broad range of factors in prescribing mobility aids. For orthoses this included: range of motion (42%), function (32%), insurance (32%), alignment (32%), tone (26%), control (26%), and gait (26%). For gait trainers or walkers this included: function (31%), stability (21%), control (17%), strength (14%), diagnosis (14%), and skills (14%).

In the caregiver interviews, the clinician knowledge, consistency, and connection with the families varied and impacted the first mobility aid provision process. Survey results from clinicians also indicated that while some reported they had received no training around some devices, most clinicians reported that they received their training on mobility aids in many different settings. These settings ranged from their entry-level professional education to on-the-job training from their peers to single/multiple courses at professional conferences with vendors and manufacturers.

Interview data from caregivers indicated that clinician availability and consistency in care were key factors in mobility aid provision. Some noted that their clinician was very helpful and accessible at different times and assisted them with the process while others noted that they had a difficult time getting scheduled with the necessary clinician or finding a clinician in the first place. Reports of consistency of care varied significantly between families. While one caregiver described staying with one particular orthotist long-term once they 'found a good one', for another caregiver, lack of access to a good care team was a barrier that led to switching clinicians and moving for better care: *"I literally moved up here for care for [child]."* – Caregiver (P3).

The connection within care teams was discussed by both caregivers and clinicians. One orthotist worked in a setting with wraparound care, defined as a team-based provision of care that is intended to provide individualized, coordinated, and family-driven care. They discussed the benefits of that structure:

> *"Within my system, what works well is the fact that wraparound care, I think within the healthcare system at large it's a little disjointed. But that's part of why I chose to practice where I practice… I can have almost instant conversation with the physician, the physical therapist, the occupational therapist, or the gait lab across the hall to interact routinely so I have the ability to fine tune the care where I see problems come up."* – Orthotist (C27)

While this care model is growing in popularity, most clinicians in the United States work in a traditional, more siloed care structure where coordinating conversations with another member of the patient's care team is not as simple. One clinician in this more siloed setting found a creative way to integrate the care team. They described a process at their clinic of a joint appointment with a PT and orthotist:

> *"We do a joint evaluation together… and then we educate the family, on what we have found, and then we discuss with the family, whether this is the direction they want to go and then we would come to a compromise or a group decision."* - PT (C9)

Both caregivers and clinicians reported that more cohesive care teams in shared networks had better communication among clinicians and easier access to the other clinicians. Unorganized care teams and lack of access to clinicians by their colleagues caused undue burden on the families and lengthy wait times for mobility aid delivery.

Clinicians discussed potential solutions to address challenges in the current provision process of first mobility aids. This included increased communication across the care team and policy changes related to who is authorized to prescribe devices. Many clinicians noted that having a joint appointment between different professionals (such as the orthotist and PT) was a positive solution to increase communication between the clinicians, improve care, and reduce time delays. One PT specifically stated:

> *"Well, I think for AFOs, I think some of it would be addressed if it was a joint orthotics/physical therapist visit, that's one way. And the other would be increased communication between the community therapist and orthotist. Another would be talking to the insurance companies."* – PT (C9)

Additionally, an orthotist also mentioned an approach that they use with prosthetics that could be translated to orthotic provision for children,

> *"I think, having more of an interdisciplinary collaborative opportunity or setting makes a lot of sense. I've seen that with amputee treatment with prosthetics and less so with orthotics, especially with children, but I think having an opportunity to have a clinic where you've got a physician an orthotist and a physical therapist would be a huge benefit and improvement to the process."* – Orthotist (C20)

Clinicians noted that the prescription process leaves a lot up to the discretion of the clinician in terms of information being shared or recommendations being made. Two clinicians noted that if they thought the family had too much on their plate, they would not recommend getting a walker or AFO for the child, specifically,

> *"I should go into those conversations openly with every single family, but sometimes you just get this feeling like I just don't think they're going to have the bandwidth for this."* – PT (C1)

In these scenarios, the clinicians acted as gatekeepers to accessing both education and the mobility aids themselves.

5.3.4 Theme 4: Access barriers

Caregivers and clinicians reported access barriers throughout the provision and use process of orthoses and walkers/gait trainers. These included but were not limited to factors such as lack of access to lending libraries or loaner equipment, challenges with insurance and paperwork, challenges achieving proper fit of devices, and the duration of the provision process from prescription to delivery. Survey data indicated that clinician satisfaction of the current provision process for first mobility aids varied (Figure 5.4). While clinicians reported they were mostly satisfied with the fitting and sizing processes for devices, they indicated lower satisfaction with availability of trial devices and shoe modification processes for orthoses.

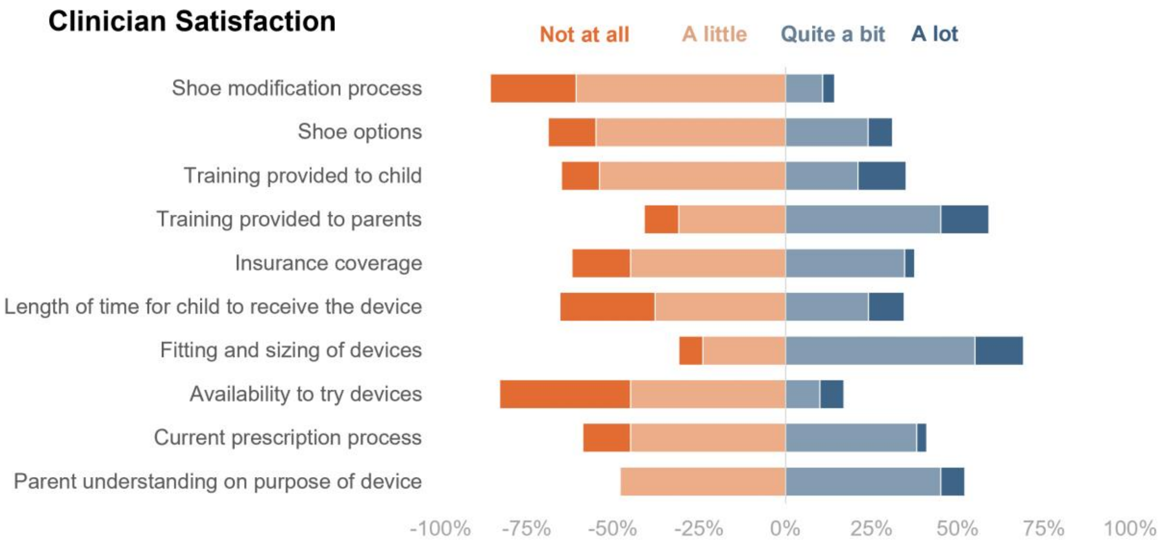

Figure 5.4 Clinician (n=29) satisfaction on the current provision process for first mobility aids.

Survey responses indicated a wide range of time between prescription and delivery of mobility aids. Even after potential issues with clinician access and insurance were overcome, the length of time it took to receive an orthosis after prescription took on average 2.5 months (range: 3 weeks - 6 months), and for walkers or gait-trainers it took on average 4.5 months (range: 3 - 9 months). Of the 10 caregivers who completed the survey, 9 of the children received an AFO at a mean age of 20 months (range: 12– 32 months) and 4 of the children received a walker or gait-trainer at a mean age of 29 months (range: 24 – 39 months).

In the interviews, insurance and related paperwork were also a common obstacle to provision. This included long wait times for approval, requiring diagnoses to get services or mobility aids, having to pay out of pocket, and paperwork. Authorization from insurance companies was the most common topic related to cost and funding brought up. One clinician noted new changes in the process that make provision even more challenging, adds extra time and financial burden on the families and clinics,

> *"Authorization is a huge problem: it's gotten worse the last two years. The insurance companies are now asking the families to go back to have one more physical visit with their provider and in that note, they have to address the orthotics specifically, and that note has to come with a script."* - PT (C9)

Clinicians and families noted that this places extra time and financial burdens on the families and clinics to have to revisit the physician. Some caregivers turned to creating their own mobility aids to sidestep challenges with insurance coverage:

> *"We made several devices just on our own, we made him a crawler and things like that that we just couldn't get insurance to cover when we needed them."* – Caregiver (P5)

Both clinicians and caregivers discussed the role of lending libraries and trial equipment during the interviews. As noted by one caregiver,

> *"We have a Kaye Walker that her early intervention physical therapist gave us [for a trial] just as something to get her up and moving. We are having an evaluation next week about getting her own gait trainer that you know is more tailored to her"*. – Caregiver (P7)

However, these lending libraries or trial devices have limited availability and are not an option for orthoses.

Clinicians proposed a few different ways to reduce the time from order to delivery of mobility aids such as expanding loan closets. One clinician noted,

> *"For walkers, I think if we had more loaner closets, and more options, particularly, if you practice in a birth-to-three center. Every birth-to-three center should have a loner closet with a variety of types of devices that are the right size for 12 months to four-year-olds or something like that."* – PT (C13)

Overall, reducing both cost as well as time between order and delivery were a primary focus for provision process improvement.

5.4 DISCUSSION

This insight from both caregivers and clinicians highlights addressable gaps and potential solutions to improve provision processes of first mobility aids. During the provision of first mobility aids for participants in this study, many barriers were reported, including 1) variable caregiver education, training, and understanding, 2) limited access to clinicians, varied clinician knowledge and prescription considerations, and 3) long provision times, insufficient insurance coverage, and limited availability of loaner devices.

Improving the timeliness for provision of mobility devices can allow children access to their mobility aids and in turn self-initiated mobility sooner. Children in this study were prescribed their first mobility aid at 17 ± 6 months for AFOs and 25 ± 8 months for walkers/gait-trainers. Which is later than what is currently recommended in the literature (12 months or around the time that nondisabled peers begin to walk) [10-13]. Especially during rapid phases of development in the first years of life, access to mobility aids is crucial. This gap in access to self-initiated mobility for children with CP has downstream implications for cognitive, sensory, and motor development [12, 13, 134].

This study identified several other opportunities for provision process improvement and design innovation. Clinicians suggested improving communication between clinicians, streamlining the insurance process, and supporting this current delay with lending libraries until this problem is resolved. This mirrors current literature, which notes that increasing communication across the care team for a child allows for more collaboration. One example is wraparound care models that offer improvements in time, cost, and family satisfaction [147, 148]. Further examinations of equity related to mobility aid provision must be considered as well. Research has noted that different types of insurance can further systematic inequities, as children with government insurance experience more delays in obtaining orthosis than those with private insurance [149].

Lending libraries can act as a temporary solution to supplement device access during the long wait time between prescription and obtaining a device, and clinicians are more likely to prescribe assistive technology to infants and toddlers if there are opportunities for the family to try or borrow devices beforehand [37]. However, lending libraries rely on the generosity of the community, availability of an appropriate device, and are not available for orthoses, which are often custom made. There are many successful models for lending libraries, however, people who need assistive technology are often geographically distant from these organizations, and barriers have been reported that include space constraints, overhead costs, and liability concerns with donated equipment [150]. More institutional lending rather than just community organizations could help make lending a more common practice as a stop-gap solution for long wait times.

The clinicians in this study noted the broad range of factors they use their professional expertise to weigh and consider in prescribing mobility aids. These factors included range of motion, level of function, alignment, tone control, insurance, and gait for orthoses, and function, stability, control, strength, diagnosis, and skills for walkers. Kane et al. (2019) conducted focus groups of clinicians working with AFOs for children with cerebral palsy and found a similar balance of body structure and function and activity level characteristics being considered for prescription. Additionally, the authors noted that the prescribing clinician's preferences, knowledge level, comfort level with orthotics, and habits influence the prescription process [112]. This was corroborated in our results as well, most notably by the clinician who discussed their own bias in evaluating a families' readiness to receive information before discussing a potential mobility aid prescription. The role of the clinician as gatekeeper of information has been widely noted in other medical literature as well, along with the level of education or comfort of clinicians with their assistive technology knowledge and training [112, 151–153]. Without a more evidence based, standardized process for mobility aid prescription and training, much is left up to the discretion and initiative of the prescribing clinician and caregiver advocacy [1].

The perceived clinical impacts of orthoses reported in this study were similar to those reported in prior research. Overall AFOs positively impact gait, standing alignment, endurance, and stability while negatively impacting transitions from floor to standing, causing discomfort, and limiting crawling. Walkers/gait trainers were noted to support upright mobility, independence to move and explore, and opportunities to socialize with peers while the negative impacts included large size and weight, transportation challenges, and lack of accessibility and physical barriers in the community. Current literature has reported AFOs as beneficial for several walking parameters such as speed, stride length, energy expenditure, and gait symmetry [154]. For example, Buckon and colleagues (2004) found AFOs were able to normalize joint kinetics and joint kinematics, reduce the energy cost of walking, and improve walking, running, and jumping skills for children with CP [155]. The negative effects of pain and skin problems from orthoses have been widely discussed by orthosis wearers with CP as well as Charcot-Marie-Tooth disease [156, 157]. The perceived clinical impacts of walkers/gait trainers in our study were also mirrored in previous literature. In a systematic review, Paleg and colleagues (2015) found that using a gait trainer improved step-taking ability as well as increased walking distance children with CP [158], paralleling the positive impacts on taking steps and supporting mobility found in this study. George and colleagues (2020) also found improvements in participation and increased independence for children with disabilities when using support walkers [22]. Environmental accessibility has previously been reported as a barrier to device use both at school and home for children with CP

[159, 160]. Navigating these non-accessible environments with hard to maneuver walkers is an additional challenge of the equipment itself [22].

Regarding caregiver education and training, caregivers reported low levels of understanding of why their child was being prescribed a device and not all received training once the device was obtained. Remedying this can help increase the confidence and understanding of families regarding their child's mobility aids. In a 2023 study, Morgan et al found parents wanted to be taught how to help their children during early diagnosis and intervention of CP [161]. Additionally, family-centered care through increased communication, collaborative goal setting, and family-friendly information was associated with positive outcomes for families of children with CP [162]. Engagement of the family in all stages of the process can be mutually beneficial for both caregivers and clinicians.

Finally, a few suggestions for improvements of device design for AFOs were discussed in this study, highlighting concerns such as skin irritation, size, bulkiness, and issues with shoe fit. Shoe fit and potential need for shoe modification has been well documented as an issue, with studies finding dissatisfaction with finding appropriate shoes post-stroke and difficulty with finding durable, stylish, inexpensive shoes that can accommodate AFOs for adults with CP [156, 163]. In the past few years, more shoe brands have emerged to attempt to solve this issue, including Billy Footwear, SureStep Shoes, Gracious May Shoes for AFOs, and other adaptive footwear options. These innovations highlight the importance of the lived experiences of caregivers and children in driving design needs.

5.4.1 Limitations

We aimed to understand the experiences and perceptions of a diverse population of clinicians and caregivers of children with disabilities who use mobility aids in the United States. As such, results related to the status of the current prescription and provision process for first mobility aids for children with CP provide guidance but may not be generalizable to other populations. We used convenience sampling which may have resulted in selection bias, in addition to a smaller number of caregivers and limited the diversity of disciplines within the clinician group. Respondents were also primarily from urban or suburban areas. Location greatly affects access to care, so results may have differed with more rural participants. While we intended to include caregiver perspectives on all orthoses, all caregivers surveyed noted their children solely used AFOs. Further research will be required to understand the caregiver's perspective on the provision, use, and impacts of SMOs or other orthoses. Second, due to the focus of this study on first mobility aids and the young ages of the participants' children at the time of provision, this study did not include children's voices directly, which is an important area of growth for future research. Finally, this study was potentially influenced by response bias, where people with very good or very bad perceptions are more inclined to share their experiences, as well as recall bias, especially for caregivers whose child received their first device long ago [164].

5.5 CONCLUSIONS

This research provides insights into the lived experiences of clinicians and caregivers of young children with CP regarding the prescription, provision, use, and impact of first mobility aids, specifically AFOs and walkers/gait trainers in the United States. The perspectives of both clinicians and caregivers are included to understand families' experiences obtaining mobility aids from individual and institutional perspectives. This study not only provides researchers and clinicians with an understanding of the current status of first mobility aid prescription and provision processes, but also offers suggestions for improvements to the process and devices themselves. While the impacts of first mobility aids varied, AFOs and walkers both had positive impacts on walking, running, and standing, but also negative impacts on play and transitions. Caregivers highlighted the gaps in education and training they received to fully understand the goals, implications, care of, and effects of such mobility aids. While the considerations for prescription were generally aligned, clinician training was reported as variable, and the current process leaves a lot up to the discretion of the clinician. A wide variety of components restricted access to an efficient provision process including insurance, clinician access, clinician coordination, and extended wait time. Clinicians and caregivers provided insight into possible solutions to these challenges informed by their rich lived experiences.

5.6 ACKNOWLEDGMENTS

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Chapter 6

QUANTIFYING TODDLER EXPLORATION IN DIFFERENT POSTURES WITH POWERED MOBILITY

Will be submitted to Assistive Technology

Nicole L. Zaino

Kimberly A. Ingraham

Mia E. Hoffman

Heather A. Feldner

Katherine M. Steele

ABSTRACT

On-time powered mobility is critical for development and access to self-initiated mobility for toddlers with disabilities. Using powered mobility in a standing posture has been theorized to support development of muscle activation and coordination, balance, head and trunk stability, and transition to ambulation while also supporting self-initiated mobility and exploration. The purpose of this study was to quantify and characterize joystick control, navigation, bodyweight support, and muscle activity while using the Permobil Explorer Mini in a seated and standing posture. Nine children with mobility disabilities participated in four study visits where they completed two 15–20-minute play sessions, one in each posture, with a break in between. We found that all toddlers were able to engage with the joystick in both postures and drove the Explorer Mini. Participants had a high number of joystick activations during play sessions and generally explored all directions of joystick movement, with different favorite regions and patterns. Generally, participants loaded a similar amount of bodyweight through their feet in both postures but had slightly higher amounts of muscle activity in the standing posture, especially while they were actively driving. These results will help inform the future design of these devices to support play and development.

6.1 INTRODUCTION

For many infants and toddlers with mobility disabilities, access to developmentally appropriate mobility technology is crucial to facilitate self-initiated movement, exploration, and social engagement. Delayed mobility (i.e., 2-4 years later than nondisabled peers) can initiate a cascade of effects such that toddlers with disabilities fall behind their peers across multiple developmental domains [1, 21]. Powered mobility is one piece of technology that can help fill this gap in self-initiated mobility.

Children under the age of 5 don't have access to powered mobility, even though it has been shown to support their independent mobility. Although some commercial powered wheelchairs are available for children in the United States, the provision of these devices is typically delayed until after children enter school (around age 5). This greatly restricts access to self-initiated mobility during the first several years of a child’s life [30]. Manual wheelchairs or strollers are often viewed as a viable, or even preferable, alternatives to powered wheelchairs, but prior research has shown that 86% of children using a powered wheelchair had independent mobility compared to only 14% of children using manual wheelchairs [52]. It is important to consider how different types of wheeled mobility may influence participation, exploration, and development. It is crucial for children to have on-time access to independent self-initiated mobility.

One of the most extensive deployments of powered mobility technologies for infants and toddlers with disabilities in the United States has been the GoBabyGo mobility and socialization program [25]. These volunteer-modified ride-on cars have been shown to improve participation and parallel play with peers in both preschool classroom and playground settings for infants as young as 6 months old [165]. However, these devices are not meant to be a permanent solution or substitute for commercially available powered mobility designed specifically for young children.

Ride-on cars have limited control capabilities and the manual steering wheels can be challenging or impossible for young children to manipulate. These drawbacks can also limit play and exploration during self-initiated mobility [25, 166].

New technology is expanding powered mobility access and options for very young children with disabilities [11, 20]. The Permobil Explorer Mini, released in 2020, is the first FDA-cleared class II pediatric mobility device available in the US specifically designed for children 12-36 months old. The Explorer Mini is a powered wheelchair that has a midline joystick, small turning radius, is lightweight and small, and has proportional speed control. One prior study with 33 toddlers with a variety of diagnoses (e.g., cerebral palsy, spina bifida, down syndrome, developmental delay) qualitatively described the initial driving and emotional experience when using the Explorer Mini [11]. 94% of kids were able to use it within two 15-min driving sessions, providing early evidence about the device's accessibility and usability in this population.

One exciting feature of the Explorer Mini is that the seating configuration is adjustable, with a saddle seat between the legs which can be raised or lowered for seated and standing postures which may be a potential therapeutic benefit. Offering the option to stand with the saddle seat in a raised position and legs extended has been proposed to potentially support development of muscle activation and coordination, balance, head and trunk stability, or transition to ambulation[11], but driving in the standing posture in the Explorer Mini has yet to be empirically evaluated. Logan et al. (2017) demonstrated feasibility and potential of standing powered mobility for young children with a modified ride-on car that activated when a child stood up, removing weight from a switch located under the seat. Their case study found that the child participated in less solitary play and more peer interaction with the ride-on car compared to his standard form of mobility with forearm crutches [167]. To our knowledge, no studies have yet evaluated the impacts of seated or standing postures on powered mobility use.

Many clinicians still express hesitancy with incorporating powered mobility as part of an early intervention program due to misconceptions that it might interfere with gross motor skill acquisition, such as walking [1, 21, 168]. In Canada, many occupational and physical therapists view early introduction of power mobility positively for children with mobility limitations; however very few of these therapists actively provide power mobility experiences [169]. The lack of knowledge on the physiological impacts of use may also be a barrier to provision. Expanding and improving the evidence of the impacts and use patterns of toddlers using powered mobility is critical to further expand the acceptance and use of early powered mobility [170].

6.2 OBJECTIVES

The objective of this study was to quantify toddler exploration in both seated and standing postures while using the Explorer Mini by investigating how they learn to activate the joystick and navigate through space. Specifically, we measured device interaction for toddlers with physical disabilities via joystick use, navigation, bodyweight support, and muscle activity to understand the navigation and neuromechanical impacts of using powered mobility in seated and standing postures during 15–20-minute play sessions.

6.3 METHODS

6.3.1 Participants

Nine children (age: 21.6±6.8 months, 6/3 M/F) (Table 6.1) and their parent(s) participated in four visits where they drove the Explorer Mini in an enriched play environment. Inclusion criteria for this study were: (1) 12-36 months old, (2) mobility delay, and (3) could sit with support for 15 minutes. The University of Washington institutional review board approved this study

(STUDY00014879), and all caregivers gave informed consent for themselves and permission for their children to participate.

Table 6.1 Participant demographics

Participant ID	Age (months)	Sex	Weight (kg)	Disability type	Mobility at study entry
P01	14	M	9.9	Neurological	Sitting
P02	16	M	10.1	Orthopedic	Cruising
P03	21	M	8.7	Neurological	Sitting
P04	24	F	9.9	Neurological	Walking
P05	28	M	10.7	Cerebral palsy	Rolling
P06	14	F	7.2	Extreme prematurity	Sitting
P07	18	F	11.3	Cerebral palsy	Rolling
P08	23	M	11.7	HIE	Rolling
P09	35	M	11.4	Developmental delay	Cruising

6.3.2 Explorer Mini

We used the Explorer Mini (Permobil AB, Sweden), a powered mobility device for children between 12-36 months of age (maximum weight limit: 35 pounds; maximum height limit: 39 inches). The joystick-controlled device has a 360º turn radius, is lightweight, and has proportional speed control with five adjustable speeds with a maximum of 1.5 mph.

6.3.3 Protocol

The Explorer Mini saddle seat and tray height were adjusted for each child, so the knees were bent at a 90-degree angle in the seated position (SIT) and the knees were straightened in the supported standing position (STAND), with the feet positioned under the hips (Figure 6.1). The saddle seat was left in place for safety and support in both postures.

Figure 6.1 Comparison of posture configurations. From left to right: SIT, seated with saddle and knees ~90°, STAND, supported standing with saddle and knees near to 180°, NO SADDLE - STAND, unsupported standing with no saddle in place.

One participant, P09, was able to stand without the support of the saddle seat so they completed one additional visit in which they completed one play session in standing posture without the seat in place (NO SADDLE - STAND) and one play session in seated posture (SIT).

Each visit consisted of two 15–20-minute play sessions, one in a seated and one in a standing posture, with order randomized and a break between. The play sessions were child-led and guided by the Assessment of Learning Powered mobility use (ALP) tool and facilitating strategies, and the Guideline for Introducing Powered Mobility to Infants and Toddlers [171–173]. Play sessions took place in a large motion capture laboratory that was set up to encourage child exploration using toys and activities, such as basketball hoops, beach balls strung from the ceiling, music toys, and other sensory or manipulative toys.

6.3.4 Outcome Measures

We developed and deployed a custom, aftermarket sensor-suite that integrates with the Explorer Mini and included joystick position tracking, wheel encoders to calculate speed and distance traveled, and four compact compression load cells in the base to measure loading from the child's legs on the device footplate. In addition to the custom sensor suite, the Explorer Mini was tracked in 3-dimensional space using 12 Qualisys motion capture cameras (Qualisys AB, Gothenburg, SE) in the play space with nine retroreflective markers placed on the Explorer Mini. Muscle activity was measured using 8 electromyography (EMG) sensors on the lower limbs. The surface EMGs (Delsys Inc, Natick, MA) were placed bilaterally on hamstring (HAM), quadricep (QUAD), tibialis anterior (TA), and gastrocnemius (GAS). For participants who wore ankle foot orthoses (AFOs), GAS was omitted, and for two children with very small femurs, HAM were omitted due to interference with the saddle seat of the Explorer Mini. Raw EMG signals were high pass filtered (4th order Butterworth; 40 Hz), demeaned and rectified, low pass filtered (4th order Butterworth; 4 Hz), a moving average with a 300 ms window was applied, and then normalized to the 95th percentile of the maximum activation across trials that day. All analysis was carried out using MATLAB (Natick, MA).

Primary outcome measures were total distance traveled, duration of each driving bout, the number of bouts, percent bodyweight support, and muscle activity. A driving bout was calculated using the joystick position— one bout is defined as the joystick being moved away from the neutral position until it was released and returned to the neutral position. We calculated percent bodyweight support as the amount of force being put on the device base normalized to each participant's body weight. EMG outcome measures included mean activity levels for each muscle (sides combined – QUAD, HAM, TA, GAS).

6.4 RESULTS

All nine participants engaged with the joystick in their first play session and learned to drive forward, successfully completed driving sessions in both seated and standing positions and engaged in both exploratory and goal-directed driving.

6.4.1 Driving and Joystick Control

Participants navigated and drove around the open play space to interact with toys, researchers, parents, and other exciting objects around the room such as cameras, walls, and desks. Participants drove on average 26.7 meters (range: 0.82 and 97.69 meters) each 15–20-minute play session. On average, participants drove 1.78 m per minute of their play session in SIT and 1.44 m per minute of their play session in STAND (normalized by the duration of the play session). For six participants, their longest driving bout each session was in SIT averaging 42.9 seconds (P01, P02, P04, P05, P07, P09) and for 3 participants (P03, P06, P08) their longest driving bout was in STAND averaging 36.6 seconds.

Movement bouts during play sessions were generally short, with periods of play and social interaction in between. On average, participants had 718 (range: 27-1305) joystick activations per session—94% of these were short bursts of less than 1 second, and 3% longer than 2 seconds in duration (Figure 6.2). On average, participants' longest joystick activation during a session was 39.7 seconds (range: 3.3 – 266.5 seconds). When comparing the joystick control in the seated and standing postures, participants had more bouts in the standing posture (stand: 746, sit: 689).

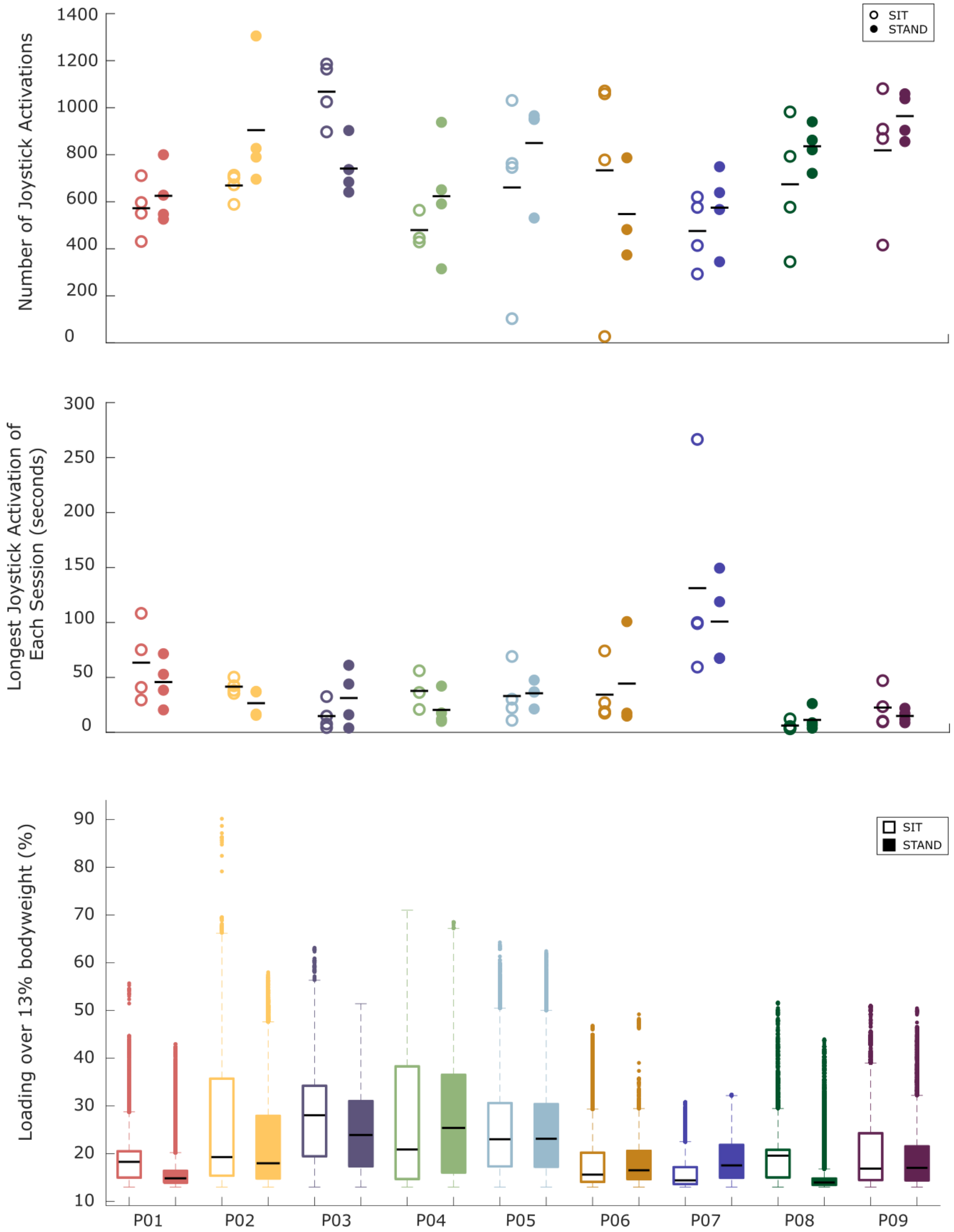

Figure 6.2 Number of joystick activations, longest joystick activation, and loading through the base over the 13% threshold in each play session for each participant for both SIT (left, open) and STAND (right, filled).

Participants had a high number of joystick activations during play sessions and generally explored all directions of joystick movement, with different favorite regions and patterns (Figure

6.3). We observed different strategies in joystick exploration. The preferred direction was quantified by the segment of the joystick workspace they spent the most time in when driving. The segment categories included: forward, forward-right, backward-right, backward, backward-left, forward-left. The preferred direction, the segment the joystick spent the most time in, was variable across participants, four preferred forward and five preferred backward. Preferred directions were similar between sitting and standing postures for each participant. Some participants would push the joystick to the edge of the joystick range and then move along the edge. Another participant used smaller joystick activations in different directions near the center, one had limited movement to each side and stayed close to the center line, and a few used a "pumping" motion front and back or side to side.

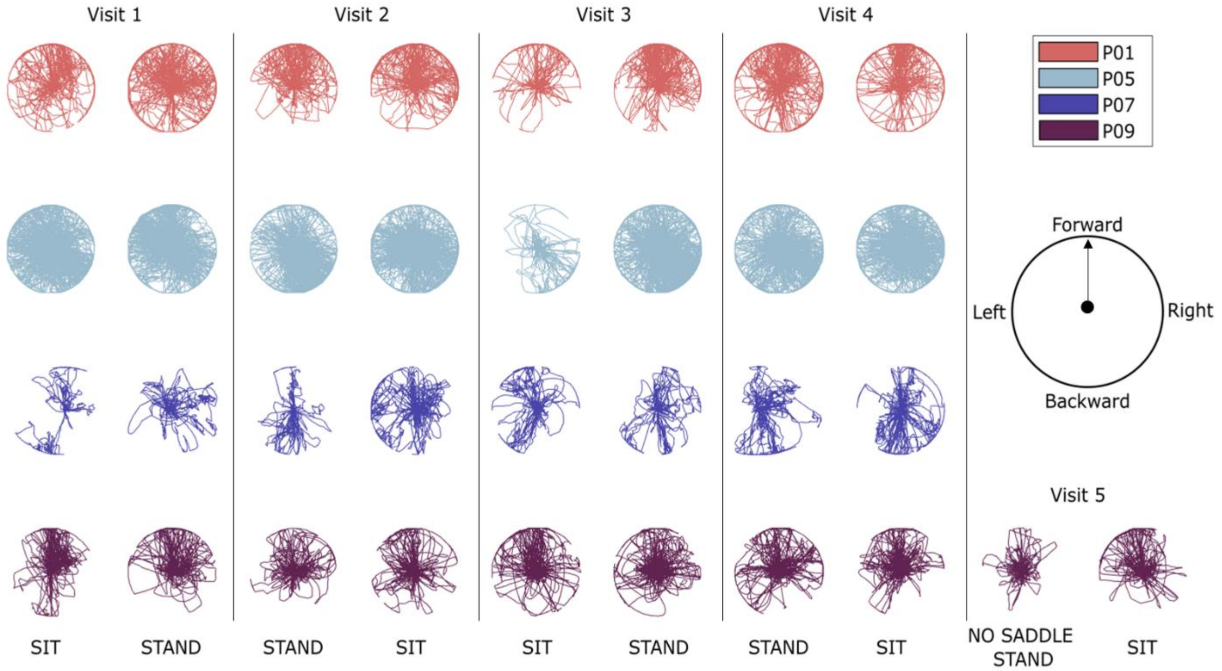

Figure 6.3 Joystick exploration maps for four participants (P01, P05, P07, P09). The joystick location is mapped with up relating to forwards and down relating to backwards. This shows the differences in how participants controlled the joystick.

6.4.2 Loading & Muscle Activity

The maximum loading value ranged between 17.8-90.2% of bodyweight. Using a threshold of 13% for estimated weight of legs [174] resting on the footplate, participants spent 0.02-18.66 minutes per session supporting part of their bodyweight through their legs.

On average, participants loaded 10.9% of their bodyweight through the footplate in SIT and 9.2% in the STAND. Participants spent 3.6 minutes in SIT and 3.4 minutes in STAND over the 13% threshold. The average maximum loading through the base of the device was 47% (range: 20-90%) for SIT and 44% (range: 18-69%) of the bodyweight for STAND.

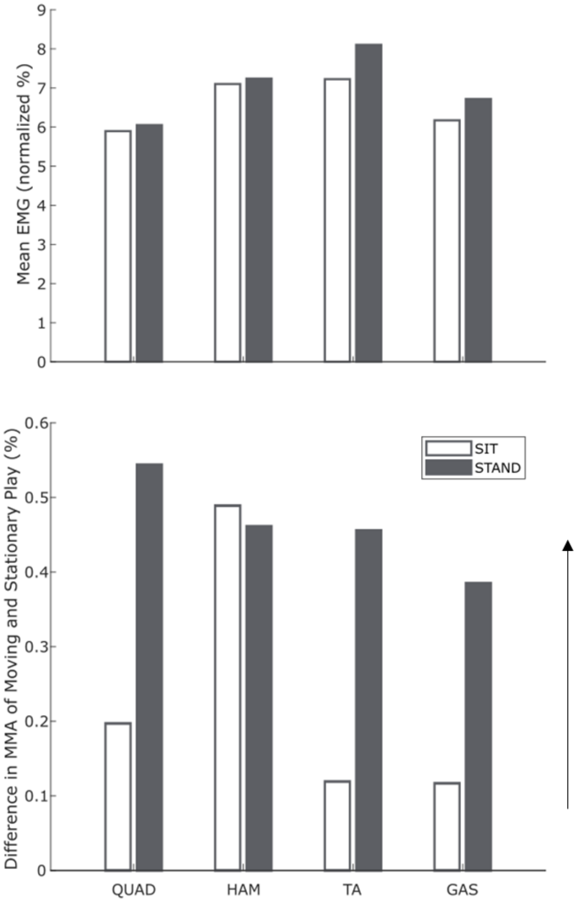

Figure 6.4 (LEFT) Mean muscle activity for each muscle across all participants, comparing the SIT and STAND sessions. (RIGHT) The difference in mean muscle activity for each muscle (QUAD, HAM, TA, GAS) when the Explorer Mini was moving vs stationary. A larger positive value represents more muscle activity during moving vs stationary. In STAND participants had more muscle activity when actively driving.

Mean muscle activity in STAND sessions was on average higher than mean muscle activity in SIT sessions across all participants. Participants had larger magnitude muscle activations when the Explorer Mini was moving (driving) compared to when the Explorer Mini was stationary, regardless of posture. In the standing posture participants had a greater difference than in the seated posture between their mean muscle activity when driving vs stationary (Figure 6.4).

6.4.3 Unsupported Standing: Case Study

One participant, P09, was able to stand without the support of the saddle seat. Hence, they completed one additional visit in which the saddle seat was removed during their standing play session in order to test the full range of posture options of the Explorer Mini (Figure 6.1).

When in unsupported standing, P09 had significantly fewer joystick activations and drove a shorter distance, compared to the seated session and previous standing sessions (Figure 6.5). Their joystick control patterns in the unsupported standing posture were different from both the seated and supported standing joystick control patterns (Figure 6.3). There was a substantial increase in the time spent loading, with 2.6 minutes in SIT and 9.8 minutes in NO SADDLE – STAND. While for the first four visits their average time spent loading was only 0.6 and 1.1 for SIT and STAND respectively. In their first four sessions, their average loading was 7.2% and 7% of their bodyweight for SIT and STAND respectively. In the final session, they loaded 10.5% and 24.6% of their bodyweight on average for SIT and NO SADDLE - STAND. Additionally, the mean muscle activity for the quadriceps specifically increased by 10 times (left) and 5 times (right) compared to the supported standing posture (STAND).

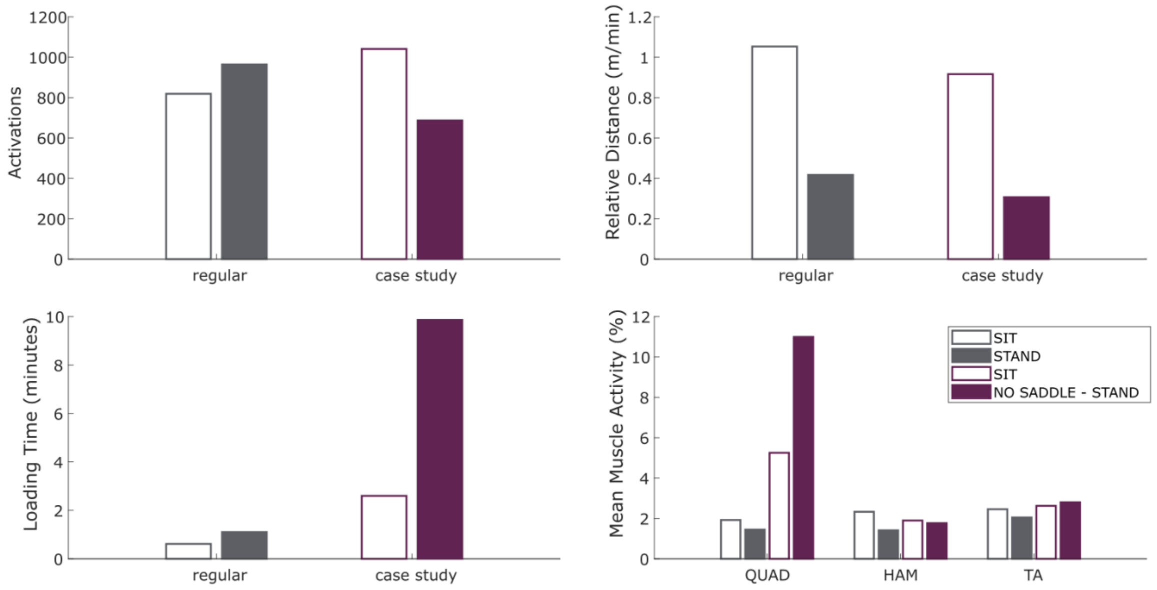

Figure 6.5 Case study of P09 completing one play session in NO SADDLE – STAND. The average of four visits is shown on the left (SIT, STAND) and value from the case study visit is shown on the right (SIT, NO SADDLE – STAND). The outcomes include: the number of activations in each session, the average activation duration, relative distance in each session, the amount of time spent over the 13% bodyweight support threshold, total distance traveled in each session, mean muscle activity for three muscles bilaterally (QUAD, HAM, TA). Note: GAS is not included due to interference with AFOs for P09.

6.5 DISCUSSION

Participants on many different motor development timelines and trajectories were able to control the joystick and navigate the play space in both seated and standing postures.

Participants supported a similar and small percentage of their body weight in both seated and standing postures. Due to the device design and positioning in the seated and standing postures, there was loading through the children's feet in both postures. This finding suggests that the seated and standing postures in the Explorer Mini may influence leg positioning, not loading, and that children continued to put a large proportion of the body weight through the saddle seat in both postures. Future studies should assess the differences in navigation and neuromechanics during device use with the saddle seat removed in the standing as shown with the case study with P09. For children who can use the device without the saddle seat for support, clinically the Explorer

Mini may be used in some sessions with and some sessions without the saddle seat to address different therapeutic goals.

Evaluating early device use with seated and standing postures provides crucial evidence to support a multimodal mobility approach to early intervention that incorporates physical therapy and powered mobility [167, 170, 175]. These results show the feasibility of short bouts of exposure (15–20-minute play sessions) to powered mobility as an effective roadmap to translation into clinical settings to provide access to powered mobility for toddlers. Children do not require extensive training or time in a powered mobility device to successfully explore mobility and engage with their surroundings.

6.5.1 Limitations

One of the challenges with working with young children with disabilities is the inherent variability. We chose to include a wide variety of disabilities, which led to a very diverse group of participants with a large distribution of cognitive and mobility abilities which limits the analysis and application of general trends. Additionally, instead of having participants perform structured driving tasks like in some previous studies [176–179], we engaged in exploratory play with the child to support participation and comfort based on their current ALP learning stage. Additionally, the sessions were structured based on the tolerance and interest of each child and, as typical of toddlers, their mood and interests varied between sessions. While there are trends, the results are still variable between children, likely representing important inter-participant differences in how they learn and engage with powered mobility. Nonetheless, this is the first study, to the authors' knowledge, that has been able to characterize this type of data across multiple participants and establish baseline data that is important for clinical translation as well as device design in the future.

6.6 CONCLUSIONS

This work provides the first quantitative data on the effects of seated and standing powered mobility use in toddlers with disabilities.

We successfully quantified toddler exploration in both seated and standing postures while using the Explorer Mini in an enriched play environment to investigate how they learn to activate the joystick and navigate through space in multiple play sessions. We found that overall toddlers frequently activate the joystick with a majority of short bursts less than 1 second. Compared to a seated posture, when in the standing posture participants drove shorter distances, had more joystick activations, and had more muscle activity when driving (compared to stationary play). While the amount of time spent loading bodyweight through their legs was low and similar in both postures. This study demonstrated important differences in toddlers' initial experience and use of powered mobility in seated and standing postures, especially in relation to joystick activations and distance travelled. Additionally, we have demonstrated the feasibility of collecting these quantitative metrics during powered mobility learning which has implications for powered mobility learning across the lifespan, and not just restricted to this age group [180].

Quantifying how children learn to engage with their environment using powered mobility devices will help inform the future design and control of these devices to support play and development.

6.7 ACKNOWLEDGEMENTS

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Chapter 7

CONCLUSION

7.1 SUMMARY

The goal of this dissertation was to leverage mixed methods approaches from engineering, disability studies, and data science to improve and support mobility for individuals with disabilities. This dissertation presents the first retrospective study with a “proper” control group to quantify energy consumption and spasticity changes after SDR for children CP. Additionally, this dissertation summarizes and disseminates lived experiences of clinicians, caregivers, and individuals with CP regarding mobility aid provision process and use, with urgent process and design challenges to address in future work. Finally, this dissertation includes the first study to quantitatively analyze how toddlers with disabilities learn and use powered mobility to interact with and explore their environment. Thus, this work provides insight on the impacts of interventions and mobility aids across the mobility spectrum.

The first objective of this dissertation was to gain a deeper understanding about the mechanisms contributing to elevated energy consumption during walking for children with CP, which impacts their mobility and endurance. In chapter 3, via a retrospective analysis of a clinical database of children with CP, we found that while SDRs reduce spasticity, they do not reduce energy consumption. A critical component of this study was the methods to identify and use a “proper” control group of children with CP who did not undergo an SDR matched by age, energy consumption, and spasticity to evaluate outcomes. This has massive implications for clinical care, which often considers elevated energy levels in the selection process of potential candidates for SDR. Not only does this work provide compelling evidence that spasticity is not a primary mechanistic contributor to elevated energetic consumption in CP, but also that the consideration criteria of this surgery and expected benefits need to be seriously reconsidered.

After our first objective, we pivot to two mixed-methods research studies to gain knowledge and insight from the lived experiences of key stakeholders. In chapter 4, we quantified and evaluated lived experiences of individuals with CP across the lifespan and their caregivers' perceptions on AFO provision and use. We found that 1) AFO provision is a confusing and lengthy process, 2) participants want more information during AFO provision, 3) AFOs are uncomfortable and difficult to use, and 4) AFOs can benefit mobility and independence. As a mechanical engineer, this work can be used to improve the provision process of orthoses, guide research, design, and development of improved AFOs to address the "pain points" highlighted by these individuals with rich experience using these devices. Specifically, further opportunities exist to support function and participation of people with CP by streamlining AFO provision processes, creating educational materials, and improving AFO design for comfort and ease of use.

While conducting our studies in chapter 4, we noticed that many individuals with CP gained knowledge gradually about their mobility aids after getting new versions every few years throughout their lifespan; therefore, leading us to investigate the provision process experience specifically for the first mobility aid that a child with CP receives. We were interested in the prescription and provision process for first mobility aids during which the family/caregiver/child do not have prior experience or knowledge. Additionally, since we know how critical access to self-initiated mobility is for cognitive, visual, and motor development for young children, it is important to know at what age children are currently receiving their first mobility aid. We conducted surveys and semi-structured interviews with caregivers of young children with CP and clinicians. We found that 1) first mobility aids have mixed impacts and use patterns, 2) there is varied caregiver education and understanding about mobility aids, 3) clinician knowledge, consistency, and connection impact care, and 4) numerous access barriers exist for families. The results of this mixed-methods study provide an understanding of the status of the prescription and provision of first mobility aids, and offers suggestions to optimize the provision process, education and training, and future device design and development. For mechanical engineering, these innovations that drive device design changes and improvement are critical to be founded in and driven by lived experiences.

The final objective of this dissertation was to examine the exploration and neuromechanical impacts of powered mobility for toddlers with disabilities or mobility delays. In Chapter 6, we conducted an experimental study with 9 toddlers with disabilities in which they used the Explorer Mini in two postures (seated and standing) across four driving sessions. This study is the first to systematically quantify how young children learn to use powered mobility in addition to incorporating custom embedded sensors to quantify joystick, navigation, and bodyweight support of the Explorer Mini. Participants had a high number of joystick activations during play sessions and generally explored all directions of joystick movement, with different favorite regions and patterns. Generally, participants loaded a similar amount of bodyweight through their feet in both postures but had slightly higher amounts of muscle activity in the standing posture, especially while they were actively driving. Children, no matter the mobility “timeline” they are on, were able to use powered mobility to achieve self-initiated mobility and explore their environment. As a mechanical engineer, quantifying the user-device-environment interaction is imperative to the development of new on-time powered mobility devices.

7.2 FUTURE WORK

The work outlined in this dissertation lays the foundation to further understand various technologies that support and improve mobility for children with disabilities. There are also many exciting avenues for future research in mobility aid device development, provision optimization, education, tool learning, and neuromechanical impacts of such devices. The following section outlines a few different research avenues to guide and motivate future progression of knowledge in this field:

7.2.1 Optimizing self-initiated exploration for children with disabilities

- **What device type is best to support self-initiated mobility for toddlers who are on a delayed trajectory to walk?**

  We know that self-initiated mobility is critical for cognitive, visual, social, and motor development. Early evidence suggests that the mode of this self-initiated mobility matters less than the fact that this movement is self-initiated. Powered mobility is used for toddlers who will be either long term wheelchair users and those who may ambulate with or without support later in their life. Posture effects visual exploration, specifically the more upright the child is the vestibular stimulation encourages vigilance, learning, and following and processing visual stimuli [181]. It is important for children to experience many different positions and postures for their development. Chapter 6 explored the differences of posture in a powered mobility device (seated vs standing); however, for the subgroup of children with disabilities who will ambulate and are able to stand with support, how does this type of self-initiated mobility impact their exploration? Future work should focus on exploring the impacts of different mobility modes (*e.g.*: powered mobility, gait trainer, etc.) on key development and mobility outcomes. For children that have leg movement and can engage in supported standing, would supported standing in a dynamic gait trainer allow for more access to explore their environment and experience on-time self-initiated mobility? Other supported on-time mobility options might be especially important for the kids who take much longer to understand the joystick control or struggle with the fine motor skills required to use a joystick. Options beyond joystick controlled powered mobility, such as the use of switched controlled powered mobility or leg propelled gait trainers, may open a path towards self-initiated mobility for a subgroup of toddlers. Metrics to investigate may include distance traveled, space explored, and eye tracking to measure exploration in toddlers.

7.2.2 Advancing the implementation science of patient and family education

- **How can we implement improved patient and family education for mobility aids?**

Education and training of individuals, caregivers, and families was a key challenge and limitation in the current provision process of mobility aids as highlighted in Chapters 4 and 5 [161]. Using the participatory action research (PAR) method to co-develop an education guide or modules with key stakeholders including individuals with CP, their caregivers, and clinicians we can determine how to best implement improved education. PAR is a qualitative method involving an iterative reflective cycle of data collection, reflection, and action and redistributes the power between the researchers and researched [182]. Co-developing with individuals with lived experience has also been used with a Delphi process to create other clinical guidelines, scores, research priorities, and guide research studies. These approaches will allow key stakeholders to determine the topics included, the format, and other key components of the education guide/modules that can be implemented in clinical and community settings.

- **How does implementation of an education guide improve patient and family education for mobility aids?**

  Any co-developed education guide should be tested in a busy clinic setting to test efficacy and allowed for iterative improvement of the education guide before broad distribution. It is important to understand questions such as, what are the impacts on a clinician? Is it feasible to implement? What are parents' perspectives of the education guide and module? This should include metrics and feedback from both clinicians, caregivers, and end-users. In the nursing field, it has been shown that education should be simple, patient centered, and multimodal to meet the literacy needs of the patients/caregivers [183]. Specifically for parents with young children with CP, they want the truth, less uncertainty, early diagnosis, and guidance [161]. We propose that better education of families and patients will lead to better care, reduction in abandonment of devices, reduction of safety concerns and overuse injuries, and patient and family empowerment.

7.2.3 *Advancing the teaching and access to powered mobility use to children with disabilities*

- **Can we develop a wheelchair skills training program for young children using powered mobility?**

  There is an adult wheelchair skills program [184, 185] which has been modified for children who use manual wheelchairs [186–188]. A few training tools exist specifically for the pediatric population, but these have not been widely implemented or tested in the field [171, 173, 189, 190]. This raises many questions about the best way to teach powered mobility skills to young children especially since at the early stages of learning, progression based tools are used and described as the best fit for especially young children in the early stages of learning [171, 173]. How can wheelchair skills training programs be made more widely available for young pediatric powered wheelchair users? At what age or skill level should powered mobility training transition from process-based to skill-based tools and strategies such as the wheelchair skills program? How can adult wheelchair skills program and pediatric manual chair skills program be combined and modified for children using powered mobility? What role might smart wheelchair accessories play in safety and training programs?

- **How does environment and exposure impact powered mobility learning in children with disabilities?**

  Many children are denied insurance coverage, or their clinician denies prescribing powered mobility due to a perceived lack of "readiness", such as not having the "right" skills or cognition to use a powered wheelchair [10]. In order for children to gain the cognition to become efficient powered wheelchair users, they need exposure to use and learn how to use powered mobility. The cognitive skills of attention, orientation, memory, new learning, and problem solving can all be gained from learning how to use powered mobility. In this way, powered mobility is not just a solution, but an intervention. So, how can this be taught and facilitated in the current restrictions of the wheelchair provision process? First, we need to understand how environment impacts the ability to learn powered mobility for young children. While we observed that the participants were able to interact with the joystick in a clinical setting in Chapter 6, we do not know how the setting impacted their learning and translation of those skills outside of that setting. What are the differences in learning between a) unlimited access to a powered wheelchair in a child's home, b) attending training sessions in a clinic and only having access to the powered wheelchair in those sessions, or c) attending training sessions in multiple settings (clinic, outside, a large gymnasium, etc.) and only having access to the powered wheelchair in those sessions. Could a program to expose a child to powered mobility enable them to gain the current “required” skills that prevent prescription and provide access to powered mobility with the currently failing wheelchair provision system?

The long-term goal of the work presented in this dissertation and the future studies outlined above aim to improve understanding of proper use, training, education, and access to technology-supported mobility. Mobility is a human right, and mechanical engineers play a key role in supporting and improving mobility, in all forms. Technology can support and supplement access to mobility for individuals with disabilities. Through the combination of computational, qualitative, and experimental studies, this research provides a foundation to improve access, training, and understanding of mobility aids to allow for the freedom of self-initiated mobility.

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APPENDIX A

A.1 CLINICIAN INTERVIEW GUIDE – CHAPTER 5

Thank you for participating in our survey. Today, our goal is to speak with you to learn more about your experience.

Opening Statement

Let me suggest some guidelines that will make our discussion more productive.

- *Your name and your comments will be kept confidential, as we discussed earlier.*
- *Should you need to take a break for any reason, please feel free to do that and we can resume the interview afterwards or we can reschedule a better time.*
- *If you don't want to answer a question, you can just tell me that you don't want to answer it. If a question doesn't pertain to you, we can skip it.*
- *Do you have any questions before we begin?*

Interview Questions

<u>Theme 1: Prescription process/expectations</u>

For this set of questions, I want you to think about the process leading up to and receiving a mobility aid for ***children with CP under the age of 5,*** *within the last year.*

First, I want you to answer these questions in regards to ***AFOs/SMOs****. Please share if there is a difference between the two.*

1. What is the current process at your clinic for a child receiving their first **AFO, SMO**?
2. What is the average age for a child in your clinic to receive their first **AFO, SMO**?
3. What do you take into account when recommending a child's first **AFO/SMO**?

4. What is your biggest challenge in getting a child their first **AFO/SMO**?
5. What do you think works well about the current process?
6. What do you think can be improved in this process for children with CP?
    a. Do you have any proposed solutions?

AFO/SMO only:

1. Are shoes included in your prescription/thought process?
    a. If yes, describe how you educate families about footwear.
2. What do you consider when creating a child's first AFO or SMO?
3. Can you walk me through your initial process as an orthotist?
4. How do you decide if an off the shelf or custom AFO is best?
    a. Is this decision made by you or different clinician?

Then answer them in regard to ***walkers****.* <u>*A reminder that this is for children under the age of 5 for their first walker.*</u>

7. What is the current process at your clinic for a child receiving their first **walker**?
8. What is the average age for a child in your clinic to receive their first **walker**?
9. What made the process of getting the walker faster?
10. What do you take into account when recommending a child’s first **walker**?
11. What is your biggest challenge in getting a child their first **walker?**
12. What do you think works well about the current process?
13. What do you think can be improved in this process for children with CP?
    a. Do you have any proposed solutions?

Walker only:

5. How do you decide what type of walker to prescribe for a child?

ALL

14. What dosage do you usually recommend at the onset of device use?
15. Does your recommended dosage change over time?

Do you have anything else to add on this section?

Theme 2: Initial use

This next batch of questions are about the initial experience for a child's first mobility aid within the last year. A reminder that this is for children under the age of 5 for their first walker/AFO.

16. Can you think back to a recent case - what were your goals prescribing their **AFO or SMO**?
    a. What was their prescription process like?
    b. What type of shoes?
    c. Did they receive any training from yourself or another clinician?
    d. What impacts did you observe from using the device?
    e. What about parents impacts?
    f. How long did it take to get this AFO/SMO?
17. Can you think back to a recent case - what were your goals prescribing their first **walker**?
    a. What was their prescription process like?
    b. Is it common that these are just dropped off and not adjusted?
    c. Did they receive any training from yourself or another clinician?
    d. What impacts did you observe from using the device?
    e. Impacts, parents?
    f. What kind of walker (front or back, how much support)?

    g. How long did it take to get this walker?

18. What type of training have you received on the **AFO or SMO** with your patients?
    a. How much?
    b. When?
19. What type of training have you received on the **walkers?**
    a. How much?
    b. When?
20. What type of training is provided to the family for **AFO or SMO**?
    a. Do you explain why a certain type is prescribed?
21. What type of training is provided to the family for **walker**?

Do you have anything else to add on this section?

Theme 3: Impact

For this final batch of questions, I want you to think about the impacts of the use of the mobility aid. I will ask these for both orthoses and walkers. A reminder that this is for children under the age of 5 for their first walker/AFO.

22. What are the short-term impacts you observe from using **AFOs or SMOs**?
23. What are the long-term impacts you observe from using **AFOs or SMOs**?
24. What is the process as the child grows and develops for **AFOs or SMOs?**
25. What are the short-term impacts you observe from using **walkers**?
26. What are the long-term impacts you observe from using **walkers**?
27. What is the process as the child grows and develops for **walkers**?

Additional:

28. How often do you think families decide not to use an AFO/Walker when it is suggested to them?
29. How long does it usually take for them to become comfortable with wanting to use the device?
30. Do these families later choose to get the suggested AFO/walker?
    a. *How do you convince them?*
    b. *Do you feel like there are enough resources for this?*
    c. *What resources do you think would be helpful?*

Cases (if time)

1. Can you recall a child you worked with that your experience with mobility aids made you incredibly frustrated?
2. Can you recall a child you worked with that your experience with mobility aids made you excited?

General

Is there anything else that you expected to talk about today that didn't come up in our conversation?

I just want to say thank you for sharing your experiences and talking with us today.

A.2 CAREGIVER INTERVIEW GUIDE – CHAPTER 5

Thank you for participating in our survey. Today, our goal is to speak with you to learn more about your experience.

Opening Statement

Let me suggest some guidelines that will make our discussion more productive.

- *Your name and your comments will be kept confidential, as we discussed earlier.*
- *Should you need to take a break for any reason, please feel free to do that and we can resume the interview afterwards or we can reschedule a better time.*
- *If you don't want to answer a question, you can just tell me that you don't want to answer it. If a question doesn't pertain to you, we can skip it.*
- *Do you have any questions before we begin?*

Interview Questions

First, I have a few questions about you.

1. What was your child's first mobility aid? (recheck from survey)
2. Which devices has your child used since then? (recheck from survey)

ORTHOSIS

First I am going to ask you questions about your experience with orthoses and then we will go through similar questions about walkers.

Theme 1: Prescription process/expectations

For this set of questions, I want you to think about the process leading up to and receiving your child's ***first Orthosis (AFOs/SMOs)***.

1. What were your goals in your child starting to use the **AFO/SMO**?
    a. What goals did your child's clinician discuss with you?
        1. What type of clinician was this?
    b. Were your goals and the clinician goals similar or different? (if needed)
2. Can you walk us through the process of getting your child's first **AFO/SMO**?
    a. Who prescribed it?
    b. Who gave it to you?
    c. Was it custom or off-the-shelf?
    d. How long did it take?
3. What went well about the process of receiving this **AFO/SMO**?
4. What did not go well about the process of receiving this **AFO/SMO**?
5. What kinds of motor skills was your child working on when they received their first **AFO/SMO**?
    a. for example, were they focusing on floor mobility like rolling, sitting, and or crawling, standing or stepping mobility, or other mobility like learning to use a mobility device?
        1. *Were they independently walking?*
        2. *Were they standing up on their own?*
        3. *Were they standing up while holding onto something?*
        4. *Was it before working on standing skills?*
6. What type of training did you and your child receive on how to use the **AFO/SMO**?

    a. Who provided the training?

7. Did you receive any guidance on what type of shoes to use with the **AFO/SMO**?
    a. Was this part of the prescription?
    b. Who gave you this guidance?

Theme 2: Initial use

This next batch of questions are about your and your child's initial experience with your child's ***first Orthosis (AFOs/SMOs)****.*

8. What were your initial expectations or assumptions about your child's use of the **AFO/SMO**?
9. What were the first weeks of using the **AFO/SMO** like?
    a. What settings or environments did they use their **AFO/SMO** in?
10. Did you have follow-up appointments with a provider to check on use or for adjustment?
11. Did your child use the **AFO/SMO** full time or part time to begin?
12. Did the frequency of **AFO/SMO** use change over time?
13. Now talking about shoes and their **AFO/SMO:**
    a. Does your child always use their **AFO/SMO** with shoes?
    b. Did you get the shoes before or after you received the **AFO/SMO**?

Theme 3: Impacts

For this batch of questions, I want you to think about the impacts of the use of that ***first Orthosis (AFO/SMO).***

14. Can you think back to when your child started using their first **AFO/SMO:**
    a. What was their reaction?
    b. What did you observe?

15. What have been the long-term impacts of using the **AFO/SMO**?
    a. Has your opinion of them changed over time?
    b. Physical impacts? *Ex: Walking distance, balance, etc.*
16. How has the **AFO/SMO** changed as your child grew and got older?
    a. Are they still using their first **AFO/SMO**?
    b. How long did they use their first **AFO/SMO** for?
    c. How did their first **AFO/SMO** transition to or impact any future devices?
17. Did/does your child use their first **AFO/SMO** more often, less often, or about as often as you expected? **Why?**
18. What are your goals for your child's **AFO/SMO** use in the future?
19. *Do you have any more comments on your child's AFO/*SMO use *before we move onto walkers?*

WALKERS

Theme 1: Prescription process/expectations

Now I'll ask you the same set of questions about the process leading up to and receiving your child's ***first*** *mobility aid, and I want you to answer them in regard to their first* ***walker.***

1. What were your goals for your child as they were starting to use the **walker**?
    a. Were these the same or different goals that your child's clinician discussed?
2. Can you walk us through the process of getting your child's first **walker**?
    a. Who prescribed it?
    b. Who gave it to you?
    c. How long did it take?
3. What went well about the process of receiving this **walker**?

4. What did not go well about the process of receiving this **walker**?
5. What types of motor skills was your child working on when they received their first **walker** (or gait trainer)?
    1. for example, were they focusing on floor mobility like rolling, sitting, and or crawling, standing or stepping mobility, or other mobility like learning to use a mobility device?
        - *a. Were they independently walking?*
        - *b. Were they standing up on their own?*
        - *c. Were they standing up while holding onto something?*
        - *d. Was it before working on standing skills?*
6. What type of training did you and your child receive on how to use the **walker**?
    - a. Who provided the training?

<u>Theme 2: Initial use</u>

This next batch of questions are about your and your child's initial experience with your child's ***first walker.***

7. What were your initial expectations or assumptions about the impact the **walker** would have for your child?
8. What were the first weeks using the **walker** like?
    - a. What settings/environments did they use their **walker** in?
9. Did you have any follow up appointments with a provider to check on use or for adjustment?
10. Did your child use the **walker** full time or part time to begin?
11. Did the frequency of **walker** use change over time?

Theme 3: Impacts

For this batch of questions, I want you to think about the impacts of the use of your child's first ***walker.***

12. Can you think back to when your child started using their first **walker.**
    a. What was their reaction?
    b. What did you observe?
13. What have been the long-term impacts of using the **walker**?
    a. Has your opinion of the walker changed over time?
    b. Physical impacts? *Ex: Walking distance, balance, etc.*
14. How has the **walker** changed as your child grew and got older?
    a. Are they still using their first **walker**?
    b. How long did they use their first **walker** for?
    c. How did their first **walker** transition to or impact any future devices?
15. Did/does your child use their **walker** more often, less often, or about as often as you expected? **Why?**
16. What are your goals for your child's **walker** use in the future?
17. Do you have any more comments on your child's walker use?

General

Is there anything else that you expected to talk about today that didn't come up in our conversation?

I just want to say thank you for sharing your experiences and talking with me today.