The Perception of Parents' Participation in Therapy for Children with Communication Disorders

Lan Marberry
Family and Human Services

Faculty Mentor: Karrie Walters
Family and Human Services

Faculty Mentor: Daniel Close
Family and Human Services

Faculty Mentor: Eileen McNutt
Speech Language Pathologist

Introduction and Background

Successful participation in speech and language therapy is essential for the success of many children with communication disorders. Parents have in-depth knowledge about their child's social communication skills, and such knowledge is vital for planning a detailed, personalized, and successful intervention. According to The Individuals with Disabilities Education Act (IDEA), in fall 2003 there were 6,068,802 children in the United States who received services for special needs; of those children, 1,460,583 (24.1%) received services for speech or language disorders (American Speech-Language-Hearing Association, 2008).

Research suggests that parents' active participation in therapy, as a part of treatment, is related to better outcomes for their children's communication development (Hurst, 2010; Justice & Ezell, 2001). Parent

participation also positively impacts social development and schooling innovation (Baxendale, Lockton, Adams, & Gaile, 2013). In the Hurst study (2010), the speech-language clinicians emphasized the benefits of parental participation. In another study, one parent reported that "the speech therapy benefitted me more at the time ... the therapist just explained to me how to deal with each problem, you know, how to help him" (Glogowska & Campbell, 2010, p. 24).

Purpose

Given findings in the literature about the benefits of parental involvement, the purpose of this exploratory, qualitative study was to discover parents' perceptions of supports and obstacles to their participation in speech therapy for their children with communication disorders. The analysis was limited to the parents of children involved with therapy in the Early Childhood CARES program at a communication class in Eugene, Oregon. Questions pertaining to supports and obstacles were designed to elicit responses regarding parental stressors, transportation issues, available resources and supports, faced obstacles, possible additional supports and resources, and participants' current interactions with the speech-language therapist. Responses to the questions provided data for the two components related to the purpose: (a) perception of supports and (b) perception of obstacles.

Method

Qualitative research helps to uncover the viewpoints of participants and their relationship to the world by analyzing the content and context of their responses and any information they might add without prompting (Rossman & Rallis, 1998). Coding interview data leads to the discovery of these points of commonality and an analytical framework. According to Marshall and Rossman (2011), coding is the process of a formal

method of discovering salient themes in a collection of data that allows a researcher to determine general issues from the data. Through the process of open coding, the researcher proceeds line-by-line through interview data, labeling segments of the recorded speech with descriptive characterizations. As more generalized patterns appear, the codes may be linked to each other to form broader concepts. These concepts then inform or help determine the themes (Marshall & Rossman, 2011).

Procedure

Qualitative, semi-structured interviews and surveys offered a way to explore the experience of parents who participate in therapy. The speech-language therapist provided additional information by summarizing each child's progress and describing relationships with parents; therefore, she was a participant to this research. However, the therapist was not present at any of the interviews with parent participants. The data collection was conducted at the Eugene Communication Classroom, where I also was involved in an internship. The relationship and connections at EC CARES added depth and understanding to the data analysis and to the research in general.

Recruitment began by sending a written recruitment letter, along with the preview package, to families with children receiving services at the Eugene Communication Classroom. The first five families who responded and met the criteria were selected. The speech language pathologist at Early Childhood CARES supervised the interview process. At the beginning of the interview, the researcher explained the procedures of the study, the rights of the participants, and reviewed the written consent form to ensure the full comprehension and agreement of each participant. (See appendices A-D for the interview protocols and consent forms.) After a participant agreed to the study and signed the consent form, the researcher continued

by introducing the questionnaire created for this study. The questionnaire examined varying levels of parent interaction and involvement, as well as the home environment for the children with communication disorders. The interview lasted approximately 60 minutes at each child's home or at a location arranged by the interviewer and parents. As the speech-language therapist is the primary teacher in the classroom, she was interviewed to obtain her perceptions of supports and obstacles that impact parent participation in therapy.

Along with the interviews, the children's profiles were reviewed to learn more about each child's background and treatment plan. As part of the consent form, parents gave permission for their child's profile to be reviewed. That form clearly outlined the specific materials to be reviewed in the profile. The children's profiles are located at the communication classroom associated with the study. With the additional permission of the classroom teacher, the researcher could review the children's profiles. The data gathered from ECC included assessment forms and student learning goals provided by classroom teachers. Student's confidential medical information was not collected for this project. After the interview with parents of each child, the researcher reminded them of the need to review their child's profile as part of the learning process. Although parents could withdraw their consent at that point, none did so. Each family received a $30 Target gift card to thank them for their participation in the research project. No additional compensation was part of this study.

Significance of the Study

This study is significant both in practical and academic terms. First, it provides a better understanding of how parents view the resources made available to them and provides insight into their views of obstacles. Administrators and therapists may use the knowledge gained in this study

to adjust the program and better meet the needs of clients. The researcher hopes that knowledge gained from this project will help produce more positive therapeutic outcomes in the future. Second, this study may contribute to a growing body of knowledge about the roles of parents in treatments of children. Research suggests that children benefit from parents who are able to learn from therapists and use therapeutic strategies in the home setting (Baxendale et al., 2013; Glogowska & Campbell, 2010; Hurst, 2010; Roberts & Kaiser, 2011). Some of the results from this study echo these findings.

Limitations

The results are relevant to the Early Childhood CARES program in association with the Eugene Communication Classroom. The primary limitation of the study is that it was not possible to generalize the results associated with the themes of this study to a broader population of families participating in the therapies of their children. Because the results reflect other studies in which the value of transferring therapeutic skills to parents has been supported, analytic generalizations can be made. However, the value of the results are limited to those participating in this specific program.

Demographic Profile of Participants and Therapist

Although socioeconomic status, gender, native language use, and race and ethnicity factors were not examined in the current study in detail, it is helpful to understand some characteristics of the participants and their children. Of the five interviews, four were with single individuals. One interview was conducted with the father and mother present. The four interviews of single parents were with mothers; therefore, five women and one man participated. Two participants did not complete high school, three had high school diplomas, and of those three, one was pursuing a

bachelor's degree at a university. Two participants, both women, were Hispanic and indicated that two languages were spoken in the home. Although bilingual factors were discussed, they were not explored in depth because of the limitations of the data. The other four participants were White and spoke only English. Because all interviews were conducted in English, all participants, regardless of country of origin, had a working command of the English language. One participant indicated that her child was being home schooled, while the children of all other participants were enrolled in some other school or program. All participants indicated that their children had been enrolled in the Easy CARE program between the ages of two and three, and all had been in the program for approximately two to three years. Finally, the therapist was a White female with more than 30 years of experience as a trained speech language therapist.

Data Collection

My established and continuing relationship as an intern with the families and staff of the Early Childhood CAREs served as an important connection for this study in large part because of the proximity and access that I had while conducting the research. Data was collected through qualitative interviews with parents who have children with communication disorder and the classroom teacher, using open-ended questions included on the structured interview guides (Appendices A and B). Information regarding the services was also gathered after permission was granted from the participants in therapy. Interviews required 60 to 90 minutes and took place at a family's home or another predetermined spot. These interviews commenced after the University of Oregon Institutional Review Board approved the research proposal and continued for approximately a month and a half after the study began.

Results

Theme 1: Transfer of Therapeutic Strategies from Therapist to Parent

Four of five participants expressed a strong interest in trying to facilitate the application of speech therapy strategies outside the classroom. They either (a) showed an awareness and interest in specific technical issues related to articulation and in improving their child's speech directly, or (b) expressed a satisfaction with or desire for more therapist-to-parent instruction. For example, regarding (a), P1 stated, "I showed her you need to bite your lip for the 'f' sound." Regarding (b), P4 remarked, "I would like to have more advice on how to improve his [child's] speech." Also, P3 remarked that "one would be telling us how to, like, teach [our child] to speak the right way and explain it." P1 indicated that she had learned to teach pronunciation from the therapist and that it had helped her feel more comfortable conveying the correct information to her child. Taken together, the theme of transference of therapeutic skills to the parent was important. The interview data suggest that there were varying degrees of support in this area, but two parents expressed a strong interest in having more support.

Theme 2: The importance of Outside Support

In their interviews, participants indicated several types of outside support that they felt were helpful, could be added, or could be improved. The specifics of these supports varied greatly from participant to participant. For example, P1 felt a family support group could help exchange ideas and connect with other parents "because sometimes you feel alone in it." She also stated that "communication is great in the classroom, but outside it is difficult for families to connect." Similarly, P2 was enthusiastic about a family support group for parents to exchange information and ideas. In contrast, P3 was more interested in an outside social group for her child to

help him "see that other kids are in a different spot, and it's not just him." Participants P5 and P6, the mother and father of one child, echoed P3's sentiments: "Another group would be great. There are not a lot of kids his age around here." The participants' statements, therefore, indicated support for at least one outside support group that would either assist with the child's socialization or help parents connect with each other to exchange information.

Theme 3: Parental Stress Associated with Emotional Vulnerability at Time of Enrollment

All participants indicated one or more emotions before their child entered the Early Childhood CARES program. After coding the interviews, expressions of stressful emotions emerged and showed that parents felt fear, worry, guilt, and confusion. The examples below illustrate how those emotions emerged.

> P1: [For my child] to be able to say how she was feeling instead of screaming or throwing a tantrum. It took stress off me, so I didn't feel like I was failing as a parent. That was a big stress.

> P4: My most concern ... I felt guilty because my son does not speak too much, and I feel afraid about his self-esteem.

> P6: We were worried. I hated school. I was a little "oh my God" he was going down the same road. I was, "oh my God."

In all instances, parents felt relief to see his or her child's improvement after being enrolled in therapy. Parents did not express stress about the current situation, which suggests the positive effects of the therapy was enough to relieve stress and indicates a positive support through therapy alone. However, the interview data also suggest that parents may need to

receive positive emotional support while their child is enrolled because that is when parents appear to be most vulnerable to negative emotions.

Perspectives from the Speech-Language Pathologist: Intersections with Theme 1

The interview with the speech-language therapist who works with the children of the participants of the study revealed ideas that inform theme 1. The therapist emphasized the importance of the transference of therapeutic strategies to parents. She noted that she and others in similar positions had formal training to help parents and that "we send home material that shows the strategies. We demonstrate the strategies we are working on."

The therapist emphasized a hands-on approach to this transference of strategies. When prompted to provide her view on which resources were important, the therapist said, "I think parents learn a lot by watching our interaction with the kids … we can tell them about the strategies. We can give them handouts about the strategies. But I think that having them see us do it [therapy] with the kids is really what helps communicate the strategy best."

When asked about the biggest obstacle parents faced, the therapist mentioned parents' limited time resources. In order to overcome this problem, the therapist again emphasized the importance of providing parents with tools applicable in the home. "The practice can be built into the routines they are doing at home," she said. Accordingly, whether eating, doing laundry, playing, or dressing, parents can incorporate language lessons into these daily tasks. This integrated approach not only allows parents to take on active roles in support of their child's therapy at home but also allows them to incorporate therapeutic strategies into their busy schedules. Further, the therapist emphasized that children from one to five years of age learn more by engaging in concrete, meaningful

routines compared to more abstract activities, such as pronunciation drills.

Although the therapist and the parents discussed a variety of specific topics during their interviews, both discussed items that informed theme 1. The fact that Theme 1 emerged from both the parent's and therapist's interview data suggests that it is perhaps the strongest shared theme to emerge from the data. The therapist also noted parents might face confusion when the child transitions to kindergarten because the learning process is less intensively centered on the family during kindergarten. The therapists felt elements associated with the transition could function as an obstacle, and her goal was to assist in the transition by actively taking part in the transition.

Conclusion

In a review of 18 studies that examined parent-implementation of speech-language therapy strategies, Roberts and Kaiser (2011) found that parents who learned and applied therapy strategies outside the classroom effectively improved the communication development of their children. Results from the current analysis suggest that both parents and therapist are acutely aware of the importance of parents being able to understand and apply communication strategies outside the classroom. The therapist viewed the primary obstacle as parents' limited time, whereas parents showed mixed perceptions of their understanding of strategies. Two parents desired better understanding of therapeutic strategies, and two other participants indicated some degree of competence when applying strategies. This mixed result suggests that the skills therapists are imparting to the parents constitute a valuable resource, but that resource may not be adequately utilized by parents. One recommendation would be that the Early Childhood CARES program increase emphasis on transference of strategies to parents and make available more strategies that focus on how to teach.

In addition, whereas the therapist focused on the importance of the post-therapy transition of children into kindergarten to ease the stress and confusion of parents, parents indicated that their primary stress occurred as they entered their child in the program. This difference seems to be logically consistent with the fact that participants' children were not yet in a transition, so that the parents' considerations were focused on their current or previous experiences. Theme 2 and the comments of the therapist suggest that most of the stress parents experience is at the time of entrance and after the exit of the child from the program. These results suggest that the program should have processes centered on those two important periods to mitigate potential stress and confusion.

Appendix A

Semi-Structured Interview Protocol: Interview Parents

Introduction: Thank you for taking the time to talk with me today. My name is Lan, and I am conducting a study that looks at your experience and perceptions about your participation in therapy. As we discussed, I will record our conversation. Is it okay if I turn on the recorder now? [Start recording] If I ask a question that you are uncomfortable answering, you can say, "skip it" or "ask me later." We can end our conversation at any time. At the end of our conversation, I will give you a $30 Target card as a thank you for helping with this study. This is a onetime compensation; it will be given to you at the end of our conversation even if you wish to withdraw before completing the interview. Do you have any questions before we get started? [Answer questions, if any.]

Let's get started by talking about you and your child.

Basic Information

1. How old is your child?
2. How many children do you have under your care?
3. How long does it take you to travel to the Eugene Hearing and Speech Center?
4. How long does it take you to travel to the speech-language-hearing clinic?
5. How old was your child when you first became concerned about his/her speech or language development?
6. How long has your child received services from the Early Childhood CARES?
7. Does your child receive speech or language services from additional sources (other school speech-language pathologist, private clinician)? If so, what services?

8. What is your highest level of education completed or received? If currently enrolled, what is the highest level attended or degree received?
9. Can you briefly explain the main reason(s) that your child is receiving treatment?
10. Does your child have an Individualized Education Plan (IEP)/Individualized Family Service Plan (IFSP)? If so, how often do you attend your child's IEP/IFSP meetings?
11. What are the main stressors that you and your family face as you cope with children who have communication disorders?
12. What are the main obstacles that hinder your participation in therapy?
13. What are the supports and resources that currently help you to participate in therapy?
14. What additional support or resources do you feel would help you to participate more actively in therapy?
15. How do you currently work with speech language pathologists to help your children with communication at home?

Appendix B

Semi-Structured Interview Protocol: Interview Teacher/therapist

Hello, [teacher] Ms.Eileen McNutt; thank you for your time and support for participating in my research. I am seeking your comments to complete each student's information. There is no direct benefit from this interview. All information from the interview, including audio recordings, will be kept in locked file at Eugene Communication Classroom until it is transcribed and converted to Electronic files. Those files will be kept on a password protected flash drive, saved in password-protected document, and kept in a locked filing cabinet at EC Cares. The researcher and staff will have access to the data. If you have any questions, please stop me anytime during our interview.

1. How long have you worked with children who have communication disorders?
2. What are the teaching and training methods that help your students and their parents achieve their goals?
3. How often do you communicate with the parents of your students?
4. What obstacles do you face as you seek to engage a parent's participation in therapy?
5. What resources do you think are most helpful for the families?
6. Do you have time and funding to help the children to continue their education?
7. What are the various ways you involve parents in therapy?
8. How do you overcome obstacles that the parents may experience?
9. How do you learn about a parent's needs and possible obstacles?
10. As a teacher/therapist, what suggestions would you offer to policy makers to help improve the lives of children with communication disorders?

Appendix C

CONSENT TO TAKE PART IN STUDY: Parents

Invitation: I invite you to participate in an interview as part of a research study conducted by Lan Marberry, a student from the University of Oregon's Family and Human Services Program. The purpose of the study is to learn about your experiences participating in therapy for your child with communication disorders. There is no direct benefit for participating in this research. All information from the interview included audio recordings will be kept in a locked file at Eugene Communication Classroom until it is transcribed and converted to electronic files. Those files will be kept on a password protected flash drive, saved in password-protected document, and kept in a locked filing cabinet at EC Cares. The researcher and staff will have access to data. I am inviting you to participate in this study because your child is currently receiving intervention or has received services in the past with the Early Childhood CAREs.

What are you being asked to do?

1. Participate in one 60 minute interview with a researcher for this study. There is no cost to participate in the study. You do not have to answer any questions that make you feel uncomfortable.
2. Allow the researcher access to your child's profile at EC Cares for the following specific information: diagnosis, intake report, treatment plan.

What are the risks in participation? This research involves only minimal risks. One potential risk to you for participating in this research study is possible discomfort when discussing issues about obstacles your family may have faced. Another potential but minimal risk is a possible breach of confidentiality. However, there will be no physical risk in this study.

What are the benefits of this research? Participating in this research gives you a unique opportunity to share your experiences about supports and obstacles you have experienced at EC Cares. At the end of this study, this researcher will provide EC Cares with a summary of the reported supports and obstacles, with all information integrated and names and identifying information removed This summary has the potential to improve services at EC Cares and help EC Cares better meet the needs of families. Your participation will also help improve future supports and help future parent participants. By talking with us, you will help give a voice to an often-underrepresented population.

Will others know what you say? No. We will audio record and type the interview for study. When we type the interview, we will use "participant #1," "participant #2," and so on to protect your identity. We will not connect your name to any comments you make during the interview. We will use the designated number if we quote you or use your comments. We will delete the audio recording after transcribing the interview. We will keep the interviews confidential.

How is my information protected and how will it be used? All information from the interviews, included audio recordings, will be kept in a locked file at Eugene Communication Classroom until it is transcribed and converted to electronic files. Those files will be kept on a password protected flash drive, saved in a password-protected document, and kept in a locked filing cabinet at EC Cares. Only research staff will have access to the data. All identifying information will be removed from the data, and the data will be destroyed 6 months after the interview with parents. Only de-identified data will be reported in any documents or presentations developed from this research.

Can I withdraw my participation? Yes. Your participation is voluntary;

you may withdraw participation at any time during the study. You will receive a $30.00 gift card even if you withdraw from the study early.

If you have any questions? Please contact the researcher Lan Marberry at (408)-338-9294. You may also contact my faculty supervisors Karrie Walters at (541)-346-5176 or teacher Eileen McNutt at (541) 684-5603. If you have questions regarding your rights as a research subject, call the Research Compliance Services, at the University of Oregon, Eugene, OR 97403, (541)-346-2510. This office oversees the research to protect your rights and is not involved with this study.

By giving verbal consent, you are saying that you:

- ☐ Have read and understand the information above.
- ☐ Willingly agree to be interviewed.
- ☐ Willingly agree to have your interview audio recorded.
- ☐ Willingly agree to allow access to your child's profile at EC Cares.
- ☐ May withdraw your consent at any time.
- ☐ May discontinue participation without penalty.
- ☐ Received the compensation for participating.
- ☐ Received a copy of this form.
- ☐ Are not waiving any legal claims, rights, or remedies.

Parent's signature _____ Date

Witness _____ Date

I agree for my interview to be audio recorded and to be used for research purposes as described above. I understand that the recording will be destroyed in six months.

Parent's signature _____ Date

Witness _____ Date

Appendix D

CONSENT TO BE INTERVIEWED: Teacher/ therapist

Invitation: I invite you to participate in an interview as part of a research study conducted by Lan Marberry, a student from the University of Oregon's Family and Human Services Program. The purpose of this study is to learn about parents' participation in therapy for their children with communication disorders. I am inviting you to participate in this study because your students received services in the past with the Early Childhood CAREs.

What are you being asked to do? Allow 60 minutes of your time to participate in an oral interview with a researcher for this study. There is no cost to participate in the study. You do not have to answer any questions that make you feel uncomfortable.

What are the risks of being interviewed? Any research may involve minimal risks. One potential risk to you for participating in this research study is possible discomfort when discussing issues about obstacles your family may have faced. Another minimal risk is a possible breach of confidentiality. However, there will be no physical risk for participating in this study.

How is my information protected and how will it be used? All information from the interview including the audio recording will be kept in a locked file at Eugene Communication Classroom until it is transcribed and converted to an electronic file. That file will be kept on a password protected flash drive, saved in password-protected document, and kept in a locked filing cabinet at EC Cares. Only research staff will have access to the data. All identifying information will be removed from the data and data will be destroyed 6 months after the interview with parents. Only de-identified data will be reported in any documents or presentations

developed from this research.

What are the benefits of this research? Your assistance will help the researcher collect complete information about each student. The study may provide insights that benefit your understanding of the effectiveness of your work and help professional to improve the services they offer to parents who have children with communication disorders. By talking with us, you will help to give a voice to an often-underrepresented population.

Can I withdraw my participation? [Yes.] Your participation is voluntary; you may withdraw participation at any time during the study.

If you have any questions? Please contact the researcher, Lan Marberry, at (408)-338-9294. You may also contact my faculty supervisors Karrie Walters at (541)-346-5176. If you have questions regarding your rights as a research subject, call the Office for Research Compliance Services, at the University of Oregon, Eugene, OR 97403, (541)-346-2510. This office oversees the research to protect your rights and is not involved with this study.

By giving verbal consent, you are saying that you:

- ☐ Have read and understand the information above.
- ☐ Willingly agree to be interviewed.
- ☐ Willingly agree to have your information from your interview be used in writing.
- ☐ May withdraw your consent at any time.
- ☐ May discontinue participation without penalty.
- ☐ Received a copy of this form.
- ☐ Are not waiving any legal claims, rights, or remedies.

Teacher's signature _____ Date

Witness _____ Date

I agree for my interview to be audio recorded and to be used for research purposes as described above. I understand that the recording will be destroyed in six months.

Teacher's signature _____ Date

Witness _____ Date

References

American Speech-Language-Hearing Association. (2008). Incidence and prevalence of communication disorders and hearing loss in children – 2008 Edition. Retrieved from http://www.asha.org/research/reports/children/.

Baxendale, J., Lockton, E., Adams, C., & Gaile, J. (2013). Parent and teacher perceptions of participation and outcomes in an intensive communication intervention for children with pragmatic language impairment. *International Journal of Language Communication Disorders, 48* (1), 41-53. doi: 10.1177/1525740110384131

Glogowska, M., & Campbell, R. (2000). Parent views of involvement in pres-school speech and language therapy. *Communication Disorders Quarterly, 33*(2), 96-110.

Hurst, N. (2010). Parental participation in speech and language therapy (Master's thesis). Available from ProQuest Dissertations and Theses database. (UMI No. 1480981)

Justice, L.M., & Ezell, H.K. (2001). A needs assessment: Perceptions and Practice of student speech-language clinicians regarding parental involvement. *Contemporary Issues in Communication Science and Disorders, 28*, 64-73.

Marshall C., & Rossman, G. B. (2011*). Designing qualitative research* (5th ed.). Thousand Oaks, CA: Sage.

Millard, S.K., Nicholas A., & Cook F.M. (2008). Is parent-child interaction therapy effective in reducing stuttering? *Journal of Speech, Language and Hearing Research, 51*(3), 636-650.

Roberts, M., & Kaiser, A. (2011). The effectiveness of parent-implemented language intervention: A meta-analysis. *American Journal of Speech-Language Pathology, 20*, 180-199.

Rossman, G. B., & Rallis, J. (1998). *Learning in the field: An introduction to qualitative research* (3rd ed.). Thousand Oaks, CA: Sage.