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A pilot qualitative study

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Research Note

Exploring Parental Perspectives of Childhood Speech and Language Disorders Across 10 Countries: A Pilot Qualitative Study

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Purpose: Although researchers have explored parental perspectives of childhood speech and language disorders, most studies have been conducted in English-speaking countries. Little is known about parental experiences across countries, where procedures of language screening and services for language disorders differ. The authors participated in the COST¹ Action network IS1406, “Enhancing Children’s Oral Language Skills Across Europe and Beyond,” which provided an opportunity to conduct cross-country qualitative interviews with parents. The aim of this pilot study was to explore ways in which parents construed and described speech and language disorders across countries.

Method: Semistructured qualitative interviews were conducted with parents from 10 families in 10 different countries. The data were analyzed using thematic analysis.

Findings: The overall theme was “acknowledging parental expertise.” The parents described, in detail, ways in which their children’s speech and language (dis)abilities had an impact on the children’s everyday life. Three subthemes were identified: impairment, disability, and changes over time.

Conclusions: The findings suggest that, across a range of countries, parents demonstrated contextualized understandings of their children’s speech and language (dis)abilities, along with the everyday functional implications of the disorders. Hence, despite not holding professional knowledge about language disorders, the voices, views, understandings, and personal experiences of parents in relation to their child’s disorder should be listened to when planning therapy services.

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The prevalence of speech disorders in young children is estimated at 3.6% (Wren et al., 2016), and language disorders (LDs) at 7% (Norbury et al., 2016). There is evidence to suggest that LDs can have long-term impacts on academic, psychosocial, and health-related outcomes (Botting et al., 2016; Feeney et al., 2012; McCormack et al., 2011; Yew & O’Kearney, 2013). However, LD has also been regarded as a neglected condition not only in research but also in debates about policy

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and practices. LD is a long-term disorder, which makes it important to prioritize and understand the voices and perspectives of parents. Furthermore, much of the evidence underpinning speech and language therapy practice is based on research conducted in western, educated, industrialized, rich, democratic, and English-speaking countries. Little is known about parental experiences in non-English-speaking countries.

With regard to parental experiences, one of the challenges that parents of children with LDs face is that the terms used to describe LDs are not well known, and children's impairments may not be visible (McGregor, 2020). Kamhi (2004) argued that some diagnostic labels, such as dyslexia and Asperger's syndrome, are successful memes compared with language disorder. This lack of awareness and visibility of LDs can lead to a lack of service provision and information to enable parents to make sense of their child's disorder. Furthermore, parents may seek the opinions of several professionals to ascertain the underlying cause of their children's LDs in the hope that "the professional who knows the cause of the problem will also know the most effective way to treat it" (Kamhi, 2004, p. 107). However, little is known about the ways in which parents construe their children's speech and language difficulties.

Patient values and preferences are one of the three pillars of evidence-based practice (Dollaghan, 2007). However, some scholars argue that parental voices, opinions, and expertise are often not recognized by professionals and may not be included in the decision-making process (Paradice & Adewusi, 2002; Roulstone et al., 2016). Improved understanding of parental views and experiences are important because they inform intervention and policy and enhance outcomes. Much of the research on parental perspectives has been conducted in English-speaking countries (i.e., Ash et al., 2020; Carroll, 2010; Davies et al. 2016; Lyons et al., 2010; Roulstone et al., 2016). In the United Kingdom, Roulstone and Lindsay (2012) found that the desired outcomes of parents for their children with speech, language, and communication needs were social acceptance and independence, rather than outcomes specifically related to their children's communication. They also found that, while some parents sense very early in their child's life that "something is wrong" with the child's language development, their worries may not be taken seriously (Roulstone, et al., 2015). Results from other qualitative studies carried out in the United Kingdom (Marshall et al., 2007, 2017) reported that parents viewed themselves as competent facilitators of their children's language development using strategies such as starting language input early, spending time talking to children, and giving children opportunities to use their language through interaction and socialization. However, parents may also be concerned that they are responsible for their child's LD, revealing worries that perhaps they did not give their children enough attention, or that they had not been patient enough with them (Roulstone et al., 2015). In a U.S. study, Ash et al. (2020) also reported that mothers reported "receiving confusing or irrelevant diagnostic terms for language

disorder" (p. 826) and that mothers were "distressed about their children's language problems" (p. 827).

The increase in global migration brings with it an interest in understanding cultural similarities and differences because these can inform service provision (Squires et al., 2020). However, little is known about parental experiences of language disorder in non-English-speaking countries. There is also little information available about service provision for children with speech disorders and LDs across countries. The authors of this research note, all of whom shared an interest in parental perspectives, participated in a European-funded COST Action IS1406 "Enhancing Children's Oral Language Skills Across Europe and Beyond." This network provided opportunities for researchers to learn about the different health and education services across countries and the different ways that children with LDs are served across countries. The network provided a unique research opportunity. One of the outcomes of this network was the publication of an edited book that illustrated similarities and differences in service provision for children with LD across European countries (Law et al., 2019). For example, the service provision for children with speech disorders and LDs in two English-speaking countries (i.e., Ireland and the United Kingdom) differ, and language screening programs are implemented in some countries (i.e., Denmark, Israel), but not in others (i.e., Croatia, Ireland). Even within countries, there may be variability with regard to implementation of screening programs (i.e., Spain uses different screening systems across its 17 territories). The diagnosis of an LD is also established by different specialists across countries. For example, in Denmark, psychiatrists are responsible for giving diagnosis based on the World Health Organization's International Classification of Diseases, but do not have any training in speech disorders and LDs. In other countries such as Spain, Ireland, and England, speech and language therapists are responsible for diagnosing children with LD. Furthermore, the dominance of both the health and the education system (i.e., Israel, Denmark, the Netherlands, Spain, and Iceland) versus the dominance of the education or the health system only (i.e., Hungary, Croatia) affects decision making of who and what services children with LD receive. Finally, a range of terms are used for LDs across countries (see Law et al., 2019, for detailed descriptions). In summary, the aim of this pilot study was to explore ways in which parents across countries construed their child's speech disorders and LDs, and cognizant that these views would be shaped by cultural factors and different models of service provision in each country.

Method

We used qualitative research to explore parental experiences across countries. Although each of researchers had experience in using qualitative research in their respective countries, none of them had experience of conducting cross-country qualitative research. Cross-country (and cross-cultural) qualitative research is still relatively new. Some advantages of cross-country qualitative research are

that there are no language barriers when the data are collected in the language of the country and the findings can provide valuable insights into cultural nuances, local policies, and different practice contexts (Chapple & Ziebland, 2017; Kaae et al., 2016). Rigour is important in qualitative research and perhaps even more in cross-country and cross-cultural qualitative research, when involving several researchers from different countries. With this in mind, the authors drew on reflections from researchers who have conducted cross-country research in other areas of health and illness (Arriaza et al., 2015, p. 76; Chapple & Ziebland, 2017; Haak et al., 2013), specifically in relation to two methodological issues: project management and language translation issues. From a project management point of view, it was important that we had regular meetings to ensure that all researchers had a shared understanding of the process and their respective roles. Analysis in qualitative research focuses on words and meanings that are embedded in cultural contexts; the analyst aims to stay close to the participant's intended meanings. Therefore, in cross-country research where the research is conducted in different languages, the issue of translation needs to be addressed.

One of the first differences identified across countries was that each country had different requirements regarding ethical approval. Five countries required and obtained ethical approval to carry out the study (see Supplemental Material S1).

Participants

We used opportunistic purposive sampling to recruit parents from 10 countries: Croatia (CR), Denmark (DEN), England (ENG), Hungary (HUN), Iceland (ICE), Ireland (IRE), Israel (ISR), the Netherlands (NET), Norway (NOR), and Spain (SP). The services for children with speech and LDs in each of these countries differed (see Law et al., 2019, for details). The inclusion criteria were parents of a monolingual child aged 6–12 years who had a speech and/or language disorder, which was the primary presenting difficulty, and child had been in receipt of services for speech and LDs within the last 4 months. We accessed the participants through gatekeepers, such as speech and language therapists, and then approached the parents individually

by telephone or face-to-face. A total of 11 parents participated consisting of nine mothers and one mother–father dyad. The age of the children ranged from 6 to 10 years, and three were girls. The characteristics of the participating parents and their children are presented in Table 1. All participants provided written consent prior to participation in the study. The study was carried out in accordance with the Declaration of Helsinki. We conducted the interviews in our respective countries. All members of the research team held a minimum of a master's degree in speech and language pathology, developmental or/and health psychology, and had experience of conducting qualitative research. The authors followed the Consolidated Criteria for Reporting Qualitative Research (Tong et al., 2007). Nine interviewers did not know the participants prior to the interview. One interviewer knew the parent because she had provided a speech and language therapy service to the child.

Procedure and Data Collection

We generated data using semistructured interviews. A topic guide was developed in English by K.J.L. and R.L. and was informed by the Danish parental interview guide currently used at the Clinic for Developmental Communication Disorders, Aalborg University, Denmark. The guide consisted of four topics: making sense of language disorder and how the parent describes it, impact on the family, getting help, followed by a closure and verifying common understanding. For each topic, suggestions for questions and probes were provided, such as, “How would other people notice that your child has a language problem or disorder?” and “Tell me about a time when this happened.” In order to manage potential biases driven by the values, prejudices, and personal positions of the individual researchers, we carried out reflective group discussions before conducting the interviews to ensure that the topic guide was balanced. For example, we realized that our lens was deficit focused, and therefore, we addressed this by ensuring that the questions in the topic guide were balanced. The topic guide included prompts that were neutral and expected to facilitate parents to discuss both positive and negative stories about their child (i.e., “Can you tell me about your child?”). We discussed the topic guide in detail and revised

Table 1. Characteristics of participants in the study.

Country and parent	Occupation and/or highest level of parent's education	Age and gender of child	Type of speech/language problem (as described by gatekeeper)
Croatia (mother)	Chemical engineer	10-year-old boy	Language delay - articulation disorder
Denmark (mother)	High school teacher	6-year-old girl	Articulation problems
England (mother)	Nursery manager	6-year-old boy	Verbal dyspraxia
Hungary (mother and father)	Work at factory (completed secondary school)	8-year-old boy	Language disorder
Iceland (mother)	Quality assessor	10-year-old boy	Language disorder
Ireland (mother)	Family business	11-year-old boy	Language learning and social skills difficulty
Israel (mother)	Architect	6-year-old girl	Language disorder
Netherlands (mother)	Housewife holding a bachelor degree	10-year-old girl	Language disorder
Norway (mother)	Higher education	8-year-old boy	Language disorder
Spain (mother)	Works and studies at university	8-year-old boy	Language delay

topics and wordings to ensure that they were culturally appropriate for each country. From a project management point of view, it was important to ensure that all researchers were clear about the aims of the project and that they were clear about the interview guide and prompts. The researchers then translated the interview guide into the respective main language of participating countries. In order to ensure that the meaning of the words and phrases were maintained after the translation, back translations were carried out by independent researchers. Finally, we revised concrete terms to ensure that the meaning was maintained across countries and languages (i.e., the term *service* was replaced by the term *help*).

Each of the authors carried out the interview at a convenient location, such as the home of the parent or in the clinic (see Supplemental Material S2). In accordance with the variation in ethics requirements between countries, summer vacations, and the subsequent identification of interviewees, data collection spanned over a period of 8 months (during 2018). Interviews ranged from 35 to 77 min (*Mdn* = 52 min) in length and were audio-recorded with consent. The digital recordings were transcribed verbatim by a local member of the research team, and six of the researchers made field notes during the interview. In cross-cultural and cross-language qualitative research, there is debate about when in the research process data should be translated into English (Chapple & Ziebland, 2017; Oates et al., 2004). One concern is that, if the data were translated before the analyses, the richness of the data may be compromised. In this pilot study, the interviews and analysis were conducted in the first language of the country. We made the decision to translate excerpts of the data to English in the final stages of the analysis when the codes and themes had already been agreed by the team.

Data Analysis

We used thematic analysis to analyze the data following the steps suggested by Horwitt (2010) and Braun and Clarke (2006). One of the challenges and opportunities in the analysis phase was the involvement of multiple researchers. The advantage of multiple analysts was the potential for analyst triangulation where codes and themes could be cross-checked for selective interpretations (Patton, 1990). Our analysis was underpinned by the assumption that coding and theme development “are assumed to be subjective and interpretive processes” (Terry et al., 2017, p. 20). We also shared the view of Greenhalgh (2016, p. 5) that analysis was “less about technical procedures (e.g., ensuring that two observers independently check the data) than about producing a convincing interpretation.” One of the aims of this pilot study was to work out a systematic and rigorous process for involving multiple analysts. We adopted a consensus approach that required ongoing discussions and meetings both virtually and in person.

The initial step of data analysis was familiarization with the data. Each member of the team read and reread their own transcripts focusing on the voice of the participant.

One member of the team coded her transcript and shared both the transcript and codes with the team (see Table 2 for an extract of this initial coding process). These codes were discussed, revised, and refined, and a Version 1 of a “code-book” was then developed with scope for analysts to add new codes. These codes were then applied by all analysts to their data. Following this step, there was further discussion about the coding process. Codes were again refined and added, which resulted in Version 2 of the code book. Each researcher coded their data using these revised codes on respective Excel sheets for each country. Excerpts of the data that mapped onto codes were translated into English to enable all researchers to review the data. Individual excerpts were tagged with initials to identify the context of the interview where they appeared, that is, DEN1 refers to the translated Danish Excerpt One.

The next step in the process was to identify patterns of meanings and themes. We secured funding through the COST Action to hold a 2-day, face-to-face meeting with six of the authors (J.F., S.H., R.L., R.N., T.S.U., and K.Z.) with the other researchers joining planned sessions of the meeting via Skype. Through a process of discussion and cross-checking the data against codes, we grouped codes into six broad themes. In this research note, we were focusing on one of those themes. Through discussions at the meeting, we used analyst triangulation as we discussed our interpretations. We also developed mind-maps to enable us to refine our interpretations (see Supplemental Material S3). Following these discussions, we modified, revised, and generated new understandings of the data. In order to enhance transparency and credibility, a shared Excel spreadsheet was designed, which allowed for cross-checking of extracted excerpts and subsequent themes by each researcher (see Supplemental Material S3). Following the 2-day, face-to-face meeting, further virtual meetings were held to further refine the themes.

Findings

Here, we describe the overall theme, “Acknowledging parents as experts,” which included three subthemes: “Impairments” mainly appear in specific difficulties experienced by their children, “Disabilities” referred to the barriers to participation caused by other’s behavior and attitudes, and “Changes over time” referred to parental perceptions of improvements as well as the persistence of speech and language disorder over time.

Theme

“Acknowledging parents as experts” referred to how parents construed their children’s speech, language, and communication (dis)abilities in a functional and contextualized way. Three parents mentioned speech or/and language disorder as a diagnosis. Nonetheless, parents described the specific challenges that their children experienced in their everyday lives.

Table 2. Extract to illustrate initial coding of Irish interview.

Excerpts from data	Code
<p>At that stage, we more or less went straight into [name of public community clinic] clinic under I suppose the umbrella of getting everything checked at that stage so he was around all the different functions between occupational therapy, speech and language, child psychology.</p>	<p>Important to get him checked Reassurance that he is developing normally</p>
<p>So the public health nurse then at that stage referred him I think from what I remember to [name of public community clinic] clinic to get him checked because obviously wanted to make sure there was no delays or anything like that with him.</p>	<p>Important to get him checked Reassurance that he is developing normally</p>
<p>But obviously he was slow to talk then as well. I suppose the fact that he wasn't talking.</p>	<p>Parental concern Parental concern Parent was familiar with his communication style Parental concern that others would not understand him</p>
<p>So they were good now in fairness, the girls [in the creche] that worked there but obviously with him not talking you know? I could understand him with the way he would communicate but others wouldn't have been able to and even when he did start talking he wouldn't have been that clear or he might have had you know? He would have pointed a lot and you know? Wouldn't necessarily have wanted to say stuff. Then what we used to find was [name of Peter's sister] would start talking for him to try and help him out so it was a bit of a no, look let him just say it for himself and stop just answering for him all the time.</p>	<p>Suggests speech difficulty Child not motivated to talk Protective role of sibling – anticipating needs and answering for him Conflict for mother – wants to let him speak for himself</p>
<p>What happened was, it was funny, [name of his first SLT] had, she had been kind of testing him all along to see where he was falling into as regards scores and stuff and actually by the time he was starting school she had retested him again and he wouldn't have qualified for resource hours on the basis of what he was scoring at just before he went in but she kind of felt that he was going to need help so she said look I'm going to rightly or wrongly, she took an older score and sent it in and got him the resource hours on that and to be honest we were glad. When she said to me first about getting him resource hours I was like oh my god that's awful. He's going to be pulled out of the classroom and taken away and he will be standing out and she was kind of like no, whatever help you can get, you know? Take it. And it's hard because I suppose when you're starting off like that you're going oh I really, I want to pretend he's ok and I don't want to be getting any help for him and he's fine and you know? And I was like no actually, you're right. He does need help. So we got the resource hours and it was</p>	<p>Comparison with normal/typical development? Meeting/not meeting eligibility criteria for services – mixed feelings SLT working around the system to get him services Conflict between upset that he would be “standing out” from peers (identity) and wanting him to be “ok” and not wanting him to be getting help with recognizing that he needed help Reassurance from SLT</p>

Note. SLT = speech-language therapist.

Subtheme 1: Impairment

The subtheme “impairments” included direct references to the child’s speech, language, and communication, and importantly where the problem was located in the child. When parents described their children’s impairments, there were references to speech, language, and communication that could be mapped onto linguistic terms used by professionals (*language comprehension, language production, pragmatic skills*). Nine parents made references to their children’s speech problems. Parents differentiated between speech from language problems. For example, the Danish parent stressed, “She has a large vocabulary...and good understanding ... it’s those articulation problems, she talks and talks and talks in a multitude even if she has articulation problems, and it’s it’s well fantastic that she doesn’t allow herself to be constrained because of it” (DEN1a). The Dutch and Icelandic parents emphasized areas where their child’s speech were intact “but her pronunciation is good” (NET1b); “It was more the language he didn’t have, he never had difficulties with speech or making the sounds” (ICE1a).

With regard to semantics, parents described ways in which their children’s word finding and fluency difficulties manifested themselves in different contexts, for example, “she

would do eh..eh..eh.. can’t say it and get stuck” (ISR1). Parents also described strategies the child used to overcome these difficulties, for example, “If he wants to say ‘book,’ he can say ‘what you read from’... He paraphrases when he can’t remember the words he needs” (NOR1). This was also the case for vocabulary difficulties and conceptual difficulties, which may have made it difficult for others to understand the child, for example, “...because she also has problems with him and her... she says ‘her’ instead of ‘him,’ I think... it becomes really messy when you say that in a sentence” (DEN1b), “He is behind in learning names [of other persons]” (HUN1), “...he started speaking late, and you couldn’t understand him well, he didn’t have much vocabulary” (SP1). The Icelandic parent provided a contextualized example of her child’s confusion about the difference between a dentist and a doctor: “I was trying to tell him that we were going to a dentist but not a regular doctor. He could not understand the difference between those two types of doctors” (ICE2a). Parents also described what professionals would call morphosyntactic difficulties (i.e., some parents described the children’s attempts to construct sentences and were aware that their children were delayed relative to others): “He was already three and a half when he connected ‘tata papa,’

'mama papa' [dad eats, mum eats]" (CR1). Parents also described their children's difficulties structuring the discourse and the impact of these difficulties on their children's intelligibility to others, for example, "I can tell you that at this time he could not express himself clearly and his sentences were all jumbled. He was not able to communicate with others" (ICE1b). Pragmatic deficits were also described in terms of concrete difficulties with narrative skills, social skills, and difficulties in having a conversation, that is,

...in conversations...if she wants to tell something, for example when she has seen a movie and you did not and she wants to tell you something about that movie that is quite hard to follow. It is hard for her to tell the who, what and when... (NET1a)

Some parents also reported that their children had difficulty staying on topic, for example, "... often times then we used to find say somebody asked him a question, he wouldn't answer what should be the right answer, he would talk about something else or he would completely go off topic or he would talk about something that was completely unrelated to what they had just asked him the question on...." (IRE1).

Subtheme 2: Disabilities

This subtheme referred to the psychological impact of the communication disability on the child and barriers to participation in everyday activities, which can be stressful for the child and the family. For example, the Croatian parent reported that her child was now able to verbalize reasons for his anger, "Also when he could say it, he would not speak. And today, when he is angry he says I'm angry because of this or that or I'm sad because of this or that. That is a huge difference" (CR2). The Danish and English parents described how their children had become more intelligible to others: "Because they [family] were not getting it, so it has obviously become better now, but when she was younger, while but they were not getting what she wanted" (DEN2). The child's language disorder was experienced as a core obstacle for the child in communicating with others, that is

He is pretty understandable now to be honest when he talks, he could get his point across and everybody probably would now understand him. (...) you know you could have a conversation with him now. He won't say reception, he'll say ception, he still misses some of the fronts of words... (ENG2a)

Parents also stressed that their children's communication difficulties were more obvious when they were in public rather than in a private context of home. The parents also reported that the disability had a direct impact on the child's self-esteem, for example, "but it was quite hard when you went to different places and they didn't know him...He does say that his friends do not understand him still, and obviously his self-confidence is quite low" (ENG3), "people just didn't seem to understand what he was saying" (IRE2), "she knows and she is embarrassed, she can't say the sentence" (ISR32). The LD also caused the child to be misunderstood in every day social interactions with peers, that is "Friends

for example, "friends were sometimes annoyed, because they did not understand her" (NET37).

Subtheme 3: Changes Over Time

Many of the parents perceived some improvements in their child's speech and/or language disorder, while some parents perceived that the difficulties were persistent. Descriptions were again embedded in contextualized everyday activities. Six of the parents reported changes in their children's speech and language abilities over time, which had positive impacts on their everyday functioning. For example, the Hungarian parents reported an improvement in their child's speech, "since then, he developed his speech substantially. He did confuse some letters. And his speech... instead of 'Viki' /viki/ he always said 'gyigyí' /jiji/. But otherwise now he says everything as expected. Even in English" (HUN2),² while the Icelandic parent expressed improvements in the child's understanding of word meanings, for example, "he could not understand the difference between those two doctors.... This was when he was around 4 years. He got better at it when he grew older" (ICE2b). The Israeli parent experienced how the disorder had become milder, "Recently I feel...I noticed...her disorder...it gets milder" (ISR2b). The Danish parent explained improvement in the child's disability in the following way:

Because they [the extended family] were not getting it [understanding the child], so it has obviously become better now, but when she was younger, while they [the extended family] were just not getting what she wanted. (DEN7)

However, some parents also reported persistent speech and language difficulties, that is, "His grammar is not correct and he still gets frustrated" (ENG2b), "language just does not work for him" (NOR2).

Discussion

The purpose of this cross-country pilot study was to explore ways in which parents construe their children's speech and/or LDs across countries. This is important because of increasing globalization and the need to understand parental perspectives in different countries, including non-English-speaking countries. Given that none of the researchers had experience of conducting cross-cultural qualitative research, we designed this pilot study to explore the feasibility of using such a method. Researchers from 10 different European countries and beyond conducted a semistructured qualitative interview with one participant. We used thematic analysis to analyze our data (Braun & Clarke, 2006) and developed processes to coordinate the involvement of multiple researchers. The overall theme we identified was "acknowledging parents as experts." The findings illustrate that despite cultural, political, and service provision differences

²Here, the parent is referring to the child's English class. English is taught in school in most European non-English-speaking countries but is not the language spoken in the home of this specific child.

across countries (see Law et al., 2019), there were many similarities among the parents regarding the way they construed their children's dis(abilities).

Participants described their children's impairments using specific terms that mapped onto the linguistic domains used by speech and language therapists, and in doing this, they described how the impairments are unfolded in everyday contexts. Despite lack of public awareness about LDs and the differences in services and languages across countries, the findings were consistent with the literature. For example, Marshall et al. (2007, 2017) also found that parents provided detailed descriptions of their children's communication abilities and perceived themselves as competent facilitators of their children's language development. Some of the parents in our sample distinguished between language and speech problems, a distinction that is often difficult to grasp even for first year students of linguistics and speech and language therapy. Parents provided socially contextualized examples of the functional impacts of their children's LD. For example, some parents provided examples of everyday contexts where their children were confused by the meaning of words like doctor and dentist or could not be understood by peers. These concerns are consistent with the findings of other studies that reported that parents' desired outcomes for their children are that they will be included socially and be independent (Roulstone & Lindsay, 2012). These findings also highlight a potential disconnect between the areas that speech and language therapists assess (i.e., discrete aspects of language such as morphology, syntax) and the functional areas that are priorities for parents. Barnes and Bloch (2019, p. 221) argued that language is often viewed as an abstract representational system (i.e., phonology, lexis, morphology, syntax) and that assessment of discrete aspects "becomes decoupled from communication, which naturally blurs and obscures its contextually sensitive features and their variation." It is important that professionals are open to acknowledging parents as experts and include them as partners in the decision-making process. While parents in our study captured changes in their children's communication abilities over time, they also expressed concern concerning the persistence of speech and language difficulties. It was also important to note that parents made associations between their children's communication abilities and their ability to express emotions, their behavior, self-esteem, and self-efficacy. These findings are also consistent with the literature on the relationship between language and communication and mental health (Durkin et al., 2017).

It was interesting that only three out of 10 parents mentioned speech or/and language disorder as a diagnosis. This finding may suggest the underdiagnosis of LDs across the different countries or a reluctance by either therapists or parents to use the label. For example, Archibald et al. (2019) reported that many Canadian speech-language therapists do not provide a label for a child's language disorder when sharing findings with the parents. Ash et al. (2020) reported that some U.S. mothers reported receiving confusing and irrelevant diagnostic terms for language disorder. Furthermore, in parental interviews conducted by Roulstone and Lindsay (2012), none of the parents used a diagnostic

label in relation to the child's communication impairment but used other labels, such as attention-deficit/hyperactivity disorder, Asperger's, or dyslexia, when referring to their children's needs. This may support Kamhi's (2004) claim that language disorder is not a successful meme compared with other well-known conditions. It is also consistent with the claims that LD is not well known compared to other, less prevalent neurodevelopmental conditions like attention-deficit/hyperactivity disorder, autism spectrum disorder, or dyslexia, rendering it an "invisible" condition (Bercow, 2008, 2018; Bishop, 2010, 2013). However, it could also be the case that speech-language therapists themselves are diagnostically agnostic, so they place low value on labels and are reluctant to diagnose children with LD (Archibald et al., 2019).

Limitations

Our study included several limitations. In this pilot study, we were conscious of methodological issues with language, translation, and analysis by multiple researchers and therefore only included one family per each of the 10 countries. Nonetheless, the interviews lasted 35–77 min (*Mdn* = 52 min) and generated rich data. It is worth noting that our sample was homogeneous regarding their educational and socioeconomic background and we do not claim that our findings are generalizable. We are cognizant of variability among parents, both within and across countries. In future research, it is important to include the voices of parents from a range of socioeconomic classes including those who may be considered underserved as well as parents of multilingual children. Within the constraints of this pilot study, we have not yet mapped parental experiences directly onto the health and service provision for their respective countries. However, one of outcomes of the European COST Action is that data about health and service provision are now available for each of the countries (Law et al., 2019, edited book), so a more in-depth analysis of the interpretation of our data in relation to different services could be carried out in the future.

Conclusions

The current study extended research on how parents construe and describe their child's speech and language disorder. Our unique contribution was the illustration of perspectives from parents across 10 primarily non-English-speaking countries, as well as the surprising degree of consensus across the sample. These results suggest that it is important that practitioners listen to, acknowledge, and value parental perspectives and aim to provide services tailored to the needs of parents. It is important that parental expertise is acknowledged and that they receive information and resources to enable them to support their children and reduce stress (Craig et al., 2016). As reported by Ritzema et al. (2018), parents' perceptions (positive or negative) and the degree to which their needs are met by the services can be good indicators of the child's level of well-being. In line with evidence-based practice and family-centered care, these findings highlight the importance of prioritizing and listening to

the voices of parents. This knowledge could be helpful in developing coordinated international guidelines for services for children with LDs. Collaboration with parents could inform functional goal settings and intervention enabling individualization of intervention for families. These findings suggest that parents should be acknowledged as experts on their own children and, as a standard, should be asked to provide detailed information about their children's lives in functional contexts.

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References

- Archibald, L. M. D., Cunningham, B. J., & Oram Cardy, J.** (2019). *Developmental language disorder: Steps towards implementation in Ontario* (An OSLA working paper). <https://www.uwo.ca/fhs/lwm/osla/index.html>
- Arriaza, P., Nedjat-Haiem, F., Lee, H. Y., & Martin, S. S.** (2015). Guidelines for conducting rigorous health care psychosocial cross-cultural/language qualitative research. *Social Work in Public Health, 30*(1), 75–87. <https://doi.org/10.1080/19371918.2014.938394>
- Ash, A. C., Christopoulos, T. T., & Redmond, S. M.** (2020). "Tell me about your child": A grounded theory study of mothers' understanding of language disorder. *American Journal of Speech-Language Pathology, 29*(2), 819–840. https://doi.org/10.1044/2020_AJSLP-19-00064
- Barnes, S., & Bloch, S.** (2019). Why is measuring communication difficult? A critical review of current speech pathology concepts and measures. *Clinical Linguistics & Phonetics, 33*(3), 219–236. <https://doi.org/10.1080/02699206.2018.1498541>
- Bercow, J.** (2008). *The Bercow report: A review of services for children and young people (0–19) with speech, language and communication needs*. Department for Children Schools and Families, Secretary of State for Health, United Kingdom.
- Bercow, J.** (2018). *Bercow: Ten years on*. <https://www.bercow10yearson.com/wp-content/uploads/2018/03/337644-ICAN-Bercow-Report-WEB.pdf>
- Bishop, D. V. M.** (2010). Which neurodevelopmental disorders get researched and why. *PLOS ONE, 5*(11), e15112. <https://doi.org/10.1371/journal.pone.0015112>
- Bishop, D. V. M.** (2013). Cerebral asymmetry and language development: Cause, correlate or consequence. *Science, 340*(6138), 1230531. <https://doi.org/10.1126/science.1230531>
- Botting, N. F., Durkin, K., Toseeb, U., Pickles, A., & Conti-Ramsden, G.** (2016). Emotional health, support, and self-efficacy in young adults with a history of language impairment. *British Journal of Developmental Psychology, 34*(4), 538–554. <https://doi.org/10.1111/bjdp.12148>
- Braun, V., & Clarke, V.** (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Carroll, C.** (2010). "It's not everyday that parents get a chance to talk like this": Exploring parent's perceptions and expectations of speech-language pathology services for children with intellectual disability. *International Journal of Speech and Language Pathology, 12*(4), 352–361. <https://doi.org/10.3109/17549500903312107>
- Chapple, A., & Ziebland, S.** (2017). Methodological and practical issues in cross-national qualitative research: Lessons from the literature and a comparative study of the experiences of people receiving a diagnosis of cancer. *Qualitative Health Research, 28*(5), 789–799. <https://doi.org/10.1177/1049732317736284>
- Craig, F., Operto, F. F., De Giacomo, A., Margari, L., Frolli, A., Conson, M., Ivagnes, S., Monaco, M., & Margari, F.** (2016). Parenting stress among parents of children with neurodevelopmental disorders. *Psychiatry Research, 242*, 121–129. <https://doi.org/10.1016/j.psychres.2016.05.016>
- Davies, K. E., Marshall, J., Brown, L. J. E., & Goldbart, J.** (2016). Co-working: Parents' conception of roles in supporting their children's speech and language development. *Child Language Teaching and Therapy, 33*(2), 171–185. <https://doi.org/10.1177/0265659016671169>
- Dollaghan, C.** (2007). *The handbook for evidence-based practice in communication disorders*. Brookes.
- Durkin, K., Toseeb, U., Botting, N., Pickles, A., & Conti-Ramsden, G.** (2017). Social confidence in early adulthood among young people with and without a history of language impairment. *Journal of Speech, Language, and Hearing Research, 60*(6), 1635–1647. https://doi.org/10.1044/2017_JSLHR-L-16-0256
- Feeney, R., Desha, L., Ziviani, J., & Nicholson, J.** (2012). Health-related quality-of-life of children with speech and language difficulties: A review of the literature. *International Journal of Speech-Language Pathology, 14*(1), 59–72. <https://doi.org/10.3109/17549507.2011.604791>
- Greenhalgh, T.** (2016). *Cultural contexts of health: the use of narrative research in the health sector*. (Health Evidence Network Synthesis Report, No. 49). WHO Regional Office for Europe.
- Haak, M., Himmelsbach, I., Granbom, M., & Löfqvist, C.** (2013). Cross-national and multi-language qualitative research: Challenges and recommendations. *British Journal of Occupational Therapy, 76*(7), 333–336. <https://doi.org/10.4276/030802213X13729279115059>
- Horwitt, D.** (2010). *Introduction to qualitative methods in psychology: Putting theory into practice* (4th ed.). Pearson.
- Kaae, S., Sporrang, S., Traulsen, J., Kildemoes, H., Norgaard, L., Jakupi, A., & Cantarero, L.** (2016). Experiences from a pilot study on how to conduct a qualitative multi-country research project regarding use of antibiotics in Southeast Europe. *Journal of Pharmaceutical Policy and Practice, 9*(20), 1–10. <https://doi.org/10.1186/s40545-016-0069-3>
- Kamhi, A.** (2004). A meme's eye view of speech-language pathology. *Language, Speech, and Hearing Services in Schools, 35*(2), 105–111. [https://doi.org/10.1044/0161-1461\(2004\)012](https://doi.org/10.1044/0161-1461(2004)012)
- Law, J., McKean, C., Murphy, C. A., & Thordardottir, E.** (2019). *Managing children with developmental language disorder: Theory and practice across Europe and beyond* (pp. 189–202). Routledge.
- Lyons, R., O'Malley, M. P., O'Connor, P., & Monaghan, U.** (2010). 'It's just so lovely to hear him talking': Exploring the early-intervention expectations and experiences of parents. *Child Language Teaching and Therapy, 26*(1), 61–76. <https://doi.org/10.1177/0265659009349975>
- Marshall, J., Goldbart, J., & Phillips, J.** (2007). Parents' and speech and language therapists' explanatory models of language development, language delay and intervention. *International Journal*

- of *Language & Communication Disorders*, 42(5), 533–555. <https://doi.org/10.1080/13682820601053753>
- Marshall, J., Harding, S., & Roulstone, S.** (2017). Language development, delay and intervention — The views of parents from communities that speech and language therapy managers in England consider to be under-served. *International Journal of Language & Communication Disorders*, 52(4), 489–500. <https://doi.org/10.1111/1460-6984.12288>
- McCormack, J., Harrison, L. J., McLeod, S., & McAllister, L.** (2011). A nationally representative study of the association between communication impairment at 4–5 years and children's life activities at 7–9 years. *Journal of Speech, Language, and Hearing Research*, 54(5), 1328–1348. [https://doi.org/10.1044/1092-4388\(2011\)10-0155](https://doi.org/10.1044/1092-4388(2011)10-0155)
- McGregor, K.** (2020). How we fail children with developmental language disorder. *Language, Speech, and Hearing Services in Schools*, 51(12), 981–992. https://doi.org/10.1044/2020_LSHSS-20-00003
- Norbury, C., Gooch, D., Ray, C., Baird, G., Charman, T., Siminoff, C., Vamvakas, G., & Pickles, A.** (2016). The impact of nonverbal ability on prevalence and clinical presentation of language disorder: evidence from a population study. *The Journal of Child Psychology and Psychiatry*, 57(11), 1247–1257. <https://doi.org/10.1111/jcpp.12573>
- Oates, M. R., Cox, J. L., Neema, S., Asten, P., Glangaud-Freudenthal, N., Figueiredo, B., Gorman, L. L., Hacking, S., Hirst, E., Kammerer, M. H., Klier, C. M., Seneviratne, G., Smith, M., Sutter-Dallay, A., Valoriani, V., Wickberg, B., & Yoshida, K.** (2004). Postnatal depression across countries and cultures: A qualitative study. *The British Journal of Psychiatry*, 184(S46), S10–S16. <https://doi.org/10.1192/bjp.184.46.s10>
- Paradice, R., & Adewusi, A.** (2002). 'It's a continuous fight isn't it?': Parents' views of the educational provision for children with speech and language difficulties. *Child Language, Teaching, and Therapy*, 18(3), 257–288. <https://doi.org/10.1191/0265659002ct238oA>
- Patton, M. Q.** (1990). *Qualitative evaluation and research methods* (2nd ed.). SAGE.
- Ritzema, A. M., Lach, L. M., Nicholas, D., & Sladeczek, I. E.** (2018). A model of well-being for children with neurodevelopmental disorders: Parental perceptions of functioning, services, and support. *Child: Care, Health and Development*, 44(2), 240–248. <https://doi.org/10.1111/cch.12541>
- Roulstone, S. E., Harding, S., & Morgan, L.** (2016). *Exploring the involvement of children and young people with speech, language and communication needs and their families in decision making — A research project*. The Communication Trust. <http://www.thecommunicationtrust.org.uk/involve>
- Roulstone, S. E., & Lindsay, G.** (2012). *The perspectives of children and young people who have speech, language and communication needs, and their parents*. <https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DFE-RR247-BCRP7>
- Roulstone, S. E., Marshall, J. E., Powell, G. G., Goldbart, J., Wren, Y. E., Coad, J., Daykin, N., Powell, J. E., Lascelles, L., Hollingworth, W., Emond, A., Peters, T. J., Pollock, J. I., Fernandes, C., Moultrie, J., Harding, S. A., Morgan, L., Hambly, H. F., Parker, N. K., & Coad, R. A.** (2015). Evidence-based intervention for preschool children with primary speech and language impairments: Child Talk — An exploratory mixed-methods study. *Programme Grants for Applied Research*, 3(5). <https://doi.org/10.3310/pgfar03050>
- Squires, A., Sadarangani, T., & Jones, S.** (2020). Strategies for overcoming language barriers in research. *Journal of Advanced Nursing*, 76(2), 706–714. <https://doi.org/10.1111/jan.14007>
- Terry, G., Hayfield, M., Clarke, V., & Braun, V.** (2017). Thematic analysis. In C. Willig & W. Stainton Rogers (Eds.), *The SAGE handbook of qualitative research* (2nd ed., pp. 17–37). SAGE.
- 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>
- Wren, Y., Miller, L. L., Peters, T. J., Emond, A., & Roulstone, S.** (2016). Prevalence and predictors of persistent speech sound disorder at eight years old: Findings from a population cohort study. *Journal of Speech, Language, and Hearing Research*, 59(4), 647–673. https://doi.org/10.1044/2015_JSLHR-S-14-0282
- Yew, S. G. K., & O'Kearney, R.** (2013). Emotional and behavioural outcomes later in childhood and adolescence for children with specific language impairments: Meta-analyses of controlled prospective studies. *The Journal of Child Psychology and Psychiatry*, 54(5), 516–524. <https://doi.org/10.1111/jcpp.12009>