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Patti Calk

University of Louisiana at Monroe, calk@ulm.edu

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Parents of Children with Physical Impairments and their Relationship with
Intervention Team Members: A Phenomenological Study

Background

As a contract therapist in early intervention and the school system, the author of this qualitative study frequently interacted with the parents of clients. The discussions between the author and parents highlighted positive and negative factors that impacted the relationships among those involved in the children's care. Perceptions of the parent-professional relationships was of great interest to the author whose aim was to answer the following questions. Do parents trust the professionals that serve their children? Do they perceive their relationship with the professionals as positive or negative? Additionally, do the parents feel adequately supported by the professionals?

Parents have discussed feelings of satisfaction, empowerment, frustration and/or disillusionment with the professionals that treat/work with their children (Cameron, 2018; Robert, Leblanc, & Boyer, 2015; Ryan & Quinlan, 2018). Conflicts and insufficient communication weaken the relationship among parents and their children's educational or healthcare providers. Inadequate support and services, lack of collaboration, and dissatisfaction with educational and medical systems have been identified as barriers to parent-professional relationships (Cameron, Tveit, Midtsundstad, Nilsen, & Jensen, 2014; Cameron, 2018). Parents identified feelings of having to "police" the professionals caring for their child and expressed the desire to "just be parents" as concerns that lead to distress (Cameron, 2018). Frequently, parents of children affected by disabilities are overwhelmed with the day-to-day tasks and responsibilities that are necessary for the care of their children (Davis & Gavidia-Payne, 2009). They report feelings of angst, stress, and struggle when faced with the challenges of getting their children's needs met (Burton, 2018; Hogan, 2012; Ryan & Quinlan, 2018). When parents are not consulted in plans for their children, they feel that their expertise and contributions are not being

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recognized, leading to feelings of disempowerment (Robert et al., 2015; Ryan & Quinlan, 2018). However, parents may also be resistant to trusting professionals in making decisions that impact their children when they do not have an understanding of the professionals' knowledge and motives (Cameron, 2018). Parents often have difficulty finding the balance between monitoring the services provided to their children and relinquishing control to others to provide what is needed. The quality and nature of these interactions can either positively or negatively impact the parent-professional relationship.

Research Question

The research question investigated was: *how do parents of children with special needs perceive their relationship with professionals on their children's educational and healthcare teams?* The characteristics that help facilitate or hinder the development of positive relationships, trust, and empowerment through meaningful interaction with team members were also investigated. A phenomenological approach was employed using a semi-structured interview with open-ended lead questions. Research indicates that mothers are typically the parent who interacts with their children's service providers (Angell, Stoner, & Shelden, 2009; Nord & West, 2001); therefore, mothers were chosen as the subjects for this study. Additionally, the author chose to seek out families of children affected by physical impairments and medical complications, as it is expected that families with multiple team members on their cases would provide a greater variety of interactions and perceptions.

Participants

A purposive sample of convenience was used to gather data for this study. The author specifically sought out mothers whose children received services from both educational and healthcare teams. Three mothers of children with multiple physical and medical disabilities were interviewed. All three mothers agreed to participate in the interview and identified the time and place that they would prefer the interview to occur. Two of the mothers (GM and MT)

participated in extensive interviews, while one only participated in a brief interview. CR was interviewed for six minutes at her place of work after work hours, per her request. No other people were present. Initially, the interviewer planned to disregard the interview since the mother appeared resistant to elaborate or discuss topics other than to provide brief answers. However, some of the responses made were relevant to the topic of this study and the comments were applicable.

GM was interviewed by telephone from her home since she lives in a distant state from the author. The interview was scheduled by email and GM identified the date and time for the author to call for the interview. The interview lasted 57 minutes. The interview was recorded upon receiving verbal permission from GM. In addition to being the mother of a child with multiple disabilities, GM is an occupational therapist.

The final interview took place in MT's home. MT chose the time and location based on her family schedule. MT was interviewed for 49 minutes. This interview was also recorded upon receiving her permission.

CR's daughter, S, was diagnosed with Spinal Muscle Atrophy (SMA) Type II, a progressive neuromuscular disease. "She has trouble standing, sitting, doing anything." She received occupational therapy (OT), physical therapy (PT), adapted physical education, and four hours a day of personal care services. Mother reports that she and her daughter "get along great" with her service team and that her daughter loves them all. CR reported that there is really no feedback that she feels that she can give about the relationship with her service providers. When asked what positive experiences with the treatment/educational team have impacted the lives of her daughter and herself, CR stated, "When my daughter tells me that she loves them, that is enough." She stated that she feels like the team members "listen to our concerns and try their best to meet S's needs. The fact that they make S feel special to them means the world to me",

GM's son, D, was diagnosed with spastic quadriplegia, epilepsy, failure to thrive,

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impaired vision, dysphagia, and is non-verbal. GM reported, “Everything is an area of difficulty” except for cognition, which is not limited. The services that D receives include private duty nursing for 103 hours per week, speech therapy (ST) in school 3 times per week and out of school twice a week, OT twice a week at school and physical PT twice a week at school and twice a week outside of school. “He doesn’t have OT outside of school because he lives with me and gets OT all of the time.” D also gets aquatic therapy from a PT and participated in therapeutic horseback riding prior to the closure of the riding clinic due to funding cuts. Lastly, he has a 1:1 Education Tech III at school through special education services. He is completely integrated into the regular kindergarten class.

MT’s daughter, A, was diagnosed with cerebral palsy, Dandy Walker Variant, G-tube dependent, and seizures. When asked if she would like to share any other information, she responded with the following comments.

She needs a lot of help. She’s not able to talk or sit up or walk. Sometimes she has to be on oxygen because she will quit breathing (during seizures). She has to be catheterized five times a day. But, she makes our world go ‘round. She is a really happy little girl as long as she’s not hurting. She smiles and laughs when you play with her.

A receives OT and adapted physical education through the school system and OT, PT, and ST privately. PT services are not offered in her school system. She used to receive direct ST in the school system; however, the ST discharged direct services and provides monthly consultation to A’s special education teacher. “I guess they thought that she would never make any progress or be able to communicate so they quit trying”. She also has a nurse that is hired two afternoons per week.

Results

Interviews were audio-recorded and transcribed verbatim. Transcriptions were reviewed

multiple times with coding of data completed line by line. Recurring topics were grouped into categories and themes were identified.

Themes. Although only three interviews were conducted and one was very brief, common elements were identified. The themes were categorized into perceived attitude of the professional toward the child, communication, desire for the members to listen, and recommendations to the team.

Attitudes. Attitudes that interfere with the parent-professional relationship include “giving up on my daughter,” “the ST doesn’t want to work with her,” “they totally underestimate him,” and “it’s the therapist’s way or the highway.” A positive attitude is paramount to building effective partnerships between parents and professional caregivers. The attitudes of professionals toward the children and parents can positively or negatively affect the parents' willingness to form partnerships with these team members (Cameron, 2018; Kayama, 2010). In the review of research by Kayama (2010), it was found that the attitudes that parents found most beneficial were those of empathy and respect. Parents identified “treating children as if they were their own, being open to asking families for help, making persistent efforts to improve the situation beyond expected duties, and sharing children's perspectives rather than applying preconceptions to children's performances” (Kamaya, 2010, p. 123) as ways of demonstrating an empathetic attitude.

Communication. The mothers repeatedly emphasized the importance of communication in the development of relationships with their children’s professionals. Communication with the parents as well as the children was discussed. Mothers’ comments on communication that they perceived as hindering the relationships consist of “they don’t talk to me or her,” “the paraprofessional doesn’t speak nicely to (S),” and “they think because he’s physically impaired that he can’t communicate, so they don’t interact with him directly.” Two of these children are non-verbal. Parents of children with communication deficits frequently do not get complete

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information about the interventions and interactions of the day (Angell et al., 2009; Cameron, 2018). These parents depend greatly on the reports and comments from the people who interact with their children throughout each day. If they are not receiving any information, they often feel “left out of the loop” as reported by one mother. Open communication, whether about problems or praises, facilitates trust (Angell et al., 2009; Cameron, 2014; Fishman & Nickerson, 2015; Lindblad, Holritz-Rasmussen, & Sandman, 2007; Robert et al., 2015).

Effective Listening. Parents feel encouraged when they have “the opportunity to narrate about their experiences to somebody who listened attentively” (Lindblad et al., 2007, p. 239).

The parents interviewed expressed the same opinions. One mother (MT) said,

Listen, listen, listen to the families, the child, even if the child can't talk, listen to their actions. Take time to really [this word was emphasized] get to know us. Sometimes, I think that her therapists are working on their goals rather than our goals. But, it could be that my goals are unattainable. I don't know where to go or what to strive for. I get down and need to be lifted up and don't feel like I get that very much. Her teacher and aide are very good at bragging on all of the good stuff that A is doing and that makes me feel good.

GM reiterated the need for team members to listen to her family's “story.”

I need someone to listen to my story. My story is so important. And my story teaches people how to interact with us. That's what I want. If I could tell that to the people that work with me, that's what I would say.

Recommendations. CR was asked to give suggestions or recommendations that would make difficult situations better or would improve negative interactions. “You can't ask somebody to change the way they are. People just need to be child friendly.”

GM wanted the professionals that work with D to know:

Our philosophy for our child is that if people listen to our story, the relationship

goes much better. I don't want a soft therapist. I don't want a mean one either. I want someone that provides D with that achievable challenge and makes him really reach for things. D loves that. He loves to show you something new he can do. For the professionals to understand, to listen to someone's story is worth their weight in gold. If you can learn what a person knows then you know where you can step in as a teacher and learn about our relationship and our philosophy. How many professionals really take the time to learn what your philosophy about raising your child is?

MT's recommendations centered around support and encouragement.

When they [service providers] tell me how much they enjoy A and how sweet she is, then they make me feel like I've done something right with her along the way. That positive reinforcement is a blessing. When they get excited about some little gain she's made or something different she's done, it gives me hope that there's still more that we can do. Don't give up on my baby. Don't ever give up. If you are frustrated and don't feel like working with her, then stop. Don't do it if your heart is not in it.

Conclusion

Results from this small study are consistent with findings by Angell et al. (2009) and Fishman & Nickerson, (2015) where parents emphasized the importance of professionals demonstrating caring behaviors, communicating frequently, understanding the child's disability, and shared decision-making to build and maintain trust. Parents of children with disabilities report greater levels of stress related to meeting the needs of their children than do parents of typically developing children (Burton et al., 2018; Hogan, 2012; Ryan, 2018). This in turn impacts their relationships with care providers as they try to navigate through educational and healthcare systems. As evidenced in this study, when parents feel supported by their child's care

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team, they are more likely to be actively involved in the team and develop effective partnerships with the team members. It is imperative for professional caregivers to realize that their attitudes, communication skills, and behaviors affect the relationship with as well as the quality of care provided to the families that they serve.

Limitations

Although, the focus of qualitative research is not to generalize to large groups, the small sample size and reluctance of response by one participant limit the findings. Redundancy of responses was found; however, the author acknowledges that a more diverse group of parents and diagnoses of children could have elicited a greater variance of information.

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Appendix

Interview Questions

Questionnaire:

1. What is your child's diagnosis or areas of difficulty?
2. What support services does your child receive? (i.e. special instructors, therapy services, nursing care, school aide, etc.)

Interview: (*The additional probing questions were used as needed*)

1. Tell me about your relationship with the professionals that work with your child? (ex. "He communicates well with us about our child's progress." or "Her therapist does not seem to have a rapport me.")
 - Describe how these professionals interact with your child.
2. What has been helpful or less than helpful in the relationship with your child's professional?
 - Can you elaborate or give some examples of what makes them easy to work with or difficult to work with?
3. What do you consider the most important needs that you want your child's professional to meet?
 - How well do you feel they are meeting your needs as well as your child's.
4. Certainly, one of the goals of the professionals is to help you feel empowered in your child's care because you know your child and his/her needs best? Tell me how well they are doing at meeting this goal.
 - What positive experiences or contributions have these professionals made in your life or the life of your child?
5. What suggestions do you have that would improve the interactions with these professional?