# **Experiences of Families With** Young Power Wheelchair Users

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### Abstract

Independent mobility in typically developing infants and young children has been linked to growth in many areas of child development and changes in family behavior and interaction. Research suggests similar benefits in young children with motor disability who use powered mobility. The purpose of this study was to gain an understanding of how families experienced their child's development, growth, and abilities after using a power wheelchair for I year with the intent to generate a preliminary model to capture the process and relationships among these experiences. Eight families participated in interviews, and using grounded theory methodology the research team investigated their experiences. Results informed the development of the preliminary model that framed three key themes: (a) child competence, (b) parenting experience, and (c) the influence of power wheelchair use along with the key category It will help in the long run that titled and anchored the model. This model provides a possible view into how the use of powered mobility may influence development by supporting both child competence and the parenting experience.

#### Keywords

child development, disabilities and developmental delay, assistive technology

### Introduction

Development of self-generated mobility in typically developing infants is viewed as an important event in their overall development that supports opportunities for infants to experience and learn in their natural environments in ways that were not possible before their independent mobility (Campos et al., 2000). Systematic reviews by Campos et al. (2000) and Yan, Thomas, and Downing (1998) found gains in infants' development of attention, spatial skills, and motivation, as well as social and emotional skills as they started to crawl or walk. Development of self-generated locomotion in typically developing infants has also been linked to changes in parent perceptions and family experiences. Researchers have reported findings that suggested parent and family behavior and interaction change with the onset of an infant's self-generated mobility (Campos, Kermoian, & Zumbahlen, 1992; Campos et al., 2000; Hendrix & Thompson, 2011). Campos et al. (1992) reported greater parental expectations including understanding of verbal communication and compliance of behavior when infants had self-generated mobility. Hendrix

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and Thompson (2011) suggested the development of self-generated locomotion be viewed as a developmental milestone not only for infants but also for parents because parenting (i.e., preparing, supporting, and responding to infants) changed as infants' new abilities became evident.

Power wheelchairs provide a means for children with motor impairment to achieve age-appropriate self-generated mobility that would not be possible without assistance. Emerging research suggests that similar developmental benefits, including social, language, and cognitive skill development, may be observed in young children with motor disability who use power wheelchairs (Guerette, Furumasu, & Tefft, 2013; Jones, McEwen, & Neas, 2012; Livingstone & Field, 2014; Lynch, Ryu, Agrawal, & Galloway, 2009; Ragonesi, Chen, Agrawal, & Galloway, 2011). The use of power wheelchairs by infants and young children with motor disability is an intervention that is rapidly gaining attention based on evidence in child-centered outcomes (Livingstone & Field, 2014).

Research, however, investigating parent perceptions and family experiences when a child with motor impairment uses a power wheelchair for self-generated mobility is lacking. Investigating family perceptions and experiences is important as families create the context and provide the opportunities for children to use power wheelchairs. Some researchers reported that parents of children with motor impairment viewed the experience with power wheelchairs as positive, especially when it allowed their child to be independent and participate with peers, even though parents initially may have been reluctant for their child to try a power wheelchair (Bottos, Bolcati, Sciuto, Ruggeri, & Feliciangeli, 2001; Tefft, Guerette, & Furumasu, 2011; Wiart, Darrah, Hollis, Cook, & May, 2004). Although this research provides insight into important family experiences, it does not explore the range of family experiences and potential relationships among these experiences. Given the recommended practice of family-centered care in early intervention and early childhood education (Division for Early Childhood, 2014), as well as the growing understanding of the role of families in the child's life and the importance of family insights and experiences, research into family experiences is needed.

Exploring the experiences of families whose young children use power wheelchairs is important as it can provide insight and guidance in providing family-centered care that supports positive outcomes for families and children. Therefore, the purpose of this study was to gain an understanding of how families experienced their child's development, growth, and abilities after using a power wheelchair for 1 year, with the intent to generate a preliminary model to capture the process and relationships among these experiences.

### Method

Using constructivist grounded theory methodology (Charmaz, 2006), we investigated how a child's early use of a power wheelchair for 1 year may influence family perceptions and experiences of raising and interacting with their child. Data for this investigation were collected as part of a larger study on the effects of power wheelchair use on development and function of young children with severe motor impairment (Jones et al., 2012). The four members of the research team included a pediatric physical therapist, who was the primary investigator and interviewer on the original research study, a pediatric occupational therapist with extensive qualitative research experience, and two pediatric physical therapists and doctoral students at a university health sciences center. Prior to initiating the analyses, each member of the research team journaled anticipated findings to gain insight into personal perspectives and provide reflexivity.

### Participants

Eight families with eight children, ages 26 to 42 months at the start of power wheelchair use, participated in recorded interviews after 1 year of power wheelchair use, as part of a larger study

Participant	Age at interview	Diagnosis	Gender	Family member interviewed	Education
I	3 years 6 months	Cerebral palsy	Male	Mother	Some college/ College graduate
2	3 years 6 months	Cerebral palsy	Female	Mother	High school diploma
3	2 years 5 months	Cerebral palsy	Female	Mother	Some college/ College graduate
4	2 years 2 months	Myotubular myopathy	Male	Mother and Stepfather	Some college/ College graduate
5	2 years 2 months	Tetraphocomelia	Female	Mother	High school diploma
6	2 years 4 months	Cerebral palsy	Male	Grandmother	Some college/ College graduate
7	2 years 9 months	Cerebral palsy	Female	Grandmother	High school diploma
8	3 years 0 months	Cerebral palsy	Female	Grandmother	Less than high school diploma

Table I. Child and Family Characteristics.

on the effects of power wheelchairs on development and function of young children with severe motor impairment (Jones et al., 2012). For the larger study, 73 children and families were referred, and 50 children met inclusion criteria (age 14-30 months, motor impairment that prevented functional independent mobility, vision adequate to use a power wheelchair safely, and cognitive abilities at least to a 12-month level or alertness and interest in the environment) and had parental consent. Researchers matched children by age, diagnosis, and mother's education level. Researchers identified pairs for 34 of the 50 eligible children who were randomly assigned to the intervention or control group. Three children in the intervention group discontinued the intervention and three additional children did not receive the intervention, as designed; two families moved out of state, and researchers lost contact with the other. The 14 children in the original intervention group received customized Invacare Power Tiger wheelchairs, which 10 children accessed through joysticks, three children through proximity switches, and one child with a head array. Researchers provided and delivered portable ramps to family homes if needed to allow children wheelchair mobility in and out of their homes. The families were asked to provide children with experiential learning and practice opportunities daily. The institutional review board at the University of Oaklahoma Health Sciences Center approved the current study. In total, the original research team completed 12 recorded interviews of the original 14 families in their intervention group. Three of the 14 families withdrew from the study, which prevented their inclusion in this study, researchers were unable to schedule final interviews with two families, and one of the interviews was inaudible. Table 1 summarizes the characteristics of the eight children and families who participated in this study.

### Data Collection

The primary investigator of the original study completed semistructured interviews and field notes with families after the children had used the power wheelchair for 1 year. Authors developed the interview questions and probes based on a review of literature and expert opinion. Interview questions were aimed at eliciting families' experiences following their children's use of a power wheelchair for a year. The semistructured interviews included a series of open-ended

#### Table 2. Interview Protocol.

Sample questions from the family interviews

All participants were asked:
Tell me about your child?
Describe a typical day for you and your family.
Tell me what your child likes to do?
Describe your experiences with your child using a power mobility wheelchair?
Additional probes:
Describe your child's communication.
What does your child do to tell you how smart he or she is?
How does your child tell you that she or he has learned something new?
How would you describe your child's emotional development?
How would you describe your child's independence?
How does your child help with everyday care?
Tell me about your child's motor development.

predetermined questions followed by probing questions. Table 2 includes a representative sample of questions asked during the interviews. Interviews and observations occurred in the family home or at another location selected by the families and typically lasted approximately 1 hr. The interviews were recorded and transcribed verbatim.

# Data Analysis

We analyzed interview transcripts using a systematic constant comparative method of grounded theory that included (a) coding, (b) focused coding, (c) categorizing, (d) creating conditional relationship guides, (e) theoretical sampling, and (f) theoretical sorting and diagramming.

*Coding.* Initial coding of two interviews attached labels to segments of data that captured the actions and meanings to the families' experience. Next, line-by-line coding of the remaining six interviews occurred to capture data in identified codes or develop new codes to represent new data. We identified 47 codes (see Table 3).

*Focused coding.* This allowed the research team to review and collapse data that represented the overriding, important, and common messages/threads. We identified 10 focused codes (see Table 4).

*Categorizing.* The research team then analyzed focused codes to identify categories that best represented the underlying meaning of the families' experiences found in each focused code. Comparative data analysis within each category clarified the ideas and processes found in the data.

*Creating conditional relationship guides.* Conditional relationship guides support analysis by creating a matrix to understand the relationships and interactions among the categories (Scott, 2004). Each member of the research team individually created conditional relationships tables for all seven categories using the following questions: (a) *What is it?* (b) *How does it occur?* (c) *When does it occur?* and (d) *Why does it occur?* We then discussed and refined our tables to form one conditional table, generated operational definitions for each category, and described relationships among the categories to explain the families' perceptions and experiences of their children's experiences with power mobility. Direct quotations from interviews were included in the table to support understanding and analysis. Table 5 provides an example of one conditional relationship guide.

#### Table 3. Code List.

- I. Typical-comparing to
- 2. Deficits
- 3. Sense of self
- 4. Child characteristics
- 5. Protest/resist
- 6. Independent
- 7. Fearless/danger
- 8. First time
- 9. Social
- 10. Preferences
- II. Things done to him
- 12. Has to
- 13. Sabotage
- 14. Mood
- 15. Family goal
- 16. Hope
- 17. Responsive
- 18. Trying (involving striving, goals, expectations)
- 19. If you show/teach him
- 20. Caregiver unfamiliarity
- 21. Burden
- 22. Intent to communicate
- 23. Problem solving
- 24. Caregiver familiarity
- 25. Child complacent
- 26. Getting a reaction
- 27. Understand
- 28. Strong willed
- 29. That's how you learn
- 30. Child choice/self-determined
- 31. Distractible
- 32. Active exploration/discovery
- 33. Child competence
- 34. Plays with peers
- 35. Determined
- 36. Amazes us
- 37. Caregiver enjoys
- 38. Caregiver change in attitude
- 39. New opportunities/because of chair
- 40. Caregiver uncertainty
- 41. Learning/blossoming
- 42. Chair features like or don't like
- 43. Parent concern/worry
- 44. Reassurance
- 45. Together
- 46. Pride
- 47. Tolerate

Theoretical sorting and diagramming. The research team individually and then collaboratively created 10 models to visually explain and represent the data, relationships, and emerging theories. Collaborative diagramming allowed us to see and discuss the relative power, scope, and direction of the categories and their relationships until we came to an agreement on a final model (see Figure 1).

Coc	les	Focused codes	Categories	Themes
1. 2. 3.	Deficits Child complacent Distractible	I	"we're always there"	Parenting experience
4. 5.	Trying Sense of self	2 3	"he lets us know"	Child competence
6. 7.	Protest Preferences			
8. 9.	Getting reaction Strong willed			
10. 11.	Social Intent to communicate			
12. 13. 14. 15.	Problem solving Determined pride			
16.	Child characteristics of same age	Dispersed		
17.	Typical	4	Collapsed with Focus Code 3 into "he'll let us know"	
18. 19.	Independent Child choice/self-determined			
20. 21. 22.	Consistency/predictable Routines Together	5	"usually"	Parenting experience
23. 24. 25. 26.	Things done to him Caregiver choice Sabotage Has to	Dispersed		
27. 28.	Family goal Trying/expectation	6	"I think it (pwc) will make a difference and I think it (pwc) will help in the long run"	Influence of pwc
29. 30. 31.	Responsive Caregiver familiarity If you show/teach him	7	"I've noticed"	Parenting experience
32. 33. 34. 35.	Caregiver uncertainty Burden Parent concern/worry Chair features didn't like	8	Burden	Parenting experience
36. 37. 38. 39. 40. 41	Understand Active exploration/discovery New opportunities Amazes us Hope First time	9	"we're thrilled"	Parenting experience
<u>42.</u>	Fearless/danger			
43.	Child competence	10	"he's figured it out"	Child competence

 Table 4. Codes, Focused Codes, Categories, and Themes.

Note. pwc = power wheelchair.

How?	When?	Why?	Example quotes
ling By the caregiver If providing guidance, nity teaching, or with assistance based t that on the families' the belief that it will next be beneficial to the child either now or in time	During typical routine activities Throughout the day as well as planned opportunities out of the ordinary When families make it happen or work	Because parenting a child with disabilities requires a lot of effort, work, and planning/thinking/ energy so to buy in families' need to have expectation of benefits for child and be able to plan for longer term sometimes	I don't think there are any negatives with it just cause I haven't gotten to work with her so much with it cause it was cold. But I think it will help in the long run a lot if I can get her to be in it, now that I've got it. I think it will make a difference in helping her do her choices—you know learn to—she's gonna have to control somehow. I think she enjoys having some time, you know, to herself. Last year she cried when I took her to school and left her, not at the school for the deaf, but the school in Guthrie. She cried and this year, when we turn the corner, she knows where we're at and she giggles. She gets so excited. And she's going to be there waiting for mom and sister, so I think she enjoys that. That's one thing I wanted her to do on the bus, is be, something new to experience. The more experiences she has, the better I think she'll do. So, now that he's independent with the chair, what are your feelings about it? It's nice now because he enjoys it. It's nice now because he enjoys it.
	Ing By the caregiver I/ providing guidance. nity teaching, or with assistance based that on the families' the belief that it will next be beneficial to the child either now or in time	Ing By the caregiver During typical providing guidance, routine activities with assistance based as well as planned on the families' opportunities out the belief that it will of the ordinary next be beneficial to the When families make in time in time to be belief that it will be beneficial to the the belief that it will be beneficial to the the belief that it will be beneficial to the When families make in time to be beneficial to the the beneficial to the beneficial t	How?     When?     When?       Iiig     By the caregiver     During typical     Because parenting a child with disabilities       iiy     providing guidance, with assistance based     Throughout the day reaching, or teaching, or teaching, or the belief that it will on the families out belief that it will of the ordinary     Because parenting a child with disabilities       heat     belief that it will on the families'     opportunities out planning/thinking/     for the ordinary       in time     in time     of the ordinary     in families' need to the and be able to planning/thinking/

Table 5. Conditional Relationship Table: "I Think It Will Help in the Long Run."



Figure 1. "It will help in the long run": Grounded theory model of experiences of families of young power wheelchair users.

Categories	Combined categories	Themes
"We're always there" "Usually"	Burden	Parenting experience
"I've noticed" "We're thrilled"	Норе	
"S/He'll let us know" "S/He's figured it out"		Child competence
"I think it (pwc) will help in	the long run"	Influence of power wheelchair use

Table 0. Relationships Among Categories and Theme	Table 6.	Relationships	Among	Categories	and	Themes
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Note. pwc = power wheelchair.

Theoretical sampling. The researcher team next tested the emerging themes and theory with the process of theoretical sampling (Charmaz, 2006), which required us to seek and consider all pertinent data to refine categories and develop the emerging theory. This process continued until we reached an agreement on the operational definitions and relationships among the categories. Table 6 represents our agreement on relationships among categories and themes.

Scientific rigor. The research team used memo writing, triangulation, reflexivity, and the development of an audit trail to support scientific rigor (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). Independent memo writing documented individual thoughts on data and relationships and allowed us to stop, reflect, and analyze our ideas about codes, emerging categories, and themes during data analysis. We used an audit trail for dependability and conformability of analysis and included process notes. We used triangulation with peer debriefing by discussing individual thoughts and interpretation of data during video conferencing to reach consensus. Rich and thick descriptions from family participants provided credibility and supported transferability of results. We shared our model with two families whose children were new users of power wheelchairs to check and support trustworthiness and credibility of our findings.

# Results

The family responses formed three key themes: (a) child competence, (b) parenting experiences, and (c) influence of power wheelchair use. These findings and their relationships informed our preliminary model (see Figure 1), It [power wheelchair] will help in the long run. The model captured the family perceptions and experiences of their young child's experience while using power wheelchair mobility and was based on the relationships among the seven prevalent categories that emerged from our data: (a) we're always there, (b) usually, (c) I've noticed, (d) we were thrilled, (e) he'll let us know, (f) he can do it/he's figured it out, and (g) it [power wheelchair] will help in the long run. The category It will help in the long run, when analyzed with comparative relationship guides, emerged as an important theme and anchored the model, as it was the overarching experience and outcome that described the parents' perceptions of the influence of power wheelchair use. The category It will help in the long run also supported the construct of the theme, the influence of power wheelchair use. The remaining six categories separated into the two other themes or constructs of the model. Parenting experiences emerged from the categories of we're always there, usually, I've noticed, and we were thrilled. The parenting experiences represented a range of what has been perceived, discovered, and learned from the burden of constant support and care of a child to parents' excitement and hope for their child's growth and competence. The next theme or construct in our model was child's competence, which emerged from the categories of s/he'll let us know and s/he can do it or s/he's figured it out. Child competence represented a continuum ranging with a child's ability to show or tell parents to the child's ability to learn and demonstrate learning. During data analysis, the use and influence of the power wheelchair emerged as a link and intermediary among the three themes. The use of the power wheelchair in our model reflects the dynamic and interdependent process that linked and influenced both the parenting experiences and the child's display of competence.

# It Will Help in the Long Run

The title and anchor of our model described the predominant experience families expressed about the influence of the power wheelchair use on their child's independence and development. *It will help in the long run* described both the broad influence of the child's use of the power wheelchair and the parental experience of hope. It represented families' experiences of providing support and opportunities for growth underscored by an expectation of future benefit to their child. Families described how they provided opportunities during both routines and specific planned child-centered activities. Families described hopes and expectations about their children's progress and witnessed mastery of new skills, which provided families with a sense of accomplishment and reinforced their efforts to create more opportunities to support their children's learning. The following quotes illustrate families' experiences and perceptions of the benefit of power wheelchair use for their child:

I think *it [power wheelchair] will help in the long run* a lot if I can get her to be in it, now that I've got it. I think *it [power wheelchair] will make a difference* in helping her do her choices—you know learn to—she's gonna have to control somehow.

When he gets older, *he's going to have a better life because of the chair*—because he has that independence. When he goes to school, he won't just be sitting in that chair; he'll be on the same level that children who can walk are on.

# Parenting Experiences

The parenting experiences represented how families perceived and experienced their everyday interactions and routines when parenting their children and is reflected as a range of parenting

experiences in our model, ranging from the burden of always being there to the hope of being thrilled at and for your child's accomplishments. Family experiences were noted to shift both to and from *we're always there* and *we're thrilled*, depending on the activity and the child's growth as experienced by the families. Grounding one end of the range of parenting experiences was the category *we're always there* where the families described experiences during the constant care and support that their child required throughout the day, as particularly noted in the following parent's description of their child's bathing routine:

I put Alyssa in it (the bathtub) and *I have to* stay there and hold her up. That's it. She hangs on to my arms. She wants to hold her back up, lift her head up . . . But *I have to* stay in there and hold her.

*We're always there* also portrayed the family's constant, attentive, and protective presence with their child as illustrated by the following statement from a parent responding to a question about their child's frustration and experience of not being able to do a particular task:

I think the realization hasn't sunk in yet—that he can't do something. You know, we'll see him reaching for something . . . *but we're always there* . . . we'll get it for him.

Examples of *we're always there* occurred when parents provided the extra support or the assistance their child needed to eat, play, or bathe.

The next category/concept along the range of parenting experiences was *usually* and described the ordinary, routine, and unvarying nature of caring for the child. It reflected the structure necessary to get all the required tasks completed and to prepare the child for what to expect and anticipate during a typical day. *Usually* seemed to indicate that families not only figured out what worked best to complete the required tasks, but also how to provide their child with an appropriate range of opportunities for learning during everyday activities and routines. The following family's description of bath time clearly illustrated the family supporting their child's growth through typical routines and everyday opportunities:

Oh, bath time. *We usually try*—*I usually try* to get her bath about 6:30 or 7 and uh, I get her in—she loves it. I've got toys that stick to the tub—that I put around for her to reach and grab and kick. But the best I've gotten out of her is the kicking; she thinks that one is just the thing. I got her little hand mittens to put on her hands, so I try to make her wash herself up.

The third category along the parenting experience continuum was *I've noticed*, which occurred when families had focused and persistent attention during an activity with their child. Families often used trial and error to determine strategies that worked best for their child to assist with the child's growth, development, or learning. *I've noticed* seemed to occur because families spent a lot of time interacting, engaging, watching, and taking care of their child and noticed subtle changes in their child's behavior and abilities. Families often used *I've noticed* to describe experiences when they discovered what supports a child might need to learn and express themselves and is illustrated in the following statements:

Then he stopped kind of driving altogether. And he would just kind of sit in it ... *I think he just decided* not to drive it for a while. In a way it wasn't serving a purpose for him. He didn't realize he was controlling it. He didn't in a way know that he could do something he wanted, not just drive.

She's too nosey-to drive it [power wheelchair]. (laughs) When I, when we took her to the mall, all she wanted to do, was look at the people. We would take it outside, and *all she wanted to do* was look at the people driving by or coming. We tried outside, and I guess it was when school got out there. Finally, we take her into the alley; where there wasn't any traffic, and *that's when* she would finally would start to practice, to really drive it [power wheelchair], when there wasn't people to distract her.

The final category along the continuum, *we're thrilled*, depicted when families described, experienced, or observed growth and competence in their child. It also depicted family hope for future learning and success. Families described it when they were proud and pleased to see their children experience success. The following statement from a family reflected and highlighted their experiences of being thrilled with their child's progress, potential, or acting with intent and autonomy.

His experiences are that he goes out, laughs and has a good time. *That's probably the best because* he can get out there and he can go. And he feels that independence going on. And sometimes you turn your head and he's gone and you wonder "where did he go now." Just like a normal little kid.

# Child Competence

This theme included the families' perceptions of their children's abilities and potential. Child competence represented not only the child's motor development but also the child's self-efficacy. Child competence across interviews occurred along a bidirectional continuum, ranging to and from *s/he'll let us know* and *s/he's figured it out*. Families described *s/he'll let us know* when they recognized children's preferences or intent to communicate wants or needs with their family. *S/he'll let us know* occurred when a child conveyed what he or she knew, wanted, or needed during routines or new experiences, and families responded to their child. Families' descriptions of *s/he'll let us know* often occurred with the category *I've noticed* found on the parenting experience continuum. The following quotes illustrate two different ways children let their parents *know*:

Like *he'll come* over (in his power wheelchair) and pull up right in front of me and *want* me to get up and chase him around, or I'll go hide and *he'll find me*, you know.

Some nights we don't have a nurse, and he wakes up just in the middle of the night. *He'll take his vent off.* But if you just go in there and sit, he won't take it off. But when you leave, he'll take it off again. Like *he wants* someone in there with him and that's the only way he can get our attention.

Families experienced *s/he'll let us know* when they perceived their child as having their own wants and the competence to convey their desires.

The second category along the continuum of child competence, *s/he's figured it out*, emerged when families described knowing their child was acting intentionally. *S/he's figured it out* occurred during play, mobility, and routines of daily living often when children acted according to their own agenda, as illustrated in the following quotes:

Chasing Michael (child's sibling), but *he's learned* to control it [power wheelchair] enough that he knows when he gets behind Michael on one of Michael's rider toys, *he can* push it. We were out there—Michael was doing something . . . he kept the wagon and had himself pushing himself to the barn. Well, Jacob *figured out* he can push that wagon right along and help. And I thought that was just amazing . . . But *he figures out things, so I know he is thinking*.

He can get out and go where he wants to. He can . . . he's in charge. You know, we all need to be in charge.

Families described *s/he's figured it out* when they saw an improvement in the child's abilities or when the child acted autonomously. Families also described it when they observed new skills and learning, which often occurred when children were using the power wheelchair.

# Influence of the Power Wheelchair Use

This theme included families' experiences of how the use of the power wheelchair influenced how they perceived their child's competence as well as how it influenced their parental perceptions and experiences. In our model, we represented the influence of the child's use of the power wheelchair as a spiraling bidirectional line depicted within the shaded portion of the model. We represented the use and influence of the power wheelchair as bidirectional line as it acts as a link for change, which occurs in either direction and at variable rates along both the parenting experience and child competence continuums, depending on the child's success, wheelchair factors, and other environmental circumstances. The line's spiraling nature represented our finding that power wheelchair use could influence the parenting experience or the child's competence or both. The following quotes demonstrated the influence of power wheelchair use on both the child and family:

It (power wheelchair) gave her the mobility to go, pretty much have some *independence* and *freedom* to go where she wanted to go. Including where we didn't want her to go.

*Her desire to want to get out there and do things has increased tremendously, to go out to feel the fence and put her hand through it I mean for her that was a <i>whole new experience, she wants to play* on the slide, and the swings, and in the sand box now. She just, her outlook is no longer just this way (lying down), it is upright to the world, and that's how she wants to be 99% of the time.

## Discussion

The purpose of this study was to gain an understanding of how families experienced their child's development, growth, and abilities after using a power wheelchair for 1 year with the intent to generate a preliminary model to capture the process and relationships among these experiences to guide both continued study and current and future interventions. To our knowledge, this study is the first to describe a family's experiences of young children using power wheelchairs in their homes for 1 year. This study contributes to our understanding of what families may experience when their young child has the opportunity to use a power wheelchair. Families in our study provided similar accounts, experiences, and perceptions that served as the basis for the development of our model.

Looking closer at our model, the importance of the sometimes overlooked parenting experience is revealed. Our model suggests that the parenting experience was influenced by both the child's use of a power wheelchair and the child's competence. During analyses, we noted the child's use of the power wheelchair seemed to allow families to recognize their child's abilities and develop various ways to support their child's development by adapting and creating a responsive environment, which often resulted in a change along the parenting experience continuum. These relationships depicted in our model appear to represent a process similar to the interactions described by the Transactional Model of Development (Sameroff & MacKenzie, 2003). Our model acknowledges the use of a power wheelchair as a potential facilitator influencing change along both the parenting experiences and child competence continuums.

Our findings along the continuum of the parenting experiences also seem to represent a movement of parent experience toward pride in their child's accomplishment with the movement from *we're always there* to and toward *we're thrilled* as children demonstrated greater competence. This finding is similar to that of Borgestig, Rytterström, and Hemmingsson (2017), who reported parents had greater hope for their child's future when children were given opportunities to use gaze-based assistive technology over a period of 9 to 10 months, both at home and at school, resulting in display of competence in initiating communication and performing activities. We also noted parents' increase in expectations, as the children moved along the child competence continuum from *s/he'll let us know* to *s/he's figured it out*. These changes appear to have occurred as the child demonstrated new competence with the power wheelchair, not unlike literature that suggests that parental expectations of infants increased when infants and young children demonstrated new movement skills such as crawling or walking (Campos et al., 1992; Campos et al., 2000; Hendrix & Thompson, 2011).

Our model also acknowledges and supports the importance of family-centered care. Familycentered care recognizes that families are a constant in the life of children and that optimal child development occurs within a supportive family context (King, Teplicky, King, & Rosenbaum, 2004). Given that families had access to the power wheelchairs and support from early interventionists in their home, families were able to provide opportunities, notice skills and behaviors, and problem solve with their child, which may have given families an opportunity to learn more about their child's abilities and adjust their parenting to provide a supportive context for their child's development. This also raises the possibility that changes in the parenting experience that were influenced by their child's use of the power wheelchair may respond similarly to other interventions and models that support the development of the family and parenting systems implemented in early intervention (Bailey, Raspa, & Fox, 2012; Davis & Gavidia-Payne, 2009). Our analysis and model, representing family experiences, may also provide insight into the development of tools and strategies to support family-centered care.

Another important finding in our study revealed that the experiences and progression of families along the parenting continuum were not directly related to their child's mastery or use of the power wheelchair for functional mobility. Instead, it appeared related to any new family perceptions of their child's competence or development of a skill, big or small. Given that parents and their children were involved in a quantitative study of development and power wheelchair skill, we were able to compare codes and family responses relative to their child's skill in using the power wheelchair. Families of children who demonstrated less proficient use of the power wheelchairs reported similar experiences and perceptions to families of children who demonstrated more proficient use of power wheelchairs. This may be important to consider as most studies involving children using power wheelchairs have included outcome measures related to children's proficiency in using them or their ability to participate in play or social interactions (Livingstone & Field, 2014), which may not be capturing these potential benefits in the parenting experience. Our model suggests additional investigation into outcomes that measure changes in parenting experiences as well as changes in the child's competence. Further investigation into children who do not succeed at using a power wheelchair for functional participation may also reveal other benefits of young children using power wheelchairs not currently being considered, such as development of self-determination skills and the influence of family perception of child competence on the development of the child. This may provide further support for the use of power wheelchairs with "non-traditional" learners who may not learn to use power wheelchairs independently, but who may experience other benefits, as recently highlighted by Feldner, Logan, and Galloway (2016).

Both quantitative and qualitative research supports the benefits of power wheelchair use by young children with motor disability through increased self-initiated movement, enhanced overall child development, and increased participation in meaningful life activities (Livingstone & Field, 2014, 2015). The range of factors and the interconnection of these factors, which influence the use of a power wheelchair as well as the child's benefits related to its use (Livingstone & Field, 2014, 2015), are documented. Our model may enhance the understanding of how some of these factors relate to one another and how benefits of power wheelchair use may be realized in the child and family.

### Limitations of the Study

We acknowledge limitations to our study. The original data were collected as part of a mixed methods (quantitative and qualitative) design by Jones et al. (2012) to identify effects of power

wheelchair use, which may have led families to give additional weight to the child's use of the power wheelchair when its use may have been only one of many factors that influenced the changes parents described. Similarly, although we designed our questions and probes to have families describe their typical daily routines and their child's abilities, we also asked them to describe their experiences using a power wheelchair because it was the focus of the intervention. We recognize that families may have felt compelled to share only positive experiences with the power wheelchairs, although they did identify barriers or challenges related to its use. Those barriers and challenges, however, did not emerge as themes.

We also acknowledge that this research and model used constructivist grounded theory methodology and therefore represents only a preliminary model that will require further study to validate. The model is based on children and families recruited for the original power wheelchair study that sampled a limited group of eligible children in a common geographic area rather than all eligible children from diverse geographic locations. As a result, the families and children were not representative of all families and children who met the inclusion criteria. Loss of families in the intervention group and families with whom researchers were unable to schedule final interviews may also represent a group of families that may have had perceptions and experiences different from the families we interviewed.

### Conclusion

Our study has implications for both continued research and current and future interventions. It is the first study to develop a model that attempts to delineate the relationships among child development and competence, parenting experiences, and the use and influence of a power wheelchair in families of young children who used power wheelchairs in their homes for 1 year. Further research is needed to test the strength of the relationships and the integrity of the model. Although the body of evidence supporting the use of power wheelchairs for young children with motor impairments is growing (Livingstone & Field, 2014), this study considers the additional influence of young children's use of power wheelchairs on their demonstration of competence as well as on changes in parenting experiences not previously measured or leveraged as outcomes of power wheelchair use.

The model presented and grounded in data from interviews with families of young children who used a power wheelchair provides a possible view into how the use of a power wheelchair may influence or provide momentum for change in the parent–child–environment triad by supporting development in child competence and influencing the parenting experience positively. This model also supports the findings of family-centered care and the importance of families in the process of access, providing learning opportunities, and supporting their child in the use of a power wheelchair. Consideration of these findings may support new initiatives toward familycentered implementation of power wheelchairs to support and realize the full benefits for children and families. This research may also provide support for research on other forms of assistive technology used by children and possible influence on parenting experiences and demonstration of child competence. Our findings support broadening the scope of outcomes when assessing the influence of power wheelchair interventions in young children to include both child factors and changes in the parenting experiences.

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Beth A. Currier is now at Northshore Education Consortium, Beverly, MA, USA. Maria A. Jones is now affiliated with Oklahoma City University, Oklahoma City, OK, USA.

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