2020

Caregivers' Perceptions of SLP Talk about Child Language and Literacy Disorders

Karmen Porter Ph.D.
Fort Hays State University, klporter@fhsu.edu

Janna B. Oetting
Louisiana State University at Baton Rouge

Loretta Pecchioni
Louisiana State University at Baton Rouge

Recommended Citation

Porter, K.L., Oetting, J.B., & Pecchioni, L (2020). Caregivers' perceptions of SLP talk about child language and literacy disorders. American Journal of Speech-Language Pathology. https://doi.org/10.1044/2020_AJSLP-20-00049

Caregivers' Perceptions of SLP Talk about Child Language and Literacy Disorders

Karmen L. Porter (Corresponding Author)
Department of Communication Sciences and Disorders
Fort Hays State University
Hays, Kansas
(785) 628-4453 (office)
klporter@fhsu.edu

Janna B. Oetting
Department of Communication Sciences & Disorders
Louisiana State University
Baton Rouge, Louisiana

Loretta Pecchioni
Department of Communication Studies
Louisiana State University
Baton Rouge, Louisiana

The authors do not have any conflicts of interest to report.

This research was supported by funding from the Faculty Summer Research and Creative Activity Grant at Fort Hays State University awarded to Karmen Porter.

Abstract

Purpose: This study examined caregiver perceptions of their child's language and literacy disorder as influenced by communications with their speech-language pathologist (SLP).

Method: The participants were 12 caregivers of 10 school-aged children with language and literacy disorders. Employing qualitative methods, a collective case study approach was utilized in which the caregiver(s) of each child represented one case. The data came from semi-structured interviews, codes emerged directly from the caregivers' responses during the interviews, and multiple coding passes using ATLAS.ti software were made until themes were evident. These themes were then further validated by conducting clinical file reviews and follow-up interviews with the caregivers.

Results: Caregivers' comments focused on the types of information received or not received, as well as the clarity of the information. This included information regarding their child's diagnosis, the long-term consequences of their child's disorder, and the connection between language and reading. While caregivers were adept at describing their child's difficulties and therapy goals/objectives, their comments indicated that they struggled to understand their child's disorder in a way that was meaningful to them and their child.

Conclusions: The findings showed the value caregivers place on receiving clear and timely diagnostic information, as well as the complexity associated with caregivers' understanding of language and literacy disorders. The findings are discussed in terms of changes that could be made in clinical practice to better support children with language and literacy disorders and their families.

Key words: caregivers, SLP communication, language disorders, literacy disorders, diagnostic labels, dyslexia, SLI, DLD

Caregivers' Perceptions of SLP Talk about Child Language and Literacy Disorders

As professionals who diagnose, treat, and support individuals with communication disorders and their caregivers, speech-language pathologists (SLPs) must frequently communicate with clients and their caregivers in a manner that encourages trust and collaboration (ASHA, 2004; 2005; Hand, 2006; Walsh, 2007). However, practices that truly integrate client values and encourage collaborative decision making require mutual understanding among all parties (Berger, 1997). In the context of speech and language assessment and intervention, effective SLP communication requires not only communicating clearly, but also seeking to understand how the communication is received and interpreted.

A growing number of studies have focused on the communication practices of SLPs (e.g., Burns et al., 2012; Ferguson & Armstrong, 2004; Fourie, 2009; Hand, 2006; Hengst & Duff, 2007; Hester & Stevens-Ratchford, 2009; Leahy & Walsh, 2008; O'Malley, 2011; Simmons-Mackie & Damico, 2009, 2011; Stone, 1992; Stoner, et al., 2006). For example, Simmons-Mackie and Damico (2009) explored how a clinician's communication practices can encourage group member engagement in aphasia groups, and Stone (1992) presented two case studies illustrating how changes in clinical interactions can influence the clinician-client relationship. A common theme across these studies is that SLPs must think about how they build relationships with clients and not just what kind of evaluation or treatment approach they are providing. While these studies provide a good start to the discussion, none directly examined how SLPs share information with clients/caregivers, or how the clients/caregivers perceived the communication practices of SLPs. Client/caregiver perspectives are a key component of evidence-based practice (EBP) – a practice that requires the integration of known research, clinical expertise, and client perspectives in the decision-making process (Hidecker et al., 2009). Given this, the lack of studies examining the perspectives of client/caregivers constitutes a significant gap in the literature and hinders the application of EBP.

One recent study by Ash, et al. (2020) did explore caregivers' understanding of their children's language disorders, as well as the role SLPs played in developing their knowledge. Results indicated that caregivers' perceptions of their SLPs were not always positive, especially when they felt they were not given sufficient information or information that was too complex. These results resonate with previous studies that show satisfaction in healthcare to often be tied to perceptions of the providers' communication (e.g., Brown et al., 2003; Donovan et al., 2005; Propp et al., 2010; van Zanten, et al., 2007; Wanzer et al., 2004). For example, Wanzer et al. (2004) found a strong positive relationship between the amount of communication behaviors perceived by the patient to be patient-centered and the patient's overall satisfaction with the medical care their children received. Furthermore, Ash et al.'s (2020) results remind us that sharing information does not always mean it is understood. In another study, caregivers' understanding of children's growth charts were examined (Ben-Joseph et al., 2009). Although 64% of the caregivers surveyed believed doctors should use charts to show them how their child was growing, only 8% correctly interpreted a set of hypothetical charts showing children's heights and weight. Studies by Ash et al. and Ben-Joseph et al. illustrate the importance of further examining caregiver perceptions of SLP communication behaviors, as well as the need to identify communication strategies that clients/caregivers consider effective.

To better understand the client/caregiver's perspective, it is also important to recognize the role of family systems. Per family systems theory, individuals exist within a larger interdependent system of family and community that influences how one perceives messages from other individuals. Thus, to communicate effectively with caregivers, SLPs must be sensitive to the role of previously established family attitudes and beliefs in the caregiver's interpretation and understanding of the communicative interaction (Pecchioni & Keeley, 2011). The level of understanding and clarity required to establish a productive relationship varies depending on the client/caregiver's age, needs, and desire for information. However, having an appropriate knowledge base of the communication disorder being treated is an important first step for the client/caregiver and SLP to be able to engage in an effective collaborative relationship (Crais, 2006; Woods et al., 2011).

Childhood Language and Literacy Disorders

Children with language and literacy disorders present with complex linguistic profiles. When children are young, their profile is often characterized by weaknesses across semantic, morphosyntactic, narrative, and phonological skills, and as they age, their profile can evolve to include weaknesses in literacy (Leonard, 2014; Paul et al., 2017; Schwartz, 2017). Even children who appear to recover from early language delays, such as late talkers, are more likely to encounter difficulties upon entering school and beginning formal reading instruction (Rescorla, 2002; Scarborough, 2001). Relationships between children's early oral language disorders and later literacy disorders are not surprising as many oral language abilities have been found to be essential for supporting reading, writing, and spelling (Seidenberg, 2018). As with oral language disorders, there is heterogeneity in children's literacy disorders. Even when the focus is on reading disorders only, some children demonstrate poor reading comprehension, others present with poor word decoding, and still others present with difficulties in both areas. (e.g., Adlof & Hogan, 2018; Catts et al., 2005; Catts et al., 2006; Catts, Fey, Tomblin, & Zhang, 2002; Saletta, 2018). Children classified as poor comprehenders consistently present with weak oral and written language skills in comparison to their peers with typical reading skills. Still, many are not identified as impaired until they begin to struggle with formal reading instruction (Petscher et al., 2018). Children who demonstrate good comprehension skills, but struggle with poor word recognition skills, are often identified as poor decoders, or children with dyslexia (Alt et al., 2019; Catts et al., 2003). They also may not be identified until their difficulty with reading and spelling becomes apparent, as they often present with standardized oral language scores within the typical range. However, studies show that as a group, poor decoders (8-9 years) are still likely to perform below their typical peers on oral and written language tasks, suggesting that as whole, language skills are an ongoing concern for all children with literacy disorders (Adlof & Hogan, 2018; Saletta, 2019).

Given this, when children present with a language and literacy disorder, the SLP must determine the best information to share with caregivers. The applicable information may vary depending upon the child's particular linguistic profile, the child's age, the newness of the diagnosis for the caregivers, and the SLP's understanding of the caregivers' knowledge about children's language and literacy disorders. Further complicating the SLP's communications with caregivers are the many diagnostic labels that are used to describe these children's psycholinguistic profiles, including but not limited to receptive and/or expressive language impairment, developmental language disorder, and specific language impairment for oral language deficits (Bishop et al., 2017; Leonard, 2014; Paul et al., 2019; Rice & Warren, 2005; Schuele & Hadley, 1999; Van Horne et al., 2018; Volkers, 2018) and learning disability, dyslexia, reading comprehension deficit, and mixed reading disorder for reading deficits (Catts et al., 2006; Dollaghan et al., 2012). The work setting (e.g., school, rehab center, early intervention) or function being served by the label (e.g., billing, diagnosis vs. eligibility, qualifying disability for individualized education plan [IEP]) also influences the SLP's communication practices with caregivers (American Psychiatric Association, 2013; IDEA 04; ICD-10-CM/PCS: World Health Organization, 2015).

Purpose and Research Questions

The purpose of the current study was to learn more about how SLP communication is perceived by caregivers of children with language and literacy disorders. Relatively few studies in the literature have examined the interpersonal practices of SLPs who work with children, and only one study by Ash et al. (2020) focused on how SLPs communicate with caregivers about childhood language disorders. The EBP process requires that SLPs integrate not only clinical expertise and research evidence, but that they also consider client values and perspectives. This study will add to what SLPs know about how caregivers of children with language and literacy disorders perceive their communicative experiences with SLPs, and provide a framework for enhancing SLP awareness of their own professional communication strategies.

As an exploratory study, no specific aspect of SLP talk was specifically targeted. Instead, this study employed a qualitative research design, and sought to discover from the caregivers what types of information they recalled receiving from SLPs regarding their child's language and literacy disorder, and how they understood and interpreted that information. The following research questions were addressed:

1. What information do caregivers describe receiving from SLPs regarding their child's language and literacy disorder?
2. How do caregivers describe their understanding of their child's language and literacy disorder?

Methods

The study was approved by the Louisiana State University Institutional Review Board and the Fort Hays State University Institutional Review Board. Consent was obtained from all participants prior to the study. In addition, the Consolidated Criteria for Reporting Qualitative Research (COREQ) was used as a guide for reporting methodology and results (Tong, Sainsbury, & Craig, 2007).

Participants

Participants were caregivers of a school-age child diagnosed with a language and literacy disorder and who had been evaluated at a Midwestern university clinic within the past 1 – 1 ½ years. All participants were native English speakers, part of the household in which the child primarily or jointly resided, and active in decisions about the child's care/education. At the time of the study, ten families connected with the clinic met these criteria, and 12 caregivers from these families agreed to participate. Eight family units consisted of one primary caregiver participating in the interview and two family units consisted of two caregivers participating (one set together and one set in separate interviews). All caregivers were White/Caucasian and came from a variety of educational and occupational backgrounds, with four working in healthcare related fields and two having or working towards education degrees (see Table 1). Each caregivers' level of experiences with SLPs varied, ranging from one experience with an SLP at the university clinic to multiple experiences over time with early intervention SLPs, school-based SLPs, and university clinic SLPs. As Table 2 delineates, each child's path to being diagnosed with a language-based literacy disorder varied depending on the initial presenting concerns. For example, one caregiver worked with several educators and special educators at her child's school, but never communicated with an SLP about her daughter's reading difficulties until she was referred to the university clinic. In contrast, another caregiver whose child presented with communication concerns early on, communicated with several SLPs over the years as her child transitioned from early intervention services, to pre-school services, and to school-based services, before she sought out additional services at the university. Despite these differences, each caregiver had the common experience of having a child with a diagnosed language-based literacy disorder.

The participants' children ranged from 8 to 16 years (see Table 3). Each child's developmental history and diagnosis was obtained from the university clinic report. Three of the participants were identified as late talkers and had received early intervention services. The remaining seven were identified as they began to have difficulties in school with reading and spelling (two had a documented IEP) prior to their evaluation at the university clinic, one had participated in title one reading services, and four were in the process of qualifying for either IEP or 504 services). All were enrolled in school (8 public; 1 private; 1 homeschooled) and had a documented language-based literacy disorder from the university clinic evaluation. Six of the children received individual or group intervention services for varying periods of time from the clinic; and at the time of the interviews, all children were receiving services from either the university clinic, their school, or both to address their language and literacy difficulties. While the children and adults in this study were heterogeneous in nature, each of their caregivers had one or more experiences receiving information from an SLP about their child's language and literacy disorder.

Procedure

Following the methods of previous qualitative studies, the data were collected via semi-structured participant interviews (e.g., Angell et al., 2009; Ash et al., 2020; Fourie, 2009; Fourie et al., 2011; Lyons & Roulstone, 2018; Shelden et al., 2010). Unlike online questionnaires or surveys, the semi-structured interview allows the examiner to ask follow-up questions to check for understanding and interpretations of meaning with participants (Kvale, 1996). Each interview represented a single unique case, which was then examined collectively to better understand what was common across caregiver experiences and perspectives (Stake, 2005).

Interviews

All semi-structured interviews were conducted in person (university clinic = 4, caregiver's home = 7) by the first author, an experienced SLP and clinical educator within the university clinic. For all but three interviews, only the first author and the participant(s) were present. For two interviews, a female graduate student was present with the participants' permission, and for one interview, the participant chose to answer questions in her living room while watching children in her care. Beyond clinical expertise in the area of language and literacy disorders, the first author, a PhD student at the time of the interviews, had completed course work in qualitative methods and health communication studies and conducted a pilot study using semi-structured interviews with caregivers from a different university clinic (Porter, 2013). Three of the family units were minimally known to the first author prior to the study through contact within the clinic; the others were solicited through the university clinic.

During the interview, caregivers were asked questions regarding their child's speech-language evaluation(s), their conversations with their SLP regarding the evaluation results, their understanding of the written report(s) they received, and their impressions of their child's current status, as well as their hopes for the future. As each interview was conducted, the interviewer made requests for clarification or additional information as necessary (e.g., "so you are saying, if somebody reads a story to him he seems to be able to comprehend it"). First author observations and notes were made throughout the interview process, and all initial interviews were audio recorded and transcribed verbatim to ensure accuracy of the provided information. The interviews ranged from 30 to 70 minutes in length.

File Reviews

Per caregiver consent, the first author also reviewed each child's university file/documents. This consent allowed the first author to review previous evaluations, reports, and progress notes, as well as demographic and social information. The files served primarily as a source for data verification.

Follow-up Interviews

Follow up interviews with nine of the original participants took place a few months following the initial interview. Caregivers were provided a written transcript of their initial interview prior to the follow up interview and were asked to review it. During the follow up interview, the first author asked any follow up questions that were needed, shared basic themes or ideas that had stood out in a caregiver's interview, and asked the caregiver(s) to provide any additional information they would like to share. The follow up interviews lasted 15 to 30 minutes and were conducted either in person or on the phone. The follow-up interviews were not transcribed.

Data Analysis

To ensure reliability of the transcripts, each transcript was reviewed three times, two times by two different graduate students, and one time by the first author. Additionally, the first author took notes during and after each interview, documenting observations of the participants and overall interactions. The research questions drove the analysis, leading the first author to focus on caregiver references to how they perceived SLP communication regarding childhood language and literacy disorders. The analysis consisted of three general phases, including data condensation, data display, and conclusion drawing/verification (Miles, Huberman, & Saldana, 2014).

Data condensation included the first author's process of selecting, simplifying, and transforming the obtained data. This phase involved creating and assigning codes to the caregivers' responses to identify categories and themes within the data. Using the qualitative program ATLAS.ti (www.atlasti.com), the first author reviewed each transcript, creating both codes that emerged from the caregivers' comments (e.g., poor memory, focus on speech) and codes that related to the literature review (e.g., diagnosis, long-term outcomes, oral language-reading connection). After reviewing each transcript, over 150 codes were created. Then, the first author narrowed these codes down to 59 (see Appendix B) through merging repetitive codes and deleting codes that did not directly relate to the research questions. To ensure reliability of the coding process, a graduate student was trained in the process of adding codes to the transcripts and given ~10% of the coded transcripts, as well as a list of the 59 codes. The first author's coding and the student's coding reached a satisfactory level of agreement achieving a Cohen's kappa of .84 (95% CI, .76 to .91), $p < .001$. Items on which the coders disagreed were discussed between both coders until agreement was reached.

The data display phase made use of the ATLAS.ti network feature. Specifically, the first author used this software to visually display and examine connections between codes and adjust categories both within and across transcripts (see Figure 2). Using the networking feature, the first author identified several general themes that consistently presented themselves across the caregivers. Six of those themes are presented here as they were the most pertinent to the research questions.

Finally, to draw conclusions and verify the conclusions, the first author utilized two strategies: triangulation and member checking (Miles, Huberman, & Saldana 2014). Triangulation involved obtaining multiple independent measures, including audio recordings and transcripts of each interview, detailed notes from the interview sessions, and reviews of each child's clinical file. With triangulation, several of the caregivers' responses suggested overlapping and consistent experiences and feelings, and the inconsistent or conflicting experiences shared by a caregiver(s) tended to reinforce the general perceptions rather than weaken them. For example, a negative experience with descriptions of what did not happen (e.g., no diagnosis was given) tended to strengthen the importance of what did happen when the experience was a positive one (e.g., a clear and understandable diagnosis was given).

Member checking occurred through confirming the first author's conclusions with the study participants. The first author did this by regularly checking for understanding throughout the interviews, restating participant comments, and directly asking participants to confirm the first author's interpretation of their comments. As noted earlier, the first author also set up follow-up interviews with the caregivers. All who participated in these interviews indicated agreement with the demographic information collected, the accuracy of the transcriptions, and the first author's interpretation of their interview responses. Four of the caregivers added additional details that they had recalled after reviewing the transcript.

Results

When examining the caregivers' interviews, several key themes emerged that related to the type and quality of information they received from the SLPs (Research Question 1) and their understanding of their children's language and literacy disorders (Research Question 2). All caregiver responses were aggregated across experiences. While experiences varied and caregivers with more frequent experiences communicating with SLPs were often able to provide a more historical perspective than others, as well as more comparative examples over time that highlighted key perceptions, the general themes identified in this study were consistent across participants. Moreover, when caregivers presented a unique experience related to an SLP interaction, that interaction often did not relate to the research questions. For example, one caregiver was raising another child with Autism, and another was the primary caretake for her brother with special needs. Due to these familial relationships, both had previous experiences interacting with SLPs. Nonetheless, individual differences across caregivers did not contradict the general agreement found across participants in describing their perceptions of SLP communication in the context of their child's language-based literacy disorder.

Information Caregivers Reported Receiving from SLPs

As a whole, caregiver perceptions of SLP communication focused on the types of information they received or did not receive and the clarity and understandability of the information given. In examining what information caregivers recalled receiving from SLPs, three overall themes emerged: caregivers valued a diagnostic label, information given about long-term consequences was lacking, and caregivers equate the quality of their experiences with their perception of the quality of information shared.

The Value of a Diagnosis

From the caregiver's perspective, the diagnosis was the most sought-after information. When asked what information had been shared with them, caregivers universally focused first on whether or not they had received a clear diagnosis.

> "They [SLP team] said she definitely had dyslexia." (Mrs. G)

> "I don't remember a degree being given at that point in terms of mild, moderate, severe but I remember it being dyslexia is what we [SLP team] are looking at here." (Mrs. C)

> "They would not label him…it was just oh well he might have this issue." (Mr. B)

> "There was never - I don't think any - and I still don't know that I know for sure what." (Mrs. D)

Whether they believed they had or had not received one, caregivers emphasized the importance of a diagnosis. As Mrs. G put it, "as a parent you want to know."

The reason the diagnosis was so valuable varied among caregivers. For Mrs. A, the diagnosis validated her concerns.

> "I got the paperwork saying you know this is the level she's at, and I really liked seeing that because we knew she was low but at least we had it documented. We have family members that aren't accepting this whole thing, and so it's black and white and here it is."

For Mrs. C, a diagnosis meant access to resources she had been seeking.

> "Having a diagnosis, I was able to walk into a new school and show them, and there was no longer a fight. It was ok, this is what we need to do."

Even when a diagnosis was given though, it did not ensure that it was understood, especially if the label was unfamiliar to the caregiver. Dyslexia was the most commonly identified diagnosis by caregivers. The five caregivers whose children received a dyslexia diagnosis (and had the label dyslexia in the report) all recalled and reported the diagnosis of dyslexia accurately, suggesting that they felt comfortable with the label. In contrast, the second most common response caregivers gave when asked about their child's diagnosis was "I still don't know". Four caregivers of the children who received a more complex diagnosis (e.g., mixed reading disorder, reading comprehension deficit) demonstrated a lack of awareness of the given diagnosis or reported conflicting diagnoses. For example, Mrs. F, who was unsure about the overall diagnosis tried to recall the report, "I know there's something in there about the dyslexia." However, per the speech and language report, her daughter "exhibits a reading comprehension deficit characterized by difficulty recalling information from a text, answering questions, and incorporating important details." No mention was made of dyslexia in the report.

It was also notable that multiple caregivers did not consider a "speech and/or language delay" a diagnosis. Three caregivers in particular, whose children had received early intervention services elaborated on this idea.

> "No I don't think he was diagnosed with anything at the time… Just a delay in speech and language" (Mr. & Mrs. J)
>
> "They just told us that he had a speech delay. That's all they told us." (Mrs. B)

Mr. and Mrs. J, and Mrs. B further reported that terms like 'delay' or 'a little behind' led them to believe that there wasn't really anything wrong with their child or that a few months of intervention would help their child 'catch-up'. The lack of clarity these caregivers experienced with the term "delay" connected closely with another theme that was prevalent, incomplete information about a child's prognosis.

Incomplete Information about Long Term Outcomes/Consequences

As a whole, caregivers believed that certain topics were not adequately addressed or made clear to them. In particular, caregivers reported receiving minimal information about the long-term outcomes/consequences associated with their children's language delays or disorders. Mrs. A expressed that her daughter's future was a regular topic of conversation between her and her husband, "You know honestly we just don't know where her future is at this point. We are hoping we get more understanding and more language out of her and more reading…We talk about that a lot." Other typical responses from caregivers, when asked if information had been given to them about possible long-term outcomes, included:

> "Not that I recall." (Mrs. E)
>
> "Nothing." (Mrs. A)

"No, it was kind of more like just more you know keep working and trying." (Mr. J)

The lack of clear prognostic information was particularly highlighted in two cases involving late talkers. Neither Mr. and Mrs. B nor Mr. and Mrs. J, the children's parents, recalled receiving any cautions regarding their sons' futures. Mrs. B shared that she believed her son would outgrow the issue, stating "I mean they just told us, get him started and surely you know a lot of kids you know overcome it you know by the time they're in kindergarten, first grade, that they're you know on board with everybody else." When asked if she sought out any other resources, Mrs. B responded, "I didn't just because I think I thought oh this is just a minor thing we're just gonna blowover. So, I just thought oh with a little extra help before school starts, we'll be good to go." Mr. B agreed, saying he thought at the time, "He'll get over it."

Mrs. J described a similar experience, saying that she had not been given any information about future concerns. Her son, who was dismissed from speech services right before kindergarten, was re-enrolled in speech services about a year later. Mrs. J noted that at the time of dismissal, she had not realized that there still might be potential concerns:

> "I wish the speech lady would have said you know Mom he's met this goal now but you know in the future sometimes we see blank blank; and that you know don't be afraid to reach out and this is how you do it."

A few of the caregivers did report receiving some long-term information, but the majority of their examples occurred after years of intervention rather than early on. Mrs. J said that her son's IEP team, specifically the principal, had shared with her and her ex-husband that their son's learning disability was a long-term diagnosis, "He actually sat down with Mr. J and was like Mr. J he has a true learning disability, it's not gonna go away."

At least five of the caregivers noted that it was not until they understood that their child was not going to 'outgrow' their speech and language difficulty that they became truly open to seeking out help for their child. For example, Mrs. A said, “I knew I can’t get her past it and so I knew I needed to reach out and find help somewhere.” Ultimately, even if it was hard to hear at first, caregivers wanted to know about future concerns and challenges that their children might face, so they could be prepared.

Given that all of the children had been diagnosed with a language-based reading disorder, one of the long-term consequences of a language impairment, caregivers were specifically asked during the interview about any information they had received regarding the connection between language and reading. At least four caregivers reported minimal to no conversations about the language and reading connection, especially early on.

> “No um no I never remember that conversation [about language connecting to reading].” (Mrs.J)
>
> “I don’t [recall having a conversation about reading and language].” (Mrs. C)

Seven caregivers said they recalled a connection between language and reading being mentioned but could not remember what had been shared. For example, Mrs. G responded, “Yeah I know she did some [discuss language and reading connection].” When asked if she remembered anything about the conversation, Mrs. G responded, “Not really.” Mrs. G’s response exemplified a typical response from the rest of the caregivers, who recalled the topic being addressed but could not recall details. Therefore, even when the information was given, there appeared to be a lack of recall on the caregivers’ part, suggesting that further information and follow up may be needed for most caregivers. Furthermore, this was one of the few areas where there was a noticeable pattern of difference between SLP settings.

In contrast to the lack of information caregivers reported receiving regarding diagnostic labels and long-term outcomes, all caregivers described receiving an abundance of information about the speech and language services provided for their children, even referring to specific goals and objectives that had been shared with them by their SLP. For example, Mrs. A shared a recently updated goal for her child, “She can do one step and two step directions, [child] can, but at three steps it’s completely - It’s gone. So yeah three - they’re gonna start working with her on the three step directions.” This perception of being informed was very important to how the caregivers viewed their child’s overall services and their experience with the SLP, although information about service provision did not help the caregivers understand their child’s diagnosis, long-term outcomes, or the relation between children’s oral language abilities and reading.

Quality of Experience Equates with Caregivers’ Perception of Information

The caregivers placed a high value on receiving information from the SLP. When asked about their experiences communicating with SLPs, caregivers consistently connected their level of satisfaction with the level of information they received during their child’s assessment or intervention experience. Caregivers who believed they had been well informed by the SLP recalled a constructive evaluation experience.

> “They came in and went over the results with me…they did a real good job of checking him out I thought.” (Mr. J)
>
> “They did really good. They detailed it really good for us so she (daughter) could understand along with me.” (Ms. I)

In contrast, caregivers who experienced feelings of frustration with the evaluation or intervention experience cited minimal to no explanations from the SLP:

> “It was a very bad experience. They didn’t explain things.” (Mrs. A)
>
> “I kind of left feeling like I wasn’t sure what was going on you know…a little more concrete information would have been - would’ve made me feel better.” (Mrs. F)

Mrs. G attempted to explain the magnitude as a caregiver of receiving or not receiving information, “I had exhausted all my resources and I was here to hand them off to you [the SLP] to figure it out. So, I really didn’t feel like I came with a lot to offer…I was looking at help us!

What do we need to do to help you help us…I'll do whatever you need!" Mrs. G went on to explain that she did not need every detail, just enough information to help her child, "You know I didn't need a five-hour meeting on it, I just need to know - is there something going, is there not, and what do we do next."

Caregivers' Reported Understanding of Language and Literacy Disorders

Although no caregiver's description of their child was exactly the same as the others', across participants, three primary themes stood out regarding their understanding of language and literacy disorders: a language and literacy disorder was a problem that needed a solution; a language and literacy disorder was most easily defined by the characteristics of their child's speech/language and academic failures; and finally, language-based literacy disorders are difficult to comprehend without personal experience.

A Problem Needs a Solution

Considering the challenges that the caregivers' children faced, it is not surprising that each caregiver described their child's language-based literacy disorder as a problem. The word 'problem' was used several times in the caregivers' discourse when discussing their child, "her problem started when" or "the problem was." In addition to using the term problem, caregivers also demonstrated a tendency to speak in absolute language using words like *never* and *always* to emphasize the severity of their child's issue:

"It was no sentences no nothing." (Mrs. B)

"He has just always struggled when it comes to letter recognition." (Mrs. D)

"She could not focus, she could not sit still, she could not do anything." (Mrs. E)

In acknowledging their child's disorder as a problem, each caregiver also acknowledged their need for help, as it was a problem they were not equipped to cope with on their own. Mrs. G shared how she tried everything she could, but nothing seemed to work:

> "We tried everything else we knew to do. We've tried after school, studying, tutors. Everything we could look up on the internet, games and we had exhausted all of my known resources, and I felt like I know enough to know I don't know everything, and it was time to call in somebody else to help."

Mrs. V shared a similar experience, noting the ongoing struggle of uncertainty:

> "As we've gone through the years and struggled through school then it was like you know we've got to have something to figure out what's going [on] here because it got to the point where it's like you know we're really struggling and something's going [on] here we need to figure out what it is so we can figure out how to work with it."

Given that caregivers often did not feel equipped to deal with their child's language and literacy disorders, many of them began to search for an explanation that would help them better understand their child's problem, hence the caregivers' comments again focused on their child's diagnosis. Diagnostic labels were often viewed by caregivers as the path to the solution. Mr. B said, "How can you start addressing the issue until you know what the issue is and you can match it with good evidence-based interventions?" In his mind, determining the best intervention for his son was directly tied to identifying the cause of his son's reading difficulty. Mrs. G also saw having a diagnosis as an essential step to understanding and helping her child or any child with a disorder:

> "Are they ok, is it something we can fix? How treatable is it? Is it going to you know is this going to affect them the rest of their life or is this something we can double down on get them past."

Her questions were similar to other questions that caregivers frequently asked in an effort to understand their child's needs. Specifically, all of the caregivers discussed their child's future as a key piece they were trying to understand, and the diagnosis was an important piece of the process to help them understand their child’s disorder, the solution to the problem. As Mrs. C said, “To me the most absolute helpful thing was just having a diagnosis.”

Speech, Language and Academic Characteristics

While the diagnosis was an essential component to how caregivers understood their children’s disorder, the practical implications of how the disorder affected their child were important as well. While a variety of characteristics were attributed to each child’s disorder, two common descriptions emerged: how the disorder affected speech and language and how the disorder affected academic performance.

Speech and language. Five caregivers referred specifically to characteristics of their child’s speech and language difficulties when describing their child, both in the past and currently. When asked to describe her daughter’s speech and language concern, Mrs. A began by describing how her daughter’s “garbled speech” had led her and her husband to seek speech-language services. Mrs. B talked about her son having no speech and language as a toddler, “ever since he was probably two - three he just really didn’t - speech was really delayed. I mean he was one word like at the age of 3.” While his expressive language has improved over the years, both Mr. and Mrs. B noted that their son still has some difficulties expressing himself. They also noted that both the SLP from his early intervention assessment and the SLP from his more recent reading assessment, reported comprehension as a strength for him. Mr. and Mrs. J also made observations regarding their son’s language, noting that he was a late talker, “[he] didn’t really start talking until - making like even normal baby noises probably till he was one, and then I really, we knew - I knew he was delayed.” Mr. J also referred to his son’s difficulty with speech sound production and sentence creation, “I think a lot of annunciations and yeah, phonics. I think that was the main focus back then, and how to pronounce groups of letters and things like that…

And I think at the time (it was) it was just his language was lacking… and his ability to form sentences." The other caregivers who commented on their child's speech and language spoke specifically about it not initially being a concern. As Mrs. D commented, "he can speak fine." In fact, Mrs. G, described her daughter's early speech and language skills as above average.

> She was advanced, she was advanced in everything…if anything she uses words that are too big for her and I wonder where she's getting them, because there are times where I'm looking at her and I think how do you know what that means? (Mrs. G)

Thus, for some caregivers, there was no concern until their child entered school.

Academic characteristics. For all but one of the caregivers, educational difficulties were the first sign that something was wrong or something more was wrong. Three of the children had been previously identified as late talkers, but one had been dismissed from services before he started struggling academically, and one had received articulation therapy only. Difficulty with spelling, reading, and writing stood out as the most frequent educational barrier. Mr. J summed up his son's educational difficulties as a language arts problem, "his grades just aren't very good you know, and he always needs additional help…he doesn't have the whole list of spelling words like all the kids do, they give him a reduced list." Mrs. B discussed her son's difficulty in mixing up his letters, spelling his name backwards, and in general not keeping up with his classmates:

> "I know like he will write (his) some of his letters backwards. I notice b and d a lot. And he has both those in his name and he still - I mean /d/ is every day and he still messes that up…if he reads it his comprehension is way down. It always seems like he's about a year behind on the grade level on his reading."

Mrs. E explained that she had never been concerned about her child's development prior to her struggles with reading in school.

> I am trying to remember back I never - nothing really clicked that there may have been something wrong…I don't like to compare my children, but I know my oldest one - things just came very easy to her. I remember her talking sooner, but

> then I had a son and it's very [different], and I don't think I was ever too much concerned with J.

In talking about her child's educational difficulties, Mrs. D summed up the general attitude that many of the caregivers believed their children had toward school, "it's always been a struggle…We never get caught up, and he is always at the bottom of his reading level. School isn't something he likes." Considering that it was often concerns about poor communication skills and poor academic achievement that led caregivers to seek help for their children, it makes sense that many caregivers would focus on some of those same characteristics when trying to define their child's disorder.

Difficult to Understand

Finally, when asked to define their child's disorder, at least seven of the caregivers talked specifically about how difficult it was for them to understand their child's diagnoses, particularly to understand what it was like for their child to have a particular disorder. Mrs. C tried to explain, "I don't understand dyslexia, I just, I don't have it. I mean I get the gist of it, but when we're sitting down doing it (homework) in the back of my mind I'm just like why can't you do this? This is easy, you sound it out." Mrs. D expressed a similar sentiment, trying to explain how hard she found it to help her son:

> "When he was little I would always try to [help], but I'm not - I don't know, the way I learn and the way he learns is way different. For example, just like spelling words when I was his age. If I needed to learn my spelling words I would just write them 10 times or something. It's like when he writes them he's writing them, but he's not going through the letters together…He could write them 100 times, but if I asked him how to spell it he still wouldn't get it right."

The difficulty some caregivers have in understanding their child's disorder appeared to relate to each caregiver's personal learning experiences. Both Mrs. C and Mrs. D noted that they did not experience the academic struggles that their children have experienced. In contrast, Ms. I shared that she “inverts words and letters all the time,” adding “that’s probably why I was more in tune [to her daughter’s academic struggles].”

Caregivers also discussed how part of the challenge of understanding their child’s disorder was the manner in which labels changed. This was especially true for the three caregivers whose children had been identified as late talkers early on. Mrs. A shared at least five labels that had been presented as possibilities at various points “speech apraxia, learning disorder, language processing disorder, dyslexia, and ADHD,” making it understandable that she struggled to define her child’s disorder. Caregivers felt frustration as well that the knowledge they did have often didn’t seem to help. The caregivers with a background in education and nursing felt that they should understand better, and felt frustrated that their education did not necessarily help them help their child. All of the caregivers expressed a desire to try to understand their child’s disorder and find ways to assist their child.

Discussion

Sharing information that supports client and caregiver understanding of communication disorders is a key component of the SLP’s roles and responsibilities. While providing clear diagnostic information is something all SLPs strive to do, the effectiveness of information sharing is dependent on the listener’s perception and retention of the given information. As professionals in health care and education, it is important that we seek to understand how the information we share is perceived by caregivers so that we can improve our services.

In the current study, we explored how caregivers perceive SLP communication and how that communication influences their perceptions of their children’s language and literacy disorders. The six themes identified in the results were obtained by asking caregivers open-ended questions about their experiences and using qualitative methods to analyze their responses and other information about their children. Each of the six themes provide relevant insights into caregiver perspectives of SLP communication.

The first three themes, which related to Research Question 1, focused on the information caregivers described receiving from SLPs regarding their child's language and literacy disorder. These themes revolved around information caregivers viewed as valuable, such as the diagnosis, information caregivers viewed as incomplete, such as long-term outcomes, and the connection between the information they perceived being given and the quality of their experiences, with more information equaling better experiences. The next three themes, which related to Research Question 2, concentrated on how caregivers conceptualize their child's language and literacy disorder. Themes related to this question included the idea that a language and literacy disorder is a problem that needs a solution, that a language and literacy disorder was often understood by the most noticeable characteristics of their child's speech, language, and academic difficulties, and that language and literacy disorders were difficult to understand. Below we briefly discuss the findings as they relate to the research questions, previous studies, and clinical practice.

The Power of a Diagnosis

The themes across both research questions highlighted the value caregivers place on receiving a diagnosis. Receiving a diagnostic label was mentioned repeatedly by the caregivers throughout the interviews; it was something they wanted from their SLPs at the time of their child's evaluation, and receiving a diagnosis was associated with positive communication experiences. Additionally, when caregivers believed they had a clear diagnosis, they felt like they had something they could act upon, whether that meant using the diagnosis to request services or using it to help them understand and explain their child's difficulties to others. For caregivers, having a diagnosis meant having the power to change their child's future. Without a clear diagnostic label, caregivers felt unsure of what came next, and were more likely to be disappointed in their communication experience.

It should also be noted that even though caregivers placed a high value on receiving information at the time of the evaluation, they also acknowledged that they struggled to recall a great deal of the information they had initially received (e.g., details regarding the diagnosis, prognostic information, descriptions of the intervention process), and valued receiving follow-up information from the SLP. As Luterman et al., (1999) notes, there are several reasons why caregivers may struggle to recall the majority of the information provided to them at an initial evaluation including an inability to cognitively process and retain rational information while in an emotionally overwhelmed state. A caregiver not recalling information does not mean it was not shared, but it does suggest that the information may not have been well enough understood to be retained long-term. SLPs need to be aware that even if a caregiver claims understanding at the time of the evaluation, the caregiver may not retain the given information and understanding of the information over time. Rather than feeling frustrated at having to repeat information, SLPs should consider information sharing an ongoing process over the course of the relationship, not a stagnant event. Furthermore, periodic checks for caregiver understanding should be considered part of a typical routine in the process of maintaining a productive relationship with a caregiver.

Clarity Is in the Eye of the Beholder

The caregivers' desire for a clear diagnosis is important to note because not all diagnoses were perceived equally by caregivers. Notably, caregivers did not always perceive certain speech-language labels as a diagnosis, referring to terms such as 'speech or language delay' as a vague description only. This finding is consistent with previous studies that have pointed to the difficulties associated with the term 'delay' and with the lack of clear and consistent labels in identifying children with language disorders (Bishop, 2014; Reilly et al., 2014; Hadley & Schuele, 1999). Also, difficulty in recognizing a diagnosis was not limited to oral language disorders. For literacy disorders, caregivers typically understood a diagnosis of dyslexia, but they did not always interpret other diagnoses such as “mixed reading disorder” and “reading comprehension deficit,” as diagnoses. One reason for this misunderstanding may be the lack of continuity in labeling language and literacy disorders across settings (Dollaghan, Nelson, & Scott, 2012). Other factors may include SLP reports that describe a child’s strengths and weaknesses without offering a diagnostic label, or a general lack of caregiver familiarity with language and literacy disorder terms beyond the well-publicized labels of autism and dyslexia.

A number of papers have been written about the value of giving caregivers clear diagnostic information and the need for the field to settle on a consistent set of terms to describe children’s language and literacy disorders (Bishop et al., 2017; Catts et al., 2006; Dollaghan, Nelson, & Scott, 2012; Leonard, 2014; Paul, Rice, & Ellis Weismer, 2019; Rice & Warren, 2005; Schuele & Hadley, 1999; Van Horne, Ebbels, Redmond, & Finestack, 2018; Volkers, 2018). However, none of these previous papers has included input from caregivers, even though caregivers are the most important stakeholders in the discussion as they seek out our services and determine whether our services are of value to their children. The current study is the second of two that has asked caregivers directly about their perceptions of SLP communication practices. As was found in the current study, caregivers interviewed by Ash et al. (2020) also placed a high value on receiving a clear diagnostic label for their children, and they were frustrated by the lack of information they felt should have been given to them, even though they were generally satisfied with their SLP’s communications regarding their child’s therapy goals and objectives.

In addition to emphasizing the importance of a clear diagnosis to caregivers, the findings from this study point to a crucial area of information that caregivers perceived to be incomplete or unclear: the long-term consequences of language disorders. Considering the important role that language plays in literacy development, it is important that SLPs address this area of incomplete information. Deciding when and how much information to share can be a challenge. SLPs must often determine what the most critical pieces of information are to share initially, as well as how much information needs to be shared and possibly re-visited over time. Furthermore, prognostic information, while reflecting the best educated guess about a child's future, may not always be accurate. However, given what the literature tells us about late talkers and the connection between early language skills and later literacy skills, sharing information about possible reading risk factors may help caregivers be more proactive and able to take steps that would reduce potentially negative consequences before their child falls behind in school (Kruse et al., 2015; Wilcox & Woods, 2011).

Finding Meaning

Caregivers as a whole expressed the view that their understanding of their child's language and literacy disorder was complicated, influenced by their history, and constantly evolving over time and with new experiences. The limited understanding that caregivers had of their child's disorder reflects key concepts within family systems theory, particularly in regard to family coping (e.g., Manning et al., 2011; McCubbin et al., 1983). Similar to this study, Manning et al. (2011) found that caregivers of children with Autism went through a complex process of trying to understand what it meant to raise a child with Autism. Factors including behavior severity and the families' ability to reframe or redefine their children's disorder were key components in how families successfully came to understand their child's disorder. This study, as well as others, emphasized the complexities of the information exchanges that occur over time, both within and outside of a family system that can shape caregiver understanding of a disorder (Pecchioni & Keeley, 2011). Furthermore, the literature shows that caregivers' perceptions of their health care provider's communication is key to shaping both their perspective of their experiences and their perspective of their child's disorder (e.g., Brown, Stewart, & Ryan, 2003; Donovan, Hartenbach, & Method, 2005; Propp et al., 2010). These findings match those of the current study, as the caregivers frequently connected SLP communication practices to their perceived quality of experience, and they also credited the SLP with shaping their attitudes and beliefs about their child's language and literacy disorder.

In seeking to establish a shared meaning, it is also important to understand how caregivers view their child's disorder. Caregiver's descriptions of their child's language and literacy disorder tended to focus on the behavioral traits that clearly manifest themselves in their child's speech, language, and educational performance over time. Each caregiver was able to describe the "garbled speech" or the "failed spelling test" that first made them aware that their child was struggling. However across caregivers, there was a lack of discussion about the broader characteristics of their child's disorder, the strengths and weaknesses presented, the connections between their particular language profile, and their specific reading struggles. A review of the reports in the university clinic files suggest that this type of information was provided in written form at least, but it may not have resonated with the caregivers whose focus was more on the functional problem at hand, how to help their child do better academically.

In contrast, caregivers presented as very knowledgeable about their child's therapy goals. Possibly this was a factor of repetition, as goals that are being addressed in therapy may be discussed more often and therefore be more memorable, or possibly this was a factor of the goals presenting as practical and functional steps that the caregivers could easily see as measures of their child’s progress towards success. In seeking to reach a mutual understanding of the disorder, one strategy may be for SLPs to communicate more frequently with caregivers about the relevance of their child’s goals and objectives to addressing the child’s specific language and literacy disorder. For example, if a child is working on identifying macrostructure within a narrative, talking with the caregiver about how the stated goal specifically addresses their child’s literacy and academic success. Making these connections could help caregivers better understand their child’s disorder and become more involved collaborators.

Clinical Implications

The findings from this study suggest several implications regarding SLP communication practices. First, the findings underscore how important it is for SLPs to provide caregivers clear diagnostic labels as part of their clinical services. Receiving a diagnosis was highlighted repeatedly throughout the interviews. Given this and given that a number of caregivers were unclear about their child’s diagnosis, SLPs should review their reports and post-evaluation family meetings to identify when and how they communicate diagnostic information to caregivers. SLPs may also want to add more direct statements about a child’s diagnosis into their reports and meetings. These statements could include “the diagnosis is _______, and this is what ________ means”, or “here is a list of possible diagnoses we’ve considered, and a diagnosis of ____________ best aligns with your child’s current communication profile for these reasons”. SLPs may also want to consider offering caregivers a list of other diagnostic terms that they may encounter for their child within other settings (e.g., schools, insurance companies) or when working with other professionals. As Murza and Ehren (2020) suggest, this will require SLPs and pre-professional SLPs to be well informed of the various labels used within and outside of the field and to share this information with caregivers, so that caregivers can better navigate the labels their child may encounter. In cases where a child's diagnosis is not clear and cannot be given, the findings also suggest that SLPs should directly discuss with caregivers why this is so, what steps can be taken without a diagnosis, and the expected time when a diagnosis might be better established. For these cases (or for children whose diagnosis is likely to change with age), the findings highlight the importance of SLPs scheduling future meetings with caregivers to discuss not only their child's progress but also their diagnosis.

Secondly, the findings underscore the importance of talking to caregivers about the long-term consequences of language disorders, and the connection between language and reading. The caregivers shared that they were often thinking about their child's future, and the connection between language and literacy represented significant gaps in their knowledge. To address these gaps, SLPs may want to consider increasing their provision of educational materials about the evolving nature of childhood language disorders and prognostic factors, and the relation between language and literacy. These materials could include short video presentations or wall displays in clinic waiting rooms, and/or podcasts, pamphlets, and infographics – all of which could be developed for specific topics and presented to families at different points of care (e.g., initial contact, review of an evaluation or progress report, service dismissal) or by month within a calendar year, with each month devoted to a different topic. SLP participation in family support groups, both locally and through social media outlets, may also help caregivers access information (and help SLPs better understand what caregivers want and need). Finally, public awareness campaigns, focused on childhood language and literacy disorders, have been recommended and are increasing within our field (e.g., https://radld.org, https://www.dldandme.org). SLP involvement in these campaigns are needed to help caregivers, their extended families, and others outside of the field understand the nature of childhood language and literacy disorders.

Finally, the results of the study highlight the importance of seeking to understand the client/caregiver's perception of their/their child's communication disorder. Understanding a caregiver's perception of his or her child's diagnosis can help the SLP respond appropriately to the caregiver's needs and expectations, and provide appropriate resources to fill in the information gaps. If an SLP had a significantly different expectation for the child than the caregiver, the divergence of expectations may result in miscommunications and fractured relationships. For example, a caregiver may not understand why a particular intervention strategy is chosen, and may become frustrated because he or she does not see how the intervention is going to help the child (e.g., the caregiver perceives the child to have a 'reading problem' and wonders why the SLP spends time working with the child on understanding and identifying story grammar elements). Similarly, if a caregiver expects a diagnosis to lead to a solution that will "fix" their child, he or she may become frustrated when months pass and their child continues to struggle. A shared understanding of the diagnosis and prognostic factors can help caregivers and SLPs truly collaborate on service and intervention decisions. It can also help caregivers to have a realistic view of how the SLP can help their child. This study focused on language and literacy disorders, but the importance of seeking to understand the client/caregiver's perspective is universal to the evidence-based assessment and treatment of any communication disorder.

Limitations and Future Studies

As with any research endeavor, there were limitations to this study. Drawn from a convenience sample, the participants lacked cultural diversity, lived in one region in the

Midwest, spoke English as their first language, and were well educated. Caregivers from more diverse backgrounds may present with different concerns and opinions about the communication they have received from their SLPs. Another limitation to the study was the timing of the interview relative to the evaluation. Although all children were receiving language services by an SLP at the time of the study, their evaluations were conducted five to 17 months before the interviews. In the future, it may be advantageous to conduct multiple interviews throughout a child's evaluation and treatment program in order to examine evolving caregiver perceptions and needs. Focusing on one SLP experience per caregiver may also yield clearer results, as some of the variance in experiences could be related to norms in different settings. Future studies may also want to target caregivers of younger and older children and children with different types of speech and language disorders to see how caregiver perceptions of SLP communications differ as a function of their child's age and diagnosis. Following the methods of Lyons and Roulstone (2018) and Fourie et al. (2011), future studies may want to target children as the interviewees to gain their perspective on their SLPs' communication about their language and literacy disorders. Finally, it's important to note that caregiver responses might have been inhibited by their knowledge that the interviewer was an SLP. Future studies may benefit from training a professionally neutral interviewer.

Conclusion

Research in the field of health communication tells us that effective information sharing with clients and caregivers can be as important as choosing the right diagnosis and treatment approach (e.g., Wanzer et al., 2004). Using literature in health communication as a guide and utilizing a qualitative methodology, the current study explored how caregivers perceive SLP communication and how that communication influences caregivers' understanding of their child’s language and literacy disorder. In terms of information sharing, caregivers universally stressed the value of receiving a clear diagnosis, and these clear diagnoses did not include all of the terms (e.g., delay, mixed reading disorder) that SLPs currently offer. Caregivers also expressed the need for more information regarding long-term language and literacy disorder outcomes, especially related to reading. Finally, not understanding their child’s disorder was a constant struggle for caregivers, especially if they did not have personal experiences to draw upon. These findings underscore the need for SLPs to: 1) offer diagnostic labels and explain these labels to caregivers, even when a child’s diagnosis is expected to change with age, 2) discuss with families the relationship between oral language and literacy and possible long-term outcomes of a language disorder, and 3) add to clinical practice, repeated opportunities to educate caregivers and check caregiver understanding of their child’s language and literacy disorder.

Acknowledgments

This research was supported by funding from the Faculty Summer Research and Creative Activity Grant at Fort Hays State University, and preliminary findings of the work were presented at the annual convention of the American Speech-Language-Hearing Association (Porter, Ash, Redmond, & Oetting, 2016). Appreciation is extended to Marcus Porter, Jayne Brandel, Jessie Havice, Ashley Crain, and other faculty members and students who helped collect and analyze the data, as well as the families who agreed to participate in the study.

References

Adlof, S. M., & Hogan, T. P. (2018). Understanding dyslexia in the context of developmental language disorders. *Language, Speech, and Hearing Services in Schools*, *49*, 762-773. https://doi.org/10.1044/2018_LSHSS-DYSLC-18-0049

Alt, M, Gray S., Hogan, T. P., Schlesinger N., & Cowan N. (2019). Spoken word learning differences among children with dyslexia, concomitant dyslexia and developmental language disorder, and typical development. *Language, Speech, and Hearing Services in Schools*, *50*(4), 540–561. https://doi.org/10.1044/2019_LSHSS-VOIA-18-0138

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. Washington, DC: Author.

American Speech-Language-Hearing Association. (2004). *Preferred practice patterns for the profession of speech-language pathology* [Preferred Practice Patterns]. Retrieved from www.asha.org/policy

American Speech-Language-Hearing Association. (2005). *Evidence-based practice in communication disorders* [Position Statement]. Retrieved from www.asha.org/policy

Angell, M. E., Stoner, J. B., & Shelden, D. L. (2009). Trust in education professionals: Perspectives of mothers of children with disabilities. *Remedial and Special Education, 30*(3), 160-176. https://doi.org/10.1177/0741932508315648

Ash, A., Christopulos, T., Redmond, S. (2020). Tell me about your child: A grounded theory study of mothers' understanding of childhood language disorder. *American Journal of Speech-Language Pathology,* 29, 819-849. https://doi.org/10.1044/2020_AJSLP-19-00064

Ben-Joseph, E. P., Dowshen, S. A., & lzenberg, N. (2009). Do parents understand growth charts? A national, internet-based survey. *Pediatrics*, *124*(4), 1100-1109. https://doi.org/10.1542/peds.2008-0797

Berger, C. R. (1997). LEA's communication series. Planning strategic interaction: Attaining goals through communicative action. Lawrence Erlbaum Associates Publishers.

Bishop, D. V. M. (2014). Ten questions about terminology for children with unexplained language problems. *International Journal of Language & Communication Disorders*, *49*(4), 381-415. https://doi.org/10.1111/1460-6984.12101

Bishop, D. V. M., Snowling, M. J., Thompson, P. A., Greenhalgh, T., & the CATALISE-2 consortium. (2017). Phase 2 of CATALISE: A multinational and multidisciplinary Delphi consensus study of problems with language development: Terminology. *Journal of Child Psychology and Psychiatry, 58*(10), 1068-1080. https://doi.org/10.1111/jcpp.12721

Brown, J. B., Stewart, M., & Ryan, B. L. (2003). Outcomes of patient-provider interaction. Handbook of health communication. (pp. 141-161). Mahwah, NJ, US: Lawrence Erlbaum Associates Publishers.

Burns, M. I., Baylor, C. R., Morris, M. A., McNalley, T. E., & Yorkston, K. M. (2012). Training healthcare providers in patient-provider communication: What speech-language pathology and medical education can learn from one another. *Aphasiology, 26*(5), 673-688. https://doi.org/10.1080/02687038.2012.676864

Catts, H. W., Adlof, S. M., Hogan, T. P., & Ellis-Weismer, S. (2005). Are specific language impairment and dyslexia distinct disorders? *Journal of Speech, Language, and Hearing Research*, 48, 1378-1396. https://doi.org/10.1044/1092-4388(2005/096)

Catts, H. W., Adlof, S. M., & Weismer, S. E. (2006). Language deficits in poor comprehenders: A case for the simple view of reading. *Journal of Speech, Language & Hearing Research, 49*(2), 278-293. https://doi.org/10.1044/1092-4388(2006/023)

Catts, H. W., Hogan, T. P., & Fey, M. E. (2003). Subgrouping poor readers on the basis of individual differences in reading-related abilities. *Journal of Learning Disabilities, 36*, 151-164. https://doi.org/ 10.1177/00222194030360020８

Catts, H. W., Fey, M. E., Tomblin, J. B., & Zhang, X. (2002). A longitudinal investigation of reading outcomes in children with language impairments. *Journal of Speech, Language & Hearing Research, 45*(6), 1142-1157. https://doi.org/ 10.1044/1092-4388(2002/093)

Crais, E. R., Roy, V. P., & Free, K. (2006). Parents' and professionals' perceptions of the implementation of family-centered practices in child assessments. *American Journal of Speech-Language Pathology, 15*(4), 365-377. https://doi.org/10.1044/1058-0360(2006/034)

Dolch, E. (1936). A basic sight vocabulary. *The Elementary School Journal, 36*(6), 456-460.

Dollaghan, C., Nelson N. W., & Scott, C. (2012). What's in a name subtyping and labeling in language disorders. Paper presented at the annual convention of the American Speech-Language-Hearing Association, Atlanta, GA.

Donovan, H. S., Hartenbach, E. M., & Method, M. W. (2005). Patient–provider communication and perceived control for women experiencing multiple symptoms associated with ovarian cancer. *Gynecologic Oncology, 99*(2), 404-411. https://doi.org/10.1016/j.ygyno.2005.06.062

Ferguson, A., & Armstrong, E. (2004). Reflections on speech-language therapists' talk: Implications for clinical practice and education. *International Journal of Language &*

Communication Disorders, 39(4), 469-477. https://doi.org/10.1080/13682820420002268 79

Fourie, R. (2009). Qualitative study of the therapeutic relationship in speech and language therapy: Perspectives of adults with acquired communication and swallowing disorders. *International Journal of Language & Communication Disorders, 44*(6), 979-999. https://doi.org/10.3109/13682820802535285

Fourie, R., Crowley, N., & Oliviera, A. (2011). A qualitative exploration of therapeutic relationships from the perspective of six children receiving speech-language therapy. *Topics in Language Disorders, 31*(4), 310-324. https://doi.org/10.1097/TLD.0b013e3182353f00

Gillam, R. B., & Pearson, N. A. (2004). Test of narrative language. Austin, TX: PRO-ED.

Hand, L. (2006). Clinicians as "information givers": What communication access are clients given to speech-language pathology services? *Topics in Language Disorders, 26*(3), 240-265. https://doi.org/ 10.1097/00011363-200607000-00007

Hare, J., Skinner, D., & Kliewer, D. (1989). Family systems approach to pediatric bone marrow transplantation. *Children's Health Care, 18*(1), 30-36. https://doi.org/10.1207/s15326888chc1801_4

Hengst, J. A., & Duff, M. C. (2007). Clinicians as communication partners: Developing a Mediated discourse elicitation protocol, *Topics in Language Disorders, 27*(1), 37-49. https://doi.org/ 10.1097/00011363-200701000-00005

Hester, E. J., & Stevens-Ratchford, R. (2009). Health literacy and the role of the speech-language pathologist. *American Journal of Speech-Language Pathology, 18*(2), 180-191. https://doi.org/ 10.1044/1058-0360(2009/08-0005)

Hidecker, M.J.C., Jones, R.S., Imig, D.R., & Villarruel, F.A. (2009). Using family paradigms to improve evidence-based practice. *American Journal of Speech Language Pathology, 18*(3), 212-221. https://doi.org/10.1044/1058-0360(2009/08-0011)

Kruse, L.G., Spencer, T.D., Olszewski, A., & Goldstein, H. (2015). Small groups, big gains: Efficacy of a tier 2 phonological awareness intervention with preschoolers with early literacy deficits. *American Journal of Speech-Language Pathology, 24*(2), 189-205. https://doi.org/10.1044/2015_AJSLP-14-0035

Kvale, S. (1996). Interviews: An introduction to qualitative research interviewing. Thousand Oaks, CA: Sage Publications.

Leahy, M. M., & Walsh, I. P. (2008). Talk in interaction in the speech-language pathology clinic: Bringing theory to practice through discourse. *Topics in Language Disorders, 28*(3), 229-241. https://doi.org/10.1097/01.TLD.0000333598.53339.5a

Leonard, L. B. (2014). Children with specific language impairment (2nd ed.). Cambridge, MA: MIT Press.

Leslie, L., & Caldwell, J. A. (2011). Qualitative reading inventory: 5. Boston, MA: Pearson/Allyn & Bacon.

Luterman, D., & Kurtzer-White, E. (1999). Identifying hearing loss: Parents' needs. *American Journal of Audiology, 8*(1), 13-18. https://doi.org/doi:10.1044/1059-0889(1999/006)

Lyons, R., & Roulstone, S. (2018). Well-being and resilience in children with speech and language disorders. *Journal of Speech Language and Hearing Research, 61*(1), 324-344. https://doi.org/10.1044/2017_JSLHR-L-16-0391

Manning, M. M., Wainwright, L., & Bennett, J. (2011). The double abcx model of adaptation in racially diverse families with a school-age child with autism. *Journal of Autism & Developmental Disorders, 41*(3), 320-331. https://doi.org/10.1007/s10803-010-1056-1

McCubbin, H. I., McCubbin, M. A., Patterson, J. M., Cauble, A. E., Wilson, L. R., & Warwick, W. (1983). Chip-coping health inventory for parents: An assessment of parental coping patterns in the care of the chronically ill child. *Journal of Marriage & Family, 45*(2), 359-370. https://doi.org/10.2307/351514

Miles, M. B., Huberman, A. M., & Saldaña, J. (2014). Qualitative data analysis: A methods sourcebook. Thousand Oaks, CA: Sage Publications.

Murza, K. A., & Ehren, B. J. (2020). Considering the language disorder label debate from a school speech-language pathology lens. *Perspectives of the ASHA Special Interest Groups, 5*(1), 47-54. https://doi.org/10.1044/2019_PERSP-19-00077

O'Malley, M. P. (2011). Exploring gender and power in clinical encounters. In R. J. Fourie (Ed.), Therapeutic processes for communication disorders. New York: Psychology Press.

Paul, R., Norbury, C., Gosse, C., & Paul, R. (2018). Language disorders from infancy through adolescence: Listening, speaking, reading, writing, and communicating. St. Louis, MO: Elsevier.

Paul, R., Rice, M. L., & Ellis Weismer, S. (2019). Child language disorder: An open conversation about identification and terminology. Session presented at the symposium for Research in Child Language Disorders, Madison, WI.

Pecchioni, L. L., & Keeley, M. P. (2011). Insights about health from family communication theories. In T. L. Thompson, R. Parrott & J. Nussbaum (Eds.), Handbook of health communication, 2nd. London: Taylor and Francis.

Petscher, Y., Justice, L. M., & Hogan, T. P. (2018). Modeling the early language trajectory of language development and its relation to poor reading comprehension. *Child Development, 89*, 2136-2156. https://doi.org/10.1111/cdev.12880

Propp, K., Apker, J., Ford, W., Wallace, N., Serbenski, M., & Hofmeister, N. (2010). Meeting the complex needs of the health care team: Identification of nurse-team communication practices perceived to enhance patient outcomes. *Qualitative Health Research, 20*(1), 15-28. https://doi.org/10.1177/1049732309355289

Porter, K. L. (November, 2013). An exploration of the perceived challenges of families raising children with communication disorders. Poster presentation at the annual convention of the American Speech Language Hearing Association, Chicago, IL.

Porter, K. L., Ash, A. C., Redmond, S. M., & Oetting, J. B. (November, 2016). Caregiver perceptions of diagnostic labels applied to their children with language/reading impairments. Paper presented at the annual convention of the American Speech-Language-Hearing Association, Philadelphia, PA.

Reilly, S., Tomblin, B., Law, J., McKean, C., Mensah, F. K., Morgan, A., . . . Wake, M. (2014). Specific language impairment: A convenient label for whom? *International Journal of Language & Communication Disorders, 49*(4), 416-451. https://doi.org/10.1111/1460-6984.12102

Rescorla, L. (2002). Language and reading outcomes to age 9 in late-talking toddlers. *Journal of Speech, Language & Hearing Research, 45*(2), 360.

Rice, M. L., & Warren, S. F. (2005). Moving toward a unified effort to understand the nature and causes of language disorders. *Applied Psycholinguistics, 26*(1), 3-6. https://doi.org/10.1017/S0142716405050022

Saletta, M. (2018). Reading disabilities in adolescents and adults. *Language, Speech, and Hearing Services in Schools*, *49*(4), 787–797. https://doi.org/10.1044/2018_LSHSS-DYSLC-18-0005

Scarborough, H.S. (2001). Connecting early language and literacy to later reading (dis)abilities: Evidence, theory, and practice. In S. N. D. Dickinson (Ed.), *Handbook for research in early literacy* (pp. 97-110). New York: Guilford Press.

Schuele, C. M., & Hadley, P. A. (1999). Potential advantages of introducing specific language impairment to families. *American Journal of Speech-Language Pathology, 8*(1), 11-22. https://doi.org/10.1044/1058-0360.0801.11

Schwartz, R. G. (2017). Handbook of child language disorders. NY: Taylor & Francis.

Shelden, D. L., Angell, M. E., Stoner, J. B., & Roseland, B. D. (2010). School principals' influence on trust: Perspectives of mothers of children with disabilities. *The Journal of Educational Research, 103*(3), 159-170. https://doi.org/10.1080/00220670903382921

Seidenberg, M., & MacDonald, M. (2018). The impact of language experience on language and reading: A statistical learning approach. *Topics in Language Disorders, 38*(1), 66-83. https://doi.org/ 10.1097/TLD.0000000000000144

Semel, E., Wiig, E. H., & Secord, W. A. (2003). Clinical evaluation of language fundamentals, fourth edition (CELF-4). Toronto, Canada: The Psychological Corporation/A Harcourt Assessment Company.

Simmons-Mackie, N., & Damico, J. S. (2009). Engagement in group therapy for aphasia. *Seminars in Speech & Language, 30*(1), 18-26. https://doi.org/ 10.1055/s-0028-110453

Simmons-Mackie, N., & Damico, J. S. (2011). Exploring clinical interactions in speech-language therapy: Narrative, discourse, and relationships. In R. J. Fourie (Ed.), Therapeutic processes for communication disorders. New York, NY: Psychology Press.

Stake, R. E. (2005). *Qualitative Case Studies.* In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (p. 443–466). Sage Publications Ltd.

Stone, J.R. (1992). Resolving relationship problems in communication disorders treatment: A systems approach. *Language, Speech, and Hearing Services in Schools, 23*(4), 300-307.

Stoner, J. B., Bailey, R. L., Angell, M. E., Robbins, J., & Polewski, K. (2006). Perspectives of parents/guardians of children with feeding/swallowing problems. *Journal of Developmental & Physical Disabilities, 18*(4), 333-353. https://doi.org/10.1007/s10882-006-9020-x

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19*(6), 349-357. https://doi.org/10.1093/intqhc/mzm042

U.S. Department of Education. (2006). IDEA Website. Retrieved from http://idea.ed.gov/explore/home.

Van Horne, A., Ebbels, S., Redmond, S., & Finestack, E. (2018). A debate on terminology in child language research programs. Panel presented at the annual convention of the American Speech-Language-Hearing Association, Orlando, FL.

van Zanten, M., Boulet, J. R., & McKinley, D. (2007). Using standardized patients to assess the interpersonal skills of physicians: Six years' experience with a high-stakes certification examination. *Health Communication, 22*(3), 195-205. https://doi.org/10.1080/10410230701626562

Volkers, N. (2018). Diverging views on language disorders. *The ASHA Leader, 23*, 44-53. https://doi.org/10.1044/leader.FTR1.23122018.44

Wagner, R. K., Torgesen, J. K., Rashotte, C. A., Pearson, N. A. (2013). Comprehensive test of phonological processing, Second edition (CTOPP-2). Austin, TX: PRO-ED.

Walsh, I. P. (2007). Small talk is "big talk" in clinical discourse: Appreciating the value of conversation in SLP clinical interactions. *Topics in Language Disorders, 27*(1), 24-36. https://doi.org/ 10.1097/00011363-200701000-00004

Wanzer, M. B., Booth-Butterfield, M., & Gruber, K. (2004). Perceptions of health care providers' communication: Relationships between patient-centered communication and satisfaction. *Health Communication, 16*(3), 363-384. https://doi.org/10.1207/S15327027HC1603_6

Wiederholt, J. L., & Bryant, B. R. (2012). Gray oral reading tests, fifth edition (GORT-5). Austin, TX: Pro-Ed.

Woods, J. J., Wilcox, M. J., Friedman, M., & Murch, T. (2011). Collaborative consultation in natural environments: Strategies to enhance family-centered supports and services. *Language Speech Hearing Services in Schools, 42*(3), 379-392. https//doi.org/10.1044/0161-1461(2011/10-0016)

Figure 1. Data Collection and Review Process

Figure 2. Network Illustrating Themes Related to Caregiver Descriptions of Receiving Information from SLPs*

*The numbers in Figure 2 represent the current number of associated caregiver “quotes” with a particular theme at the time this visual was created. These numbers changed several times throughout the analysis process as final themes were established.