

Pediatric Physical Therapists' Perceptions of Caregivers' Attitudes Toward Powered Mobility  
for Children with Disabilities

by

Christina Ann Cafferata

A THESIS

submitted to

Oregon State University

Honors College

In partial fulfillment

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degree of

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Abstract approved:

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Samuel Logan

The purpose of this study was to understand current caregiver attitudes towards powered mobility devices for young children with disabilities. This data was obtained by collecting surveys from pediatric physical therapists who interact with many caregivers on a daily basis and often act as the bridge between families and access to powered mobility devices. Overall, physical therapists reported that they did not always have conversations regarding powered mobility and that caregivers were not likely to initiate these conversations. Results showed that 79.1% of physical therapists indicated that none or very few caregivers brought up the topic of powered mobility and 28.7% of physical therapists rarely or never talk about powered mobility to caregivers with children who are potential candidates. Physical therapists also reported there is a wide range of emotions that caregivers express toward powered mobility for young children, with the most common being negative attitudes (34%). The attitudes of caregivers and pediatric physical therapists towards powered mobility devices for young children affects the number of caregivers who obtain information about the benefits of powered mobility and the number of children who gain access to these devices early in life.

Key words: powered mobility, pediatric physical therapy, caregivers, attitudes, modified ride-on cars, disability

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I understand that my project will become part of the permanent collection of Oregon State University, Honors College. My signature below authorizes release of my project to any reader upon request.

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Christina Cafferata, Author

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# Pediatric Physical Therapists' Perceptions of Caregivers' Attitudes Toward Powered Mobility for Children with Disabilities

## **Introduction**

### All disability

In 2017, 7.3% of children in the United States between the ages of 5 and 17 had been diagnosed with a disability (Kraus, Lauer, Coleman & Houtenville, 2018). In the 2014-2015 school year the Individuals with Disabilities Education Act served 6,555,000 children with disabilities between the ages of 3 years and 21 years in public schools in the United States (National Center for Educational Statistics, 2018). Approximately 52,000 of these children were classified as having an orthopedic disability (cerebral palsy, spina bifida, muscular dystrophy, etc). Cerebral palsy is one of the most common childhood motor disabilities, with 3.1 out of 1,000 children diagnosed. 58.2% of children diagnosed with cerebral palsy walk independently, 11.3% use a hand-held mobility device, and 30.6% do not walk (Christensen et al., 2013). Many children with orthopedic disabilities use assistive technology, including crutches, walkers, standers, manual wheelchairs, and powered wheelchairs to move through their environments.

Children who are unable to walk may use a powered mobility device (PMD) at some point either at home or at school. A PMD is defined by the Americans with Disabilities Act as “any mobility device powered by batteries, fuel, or other engines that is used by individuals with mobility disabilities for the purpose of locomotion, whether or not it was designed primarily for use by individuals with mobility disabilities” (ADA National Network, 2014). Research suggests that children with disabilities demonstrate developmental benefits as a result of access to powered mobility devices (Feldner, Logan, & Galloway, 2016; Kenyon, Mortenson, & Miller,

2018; Logan, Feldner, Galloway, & Huang, 2016; Berry, McLaurin, & Sparling, 1996; Jones, McEwen, & Neas, 2012).

## Benefits of Powered Mobility Devices

### *Motorized Wheelchairs*

Motorized wheelchairs are an original form of powered mobility device that has assisted individuals with disabilities to move independently since the mid-twentieth century. The first motorized wheelchair was invented by Canadian George Klein in response to the increased number of veterans who were quadriplegic after the second world war. He is credited with developing technologies such as the joystick, tight wheel turning systems, and separate wheel drives that are still used in adult and pediatric powered mobility devices today (Bourgeois-Doyle, 2017).

Research on pediatric powered mobility is still a developing field. The first study involving young children with limited mobility driving electric wheelchairs found that 8 of 9 children learned to drive motorized wheelchairs with a joystick controller (Butler, Okamoto, & McKay, 1983). The caregivers of these children all indicated positive effects of using the motorized wheelchairs on their children's intellectual, social, and emotional behavior, as well as an increased interest in other forms of movement (Butler, Okamoto, & McKay, 1983). Other research similarly demonstrates the benefits of introducing powered mobility at an early age, for example (Cooper et al., 2008; Jones, McEwen, & Neas, 2012).

### *Modified Ride-on Cars*

Modified ride-on cars (ROC) are a relatively new powered mobility option for children with disabilities (Feldner, Logan, & Galloway, 2016; Logan, Huang, Stahlin, & Galloway, 2014). ROCs can be bought in stores or online in a variety of different styles (cars, jeeps,



motorcycles, etc.) and for usually less than \$400 (Huang & Galloway, 2012). These ROCs can be modified electrically and structurally to make them usable and safe for children with a wide range of disabilities. The motor can be rewired from the gas pedal to a large easy to press button on top of the steering wheel so children can make the car move without using their feet. PVC supports, a larger backrest, and pelvic positioning straps can be added so the child is held more safely and securely inside the car (Feldner, Galloway, & Huang, 2016).

There are several benefits for families that choose to use a modified ROC for their child. As well as providing both cognitive and developmental benefits to the child, as with any PMD, (Logan, Huang, Stahlin, & Galloway, 2014; Logan, Feldner, Galloway, & Huang, 2016), modified ROCs are thousands of dollars cheaper than a standard motorized wheelchair. This low cost alternative also provides clinicians, including physical therapists (PTs), and families the option of using PMDs on a temporary, or short-term basis.

### Role of Physical Therapists

In general, the role of a PT in regards to the use of assistive technology for children with disabilities includes assessing whether the child is a candidate for assistive technology, recommending the appropriate device(s), and advocating for the use of assistive technology when appropriate (American Physical Therapy Association, 2009). In this way, PTs play a critical role in introducing families to PMDs, as well as supporting them through the process of obtaining a device.

PTs are often the first allied health professionals to discuss the possibility of a PMD with families of children who are considered to be potential candidates (Berry, McLaurin, & Sparling, 1996). Once caregivers decide to pursue this option, there are several paths to obtaining the PMD. A PT may work with an assistive technology supplier to decide which style and brand of

powered wheelchair would be best for the child and whether any additional modifications are necessary. Families can also buy an “off the shelf” style PMD that would not be customized. Modified ride-on cars can be found through a local Go Baby Go program or modified through the use of instructional resources (Feldner, Logan, & Galloway, 2016).

Traditionally, physical therapy has largely focused on treating and improving the functioning of individuals with disabilities and preventing disability whenever possible (Roush & Sharby, 2011). Historically PMDs have been thought of as a last resort option by many PTs (Wiert, Darrah, Hollis, Cook & May, 2004), used only after every attempt at walking has failed. However, a new disability model, the social model, tends to view disability less as a critical illness that requires a cure, and more as a result of the way in which society is structured to fit only the needs of able-bodied people. For many PTs, the challenge is determining how to balance valuing disability as diversity while working to improve the functioning of many patients with disabilities (Roush & Sharby, 2011). There are several tools available to PTs to help combine both the traditional medical model and emerging social model of disability.

The International Classification of Functioning, Disability, and Health (ICF) is an example of a classification system that has integrated both medical and social models of disability into one universal model (Centers for Disease Control and Prevention). The ICF values “Body Functions and Structures” equally as much as both “Activities” and “Participation,” which means that it places equal importance on how the body physically looks and functions (medical model) and how well the individual can interact and participate in their environment (social model). This classification system is now used widely in clinical settings to measure functioning, and it serves as a key tool to study disability (Centers for Disease Control and Prevention). It is also an extremely useful tool for PTs who are actively transitioning from

only using the traditional medical model of disability to combining both the medical and social models together to become a better ally for individuals with disabilities (Roush & Sharby, 2011).

As more PTs place equal importance on body function and participation in environment, PMDs are being used earlier, more frequently, and sometimes on a temporary basis (Livingstone & Field, 2015). Providing children who are unable to walk access to powered mobility as early as possible helps them keep up with their peers both socially and developmentally. Pediatric PTs are responsible for providing effective care, being aware of current research regarding PMDs, and communicating this information to the caregivers of children who are potential candidates for PMDs.

### Role of Caregivers

Introducing a child with a disability to a PMD can be an emotional process for the caregivers as well as the child (Wiar, 2004; Kenyon et al., 2018). Research has shown that this initial conversation can lead to a broad variety of responses from the caregivers that may include joy, excitement, uncertainty, and worry from the caregivers (Kenyon, Mortenson, & Miller, 2018). For many caregivers seeing their child in a PMD means letting go of the hope that their child will ever walk while simultaneously watching the child move independently for the first time (Kenyon et al., 2018). However, the attitudes surrounding PMD use has the potential to play a large role in whether or not a caregiver advocates for or accepts their child's use of a PMD early in childhood.

The culture of the caregivers often is a contributing factor to their willingness for their young child to use a PMD (Ripat & Woodgate, 2011). Disability and the causes of disability are thought of in very different ways even within the United States. Families that think about disability solely in terms of "curing an illness" will be less inclined to advocate for their child to

obtain a PMD at an early age because using a PMD can often feel like the “last resort” option when walking is the main focus of physical therapy (Wuart, 2004). In comparison, a family that regards a PMD as an opportunity to help their child best participate in their environment will likely be more open to advocating for access to PMDs (Ripat & Woodgate, 2011). It is important for clinicians, including PTs, to get to know the family and learn about what cultural groups they identify with as well as how they view disability in order to have a productive and respectful conversation about PMDs.

A common fear and misconception among caregivers is that encouraging independent mobility with the use of a PMD will cause their young child to lose the motivation to walk and they will become fully reliant on the PMD (Wuart, 2004). Society places such a high value on walking that many caregivers see it as the single most important skill their child can learn (Wuart, 2004). However there is no evidence that supports this fear. A 2012 randomized controlled study followed young children using powered wheelchairs for one year and found that there was not any decline, or plateau of motor skills, observed compared to prior to the use of powered wheelchairs (Jones, McEwen, & Neas, 2012). There is also evidence that for some children using a wheelchair as a PMD can help reduce joint deterioration and fatigue which can actually preserve the capability to walk (Cooper et al., 2008).

Other common caregiver concerns about PMDs include cost of the device, ability to transport it, and space in the house to store it (Kenyon et al., 2018; Huang & Galloway, 2012). Typically state or privately funded insurance will not help pay for a PMD until a child is at least three years old (Feldner, Logan, & Galloway, 2016). This causes many families to pay out of pocket or travel to other countries to gain access to a powered wheelchair. Additionally, the process for a family to obtain a PMD can be long, involving extensive paperwork and hassle for

the family. These wheelchairs, and other PMDs, can be large and may not fit in a regular car which may mean the family has to buy a new larger van that can accommodate the PMD (Huang & Galloway, 2012). Storage may also be a challenge in a small house. For these reasons, many families opt to use strollers and/or carry their children who are unable to walk.

#### Gap (extending previous work)

Previous work has examined both caregiver's and PT's attitudes towards PMDs (Wiar, 2004; Berry, McLaurin, & Sparling, 1996; Kenyon, Mortenson, & Miller, 2018). Kenyon et al. (2018) examined the attitudes of both pediatric PTs and caregivers, confirming the process of obtaining a PMD is complex and dependent on the attitudes and motivation of the PT, caregiver, and child. There are no other studies that have examined PT's perspectives of caregiver attitudes, despite the fact that PTs often act as "gate keepers," or the link between families and powered mobility devices. Since PTs interact with many caregivers over the course of their careers, this study surveyed PTs to gauge current caregiver attitudes toward PMDs for young children with disabilities.

#### **Purpose**

The purpose of this study is to examine physical therapist's perceptions and experiences of conversations with caregivers of young children with mobility disabilities regarding powered mobility devices.

#### **Participants**

The data were obtained from mixed methods surveys given to a purposeful sample of physical therapists who work with pediatric populations from 16 professional development workshops. The sample included 414 clinicians ( $n= 244$  PTs). Workshops were held in several states: California, Colorado, Florida, Louisiana, Maryland, Mississippi, Missouri, North

Carolina, Texas, Virginia, and Washington. The learning objectives of the workshop included: (1) Discuss recent advances in science, training, and technology related to self-directed mobility in early childhood; (2) Describe mobility solutions that allow children with disabilities to independently explore their environment; and (3) Complete electrical and seating modifications to a ride-on car for a child with a disability. The workshops were voluntary, required a fee, and provided 0.7 Continuing Education Units to participants.

## **Methods**

All procedures were approved by the university's Institutional Review Board and written informed consent was obtained from all participants. This study is part of a larger study that examined clinicians' attitudes toward individuals with disabilities, disability model orientation, self-directed mobility, and the conversations happening between PTs and caregivers regarding PMDs and disability.

This content analysis was used to review the responses of the PTs and categorize them into themes. Only the responses from licensed PTs were included. Six free response questions and a large amount of Likert scale questions were included in the survey but only the first three free response questions were analyzed here.

## **Materials**

The three free response questions used in this analysis were:

1. How many caregivers of young children who might be a candidate for a powered mobility device brought up the topic to you?
2. Do you commonly talk to caregivers about the potential use of powered mobility devices for their young children that may be candidates?
3. What are caregivers' common reactions to powered mobility devices?

## **Data Analysis**

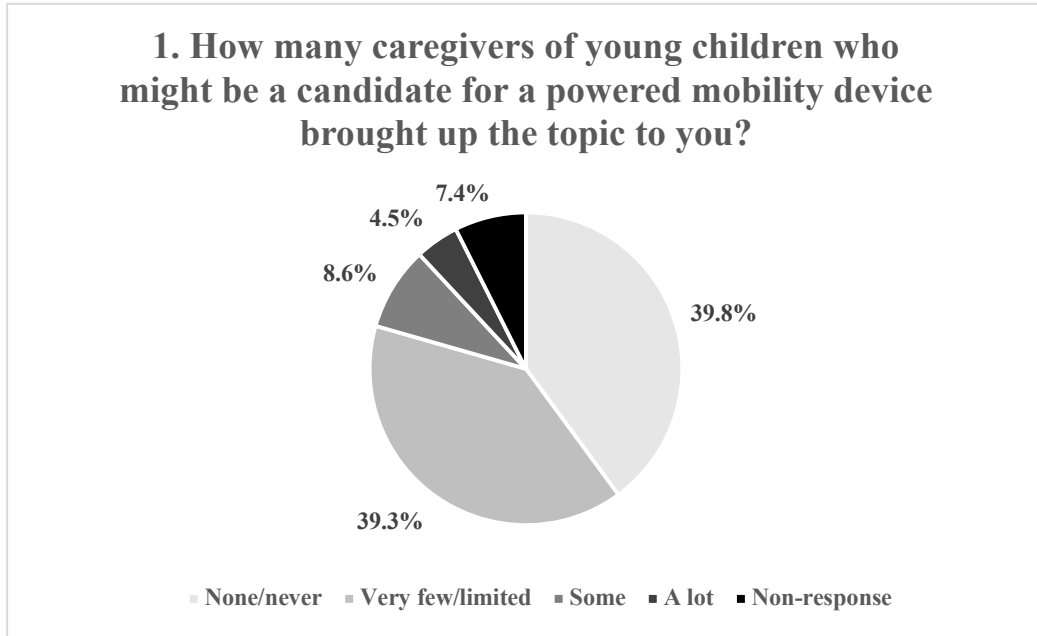
The responses to the three free response questions were read over by two researchers, and a thematic analysis was performed to analyze common themes present in the responses for each question. Each researcher came up with a list of themes for each question, the researchers discussed and modified the themes, the responses were read over again, and a list of common themes was created. Multiple examples for each question based on the common themes were pulled from the data and then each participant's response was coded into one of the themes for each question. Two researchers each coded a random 10% of the data based on the coding guidelines (Table 1) to determine which themes were represented in each response. Following the first coding session, researchers modified the coding guidelines based on discussions of any disagreements in coding (Table 1). They each coded 10% more of the data to reach a 80% agreement. One researcher coded the remaining data. Krippendorff's alpha, a reliability coefficient commonly used in content analyses, was used to confirm reliability between the researchers. These codes were used to calculate percentages of the responses that were in each theme which can be used to examine conversations between PTs and caregivers regarding powered mobility devices and the common reaction of caregivers.

## **Results**

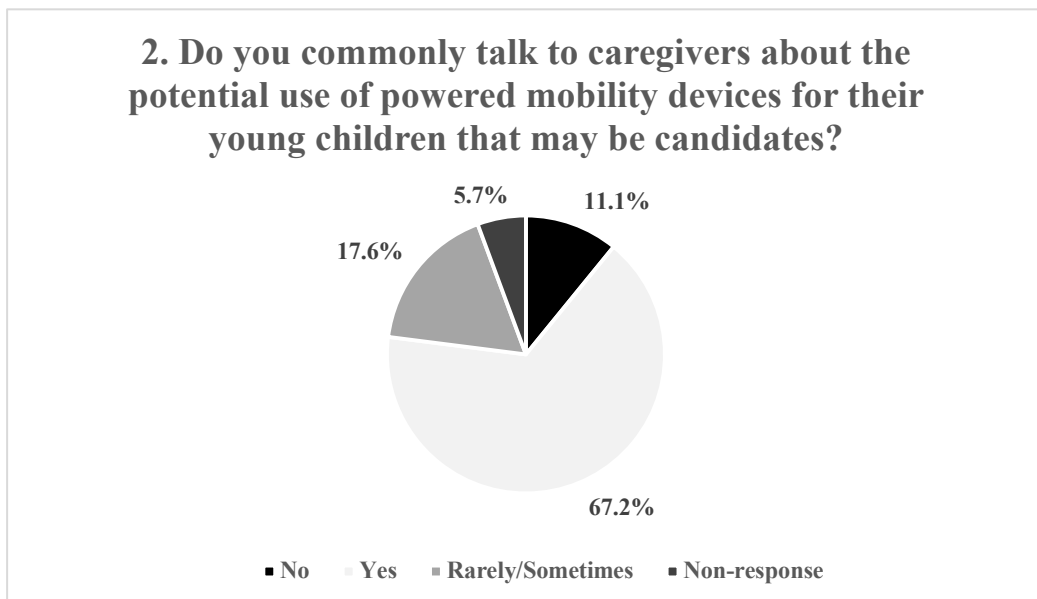
Krippendorff's alpha values indicated that the coding of the free response questions was reliable (Question 1: .8588; Question 2: .8172; Question 3: .9562).

Question 1. The two most common responses were "None/never" had 39.8% of responses and "Very few/limited" had 39.3% (see Figure 1). Question 2. "Yes" was the theme with the majority of the responses (67.2%) (see Figure 2). Question 3. "Negative attitudes" was the most popular (34.0%), with responses such as "feel it will limit child's long-term mobility."

This was followed by “Specific concerns” (23%), such as a caregiver fearing that their child won’t be a safe driver. “Positive attitudes” (22.1%) was the third highest with comments like “amazement that their child can move independently.”

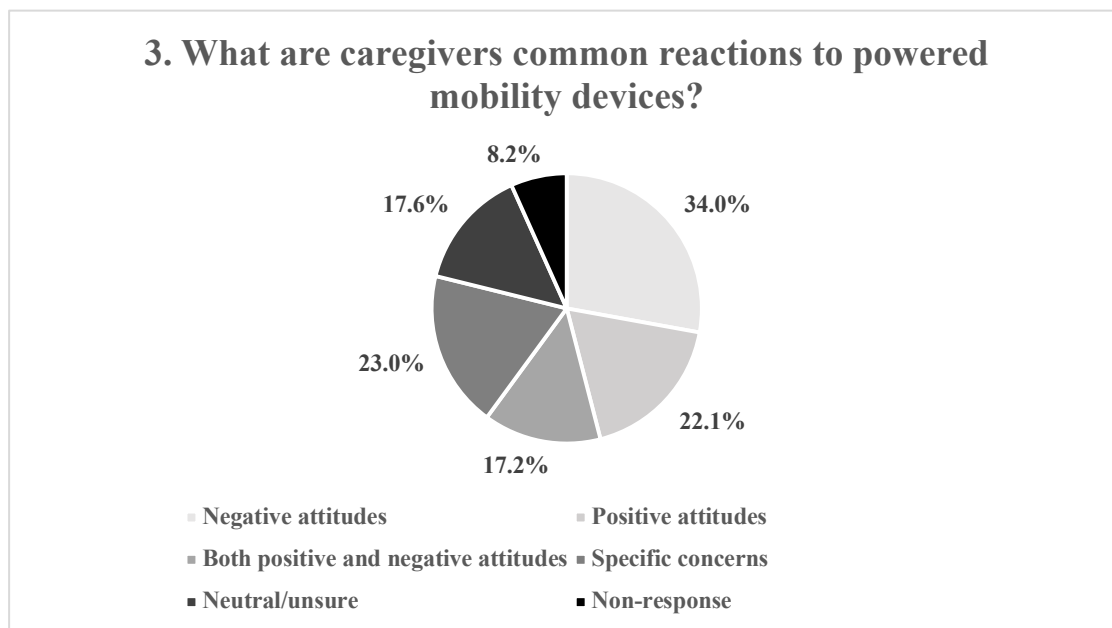


**Figure 1:** Number of caregivers who brought up topic of powered mobility to clinician for the first time



**Figure 2:** How often clinicians talk to caregivers about powered mobility devices for children who are candidates





**Figure 3:** Common caregiver reactions to powered mobility devices

### Discussion

The purpose of this study was to examine PTs’ perceptions and experiences of conversations with caregivers of young children with mobility disabilities regarding powered mobility devices. This study provides insight into caregivers’ current attitudes toward PMDs for their children from the perspective of PTs. PTs interact with many different families every day. Surveying PTs provides a much larger sample of caregiver attitudes compared to surveying individual caregivers.

#### **Question 1. How many caregivers of young children who might be a candidate for a powered mobility device brought up the topic to you?**

The majority of PTs (79.1%) reported that either “none or never” or “very few, limited” number of caregivers brought up the topic of PMDs to the PT (Figure 1). Based on an understanding of previous research and widespread PMD use attitudes, this is not surprising and

it means that there is more work to be done educating caregivers about the benefits of PMDs and dispelling some of the fears and concerns associated with them. Caregivers are often hesitant about using a PMD with their young child because they view powered mobility as a last resort option (Wiat, 2004). It is possible that increased education about the benefits of PMDs can help caregivers feel more confident bringing up the topic of powered mobility with their child's early intervention team. This may be accomplished through the introduction of powered mobility discussions in support groups for caregivers with young children with disabilities who have used power mobility devices. If caregivers hear positive success stories from other parents they trust, their attitudes towards powered mobility may become more positive.

PTs can help by actively working to reduce the stigma surrounding powered mobility when interacting with caregivers. The more powered mobility is viewed in a positive light the more comfortable caregivers will be talking about it. Only 4.5% of PTs reported that "a lot" of caregivers brought up the possibility of a PMD to them first (Figure 1). Although 4.5% is a small amount it is encouraging to hear that some PTs have experience with caregivers bringing up the topic of powered mobility first.

**Question 2. Do you commonly talk to caregivers about the potential use of powered mobility devices for their young children who may be candidates?**

A majority of PTs (67.2%) responded that they commonly talk to caregivers about children that are possible candidates for PMDs (Figure 2). It was encouraging to see that over half of the PTs surveyed are having conversations about powered mobility. The findings from this question are similar to Kenyon et al.'s 2018 studies which found that most of the PTs surveyed had positive attitudes toward powered mobility (Kenyon et al., 2018, Kenyon, Mortenson, & Miller, 2018).

Although these results are fairly encouraging, there is still work to be done. The ideal would be for 100% of PTs to answer that they commonly talk about PMDs to caregivers of children who are considered possible candidates. However the best way to translate these conversations into increased PMD access early in childhood is still unknown. The next most common response was “Rarely/sometimes” with 17.6% and “No” with 11.1% of responses (Figure 2). It was slightly surprising to find that 11.1% of PTs surveyed reported that they never talk to families about PMDs when the child is a candidate. A central role of pediatric physical therapy is advocating for the use of assistive technology, including PMDs, when appropriate. This small percentage of PTs might be older individuals that are not up to date on current advancements in powered mobility.

### **Question 3. What are caregivers’ common reactions to powered mobility devices?**

The response with the highest percentage for question 3 was “negative attitudes” (34%) (Figure 3). Examples of responses that were coded as negative attitudes include: “scared, worried, intimidated,” “not interested, overwhelmed,” or “many start off against it” (see Table 1). As research has shown that caregivers are often initially hesitant about powered mobility (Wiat 2004), this again was not very surprising. It is more typical to see a caregiver transition to a more positive attitude after watching their child participate and engage more with the PMD than in an initial conversation (Kenyon et al., 2018). The next highest category was “specific concerns” with 23% of responses (Figure 3). Specific concerns referred to any response mentioning cost, transportation, or space for the PMD. These concerns are some of the largest barriers for families to obtain a PMD, so it makes sense that these are common concerns for caregivers. “Positive attitudes” were represented in 22.1% of responses (Figure 3). Examples of responses that were coded as positive attitudes include: “excitement, positivity,” “they like the

joy it brings their children,” and “relief, excitement” (see Table 1). Assuming that all of the PTs talking about PMDs had positive attitudes towards them, it is reasonable that caregivers would have significantly less positive attitudes about powered mobility. PTs have spent years studying disability, development, and the benefits of mobility, whereas caregivers’ sole focus is the safety and well-being of their child. A separate category for responses including both positive and negative attitudes was created due to the relatively high number of mixed responses (17.2%). Many PTs talked about interacting with caregivers who are happy that their child is moving independently, while at the same time being disappointed that their child may never reach some of the goals they set for them even before birth. The “neutral/unsure” category included 17.6% of the responses meaning that caregivers did not seem to have strong negative or positive attitudes towards powered mobility and/or were curious about the possibility of powered mobility (Figure 3). This was encouraging because it means that most of these caregivers were open to learning more about powered mobility and did not have any strong preconceived notions about PMDs. However it could also mean that they had not heard much about powered mobility and further supports the idea that more caregiver education about powered mobility is needed.

### **Limitations**

One limitation to this study was that the survey the data were collected from PTs who self-selected to participate in a continuing education workshop focusing on assistive technology (specifically modified ride-on cars) for young children with disabilities. It is possible that clinicians who had specific negative attitudes toward powered mobility for young children did not participate in this continuing education workshop. There were also a large number of Likert scale questions prior to the free response questions so fatigue or boredom could have caused some clinicians to leave some or all of the free response questions blank. Another limitation was

that although responses came from a variety of states, it was beyond the scope of this study to examine regional differences in responses. Attitudes towards powered mobility in different regions of the country may not be the same and having data from different states does not completely control for that factor. Finally for the PTs that reported having conversations about PMDs with caregivers, we do not know what age the child was when the conversations were happening. If the conversations happened when the child was older, caregivers might have been more open to the possibility of a PMD compared to caregivers of a very young child.

### **Future Directions**

Currently, there is limited research on PTs' attitudes towards powered mobility. One direction may include examining the relationship between PTs' disability model orientation (i.e. medical or social model) and their advocacy or lack thereof for PMDs for young children with disabilities. Another direction may include examining the strength of the relationship between caregivers' positive attitudes towards powered mobility and if their eligible child received a powered mobility device. This would be useful in fully understanding how important caregiver attitudes are in the process of prescribing and advocating for a powered mobility device.

### **Conclusion**

Understanding caregivers' attitudes toward powered mobility may help predict access to PMDs for their children with disabilities. Powered mobility devices used early in childhood and/or on a temporary basis have been shown to improve socialization and cognition in children with disabilities, and it is our goal to have all pediatric PTs having conversations with the families of all eligible children about powered mobility. Powered wheelchairs and other devices have traditionally been stigmatized and understanding current caregiver attitudes toward powered mobility devices is the first step to breaking those stigmas down.

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Table 1: This table describes how the physical therapists' responses were coded into different themes for each of the three questions. The examples column lists actual responses from participants.

Theme	Definition	Examples
<b>Question 1. How many caregivers of young children who might be a candidate for powered mobility brought the topic up to you?</b>		
1. None/never	Response indicates that caregivers have not brought up the topic	<ul style="list-style-type: none"> <li>• zero</li> <li>• none</li> </ul>
2. Very few, limited	More than none, but still very few caregivers have brought up the topic of powered mobility	<ul style="list-style-type: none"> <li>• 1-4 (total)</li> <li>• rare</li> <li>• limited</li> <li>• few</li> </ul>
3. Some	More than a handful, more than 10%, more than just a couple – but still not the majority or a lot. A few per year.	<ul style="list-style-type: none"> <li>• 1 of 10</li> <li>• 3 per year</li> <li>• 25%</li> <li>• 5-10</li> <li>• occasionally</li> </ul>
4. A lot, most	Greater than just some, the majority or more than 50% of caregivers	<ul style="list-style-type: none"> <li>• too many to count</li> <li>• most</li> <li>• 50%</li> <li>• &gt;10</li> </ul>
<b>Question 2. Do you commonly talk to caregivers about the potential use of powered mobility devices for their young children that may be candidates?</b>		
5. No	Response indicates that this is not common practice or it is not done	<ul style="list-style-type: none"> <li>• no</li> <li>• not commonly</li> <li>• not often</li> </ul>
6. Yes	Response indicated that this is common practice and is frequently done	<ul style="list-style-type: none"> <li>• with every patient</li> <li>• a lot</li> <li>• yes</li> <li>• constantly</li> </ul>
7. Rarely/sometimes	Response is somewhere between yes (routinely) and no (never)	<ul style="list-style-type: none"> <li>• rarely</li> <li>• not often</li> <li>• on occasion</li> </ul>
<b>Question 3. What are caregivers common reactions to powered mobility devices?</b>		
8. Negative attitudes	Response indicates negative behavior, cognition, or attitude towards powered mobility devices	<ul style="list-style-type: none"> <li>• negative</li> <li>• fear</li> <li>• stigma</li> <li>• giving up</li> <li>• worried</li> <li>• delays in gross motor/walking</li> </ul>
9. Positive attitudes	Response indicates positive behavior, cognition, or attitude towards powered mobility devices	<ul style="list-style-type: none"> <li>• good</li> <li>• excitement</li> </ul>



10. Both positive and negative attitudes	Responses include both negative and positive attitudes	
11. Neutral/unsure	Response is neither positive nor negative, is neutral or unclear	<ul style="list-style-type: none"> <li>• muted</li> <li>• varied</li> <li>• hesitant</li> <li>• curious</li> </ul>
12. Specific concerns	Response indicates that caregivers have concerns that are specific barriers to use of PMDs	<ul style="list-style-type: none"> <li>• cost concerns</li> <li>• transportation</li> <li>• space</li> </ul>