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

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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

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

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

58 A growing number of studies have focused on the communication practices of SLPs (e.g.,
59 Burns et al., 2012; Ferguson & Armstrong, 2004; Fourie, 2009; Hand, 2006; Hengst & Duff,
60 2007; Hester & Stevens-Ratchford, 2009; Leahy & Walsh, 2008; O'Malley, 2011; Simmons-
61 Mackie & Damico, 2009, 2011; Stone, 1992; Stoner, et al., 2006). For example, Simmons-
62 Mackie and Damico (2009) explored how a clinician's communication practices can encourage
63 group member engagement in aphasia groups, and Stone (1992) presented two case studies
64 illustrating how changes in clinical interactions can influence the clinician-client relationship. A
65 common theme across these studies is that SLPs must think about how they build relationships
66 with clients and not just what kind of evaluation or treatment approach they are providing. While
67 these studies provide a good start to the discussion, none directly examined how SLPs share
68 information with clients/caregivers, or how the clients/caregivers perceived the communication
69 practices of SLPs. Client/caregiver perspectives are a key component of evidence-based practice
70 (EBP) – a practice that requires the integration of known research, clinical expertise, and client
71 perspectives in the decision-making process (Hidecker et al., 2009). Given this, the lack of

72 studies examining the perspectives of client/caregivers constitutes a significant gap in the
73 literature and hinders the application of EBP.

74 One recent study by Ash, et al. (2020) did explore caregivers' understanding of their
75 children's language disorders, as well as the role SLPs played in developing their knowledge.
76 Results indicated that caregivers' perceptions of their SLPs were not always positive, especially
77 when they felt they were not given sufficient information or information that was too complex.
78 These results resonate with previous studies that show satisfaction in healthcare to often be tied
79 to perceptions of the providers' communication (e.g., Brown et al., 2003; Donovan et al., 2005;
80 Propp et al., 2010; van Zanten, et al., 2007; Wanzer et al., 2004). For example, Wanzer et al.
81 (2004) found a strong positive relationship between the amount of communication behaviors
82 perceived by the patient to be patient-centered and the patient's overall satisfaction with the
83 medical care their children received. Furthermore, Ash et al.'s (2020) results remind us that
84 sharing information does not always mean it is understood. In another study, caregivers'
85 understanding of children's growth charts were examined (Ben-Joseph et al., 2009). Although
86 64% of the caregivers surveyed believed doctors should use charts to show them how their child
87 was growing, only 8% correctly interpreted a set of hypothetical charts showing children's
88 heights and weight. Studies by Ash et al. and Ben-Joseph et al. illustrate the importance of
89 further examining caregiver perceptions of SLP communication behaviors, as well as the need to
90 identify communication strategies that clients/caregivers consider effective.

91 To better understand the client/caregiver's perspective, it is also important to recognize
92 the role of family systems. Per family systems theory, individuals exist within a larger
93 interdependent system of family and community that influences how one perceives messages
94 from other individuals. Thus, to communicate effectively with caregivers, SLPs must be

95 sensitive to the role of previously established family attitudes and beliefs in the caregiver's
96 interpretation and understanding of the communicative interaction (Pecchioni & Keeley, 2011).
97 The level of understanding and clarity required to establish a productive relationship varies
98 depending on the client/caregiver's age, needs, and desire for information. However, having an
99 appropriate knowledge base of the communication disorder being treated is an important first
100 step for the client/caregiver and SLP to be able to engage in an effective collaborative
101 relationship (Crais, 2006; Woods et al., 2011).

102 **Childhood Language and Literacy Disorders**

103 Children with language and literacy disorders present with complex linguistic profiles.
104 When children are young, their profile is often characterized by weaknesses across semantic,
105 morphosyntactic, narrative, and phonological skills, and as they age, their profile can evolve to
106 include weaknesses in literacy (Leonard, 2014; Paul et al., 2017; Schwartz, 2017). Even children
107 who appear to recover from early language delays, such as late talkers, are more likely to
108 encounter difficulties upon entering school and beginning formal reading instruction (Rescorla,
109 2002; Scarborough, 2001). Relationships between children's early oral language disorders and
110 later literacy disorders are not surprising as many oral language abilities have been found to be
111 essential for supporting reading, writing, and spelling (Seidenberg, 2018). As with oral language
112 disorders, there is heterogeneity in children's literacy disorders. Even when the focus is on
113 reading disorders only, some children demonstrate poor reading comprehension, others present
114 with poor word decoding, and still others present with difficulties in both areas. (e.g., Adlof &
115 Hogan, 2018; Catts et al., 2005; Catts et al., 2006; Catts, Fey, Tomblin, & Zhang, 2002; Saletta,
116 2018). Children classified as poor comprehenders consistently present with weak oral and
117 written language skills in comparison to their peers with typical reading skills. Still, many are not

118 identified as impaired until they begin to struggle with formal reading instruction (Petscher et al.,
119 2018). Children who demonstrate good comprehension skills, but struggle with poor word
120 recognition skills, are often identified as poor decoders, or children with dyslexia (Alt et al.,
121 2019; Catts et al., 2003). They also may not be identified until their difficulty with reading and
122 spelling becomes apparent, as they often present with standardized oral language scores within
123 the typical range. However, studies show that as a group, poor decoders (8-9 years) are still
124 likely to perform below their typical peers on oral and written language tasks, suggesting that as
125 whole, language skills are an ongoing concern for all children with literacy disorders (Adlof &
126 Hogan, 2018; Saletta, 2019).

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

141 caregivers (American Psychiatric Association, 2013; IDEA 04; ICD-10-CM/PCS: World Health
142 Organization, 2015).

143 **Purpose and Research Questions**

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

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

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

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163

164

Methods

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

Participants

171 Participants were caregivers of a school-age child diagnosed with a language and literacy
172 disorder and who had been evaluated at a Midwestern university clinic within the past 1 – 1 ½
173 years. All participants were native English speakers, part of the household in which the child
174 primarily or jointly resided, and active in decisions about the child’s care/education. At the time
175 of the study, ten families connected with the clinic met these criteria, and 12 caregivers from
176 these families agreed to participate. Eight family units consisted of one primary caregiver
177 participating in the interview and two family units consisted of two caregivers participating (one
178 set together and one set in separate interviews). All caregivers were White/Caucasian and came
179 from a variety of educational and occupational backgrounds, with four working in healthcare
180 related fields and two having or working towards education degrees (see Table 1). Each
181 caregivers’ level of experiences with SLPs varied, ranging from one experience with an SLP at
182 the university clinic to multiple experiences over time with early intervention SLPs, school-
183 based SLPs, and university clinic SLPs. As Table 2 delineates, each child’s path to being
184 diagnosed with a language-based literacy disorder varied depending on the initial presenting
185 concerns. For example, one caregiver worked with several educators and special educators at her
186 child’s school, but never communicated with an SLP about her daughter’s reading difficulties

187 until she was referred to the university clinic. In contrast, another caregiver whose child
188 presented with communication concerns early on, communicated with several SLPs over the
189 years as her child transitioned from early intervention services, to pre-school services, and to
190 school-based services, before she sought out additional services at the university. Despite these
191 differences, each caregiver had the common experience of having a child with a diagnosed
192 language-based literacy disorder.

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

207 **Procedure**

208 Following the methods of previous qualitative studies, the data were collected via semi-
209 structured participant interviews (e.g., Angell et al., 2009; Ash et al., 2020; Fourie, 2009; Fourie

210 et al., 2011; Lyons & Roulstone, 2018; Shelden et al., 2010). Unlike online questionnaires or
211 surveys, the semi-structured interview allows the examiner to ask follow-up questions to check
212 for understanding and interpretations of meaning with participants (Kvale, 1996). Each interview
213 represented a single unique case, which was then examined collectively to better understand
214 what was common across caregiver experiences and perspectives (Stake, 2005).

215 *Interviews*

216 All semi-structured interviews were conducted in person (university clinic = 4,
217 caregiver's home = 7) by the first author, an experienced SLP and clinical educator within the
218 university clinic. For all but three interviews, only the first author and the participant(s) were
219 present. For two interviews, a female graduate student was present with the participants'
220 permission, and for one interview, the participant chose to answer questions in her living room
221 while watching children in her care. Beyond clinical expertise in the area of language and
222 literacy disorders, the first author, a PhD student at the time of the interviews, had completed
223 course work in qualitative methods and health communication studies and conducted a pilot
224 study using semi-structured interviews with caregivers from a different university clinic (Porter,
225 2013). Three of the family units were minimally known to the first author prior to the study
226 through contact within the clinic; the others were solicited through the university clinic.

227 During the interview, caregivers were asked questions regarding their child's speech-
228 language evaluation(s), their conversations with their SLP regarding the evaluation results, their
229 understanding of the written report(s) they received, and their impressions of their child's current
230 status, as well as their hopes for the future. As each interview was conducted, the interviewer
231 made requests for clarification or additional information as necessary (e.g., "so you are saying, if
232 somebody reads a story to him he seems to be able to comprehend it"). First author observations

233 and notes were made throughout the interview process, and all initial interviews were audio
234 recorded and transcribed verbatim to ensure accuracy of the provided information. The
235 interviews ranged from 30 to 70 minutes in length.

236 *File Reviews*

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

241 *Follow-up Interviews*

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

250 **Data Analysis**

251 To ensure reliability of the transcripts, each transcript was reviewed three times, two
252 times by two different graduate students, and one time by the first author. Additionally, the first
253 author took notes during and after each interview, documenting observations of the participants
254 and overall interactions. The research questions drove the analysis, leading the first author to
255 focus on caregiver references to how they perceived SLP communication regarding childhood

256 language and literacy disorders. The analysis consisted of three general phases, including data
257 condensation, data display, and conclusion drawing/verification (Miles, Huberman, & Saldana,
258 2014).

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

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

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

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

297 **Results**

298 When examining the caregivers' interviews, several key themes emerged that related to
299 the type and quality of information they received from the SLPs (Research Question 1) and their
300 understanding of their children's language and literacy disorders (Research Question 2). All
301 caregiver responses were aggregated across experiences. While experiences varied and

302 caregivers with more frequent experiences communicating with SLPs were often able to provide
303 a more historical perspective than others, as well as more comparative examples over time that
304 highlighted key perceptions, the general themes identified in this study were consistent across
305 participants. Moreover, when caregivers presented a unique experience related to an SLP
306 interaction, that interaction often did not relate to the research questions. For example, one
307 caregiver was raising another child with Autism, and another was the primary caretaker for her
308 brother with special needs. Due to these familial relationships, both had previous experiences
309 interacting with SLPs. Nonetheless, individual differences across caregivers did not contradict
310 the general agreement found across participants in describing their perceptions of SLP
311 communication in the context of their child's language-based literacy disorder.

312 **Information Caregivers Reported Receiving from SLPs**

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

319 *The Value of a Diagnosis*

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

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

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

326
327 “They would not label him...it was just oh well he might have this issue.” (Mr. B)

328 “There was never - I don’t think any - and I still don’t know that I know for
329 sure what.” (Mrs. D)

330
331 Whether they believed they had or had not received one, caregivers emphasized the importance
332 of a diagnosis. As Mrs. G put it, “as a parent you want to know.”

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

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

339
340 For Mrs. C, a diagnosis meant access to resources she had been seeking.

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

343
344 Even when a diagnosis was given though, it did not ensure that it was understood, especially if
345 the label was unfamiliar to the caregiver. Dyslexia was the most commonly identified diagnosis
346 by caregivers. The five caregivers whose children received a dyslexia diagnosis (and had the
347 label dyslexia in the report) all recalled and reported the diagnosis of dyslexia accurately,
348 suggesting that they felt comfortable with the label. In contrast, the second most common
349 response caregivers gave when asked about their child’s diagnosis was “I still don’t know”. Four
350 caregivers of the children who received a more complex diagnosis (e.g., mixed reading disorder,
351 reading comprehension deficit) demonstrated a lack of awareness of the given diagnosis or
352 reported conflicting diagnoses. For example, Mrs. F, who was unsure about the overall diagnosis
353 tried to recall the report, “I know there’s something in there about the dyslexia.” However, per
354 the speech and language report, her daughter “exhibits a reading comprehension deficit

355 characterized by difficulty recalling information from a text, answering questions, and
356 incorporating important details.” No mention was made of dyslexia in the report.

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

360 “No I don’t think he was diagnosed with anything at the time... Just a delay in speech
361 and language” (Mr. & Mrs. J)

362
363 “They just told us that he had a speech delay. That’s all they told us.” (Mrs. B)

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

369 ***Incomplete Information about Long Term Outcomes/Consequences***

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

378 “Not that I recall.” (Mrs. E)

379 “Nothing.” (Mrs. A)

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

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

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

394 “I wish the speech lady would have said you know Mom he’s met this
395 goal now but you know in the future sometimes we see blank blank; and
396 that you know don’t be afraid to reach out and this is how you do it.”
397

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

403 At least five of the caregivers noted that it was not until they understood that their child
404 was not going to ‘outgrow’ their speech and language difficulty that they became truly open to

405 seeking out help for their child. For example, Mrs. A said, “I knew I can’t get her past it and so I
406 knew I needed to reach out and find help somewhere.” Ultimately, even if it was hard to hear at
407 first, caregivers wanted to know about future concerns and challenges that their children might
408 face, so they could be prepared.

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

414 “No um no I never remember that conversation [about language connecting to reading].” (Mrs.J)

415 “I don’t [recall having a conversation about reading and language].” (Mrs. C)

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

425 In contrast to the lack of information caregivers reported receiving regarding diagnostic
426 labels and long-term outcomes, all caregivers described receiving an abundance of information
427 about the speech and language services provided for their children, even referring to specific
428 goals and objectives that had been shared with them by their SLP. For example, Mrs. A shared a

429 recently updated goal for her child, “She can do one step and two step directions, [child] can, but
430 at three steps it’s completely - It’s gone. So yeah three - they’re gonna start working with her on
431 the three step directions.” This perception of being informed was very important to how the
432 caregivers viewed their child’s overall services and their experience with the SLP, although
433 information about service provision did not help the caregivers understand their child’s
434 diagnosis, long-term outcomes, or the relation between children’s oral language abilities and
435 reading.

436 *Quality of Experience Equates with Caregivers’ Perception of Information*

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

442 “They came in and went over the results with me...they did a real good job of checking
443 him out I thought.” (Mr. J)

444
445 “They did really good. They detailed it really good for us so she (daughter) could
446 understand along with me.” (Ms. I)

447
448 In contrast, caregivers who experienced feelings of frustration with the evaluation or intervention
449 experience cited minimal to no explanations from the SLP:

450 “It was a very bad experience. They didn’t explain things.” (Mrs. A)

451 “I kind of left feeling like I wasn’t sure what was going on you know...a little more
452 concrete information would have been - would’ve made me feel better.” (Mrs. F)

453
454 Mrs. G attempted to explain the magnitude as a caregiver of receiving or not receiving
455 information, “I had exhausted all my resources and I was here to hand them off to you [the SLP]
456 to figure it out. So, I really didn’t feel like I came with a lot to offer...I was looking at help us!

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

461 **Caregivers' Reported Understanding of Language and Literacy Disorders**

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

468 ***A Problem Needs a Solution***

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

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

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

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

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

481 "We tried everything else we knew to do. We've tried after school, studying,
482 tutors. Everything we could look up on the internet, games and we had
483 exhausted all of my known resources, and I felt like I know enough to know I
484 don't know everything, and it was time to call in somebody else to help."
485

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

487 "As we've gone through the years and struggled through school then it was like
488 you know we've got to have something to figure out what's going [on] here
489 because it got to the point where it's like you know we're really struggling and
490 something's going [on] here we need to figure out what it is so we can figure out
491 how to work with it."
492

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

502 "Are they ok, is it something we can fix? How treatable is it? Is it going
503 to you know is this going to affect them the rest of their life or is this
504 something we can double down on get them past."
505

506 Her questions were similar to other questions that caregivers frequently asked in an effort to
507 understand their child's needs. Specifically, all of the caregivers discussed their child's future as
508 a key piece they were trying to understand, and the diagnosis was an important piece of the

509 process to help them understand their child's disorder, the solution to the problem. As Mrs. C
510 said, "To me the most absolute helpful thing was just having a diagnosis."

511 *Speech, Language and Academic Characteristics*

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

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

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

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

540
541 Thus, for some caregivers, there was no concern until their child entered school.

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

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

555
556 Mrs. E explained that she had never been concerned about her child’s development prior to her
557 struggles with reading in school.

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

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

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

570 *Difficult to Understand*

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

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

584 The difficulty some caregivers have in understanding their child's disorder appeared to relate to
585 each caregiver's personal learning experiences. Both Mrs. C and Mrs. D noted that they did not
586 experience the academic struggles that their children have experienced. In contrast, Ms. I shared

587 that she “inverts words and letters all the time,” adding “that’s probably why I was more in tune
588 [to her daughter’s academic struggles].”

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

599 Discussion

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

606 In the current study, we explored how caregivers perceive SLP communication and how
607 that communication influences their perceptions of their children’s language and literacy
608 disorders. The six themes identified in the results were obtained by asking caregivers open-ended
609 questions about their experiences and using qualitative methods to analyze their responses and

610 other information about their children. Each of the six themes provide relevant insights into
611 caregiver perspectives of SLP communication.

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

624 **The Power of a Diagnosis**

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

633 clear diagnostic label, caregivers felt unsure of what came next, and were more likely to be
634 disappointed in their communication experience.

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

650 **Clarity Is in the Eye of the Beholder**

651 The caregivers' desire for a clear diagnosis is important to note because not all diagnoses
652 were perceived equally by caregivers. Notably, caregivers did not always perceive certain
653 speech-language labels as a diagnosis, referring to terms such as 'speech or language delay' as a
654 vague description only. This finding is consistent with previous studies that have pointed to the
655 difficulties associated with the term 'delay' and with the lack of clear and consistent labels in

656 identifying children with language disorders (Bishop, 2014; Reilly et al., 2014; Hadley &
657 Schuele, 1999). Also, difficulty in recognizing a diagnosis was not limited to oral language
658 disorders. For literacy disorders, caregivers typically understood a diagnosis of dyslexia, but they
659 did not always interpret other diagnoses such as “mixed reading disorder” and “reading
660 comprehension deficit,” as diagnoses. One reason for this misunderstanding may be the lack of
661 continuity in labeling language and literacy disorders across settings (Dollaghan, Nelson, &
662 Scott, 2012). Other factors may include SLP reports that describe a child’s strengths and
663 weaknesses without offering a diagnostic label, or a general lack of caregiver familiarity with
664 language and literacy disorder terms beyond the well-publicized labels of autism and dyslexia.

665 A number of papers have been written about the value of giving caregivers clear
666 diagnostic information and the need for the field to settle on a consistent set of terms to describe
667 children’s language and literacy disorders (Bishop et al., 2017; Catts et al., 2006; Dollaghan,
668 Nelson, & Scott, 2012; Leonard, 2014; Paul, Rice, & Ellis Weismer, 2019; Rice & Warren,
669 2005; Schuele & Hadley, 1999; Van Horne, Ebbels, Redmond, & Finestack, 2018; Volkens,
670 2018). However, none of these previous papers has included input from caregivers, even though
671 caregivers are the most important stakeholders in the discussion as they seek out our services and
672 determine whether our services are of value to their children. The current study is the second of
673 two that has asked caregivers directly about their perceptions of SLP communication practices.
674 As was found in the current study, caregivers interviewed by Ash et al. (2020) also placed a high
675 value on receiving a clear diagnostic label for their children, and they were frustrated by the lack
676 of information they felt should have been given to them, even though they were generally
677 satisfied with their SLP’s communications regarding their child’s therapy goals and objectives.

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

691 **Finding Meaning**

692 Caregivers as a whole expressed the view that their understanding of their child's
693 language and literacy disorder was complicated, influenced by their history, and constantly
694 evolving over time and with new experiences. The limited understanding that caregivers had of
695 their child's disorder reflects key concepts within family systems theory, particularly in regard to
696 family coping (e.g., Manning et al., 2011; McCubbin et al., 1983). Similar to this study, Manning
697 et al. (2011) found that caregivers of children with Autism went through a complex process of
698 trying to understand what it meant to raise a child with Autism. Factors including behavior
699 severity and the families' ability to reframe or redefine their children's disorder were key
700 components in how families successfully came to understand their child's disorder. This study,

701 as well as others, emphasized the complexities of the information exchanges that occur over
702 time, both within and outside of a family system that can shape caregiver understanding of a
703 disorder (Pecchioni & Keeley, 2011). Furthermore, the literature shows that caregivers’
704 perceptions of their health care provider’s communication is key to shaping both their
705 perspective of their experiences and their perspective of their child’s disorder (e.g., Brown,
706 Stewart, & Ryan, 2003; Donovan, Hartenbach, & Method, 2005; Propp et al., 2010). These
707 findings match those of the current study, as the caregivers frequently connected SLP
708 communication practices to their perceived quality of experience, and they also credited the SLP
709 with shaping their attitudes and beliefs about their child’s language and literacy disorder.

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

721 In contrast, caregivers presented as very knowledgeable about their child’s therapy goals.
722 Possibly this was a factor of repetition, as goals that are being addressed in therapy may be
723 discussed more often and therefore be more memorable, or possibly this was a factor of the goals

724 presenting as practical and functional steps that the caregivers could easily see as measures of
725 their child's progress towards success. In seeking to reach a mutual understanding of the
726 disorder, one strategy may be for SLPs to communicate more frequently with caregivers about
727 the relevance of their child's goals and objectives to addressing the child's specific language and
728 literacy disorder. For example, if a child is working on identifying macrostructure within a
729 narrative, talking with the caregiver about how the stated goal specifically addresses their child's
730 literacy and academic success. Making these connections could help caregivers better understand
731 their child's disorder and become more involved collaborators.

732 **Clinical Implications**

733 The findings from this study suggest several implications regarding SLP communication
734 practices. First, the findings underscore how important it is for SLPs to provide caregivers clear
735 diagnostic labels as part of their clinical services. Receiving a diagnosis was highlighted
736 repeatedly throughout the interviews. Given this and given that a number of caregivers were
737 unclear about their child's diagnosis, SLPs should review their reports and post-evaluation
738 family meetings to identify when and how they communicate diagnostic information to
739 caregivers. SLPs may also want to add more direct statements about a child's diagnosis into their
740 reports and meetings. These statements could include "the diagnosis is _____, and this is what
741 _____ means", or "here is a list of possible diagnoses we've considered, and a diagnosis of
742 _____ best aligns with your child's current communication profile for these reasons".
743 SLPs may also want to consider offering caregivers a list of other diagnostic terms that they may
744 encounter for their child within other settings (e.g., schools, insurance companies) or when
745 working with other professionals. As Murza and Ehren (2020) suggest, this will require SLPs
746 and pre-professional SLPs to be well informed of the various labels used within and outside of

747 the field and to share this information with caregivers, so that caregivers can better navigate the
748 labels their child may encounter. In cases where a child’s diagnosis is not clear and cannot be
749 given, the findings also suggest that SLPs should directly discuss with caregivers why this is so,
750 what steps can be taken without a diagnosis, and the expected time when a diagnosis might be
751 better established. For these cases (or for children whose diagnosis is likely to change with age),
752 the findings highlight the importance of SLPs scheduling future meetings with caregivers to
753 discuss not only their child’s progress but also their diagnosis.

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

770 their extended families, and others outside of the field understand the nature of childhood
771 language and literacy disorders.

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

790 **Limitations and Future Studies**

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

793 Midwest, spoke English as their first language, and were well educated. Caregivers from more
794 diverse backgrounds may present with different concerns and opinions about the communication
795 they have received from their SLPs. Another limitation to the study was the timing of the
796 interview relative to the evaluation. Although all children were receiving language services by an
797 SLP at the time of the study, their evaluations were conducted five to 17 months before the
798 interviews. In the future, it may be advantageous to conduct multiple interviews throughout a
799 child's evaluation and treatment program in order to examine evolving caregiver perceptions and
800 needs. Focusing on one SLP experience per caregiver may also yield clearer results, as some of
801 the variance in experiences could be related to norms in different settings. Future studies may
802 also want to target caregivers of younger and older children and children with different types of
803 speech and language disorders to see how caregiver perceptions of SLP communications differ
804 as a function of their child's age and diagnosis. Following the methods of Lyons and Roulstone
805 (2018) and Fourie et al. (2011), future studies may want to target children as the interviewees to
806 gain their perspective on their SLPs' communication about their language and literacy disorders.
807 Finally, it's important to note that caregiver responses might have been inhibited by their
808 knowledge that the interviewer was an SLP. Future studies may benefit from training a
809 professionally neutral interviewer.

810 **Conclusion**

811 Research in the field of health communication tells us that effective information sharing
812 with clients and caregivers can be as important as choosing the right diagnosis and treatment
813 approach (e.g., Wanzer et al., 2004). Using literature in health communication as a guide and
814 utilizing a qualitative methodology, the current study explored how caregivers perceive SLP
815 communication and how that communication influences caregivers' understanding of their

816 child's language and literacy disorder. In terms of information sharing, caregivers universally
817 stressed the value of receiving a clear diagnosis, and these clear diagnoses did not include all of
818 the terms (e.g., delay, mixed reading disorder) that SLPs currently offer. Caregivers also
819 expressed the need for more information regarding long-term language and literacy disorder
820 outcomes, especially related to reading. Finally, not understanding their child's disorder was a
821 constant struggle for caregivers, especially if they did not have personal experiences to draw
822 upon. These findings underscore the need for SLPs to: 1) offer diagnostic labels and explain
823 these labels to caregivers, even when a child's diagnosis is expected to change with age, 2)
824 discuss with families the relationship between oral language and literacy and possible long-term
825 outcomes of a language disorder, and 3) add to clinical practice, repeated opportunities to
826 educate caregivers and check caregiver understanding of their child's language and literacy
827 disorder.

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1054

1055 Figure 1. Data Collection and Review Process

1056

1057 Figure 2. Network Illustrating Themes Related to Caregiver Descriptions of Receiving
1058 Information from SLPs*

1059

1060 *The numbers in Figure 2 represent the current number of associated caregiver “quotes” with a
1061 particular theme at the time this visual was created. These numbers changed several times
1062 throughout the analysis process as final themes were established.