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PERCEPTIONS OF THE CAREGIVER-PEDIATRIC PHYSICAL THERAPIST
RELATIONSHIP

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Abstract

The collaboration that occurs between physical therapists and caregivers of children who receive physical therapy is integral to both the functional outcomes of the child and the wellbeing of the caregiver. Successful collaboration is dependent upon a variety of factors, including the therapeutic relationship built within the caregiver-therapist dyad. However, the nature of these relationships is not well understood. The purpose of this study was to explore the caregiver-therapist relationship from the viewpoints of both the caregiver and physical therapist. An enhanced understanding of these therapeutic relationships may be of benefit to healthcare providers. A qualitative case study methodology was used in which a caregiver and pediatric physical therapist represented a bounded case. Each caregiver and therapist within a dyad engaged in separate, semi-structured, in-depth interviews. Through within- and cross-case coding, three major themes were identified: physical therapist as a guide, social and emotional connection, and professional qualities and performance. These themes help to provide a rich understanding of the therapeutic relationships that can occur between therapists and caregivers.

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Perceptions of the Caregiver-Pediatric Physical Therapist Relationship

The number of children affected by disabling conditions is on the rise. The prevalence of children between the ages of 3 and 17 years old with any developmental disability increased from 5.76% in 2014 to 6.99% in 2016 (Zablotsky, Black, & Blumberg, 2017). Cerebral palsy (CP) is the most common physical disability of childhood, affecting 2.6 to 2.9 out of 1000 live births in the United States (Maenner et al., 2016), and approximately 5,300 babies with Down Syndrome are born each year (Graff, Buckley, & Skotko, 2015). Autism currently is known to affect 1 in 68 children (Christensen et al., 2016). These are just a few examples of conditions for which families may seek the services of a pediatric physical therapist (PT).

Pediatric PTs work with children and families to improve independence, participation, and function in all areas of life, such as home and school, as well as a variety of social settings (American Physical Therapy Association [APTA], 2009). There are no set guidelines for the duration, intensity, or frequency of pediatric physical therapy, though pediatric PTs often work with a child and the family for 30-60 minutes at a time, one to two times a week, and often for a year or more (APTA, 2012). This prolonged involvement with the child and family gives pediatric physical therapists a unique opportunity to build professional relationships and, at times, personal ones.

The therapeutic process relies on a model of teamwork among therapy practitioners, but it also relies on the relationship among the caregiver-child-therapist triad, which should be viewed as a partnership. This partnership requires collaboration between families and therapists that is comprised of trust, honesty, support, and shared decision making (An et al., 2015; Broggi & Sabatelli, 2010; Peplow & Carpenter, 2013; Piggot, Paterson, & Hocking, 2002). Because this

relationship is critical, a solid understanding of the caregiver-therapist relationship, from both the caregiver's and PT's point of view, is necessary.

Problem Statement

Current literature reflects a lack of understanding regarding how caregivers and pediatric PTs perceive their relationship with one another. Additionally, little is known about the role of the caregiver-pediatric PT relationship in promoting effective teamwork. Lack of trust and poor communication have been identified as causes for concern and frustration for parents of children receiving therapy (Peplow & Carpenter, 2013), and parents have reported a desire to feel supported by their child's physical therapist (Chan, Lau, Fong, Poon, & Lam, 2005). Despite this reality, information is lacking on how best to develop a working relationship that more fully meets caregivers' needs.

Purpose Statement

The purpose of this qualitative case study was to explore longer-term (six months or more) caregiver-pediatric PT relationships from both the caregivers' and PTs' points of view. The results from this study provide deeper insight into the caregiver-pediatric PT relationship.

Research Question

This study addressed the following primary research question and associated sub-question:

- How do caregivers of children with special needs and pediatric PTs, who have been in a therapeutic relationship for at least six months, perceive and experience their relationship with one another?
 - What role do the perceptions of the caregiver-pediatric PT relationship play in the decision-making process throughout the continuum of care?

Significance of the Study

Pediatric PTs, as well as other healthcare professionals, could benefit from an enhanced understanding of how to build a relationship with families that will best serve them and the child. Improved insights into the experiences of caregivers can help therapists enhance family-therapist collaboration to meet family's needs and improve long-term outcomes.

Definition of Terms

Pediatric physical therapist. Pediatric PTs work with children and their families to assist each child in reaching their maximum potential to function independently and to promote active participation in home, school, and community environments. Physical therapists use their expertise in movement and apply clinical reasoning through the process of examination, evaluation, diagnosis, and intervention (APTA, 2009).

Caregiver. The individual who identifies themselves as the person who primarily provides care for the child, including involvement with physical therapy (Redquest, Reinders, Bryden, Schneider, & Fletcher, 2015).

Special needs. A term applied to individuals with physical disabilities that may range from mild to severe who require more care than an individual without physical disabilities (Redquest et al., 2015).

Literature Review

Family-centered care should be considered best practice when providing healthcare services, including physical therapy, to children with special needs (Rosenbaum, 2011). The World Health Organization's International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY) provides a framework for understanding the various factors that contribute to a child's situation (World Health Organization, 2007). A child's primary context is within their family unit; therefore, to consider what is best for the child, what

is best for the family needs to be addressed by partnering with the family to identify what is important to them (Rosenbaum, 2011).

An important element of family-centered care is collaboration (An et al., 2015), which is dependent upon the relationship between the caregiver and the PT. When collaboration takes place between the family and the pediatric PT, parents' confidence in parenting and caring for their child with special needs increases (An et al., 2015). The process of shared decision-making and open communication--hallmarks of collaboration--also decreases parent stress, improves functional outcomes, and improves family satisfaction with healthcare services (An et al., 2015; Broggi & Sabatelli, 2010; Håkstad, et al., 2016). A power imbalance naturally exists in a healthcare provider-patient/family relationship; one reason collaboration is effective may be due to its role in equalizing this imbalance and making the care more focused on the family's needs (O'Neil, Palisano, & Westcott, 2001; Peplow & Carpenter, 2013). Parents have also expressed that feeling a sense of connection with their child's therapist strongly influences the process of therapy itself (Piggot, Paterson, & Hocking, 2002). For example, a parent in one study reported that "the relationship between the physio and the child and the parent is central to absolutely everything [in terms of managing cerebral palsy]" (Peplow & Carpenter, 2013, p. 292).

Another reason that a supportive, collaborative relationship may be effective is because it meets the family's need for social support. Parents of children with special needs often feel socially isolated (Caicedo, 2014; Redquest et al., 2015); they may not get out of the house as often as their peers and may not have someone readily available with whom they can discuss their child. Parents have expressed wanting support from their healthcare professionals (Chan et al., 2005); parents with a support system feel less stressed and burdened (Daudji et al., 2011). Pediatric PTs have identified that one role of a PT is to be a resource and provide support for

families, ranking this higher than roles such as preventing deformity and promoting normal development (Dule, Korner, Williams, & Carter, 1999). More current research is needed to understand more about how PTs view their role as a support system for families.

Collaboration has been identified as important to therapists, but implementing such collaboration can be challenging (LaForme Fiss, McCoy, Chiarello, & Move & Play Study Team, 2012; O'Neil et al., 2001; Young, Moffett, Jackson, & McNulty, 2006). This is in part due to limited research on specific processes or strategies to promote collaboration (An et al., 2015; Darrah, Wiart, Magill-Evans, Ray, & Andersen, 2012). Pediatric PTs express a positive attitude regarding collaboration, but many do not understand how best to include it in their practice (An et al., 2015).

Collaboration and how it manifests may differ among therapeutic approaches and models of care (Dirks & Hadders-Algra, 2011), which could explain why families and providers are uncertain how best to develop a working, collaborative relationship. For example, according to the Individuals with Disabilities Education Act (IDEA), Part C, which provides early interventions services, a coaching model is ideal. With this model, therapists assist caregivers in carrying out interventions and provide feedback as necessary (Friedman, Woods, & Salisbury, 2012). This model of therapy provision is wholly dependent upon a relationship between the caregiver and therapist that is supportive, collaborative, and built on trust and open communication (Rush, Shelden, & Hanft, 2003). Additionally, family-therapist relationships in the early intervention setting that are perceived as collaborative by the parents may positively influence outcomes (Broggi & Sabatelli, 2010).

Another example of how the family-therapist relationship (including collaboration) may differ by setting is that of school-based therapy. IDEA mandates that children with disabilities be

provided PT if such services assist the child in meeting their educational goals (IDEA, 2004). IDEA also requires that parents be involved in the process (IDEA, 2004), but it is often unclear how best to facilitate a parent-caregiver relationship in this setting, which can be complicated due to a variety of factors such as miscommunications and misconceptions about the nature of school-based therapy (Holt, Kuperstein, & Effgen, 2015). A model of collaboration, such as the coaching seen in early intervention is not applicable to school-based therapy because family members are not generally present during therapy sessions, since they take place at school.

Hospital-based pediatric PTs may take yet a different approach, implementing more of a medical model of care that tends to be more focused on addressing immediate physical needs and limitations of the child (Ideishi, O'Neil, Chiarello, & Nixon-Cave, 2010). There may also be confusion about the role of the family in this setting (Tecklin, 2015). However, a family-centered approach highlighting good communication and consideration of the family's needs is considered best practice in a hospital setting as it is in other settings (APTA, 2013).

The caregiver-PT relationship may need to differ depending upon the setting in which care is delivered. The variations inherent in different settings highlight the need for an enhanced understanding of the pediatric PT-caregiver relationship, so as to meet the unique needs not only of each family, but also of each setting.

The process of collaboration may also be limited in effectiveness if parents do not adequately understand their role in it. They may instead defer to the PT as an expert and undervalue their role in decision making (Young et al., 2006). An important tenet of family-centered care is that families are the true experts when it comes to their child, family structure, and needs (Dirks & Hadders-Algra, 2011). Currently, collaboration is largely focused on goal planning and implementing treatment plans (An et al., 2015; Øien, Fallang, & Østensj, 2010).

While this does improve therapists' ability to tailor treatments to individual family/child needs, it may not provide the family with the support system they desire.

Good communication is critical to the family-therapist relationship and to collaboration (An et al., 2015; Nolan, Orlando, & Liptak, 2007; O'Neil, Ideishi, Nixon-Cave, & Kohrt, 2008). Providing reassurance, encouragement, and honesty can decrease tension in the provider-parent relationship (Parisien et al., 2016; Peplow & Carpenter, 2013) as can engaging the child and family in general discussions not necessarily related to the child's healthcare (Konstantynowicz, Marcinowicz, Abramowicz, & Abramowicz, 2016). Additionally, communication is the only way to get to know the family and their needs, which must be done to foster a concept of the family at the center of care. Each family is unique and that must be taken in to consideration for all aspects of a course of pediatric PT (Kruijsen-Terpstra et al., 2014).

In contrast, poor communication can lead to feelings of parental stress and of feeling judged by the therapist as well as increased difficulty in carrying out home exercise programs (Parisien et al., 2016; Peplow & Carpenter, 2013). Despite the known importance of communication, deficits in this area for therapists and families are not uncommon (LaForme Fiss et al., 2012). Many healthcare providers, including pediatric PTs, cite the lack of time as a reason for the gap in communication (O'Neil et al., 2008). Though this may be true, a focus on family-center care may require reexamining how time and resources are spent (Rosenbaum, 2011). A clearer understanding of the caregiver-PT relationship, including communication styles and preferences, will be beneficial to that process of reexamination.

Relationships marked by features identified as critical to family-centered care such as trust, honesty, communication, and collaboration take time to build (Kruijsen-Terpstra et al., 2014). Continuity of care, defined as having the same therapist versus more than one therapist

through the course of care, has been linked to patient satisfaction and trust in adult patients (Beattie, Dowda, Turner, Michener, & Nelson, 2005). Caregivers of medically complex children have reported the feeling that a prolonged relationship with the same providers results in better outcomes, largely because it translates to a better understanding of the child (Chan et al., 2005; Miller et al., 2009), though this has not been studied specifically with regard to the caregiver-pediatric PT relationship. The role the length of the caregiver-pediatric PT relationship plays is not well understood and further research is needed.

The concept of the family-therapist relationship has been explored in various studies throughout the past 25 years, and its role in the provision of rehabilitation services has evolved (Dirks & Hadders-Algra, 2011). However, it is often a minor aspect of a study with a larger or different focus, such as the burden of care experienced by caregivers of medically complex children (Caicedo, 2014), therapists' perspectives on care coordination (Ideishi et al., 2010), or caregiver views on their child's activity and participation levels (Chan et al., 2005). Current studies do not fully explore the therapist-caregiver relationship nor is any practical guidance offered. Some studies explore specific characteristics such as trust, confidence, and respect, but use of a survey format limits the researchers' ability to gain deeper knowledge on the topic from the caregiver's or PT's perspective (Broggi & Sabatelli, 2010; Chan, et al., 2005; LaForme Fiss et al., 2012; O'Neil et al., 2001). Other studies have identified pertinent elements of the physical therapist-patient relationship, such as trust and feelings of bonding, but were conducted with adult physical therapy patients, not children and families (Ambady et al., 2002; Hall, Ferreira, Maher, Latimer & Ferreira, 2010).

Qualitative studies that explore the family-therapist relationship have been conducted, revealing helpful information such as how caregivers seek emotional and social support from

their child's therapist (Daudji et al., 2011; Hinojosa, 1990; Ideishi et al., 2010; O'Neil et al., 2008). For some families, the child's therapist may be viewed as a friend, advocate, mentor, or part of the family (Hinojosa, 1990; Washington & Schwartz, 1996), but the characteristics of the relationship that were associated with these feelings have not been fully explored nor has more current research been conducted. Given this, important questions remain, such as whether or not caregivers want or need to have a personal relationship (i.e., social involvement, friendship) with their child's therapist and what features of the relationship make it more or less difficult to engage in sensitive or difficult conversations.

There are aspects of pediatric physical therapy that lend themselves to building relationships with patients and families. As mentioned, continuity of care is a model common in pediatric rehabilitation; pediatric PTs often see their patients for years at a time, which can be a ready-made foundation for developing a relationship. Communication, in some form, has to take place between the caregiver and therapist as a part of pediatric physical therapy because the patient, a child, cannot be responsible for many components of care, including making decisions. It is clear from the literature that the PT-caregiver relationship is vital for a variety of reasons. What is less clear is how caregivers and pediatric PTs perceive their relationship, both as it is and how they might desire it to be.

Therapists value family-centered care, but this does not always translate into practice (Dirks & Hadders-Algra, 2011). Perhaps a better understanding of the nature of the relationship between a caregiver and their child's PT can provide insight in to ways to make family-centered care common practice, not just an idea.

Method

Study Design

A qualitative case study methodology was used, which primarily aligns with the concept that “reality is constructed by individuals interacting with their social worlds” (Merriam, 1998, p. 6). This study focused on the lived experience of caregivers and pediatric physical therapists (PT) who represented a bounded case. A bounded case has specific parameters such as place or time, but also can be broad enough to include any phenomenon that occurs within that bounded context (Merriam, 1998). The relationship between a caregiver of a child with special needs and the child’s pediatric PT qualifies as both a phenomenon and a situation that has boundaries. Additionally, it is helpful for the case to be one that is in progress so that information can be gathered in real-time (Creswell, 2013). A holistic case study approach is ideal for this line of inquiry as it allows the exploration of a real, in-progress event (Yazan, 2015; Yin, 2014) which in this study, was the PT-caregiver relationship.

Data collection took place from January 2018 to August 2018. Prior to participant recruitment, the study was approved by the Institutional Review Board at The University of Indianapolis.

Participants

Purposeful sampling was used throughout this study, which allowed the researcher to use best judgment to determine if the potential participants fit the criteria and needs of the study (Creswell, 2013; Portney & Watkins, 2009). All participants met the study’s inclusion criteria and were willing to openly and honestly share their thoughts and feelings (Portney & Watkins, 2009; Seidman, 2013). Convenience sampling was also used; the researcher used known PT contacts to initiate recruitment.

Participants were categorized as either a caregiver or a pediatric PT. A caregiver in this study was defined as someone who has primary decision making responsibilities for a child (ages

birth to 21 years) currently receiving physical therapy services at the time of the study for any diagnosis and who had the most direct involvement in their child's physical therapy. Participants self-identified their role as the primary caregiver, which was confirmed in the interview. For this study, a pediatric PT could participate if they were a licensed, practicing physical therapist who has been engaged in a therapeutic relationship with the caregiver participant and their child for at least six months.

Exclusion criteria included the presence of any cognitive deficits that would prevent a participant from being able to provide consent and answer a series of questions in an interview format and the inability to speak fluent English, since the interviews were conducted only in English.

For this study, each case was comprised of one caregiver and one pediatric PT. A total of five cases equaling 10 participants were involved in this study. This met the targeted number of participants allowing themes to be developed within and across cases without having so many cases that the amount of detail has to be limited (Creswell, 2013).

Procedures

Each caregiver and pediatric PT within a dyad engaged in separate, semi-structured, in-depth interviews. One-on-one interviews allowed for in-depth exploration of each participant's experience; each person could tell their story, which resulted in a compelling way to gain insight into important issues that otherwise might go unnoted (Seidman, 2013). Interviews were conducted either in person or via phone call, selected at the participant's convenience.

Recruitment. To initiate recruitment, the primary researcher contacted local pediatric PTs from a variety of settings such as outpatient clinics, hospitals, and home health agencies by sending a recruitment email (Appendix A). After this initial stage of recruiting did not yield any

interested participants, the email was sent to the listserv for the Academy of Pediatric Physical Therapy of the American Physical Therapy Association as well as distributed to an internet message board for parents of children with special needs. The addition of these recruitment methods resulted in eight individuals responding with interest. The primary researcher contacted all those who expressed interest to explain more about the study and to answer any questions. Ultimately, two caregivers and three pediatric PTs agreed to be in the study. The caregivers contacted their child's PT to discuss the study and ask them to participate. The PTs chose a caregiver of a current patient to participate. The primary researcher then followed up with all potential participants to answer any questions, confirm willingness to participate, obtain consent, and schedule interviews; this yielded a total of 10 participants in five dyads. The other three individuals who initially expressed interest did not respond after repeated attempts to engage them by the primary researcher.

Informed consent. Prior to initiation of the interview, each participant signed a written informed consent document (see Appendix B). The written informed consent document fully explained the purpose of the study and the procedures that would take place (Portney & Watkins, 2009), including how long the interviews may last and the participant's right to stop the interview at any time and/or request that parts of the transcript not be used. Risks and benefits of participation were clearly outlined. The consent form was emailed to each participant prior to scheduling an interview, to allow adequate time for the individual to consider consent and for any questions to be addressed prior to the initiation of an interview. Prior to the start of the interview, key components of the informed consent were discussed with each participant; questions and concerns were addressed as needed and then each participant signed the informed consent document.

Data Collection Process. Interviews were conducted either face-to-face or via telephone with each participant and primary researcher. Face-to-face interviews provided the most interaction between interviewer and interviewee, including nonverbal communication (Creswell, 2013), but telephone interviews were conducted when participants could not engage in an in-person interview (e.g., lived in a different state than the primary researcher). Interviews were conducted at a time and in a place convenient to the participant and were audio recorded using a digital recorder. Ideally, the interview location should be quiet and where the interview process will not be disturbed, and the participant will not be distracted (Creswell, 2013). However, in reality, some interviews took place in areas with distractions (e.g., caregivers home with children, coffee shop) though all attempts were made to mitigate them. Interviews ended when no new information was revealed; the length of interviews ranged from 21 to 30 minutes.

Interviews were conducted using a semi-structured interview guide (see Appendix C) comprised of general, open-ended questions designed to facilitate discussion (Creswell, 2013). The interview guide was constructed by the primary researcher and refined based on input from three additional experienced researchers. Participants were also asked general background and demographic information (see Appendix D).

The primary researcher was a pediatric therapist with over 13 years of experience, which could introduce potential bias to the study's data collection and/or analysis process. Accordingly, efforts were made to limit any potential bias through the use of field notes before, during, and after the interviews. Through the use of the field notes, the researcher recorded any thoughts or feelings that arose during the process in order to maintain credibility and confirmability and thus enhance the study's overall trustworthiness (Henderson & Rheault, 2004).

Data Management & Analysis

Interviews were transcribed verbatim by the researcher by hand. Transcribing the recordings verbatim allowed the researcher to get the fullest picture of the interview and the context in which answers were given. This allowed for more accurate coding of the data (Seidman, 2013). The data analysis software Dedoose (version 8.1.8) was used to store the electronic files of the audio recordings as well as the typed transcripts, which were de-identified. Each participant received a copy of their interview's transcript, with instructions to review it and if needed, to correct any errors, add information, or remove information. One participant requested a specific comment she made not be used. Another inquired about some content that did not seem to make sense, so the researcher reviewed the recording and the transcript to confirm, after which the participant had no additional concerns. This process, referred to as "member checking", enhances the study's credibility by ensuring the data is as accurate as possible (Henderson & Rheault, 2004; Seidman, 2013).

The transcripts were thoroughly reviewed multiple times by the primary researcher. During the initial review, memoing was used to record the reviewer's initial interpretations and perceptions about the data (Creswell, 2013); this was done through the Dedoose data management software. In the second review, key information related to the research question was identified and assigned individual codes, a process referred to as "open coding". The number of codes varied among transcripts, depending upon the breadth of data provided. These codes were single words or phrases; some were exact words a participant used.

At this stage, transcript excerpts for participants A1 and A2 were provided to a secondary researcher who has extensive experience in qualitative methodology. The secondary researcher reviewed and coded the excerpts independent from the primary researcher. Afterward, the primary and secondary researcher met via video conference to discuss codes. Though the two

sets of codes were not identical, both agreed that the codes were very similar in nature and captured the essence of the transcript excerpts.

Following open coding, a process known as “axial coding” was conducted to categorize the codes and establish relationships between them. Axial coding is a second-cycle coding method in which the researcher determines which codes are most relevant and eliminates any redundancies that may have come about from the first cycle of coding (Saldana, 2016). To manage the codes that accumulated, a codebook, within Dedoose, was used. The codebook contained a list of the codes, descriptions, and sample data for reference as recommended (Saldana, 2016).

Throughout the coding process, the concepts developed were compared to one another to explore the similarities and differences. This “constant comparative method” allowed for better refinement of the codes and identification of patterns in the data (Boeije, 2002). After open and axial coding were completed, the codes were combined into categories representing themes that emerged (Creswell, 2013).

For further assurance that results of the coding are trustworthy, a third researcher with extensive experience in qualitative study methodology, reviewed the codebook. Following the third researcher’s review, a discussion took place with the primary researcher regarding themes. The primary researcher developed themes and further refined them after this discussion. This process of triangulation helps verify the credibility of the results (Henderson & Rheault, 2004).

During the processes described above, the researcher maintained an audit trail in the Dedoose data management software and in hardcopy form. An audit trail provides details of the entire research process, so the decision-making process and actions made throughout the study can be clearly followed. The audit trail outlined specific steps of the study such as the initial

proposal, participant selection, how data were analyzed, and previously-mentioned field notes that document the researcher's thoughts and potential biases (Ryan-Nicholls & Will, 2009). An audit trail makes it more likely for another researcher to be able to determine how the codes and themes were generated, thus making the study more trustworthy (Henderson & Rheault, 2004).

Results

The five cases (10 total participants) in this study are described in Table 1. Characteristics of the patients (children receiving PT) are listed in Table 2. Where names are present in quotations, pseudonyms were used to protect privacy. Additionally, codes were used to protect privacy of participants. All caregivers who participated were mothers. All PT participants self-identified as pediatric therapists and had years of experience ranging from 15 to 30 (mean 24.8 years). The settings in which the child received PT were either in the home or in the clinic, with one participant's child receiving PT both in the home and at an outpatient clinic. The length of the caregiver PT relationship ranged from 1 to 9 years (mean 3.3 years). Interviews ranged from lasting 21 to 30 minutes. Four interviews were conducted face-to-face, and six were conducted on the phone.

Three major themes emerged: PT as a guide, social and emotional connection, and professional qualities and performance. These major themes combined with subthemes help create a picture of the PT-caregiver relationships in this series of case studies (Figure 1).

Theme 1: PT as a Guide

The role of the PT as a guide surfaced as an overarching theme, both within and across all cases. For these participants, a guide is someone who can help direct the way to a specific path or purpose by providing direction, assistance, advice, and leadership and does so on the basis of trust. Interviews with participants indicate PTs serve in this capacity in a variety of ways. One

participant said, “She [PT], you know, helps to make sure everything is going as we want, um, makes sure that we have everything we need and kind of guides us...”.

For the PT to serve as a guide for a family, each must trust and rely on one another. Otherwise, the PT’s thoughts and opinions would not be relevant to the family, and the PT could not rely on the family to provide an honest exchange of information. One PT participant said, “I think that trust bond automatically kinda happens. It's something--they're putting their child in your care, so automatically I'm trusting you. And then, how you manage their child further builds that trust, or doesn't go anywhere”.

Another PT said:

I think trust is huge...I think that she's [patient’s mother] done a great job of just letting me know how much she trusts me and also feels that my opinions and my perspective on things do somewhat drive some of his care.

Families and therapists in this study reported seeking guidance from their PT about a variety of issues. Some of the matters discussed were directly related to physical therapy such as decisions about assistive devices, braces, and adjunct treatments such as Botox injections. Other topics discussed were related to health insurance, other medical appointments and decisions, other therapy disciplines, behavior management, and social situations for the child such as school, family, and community outings. One reason families may seek guidance from their PT on such a wide range of topics seems to be due to the relationship that is built, usually over time. Since PTs often work with children and families for extended periods of time, which ranged from 1 to 9 years in this study, the PT reaches a high level of familiarity with the child and the family. This familiarity is not just diagnosis or disability-related but also encompasses an understanding of the family’s dynamics, their likes and dislikes, and their priorities. This close,

intimate knowledge puts a PT in a unique position to guide a family through many processes and decisions.

One participant stated:

PT A2: Um, I think the fact that mom turns to me for a lot of advice on different things that ... I wouldn't say they're outside of the scope of PT practice, but kind of looking at how the gross motor and just his movement and his diagnosis in general affects his day to day living. And I feel like as the PT I definitely get to know him a little bit more than even some of his specialists that he would see.

Additionally, one caregiver reported:

Caregiver H1: And my husband says to me all the time 'you're the only other person in the world who understands how I feel about it and how much we love this child of ours and how much, how special he is...and I have to tell you that I think our physical therapist is a close second in there, about understanding all of that...she knows what a great kid he is, she knows what he came from...and sees how far he's come.

Caregiver F1 indicated that:

Every doctor has a piece of the puzzle and our pediatrician is great, but really Allie [PT] and I are the only ones that have the big picture and have the full picture, and she is my sounding board for almost everything and anything because she knows Beth as good as I do.

Additionally, PT H2 stated:

And, and that, I feel fortunate to be a pediatric PT cause I, you know, I think we have the capability of building relationships a lot more than a lot of other specialties or professions even, um, because we do really get to know the families.

The ways in which a PT guides a family expands to many domains, and while each family has unique concerns and challenges, similarities could be seen across the cases in this study. Two additional themes emerged to help identify what factors drive the PT-caregiver relationship forward and support their role as a guide.

Theme 2: Social and Emotional Connection

There are elements of the social and emotional domain that become a part of the PT-caregiver relationship.

Social. At times, a social or personal relationship forms between caregivers and PTs. PTs and caregivers often connect over their shared interest of and concern for the child receiving therapy.

One PT stated:

PT F2: I think it's a bond because you are connecting over this child and you, I think, that the parents especially appreciate you because you, you know, they appreciate your expertise, they know that you kind of get it, because they, um, because I've been doing this for a long time...

They also sometimes connect over mutual interests such as hobbies, personal values, and mutual acquaintances, which helps forge a bond. As Caregiver A1 indicated:

I like to have a personal relationship with them. You know, I share...a lot of our stuff with them, you know. I don't, for instance, share stuff like, okay my relationship with my husband or anything like that, but Charlie, being my child, is the biggest part of my life, so they know an intimate part of my life.

Additionally, when a PT sees a child once a week for a course of physical therapy that often lasts years, a social connection can form as a natural byproduct. Caregivers and PTs often

engage in social talk (conversation not directly related to PT) in the natural course of the PT-child-family relationship. One participant stated, “But it has strengthened our bond in the fact that I know—I know more about her and she knows more about me, which just connects us on a more...that need for our relationship and a relational level” (Caregiver F1).

This seems to be somewhat magnified when the PT treats the child in the home, adding to the familiarity of the relationship. As one participant put it, “So, you know, with Dana, it started off as professional and I think being in the home it kind of creates that atmosphere... Um it makes it a little bit easier to establish that friendship...” (Caregiver B1).

PTs and families often engage in social talk out of politeness, exchanging pleasantries about their day or social activities. “Um, yes, sometimes they're social [conversations], you know, just like ‘how was your Mother's Day?’ or that kind of thing (Caregiver B1)”. At other times, conversations may turn social out of shared interests that were either present before the relationship began or have been built since it started. One PT expressed the following:

I also had a son, um, our son, two and a half years ago suffered a severe traumatic brain injury, so I think she [mom] gets it from that point, that I, you know, I am a parent myself and I have experienced being on the patient side of things...and I think it helps her to be able to talk about those kind of things because not only have I been a parent, I have worked with families that have children with disabilities for so long that I have a lot of perspective, so, I think it goes way beyond just what we do in the clinic...

Social talk also occurs because it may be indirectly related to PT. For example, a caregiver may talk to their PT about an upcoming vacation; this could be indirectly related to PT as the family may have questions or seek advice on how best to navigate a vacation with their child who may have different mobility or sensory needs. In turn, PTs may discuss social

activities as a byproduct of keeping the family informed, such as needing to cancel or rearrange an appointment due to an illness or family event.

Caregivers and PTs did sometimes refer to their relationship as a friendship, while also indicating this was secondary in priority to the child's PT. A friendship may form over the course of the PT-caregiver relationship, but PTs and caregivers can have a meaningful, successful relationship as part of the child's life without rising to the level of friendship.

According to Caregiver B1:

All that matters is that they're a good therapist. A lot of our therapists we've had for years and you do develop a friendship, but we don't initiate that from the beginning. I would much rather someone be our daughter's therapist than be our friend if there is an either or...

Emotional. The PT-caregiver relationship often involves an element of emotional support at various times such as during stages that involve the diagnostic process, difficult treatment decisions, and celebrating the child's successes. "And I got a very tearful conversation. What have we done? Is this going to last forever? Am I making the right choice" (PT F2)? "And, you know, I, it was so exciting cause he walked for the first time in our session and it was like—we all cried..." (PT H2). One participant stated:

Caregiver H1: So, um, for us, it was just a really emotional time, you know, we were dealing with this baby that we were in love with and um, we were concerned about what was to come for him... she cares about the emotional side of it for us, too.

Also, the PT can offer a safe, supportive space for the caregiver to express ideas and emotions, while also offering validation. "I just listened and offered them a space for them to cry...It was okay to cry, and there's no judgement there...reassuring, I know this hurts" (PT F2).

“...when she [mom] has questions and ideas, I feel like I’m telling her ‘oh yeah, those are great ideas...you’re right on.’ ...I reiterate that she’s doing all the right things for her daughter” (PT B2). “I might be the only person that's going to tell them, hey, you're doing a good job” (PT F2).

While not a primary focus of pediatric physical therapy, the role of social and emotional connections should not be ignored. For caregivers and PTs in this study, this type of support can serve to move the relationship forward in a positive way and set the stage for other important elements of the therapeutic process such as treatment planning and shared decision making. “It would be harder for me to take advice from them if my personality didn't match as well”

(Caregiver F1). Additionally, one PT participant described the following:

PT H2: And, um, she [patient’s mom] just said, “I just needed to hear there was hope.”

But I was glad that she felt comfortable enough to say, you know, “I just need to know that there’s hope.” I’m glad she was able to express that. And you know, she says, looking back, she said she knew that day that we were a good match.

Theme 3: Professional Qualities and Performance

Within each case as well across all cases, a high priority for both the caregiver and the PT was how well the PT carried out the various professional aspects of the relationship.

Skill as PT. For caregivers, having a skilled, knowledgeable therapist who engaged well with their child was of utmost importance. As one participant stated:

Caregiver A1: My biggest priority is Charlie and so my biggest thing about the PT is that...so, my biggest thing is just that they're, um...skill and they're kind of like, uh, they're good at what they do, you know what I mean? It's not so much--my focus is not so much on my personal communication with her and everything, like building a personal relationship. Um, it's just, uh, I want him to have good therapists.

While the lack of a personal relationship or friendship was not mentioned as a reason for selecting or keeping a PT, a lack of skill or knowledge as a PT was important enough to caregivers that it would cause them to pursue a new therapist. One caregiver conveyed the thought in this way:

Caregiver F1: I think the other clicking that happened between Allie and I was because I could tell she had a deep, vast knowledge base and had experience that came through in a level of confidence and just in a level of ... I could tell outside of our one hour she had done research and she had a plan for what we were going to do the next time that I didn't necessarily feel like had been coming from the previous therapist.

Collaboration.

The caregiver-PT relationship was often described in terms such as a “partnership”, “teamwork”, and “collaboration”. Establishing open, honest lines of communication is an essential component to collaboration. Doing so will help the PT understand what is most important for the child and family. As one participant indicated:

PT A2: allowing them to also have a role in guiding their child's care so that it's--if it's not important for them to learn to do a balance beam, then that's not something we're necessarily gonna focus on, but when she tells me what's important I'll say, "Well here's what we're gonna do to try to get there." So, I think that's huge too, is giving them a voice.

Often, this type of communication ventures into different aspects of the family's life that are not directly related to PT. However, participating in these types of conversations can help the PT gain a better understanding of the family and the child's role in it. One of the PT participants said:

B2: Um...I think it's part of getting a whole picture of the family...um...I think it's important to engage, like, so that I can better support the family if I know-oh they go to grandparents, or swimming...so, it's part of getting a good picture of the whole family and supporting the whole family.

Shared decision-making. Another component of collaboration that was important to both caregivers and PTs was that of a shared role in decision-making. When decisions needed to be made regarding the child's care, caregivers and PTs engaged in dialogue during which the caregiver could ask questions and the PT offered advice, based on experience and research. Conversations may be initiated by either the parent or the PT, depending on the situation and the topic of discussion. After an exchange of information and ideas, the caregivers and their family make the decisions. "These are the options and this is what I would recommend, but you know, you have to figure out what works for you" (PT H2).

Caregiver F1: I think she's done a good job of empowering me to make sure-to remind me that I can say no, but she always will give me her opinion and will always remind me that I can-I can disagree with whatever she's saying, you know, she is very clear that it is her opinion, just like the doctors have an opinion-

Education. Another relevant area of the PT as a professional that was important to both caregivers and PTs was that of education. Caregivers valued the education their PT provides them. This can take on many forms such as educating the caregiver about their child's condition or providing information based on past experiences and available research. As Caregiver B1 reported:

We didn't understand body awareness and how that's not just a sensory processing disorder but you know how that goes in to her low muscle tone so her educating us has been really crucial for us understanding this side of our daughter that we didn't before.

Additionally, one participant stated:

PT H2: I think, um, you know I always think it's a fine balance of educating and kind of having—having knowledge, um, and never coming across like I'm the expert and you have to do what I say, you know—

Progress in physical therapy. In addition to the skill of providing physical therapy the therapist brings, the caregiver-PT relationship itself could have an influence on how the child progresses in therapy. Caregiver A1 said:

But I think maybe if I didn't have a good relationship with her maybe that would inhibit his progress...I think that maybe if it was a bad relationship then he wouldn't get as much out of it, you know, because maybe our own tension would hinder that.

Therapists and caregivers recognize that therapy is limited to once or twice per week and progress is really made when activities are carried over in the times between therapy sessions. Having a relationship built on mutual goals, trust, and good communication can help a caregiver better understand how best to do this, therefore furthering the child's progress. "I think though that, um, the relationship that we have with her has for sure, um, it has benefited my son tremendously" (PT H1).

There was a considerable amount of consistency within each case. The caregiver and therapist often shared the same story, though interviews were done separately. They each described their relationship in similar terms. The themes and sub-themes arrived at through the coding process are a good representation of both caregivers' and PTs' experiences.

Discussion

When a child begins receiving physical therapy, a relationship is established between the child and the PT as well as the PT and the caregiver(s) of the child. A child involved in physical therapy cannot access it on their own, nor can they make decisions on their own behalf. Therefore, a relationship with the caregiver and PT is inevitable. It is up to the PT and the child's family to determine aspects of their relationship that will best serve the family and child. There is no one right way for PTs and caregivers to interact with one another, though best practices, such as family-centered care, have been identified and recommended for practice. This exploration of five PT-caregiver dyads revealed themes of guidance, social and emotional connection, and professional PT qualities; these concepts may help all parties reflect on and build this critical relationship.

Both caregivers and PTs in this study identified numerous ways in which the PT serves as a guide for the family as they navigate the process of caring for a child with special needs. A past study found that pediatric PTs highly ranked their role as a resource to the families they serve (Dule et al., 1999), but no specifics were provided as to what this entailed; participants simply ranked various items on a scale as part of a questionnaire. One qualitative study on mothers' perceptions of their children with disabilities found that rehabilitation services helped "to mitigate mothers' perceived suffering and burden of care..." (Daudji et al., 2011, p. 517), though ways in which this occurred were not delineated. The findings of this current study indicate that supporting a family is done in many ways, including giving information and advice on a wide variety of topics, providing education on their child, and sharing in the decision-making process. The ability to do this is enhanced by the PT's familiarity and time spent with the child and family, characteristics that were identified as critical to the provider-caregiver relationship in a

study on the perspectives of parents with chronically ill children (Miller et al., 2009). Other medical practitioners acknowledge they often lack the time to address the family's needs effectively (O'Neil et al., 2008).

The finding that an emotional and social connection between a caregiver and their child's PT is important to caregivers aligns with other studies whose results indicated social and emotional support can improve care (Ideishi et al., 2010), lead to deeper relationships (Hinojosa, 1990), and help validate the caregiver's abilities (O'Neil et al., 2008). However, this current study expanded on the idea more fully than in past studies. The caregiver-PT relationship has many qualities in common with those of a friendship such as trust, open and honest communication, and shared interests. Though a friendship may form between caregiver and PT, it is not a primary focus for either party. The role of discussions related to social topics is an important one revealed in this study. It can be a useful way for the caregiver and PT to get to know each other for the purpose of better serving the child receiving therapy. It also may help to mitigate the perception of a power differential in a healthcare provider-patient/family dynamic. This study confirmed that caregivers value being validated and also revealed that PTs actively work to provide such validation to caregivers, which may also serve to strengthen the relationship.

This study highlighted the fact that for a caregiver whose child is involved in physical therapy, the most important role of the PT is to demonstrate skills, knowledge, and effectiveness throughout the course of their child's care. Parents in a study about their perception of physical therapy in a pediatric critical care unit indicated a similar feeling; the PT's role is to help their child improve (Parisien et al., 2016). To that end, this study brought to a light a concept not explored before in other studies, which is that the relationship between the caregiver and the PT

could have a direct effect on the child's progress toward goals in therapy. If the groundwork of communication, trust, and partnership is not present, a caregiver may be less likely to take advice from their PT or carry over the PT plan of care in the home (Navarro et al., 2005). As a result, the child may not progress toward goals as quickly as if the caregiver and PT had a good working relationship.

Family centered care is considered best practices for pediatric physical therapy (Rosenbaum, 2011) and is among the recommended core competencies in pediatric physical therapy education (Rapport et al., 2014). Past studies indicate that though therapists understand and value family-centered care, it is difficult to implement it in every day practice (Dirks & Hadders-Algra, 2011). However, both the caregivers and PTs in this study described the presence of many family-centered characteristics that were woven in to the course of physical therapy. This included being mindful of the child's role in the family unit, understanding what the family values when developing goals, and making decisions as partners. The themes identified in this study of guidance, emotional and social connection, and professional qualities and performance reveal how pediatric PTs are engaging in family-centered care and that caregivers recognize and value these attributes in the caregiver-PT relationship.

Limitations

This, like any study, has its limitations. There is a risk of researcher bias in this study since the primary researcher is a pediatric physical therapist. However, strategies were employed to mitigate bias during data collection and analysis through tools such as field journaling, an audit trail, and triangulation. Additionally, the primary researcher was not the therapist for any families included in this study. Using a case study methodology required a bounded unit--the caregiver and PT--to participate. Recruitment allowed for either the caregiver or PT to initiate

contact and then recruit the other participant. It could be that this study only represents caregiver-PT dyads who have close relationships since they both needed to feel comfortable participating in the study and discussing their shared relationship.

Implications for Practice and Future Research

Even with the stated limitations, this study serves to highlight salient aspects of the caregiver-pediatric physical therapist relationship. While the study is representative only of the bounded cases that were explored, the insight provided can be useful for caregivers and pediatric physical therapists as they navigate their relationship. The need for guidance, an emotional and social connection, and the importance of the PTs professional performance are all mirrors in which caregivers and pediatric PTs can look to for reflection of their own relationship. While not setting these conditions as the patterns by which all relationships should conform, these insights could be a helpful way to start the conversation between caregiver and PT to determine what characteristics of their relationship are most meaningful to them and in what areas they may want to see improvement.

Future research into the caregiver-pediatric PT relationship could expand on these findings. A well-designed survey given to caregivers and pediatric PTs could provide more data on the relationship and could represent a larger sample of participants. For example, a survey could help objectively quantify if any particular factors seemed to influence the caregiver-PT relationship such as the race, gender, education level of any of involved parties or the age or diagnosis of the child involved in physical therapy.

Additionally, a longitudinal study of the caregiver-PT relationship could help explore the factor of time and capture aspects of the relationship at more than just one point in time as this current study did. For example, participants could be given a survey at the beginning of their

involvement with a pediatric PT and then again at other points in time. This would allow for direct comparison of the relationship over time. This study indicated that the length of the relationship was part of the reason PTs came to know the child and family well, but a quantitative examination of this could be helpful.

One concept that emerged from this study was the idea that the caregiver-PT relationship could play a role in the child's outcomes with regard to improving function and independence. These outcomes are measured in a variety of ways such as through the PT's observation, progress toward specific goals, and performance on standardized tests. A future study that compared objective ratings of the caregiver-PT relationship (such as from a survey) with measured outcomes could help determine if the relationship does directly have an influence on the child's outcomes.

Additionally, future qualitative studies of other types of caregivers (e.g., fathers or foster parents) could be helpful; this study's participants were all mothers, just by nature of who volunteered to be part of the study. Another qualitative study that could be beneficial is one in which caregivers are asked to share experiences specifically regarding any negative experiences they have had with their child's physical therapist. It could be helpful to find out any specific attributes that cause caregivers to feel the care being provided to them is not family-centered; this information could help create educational sessions or training modules for therapists. The therapists who participated in this study were experienced PTs; a potential qualitative study that might be beneficial is one that explores the caregiver-pediatric PT relationship when the PT has five or fewer years of experience as it is possible the views of a novice PT may differ from those of with more experience.

Conclusion

A pediatric PT and caregiver of a child who receives PT must form a relationship so that the child can receive optimal care. The exact nature of this relationship is unique to each family, but guiding principles can be useful to both parties, as it can be difficult to know what to expect from such a relationship. This study provides the knowledge that for the participants interviewed, the caregiver-PT relationship is important; it involves the PT serving as a guide in many ways for a family and often, an emotional and social connection is formed. It is also critical that the PT displays professional characteristics, including being knowledgeable about a variety of topics and being skilled at carrying out physical therapy interventions. The ultimate goal is for the child receiving physical therapy and their family to have their goals and needs met. The relationship with the child's PT plays an important role in that goal.

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Participant Characteristics

Table 1

Participant Characteristics

Participant	Role	Length of Relationship	Years of PT Experience	Treatment Setting
A1	Mother	2 years	----	Home
A2	PT	-----	15	Home
B1	Mother	3 years	----	Home
B2	PT	-----	30	Home
D1	Mother	1.5 years	----	Home and Clinic
D2	PT	-----	23	Clinic
F1	Mother	1 year	----	Clinic
F2	PT	-----	28	Clinic
H1	Mother	9 years	----	Clinic
H2	PT	-----	28	Clinic

Patient Characteristics

Table 2

Patient Characteristics

Caregiver of Patient	Current Age of Patient	Patient's Diagnosis
A1	2 ½ years	Congenital Myasthenic Syndrome
B1	7 years	Cohen Syndrome
D1	2 years	Cerebral Palsy
F1	3 years	Cerebral Palsy
H1	9 years	Central Core Myopathy

Appendix A

Recruitment Email

Subject Line: Research Regarding the Physical Therapist-Caregiver Relationship

My name is Jodi Thomas, and I am a student in the Doctor of Health Science Program at the University of Indianapolis. I am also a pediatric therapist and have been practicing for over 12 years. In that time, I have become very interested in the unique features of the relationship between pediatric PTs and the caregivers of the children with whom they work. As a result, I decided to conduct research on this topic for my doctoral project. You are receiving this email because I thought you might be interested in participating.

This study involves the participation of a pediatric PT along with a primary caregiver of a child who has been their patient for six months or longer. Both the pediatric PT and the primary caregiver would each participate in an interview with me (about 30-60 minutes long). Then, the pediatric PT and primary caregiver would participate in another interview together (also about 30-60 minutes long). Participants who complete both interviews will have their names entered in to a drawing to win a gift card.

If you are interested and/or have questions, please contact me at jolthomas@uindy.edu or (325) 280-7878.

Once you establish interest in participating, the next step is to find a caregiver of a child you treat who would be willing to participate. In order to maintain patient confidentiality, I will ask that you contact a caregiver and they can then contact me with any questions.

Sincerely,
Jodi Thomas

Appendix B

University of Indianapolis Institutional Review Board

Principal Investigator: Laura Santurri
Co-investigator: Jodi Thomas
School/Department/Division: College of Health Sciences
Telephone: 317-788-2409

Co-Investigator(s): Jodi Thomas

INFORMED CONSENT FOR PARTICIPATION IN RESEARCH ACTIVITIES
Perceptions of the Pediatric Physical Therapist-Caregiver Relationship

1. INTRODUCTION

The investigators invite you to participate in a research study. The purpose of this Informed Consent Form (ICF) is to provide information you should have in order to make a well-informed decision to consent to participate in the study. Please read the form carefully. You should ask questions about why the research is being done, what you will be asked to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. Your consent must be well informed and voluntary, without influence from the investigators or anyone else associated with this study. This process is called “informed consent.”

2. PURPOSE OF THIS RESEARCH STUDY

The purpose of this research study is to explore longer-term (six months or more) caregiver-pediatric PT relationships from both the caregivers’ and PTs’ points of view. You are invited to participate in this research study because you meet the criteria listed below.

Inclusion criteria:

- Participants will be categorized as either a caregiver or a pediatric PT.
 - A caregiver in this study will be someone who has primary decision making responsibilities for a child (ages birth to 21 years) who is currently receiving physical therapy services for any diagnosis. This person will have direct involvement in their child’s physical therapy. In the event that more than one person fits this definition (e.g., the child’s father and mother), it will be up to the caregivers to self-select one person to participate in the interview.
 - For this study, a pediatric PT must be a licensed, practicing physical therapist who has been engaged in a therapeutic relationship with the caregiver participant and their child for at least six months.

Exclusion criteria:

- Potential participants will be excluded if they have any cognitive deficits which would prevent them from being able to provide consent and answer a series of questions in an interview format.
- All interviews will be conducted in English, so individuals who do not speak English will be excluded.

Your participation in this study will require two interviews, each of which may last 30-45 minutes. If you consent, then you will be one of approximately 10 persons participating in this study.

3. WHAT WILL BE DONE / PROCEDURES

You will be asked about your experience with the pediatric physical therapist-caregiver relationship through two in-person, semi-structured interviews. A “semi-structured interview” is a type of interview that involves “primary” or required questions along with “secondary” or “probing” questions that are used depending on your responses to the primary questions. One interview will be between you and the researcher; the other interview will include you, a pediatric therapist, and the researcher.

The interview will occur either locally or remotely depending on your convenience. A local interview will be performed privately in a place of your choosing. A remote interview will occur using telecommunication technology, such as the telephone or web-based program like Skype. Each interview will be audio-recorded and should last between 30 and 45 minutes. Breaks during the interview will be provided for you if requested. After the interview, the recording will be transcribed (i.e., typed out) and given to you for review to ensure that the investigator represents as accurately as possible what you said during the interview. Upon reviewing the transcript, you can request clarifications or corrections of errors as well as request that any part of the transcript not be used.

4. POSSIBLE BENEFITS

The investigators do not intend and cannot guarantee that you will receive any benefit from participating in this study. Potential benefit to others may result from the knowledge gained from your participation in this research study.

5. POSSIBLE RISKS AND DISCOMFORTS

The context and methods of this research study expose you to little, if any, risks. Possible, slight risks may include psychological or emotional distress such as embarrassment or nervousness associated with discussing perceptions and memories. The investigators will attempt to conduct your interview in a relaxed and supportive manner to ease possible discomfort. The interviewer will be trained to assess for participant discomfort. If at any time you do feel uncomfortable you may stop the interview. At that point, the information you have provided will be destroyed.

CONFIDENTIALITY OF RECORDS

Any information learned about you from this study will remain confidential. The investigators will NOT ask you for information, such as your name, email address, phone number, etc. that during the interview. You should try NOT to use names or other identifying

information during the interview. If you disclose personally identifiable information, then the investigators will NOT transcribe the information from the recording.

If your interview is remote using a web-based program such as Skype, then the investigators will use the confidentiality protections built into Skype or a similar program. The investigators will record ONLY the audio portion of the Skype interview. To better protect your privacy, you should conduct the interview in private setting using a secure internet connection.

The investigators will ask for your contact information in order to send you a copy of your interview transcript. The investigators will establish and maintain confidentiality by:

- Storing identifiable information in a secure location with limited access
- Storing identifiable information in a locked container (e.g., file cabinet, desk drawer etc.)
- Storing identifiable information AWAY from your interview information

All records will be stored in an online data management system called Dedoose. Only the investigator and members of the research team will have access to these records. If information learned from this study is published, you will not be identified by name. However, your consent to participate in this research study authorizes the investigators to make your research records available to the University of Indianapolis (UIndy) Human Research Protections Program (HRPP), law enforcement, and regulatory agencies as required by law.

Although investigators will maintain the confidentiality of your information in order to protect your privacy, confidentiality may not be absolute or perfect. There are some circumstances where research staff might be required by law to share your information, such as, but not limited to:

- You provide information indicating that a child is being abused (or has been abused). The interviewer is required by Indiana state law to file a report with the appropriate agencies;
- You provide information indicating that you are being (have been) abused (in the past). The interviewer **may** have to file a report.
- You threaten serious harm to yourself or another person. The interviewer may have a duty to warn your intended victim, notify the police or take the steps to seek hospital-based treatment.

6. OFFER TO ANSWER QUESTIONS AND RESEARCH INJURY NOTIFICATION

Either Dr. Santurri (PI) or Dr. Thomas (co-investigator), responsible for this research study, must provide all information and answer any questions regarding your participation in this research study. If you have any further questions, then you can contact Dr. Santurri (PI) at 317-788-2409 or Dr. Thomas (co-investigator) at 325-280-7878. You **MUST** receive a copy of this informed consent document for your records.

7. COST TO THE SUBJECT / PAYMENT TO SUBJECT FOR PARTICIPATION

Your participation in two interviews will result in your eligibility for a drawing to win one of two \$75 Amazon gift cards. Participation is defined as being a part of the process from initiating contact with the researcher through completion of an interview with the researcher. An interview is considered completed if the participant answers at least one question. Completion is not based on any pre-set length of time spent in the interview. If you discontinue the interview before answering a question, which is your right to do, the interview will be considered incomplete and you will not be eligible for the drawing. If you enter the drawing, then you will be one of as many as ten other participants in the drawing. If you are a gift card winner, then you will electronically receive your gift card.

8. VOLUNTARY PARTICIPATION WITH RIGHT OF REFUSAL

Your participation in this research study must be voluntary. Although you have been contacted by the investigators and/or a Physical Therapist, you are free NOT to consent. If you consent to begin the study and later change your mind, then you are free to withdraw from this study at any time without penalty. If you choose to withdraw after you complete an interview, then you should contact Dr. Santurri at 317-788-2409 or Dr. Jodi Thomas at 325-280-7878.

9. IRB REVIEW AND IMPARTIAL THIRD PARTY

The UIndy HRPP has reviewed and approved this research study as “exempt,” which means the study poses little to no risk to you. The HRPP is responsible for protecting the rights and welfare of all who conduct or participate in human subjects research. If you have questions or concerns about your rights or welfare as a participant in this research study, then you should contact the UIndy HRPP Team at hrpp@uindy.edu; (317) 781-5774; or (800)-232-8634 ext. 5774.

10. VOLUNTARY PARTICIPATION AS CONSENT

Before you choose to participate, you must all information you require to make an informed choice to participate. **If you choose to participate, then your participation is your implied, voluntary consent.** Because the primary risk to you is loss of confidentiality and privacy as a result of disclosing your personally identifiable information, and because the investigators will NOT collect personally identifiable information as research data, the investigators will not require you to sign an Informed Consent Form (ICF).

Participant name:

Participant signature:

Date:

Appendix C

Semi-structured Interview Guides**For Caregiver****Introduction.**

Thank you for agreeing to participate in this interview. My name is Jodi Thomas, and I will be conducting the interview; I am also the primary researcher for this project. We are here today because you responded to an inquiry I sent out asking for participants who are caregivers of children with special needs in physical therapy to speak about their relationship with their child's PT. This interview will last 30-60 minutes. I will guide the interview with questions, but please feel comfortable speaking freely; there are no right or wrong answers. Everything you say today will be confidential; portions of your interview may be used for the final research paper, but no identifying information will accompany it. To ensure I capture your perspective accurately, I would like your permission to record the interview. The recording will not be used for any other purposes and will be destroyed at the project's conclusion. Are you ready to begin? Once participant acknowledges readiness, the interviewer will begin recording and will state, "We have now begun the recording".

1. Tell me about your relationship with your child's PT.
2. Describe a typical therapy session with your child
3. Describe conversations with your child's PT.
 - a. Describe a time you had discussion with your child's PT about topics not related to your child's care (e.g., social activities, family, etc.)?
 - b. Describe, if possible, a situation in which you and your child's PT had a conversation that was difficult or uncomfortable.

4. Describe how you and your child's PT go about making decisions for your child's care.
 - a. Describe your comfort level with approaching your child's PT to discuss treatment plan(s) for your child.
5. What aspects of your relationship with your child's PT are most important to you?
6. In what way, if any, does the relationship between caregiver and PT, play a role in the therapeutic process?
7. Is there anything else that you would like to share that we have not covered in our discussion?

For PT

1. Tell me about your relationship with the caregiver in question.
2. Describe a typical therapy session.
3. Describe conversations with the child's caregiver
 - a. Describe a time you had a discussion with the child's caregiver about topics not related to your child's care (e.g., social activities, family, etc.)?
 - b. Describe, if possible, a situation in which you and your patient's caregiver had a conversation that was difficult or uncomfortable.
- c. 4. Describe how you and your patient's caregiver go about making decisions for the child's care.
 - d. Describe your comfort level with approaching your patient's caregiver to discuss treatment plan(s) for the child.
4. What aspects of your relationship with your patient's caregiver are most important to you?

5. 4. In what way, if any, does the relationship between caregiver and PT play a role in the therapeutic process?
6. Is there anything else that you would like to share that we have not covered in our discussion?

Appendix D

Demographic and Background Information

Caregiver

1. How long has your child been seeing their current PT?
2. How often does your child see his/her PT?
3. How old is your child?
4. What is your child's diagnosis?
5. What is the primary setting in which your child sees their PT? (e.g., at home, school, clinic, etc.)

Age:

Family role: (e.g. mom, dad, grandmother, etc.)

PT

1. How long have you been a PT?
2. How many years of that have you been primarily working with pediatric patients?
3. What percentage of your caseload is pediatric patients?

Visual Representation

Figure 1 Perceptions of the Caregiver-Pediatric Physical Therapist Relationship

