ORIGINAL ARTICLE

Rearing a child with a language disorder: parents experiences with speech and language therapy services in 10 countries

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Abstract

Aim Collaboration between speech and language therapists and parents to help children with language disorders has always been important. The majority of published work is from the perspective of the therapist and what they think and feel parents need to help their children. However, less is known about (1) the processes parents try to access and receive services; (2) how they perceive the journey; and (3) what they think about the service provided to their child. This paper describes an exploration of how parents experience identification and access of services for their children living with language disorders.

Subjects and methods Parents from ten countries, with a child who had received services for speech language disorder participated in semi-structured qualitative interviews. Thematic analysis was used to interpret the data.

Results Two main themes were constructed: (1) Parental recognition of the need for services; and (2) difficulties accessing services. Parents detailed how they recognised that their children needed services and how they went about securing them. Parents recounted the process they undertook; from their initial concerns about their child's development, the feelings this engendered, and how they tried to get support and treatment. Parents talked about the factors that made them decide they had to fight to gain access to services for their children.

Conclusions Across countries, parents encounter similar experiences. The major obstacles identified by parents lead to the perception of delay in obtaining access to services. Identifying the services that children required was the first hurdle, even before getting a referral to them.

Keywords Cross-cultural · Parental perspectives · Childhood speech and language disorders

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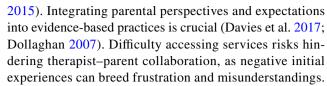
Background

Boosting speech language practitioner—parent collaboration remains a key goal in the field. While we know a lot about how therapists understand parents' needs (Davies et al. 2017; Klatte et al. 2019), there is less information available on the flip side (Klatte et al. 2023). Specifically, we lack data on parents' challenges navigating support services for their children with language disorders (Davies et al. 2017). The 1989 Convention on the Rights of the Child established child development as a fundamental right (UNICEF 1989). However, the World Health Organization emphasised integrating children with communication difficulties into healthcare, ensuring timely access to early intervention only since 2020 (World Health Organization 2020).

Early speech and language issues can have lasting impacts, affecting literacy, social-emotional well-being and even employment (Beitchman et al. 2003; Berkman et al. 2015). Early identification allows for timely intervention, potentially reducing long-term negative consequences. The effectiveness of intervention is well-documented (Ebbels et al. 2019). The challenge lies in pinpointing who needs help and how services can be provided to lead to effective treatment. ICAN, a UK children's communication charity, observed that while some children improve with support, others face persistent needs (ICAN 2009). Up to two-thirds of children with diagnosed language needs will not show spontaneous improvement (Broomfield and Dodd 2011; Roulstone et al. 2003). Previous reviews, citing the complexity of language development and lack of robust evidence, did not recommended universal screening (Law et al. 1998; Berkman et al. 2015); however, recent and ongoing work is establishing screening of a UK population (Law et al. 2023) and bilingual Welsh children (Baker et al. 2022). Even so, this work is in its infancy and under-diagnosis may therefore obstruct service access for children with developmental language disorders (McGregor 2020).

While some countries explore universal language screening (Public Health England 2020), currently, the onus often falls on parents and their network to suspect a language delay. Mothers, friends, neighbours and religious leaders are often the first to voice concerns and suggest strategies before parents approach healthcare professionals (Marshall et al. 2017; Roulstone et al. 2015). However, we know less about parents' specific experiences when navigating speech and language therapy services for children suspected of having a language disorder.

In Western societies, patient and caregiver voices are often overlooked, rarely influencing clinical practice or, even less frequently, policy making (Roulstone et al. 2015). Integrating parental perspectives and expectations into evidence-based practices is crucial (Davies et al. 2017; Dollaghan 2007). Difficulty accessing services risks hindering therapist–parent collaboration, as negative initial experiences can breed frustration and misunderstandings.

This current study is explorative and inductive, with the aim of understanding the lived experiences of parents who are seeking access to speech and language therapy services. It was believed that this can lead to the discovery of fresh themes and surprising connections that can help construct more comprehensive, context-specific theories that can be of use to therapists working collaboratively with parents (Charmaz 2006).

Aims

This paper report's themes from an explorative, rather than theory driven research exploring parental perspective of speech and language disorders. In the current paper we explore how parents talk about their experiences of identification and access to speech and language therapy services for their language impaired children.

Methods

This research extends the exploration of the services provided for the children with language disorder started within the COST Action IS1406 'Enhancing children's oral language skills across Europe and beyond' in which the authors of the paper participated.

Ethics

Cross-national differences existed in relation to the procedures for applying for ethics. Five countries required and obtained ethical approval to carry out the study (Supplementary Material S1).

Interviews were conducted in the authors' respective countries and native language. All members of the research team held a minimum of a master's degree in speech and language pathology, developmental or health psychology, and had experience conducting qualitative research. The authors followed the Consolidated Criteria for Reporting Qualitative Research (COREQ; 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.

Participants

The inclusion criteria for parental participation were parents of a monolingual child aged 6 to 12 years who had a

speech and/or language disorder as the primary presenting difficulty; and that their child had been in receipt of services for speech and language disorders within the past 4 months.

An opportunistic purposive sampling was used to recruit parents from ten countries: Croatia, Denmark, England, Hungary, Iceland, Ireland, Israel, the Netherlands, Norway and Spain. Ten interviews were conducted, one for each participating country. In nine interviews, data were given by mothers, while in one country, a mother and father pair participated together in the interview (Table 1).

Reflexivity

This study is multinational qualitative research which poses several challenges in different stages of the research: developing the unique interview schedule for different countries and cultural contexts; analysis of the data obtained in different languages; multiple researchers/data analysts. We used a consensus approach where each step was discussed via teleconferencing platforms, in-person or a combination.

An interview schedule was developed to ensure that data collection was conducted with cultural sensitivity, whilst collecting comparable data. During the data analysis, multiple meetings facilitated modification and refinement of interpretation as well as generation of new codes, using the analyst triangulation (Patton 2002). Data were shared in English in online spreadsheets to ensure that every researcher had access to all the excerpts from different countries. In this way, codes and themes could be cross-checked and discussion stimulated.

Data were collected in nine different languages. Analyses were undertaken in the original language to keep the nuances in the meanings, cultural context and the voice of the participants. The research team consisted of multiple researchers who could analyse the data in the native language of the participants. Excerpts illustrating the codes were translated into English for the shared spreadsheets, with the comments for the translation and further explanations where needed.

Procedure and data collection

Semi-structured interviews were used. The interview schedule was inspired by a topic guide applied at Aalborg University's Clinic for Developmental Communication Disorders and adapted in English by K.J.L. and R.L. (Supplementary Material S2). The interview guide was then translated by the researchers into each of the participating nations' official languages. Independent scholars performed back translations to make sure the meaning of the words and phrases were intact following the translation.

Each of the authors carried out the interview at a convenient location, such as the home of the parent or in the clinic (Supplemental Material S3). Interviews were audio-recorded and transcribed verbatim by a local member of the research team. Duration of the interview was on average 54 min (35 to 77 min; median = 52 min). There is disagreement over when data from cross-cultural and cross-linguistic qualitative research should be translated into English (Chapple and Ziebland 2017). One worry is that the data's richness might be reduced if it were translated before the analyses. For this reason, the nation's primary language was used for the interviews and analysis and only in the latter stages of the study, after the team had decided on the codes and themes, were segments translated into English.

Data analysis

Thematic analysis following the procedure of Horwitt (2010) and Braun and Clarke (2006) was undertaken. The first step of the analysis was familiarisation with the data where every researcher reread the transcript from her country to get the main ideas that parents were communicating. To establish the

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

common coding, initially one member of the team coded her interview and shared the codes and the respective transcript with the full research team. For this step, one of the interviews undertaken in English was chosen, to ensure that all the members of the team could reflect on the initial coding with the entire interview available. These initial codes were discussed, and revised, new codes were added, and the initial 'codebook' was applied for all the interviews. This process was repeated with a second round of discussion (now with the coding from all countries) where the final codebook was developed and then used for each country. The excerpts of the interviews mapped to the specific codes were translated to English.

The second step in the analysis was the identification of themes which took place in a two-day meeting where seven authors participated face-to-face and other researchers joined them online in specifically planned sessions where data was discussed and cross-checked against codes. Codes were grouped into broad themes. Themes were further refined during multiple online meetings. In light of these conversations, we made changes to the data and came up with fresh interpretations. A shared Excel spreadsheet that enabled cross-checking of extracted excerpts and subsequent themes by each researcher was created to improve transparency and reliability (Supplemental Material S4).

Results

In the interview texts, parents provided descriptions of how they recognised the need for services for their children and how they went about accessing and securing these services. Parents recounted explicitly the process they went through; watching their children grow and develop, the feelings that arose in them when they either thought or were made aware that their child needed some help with their language development. Parents report on how they decided to fight for services for their children and the rationale for these decisions.

Two main themes are reported in this article. The first main theme is 'parental recognition of the need for services' which included two codes: (1) 'observing a difference', referring to the parents' observation and recognition of the difference in their child's behaviour compared to that of other children or their impressions of their child's behaviour in comparison to others and, (2) 'unmet needs of their child', specified as the parent's beliefs/impressions about the child's existent but so far unsatisfied needs. These are presented in turn, and the codes within them discussed (Table 2).

Theme 1: Parental recognition of the need for services

Code 1.1 – Observing a difference, referring to the parents' observation and recognition of the difference in their child's behaviour compared to that of other children or their

Table 2 Themes and codes

Overarching theme	Main themes	Codes
Accessing services	Parental recognition of the need for services	Observing a difference
		Unmet needs of their child
	Obstacles to accessing services	Identifying pathways to services
		Ready to fight for my child
		Finding the right person

impressions of their child's speech, language behaviours in comparison to others, including siblings.

Parental reports of speech, language behaviour represented their experiences and observations of their child's behaviours and skills. Parents reported noticing differences in their children's past and present behaviour and this experience was typically coupled with being aware of their own feelings relating to their belief that their child was not developing as they expected. Specifically, parents' first sense was that their child's development was slow when compared to their own expectations, or experience of other children.

> *so when she came close to being 3 years-old, that I tried to say to the day care person, that it seemed strange to me that she still doesn't have better language, and what should be done about it... in relation to if they understand what Klara says* (Denmark)
> *I saw when he was two months old that he does not have a firm hand. I said to my husband, we should not wait. Let's go immediately to [name of city]".* (Croatia)

Parental worries led them to seek help from professionals, reporting the changes they perceive in their child's behaviour as evidence of therapeutic need, e.g. *We noticed that the child needed something more (in addition to medication) so we started with speech therapy.* (Spain).

Code 1.2 – Unmet needs of their child, represented the parent's reports about the needs of their child in relation to speech and language and how these had not been met by health care services.

When parents felt that their child was different from other children of the same age, they were quick to discuss the needs of their child with friends and family, and then healthcare professionals. These parental concerns sometimes lead to formal assessment of unmet needs to be addressed or to parents being asked to wait and watch for further development.

> *We had the impression that he understood everything that we said, because he responded adequately... but around the age of 3, he still did not really talk, and then we wondered a bit... the results of the test really*

surprised us, because we thought he understood everything (Norway)

Other parents noted that their child had communication difficulties but there was a reticence from the preschool to acknowledge a need.

Soon as we started preschool there, I start to talk about his language development, but they didn't feel it was very serious and talked about that he was a good boy. They said that he used his own methods to cope with it. 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. (Iceland)

Theme 2: Obstacles to accessing services

This second theme has three codes: 'identifying pathways to services', 'ready to fight for my child' and 'finding the right person'. The three codes are interwoven as parents described them as part of an unfolding journey to services. In essence they might be viewed as way points or viewing platforms on the treatment pathway.

Code 2.1 – Identifying pathways to services

Pathways to the needed services that are available for these families are often unclear. Parents reported that they didn't know what services they needed to help their child, and the information they readily accessed did not provide information on who to talk to.

Well it's frustrating because we are no means the experts. Like we are depending on other people who are working in these areas to tell you where you're supposed to be going and then when you get sent off to this place and you're kind of feeling like this is definitely not where he needs to go (Ireland)

Consequently, parents related how they felt confused and frustrated trying to navigate the system in order to find relevant services for their child.

…now we are in the service system and we know who the healthcare professionals are and their special area(s) of expertise and to whom I need to ask my questions. But at the beginning it was unclear… (Netherlands)

Importantly, parents recounted how vital other parents were as a source of information about the available services in their community and the routes to get access and make use of services.

I was always talking if I heard that somebody has a child with some difficulties, you say, you hear from others, there is this thing there, that thing in that place. (Croatia)

There appeared to be common agreement across parents of the importance of access to speech and language therapy services. However, parents voiced that knowing your and your child's rights are important.

… it took us a few months until someone also told me "Go get private, get refunds". And then we actually started some kind of a process… (Israel)

Parents conveyed that knowing that there are services their child has a right to access was not always sufficient. Their experience was that even when the need for referral was recognised, there were often delays between this and having an initial appointment with a speech language therapist.

Everything started. Only 4 months until summer vacation and then the school would start. There was no time to lose. He had the right to professional support, but it was too late to hire a person to support him. So the preschool teachers took on the treatment. They worked on his self-confidence and helped him to make friends. (Iceland)

Code 2.2 – Ready to fight for my child

Concerns were raised by some parents that they needed to fight for recognition that their child needed referral or intervention; with many commenting that they had to keep pushing or fighting to be seen.

You have to push, you just have to push for everything. You have to find and speak to different services out there.......as a parent, you have to fight for everything that you want.....I always sort of think that I have been quite lucky because I have pushed, and I know the right people to push. (England)
when she was 3, I contacted the municipal again to tell them I felt it [her speech development] was developing too slow… (Croatia)

In some cases, when parents turn to a person or an institution they believe could provide the services they feel their child may benefit from, they get rejected without even being heard or the child being assessed.

So I asked her if it [the service at the speech institute] could be offered to Klara, and she says no, they can't take her, the children there are all children with diagnoses, and Klara, she is a normal child, and I can't

imagine in any way that it would give Klara anything to go sit with other children that have big articulation problems and this and that. (Denmark)

Parents report that, once they knew that the child needed to be seen by an SLT they were unable to get access to treatment due to no service availability (Ireland). In other cases, the lack of government-funded services forced the parents to seek out a private provider (Croatia, Israel) while waiting on the government-funded services waiting list, sometimes even for a rather extended period of time (Israel).

… at the time when they were referring her for speech and language we couldn't get, I couldn't get any help for her. I couldn't find anyone at the time. There was a lack of speech therapists in [name of city] at the time when she was going through and I was trying to say, when the paediatrician said oh she is going to need help with speech or she wasn't talking or whatever, I said oh it's fine I'll bring her private and he kind of laughed at me and was like, there isn't anybody. (Ireland)

Code 2.3 – Finding the right person

Once parents found the right person, they evaluated therapists and valued the relationships they built with them.

I knew that they will only help him… I noticed how kind and dedicated they are and that they have a positive attitude towards things, Peter and all the children… the kindness and the hard work they put in… it is easy to see that they are really helping the children. This is what I noticed. And I was so glad… (Hungary) *If she [the Speech and Language Therapist] had not turned up, I would perhaps still be lost.* (Iceland)

However, frequent frustration is reported resulting from high staff turnover.

One of the barriers was the turn around of staff in the speech and language was really high, so he would get a relationship with one person, then 3 weeks later you would be seeing another speech and language person… so that would be a real barrier so it was almost like building those relationship right again… (England)

As well as some parents reporting a breakdown in the therapeutic partnership, due to the feeling that therapists are expecting them to deliver the therapies to their child, and the fear that they are not knowledgeable enough, and that they may do more harm than good.

… in the end I was so frustrated, I could read this and read and read, but I am not a speech pedagogue, so I can't find out on my own, in the end, find out what it is I should do… to support it… (Denmark)

Discussion

This paper explored how parents experienced the identification and access of speech and language therapy services for their language impaired children. It is clear from the parents' views collected in this research that they believe they have an important role to play in their child's language development. However, they also recognised that there is a lack of access to health care professionals, in this case specifically speech and language therapy.

Parents can identify that their children have speech and language difficulties at an early stage (Johnson and Bountziouka 2020), but navigating healthcare systems to access the best services for their child's needs appears to be a challenge across countries. Mancilla-Martinez et al. (2016) argued that parent report is a valuable tool for assessment, as well as being cost-effective for a service it avoids task and context bias. There is a body of research that validates parents' ability to assess language development (Feldman et al. 2000, 2005; Johnson and Bountziouka 2020; Mancilla-Martinez et al. 2016; Nayeb et al. 2021). Studies using versions of the Child Development Inventories (CDI) have found significant correlations between children's productive vocabulary as reported by parents and when directly assessed or observed (Mancilla-Martinez et al. 2016; Marchman and Martinez-Sussman 2002). There are even stronger associations between parent report and productive vocabulary than receptive vocabulary, suggesting that parents may be better able to report on the words their child uses than those they only understand (Mancilla-Martinez et al. 2016).

Parents have a meaningful role to play in recognising their child's development needs, to a level which should be recognised by health care professionals, to warrant clinical assessment of need.

Most European countries have a Universal Public Health Care System in place where accessibility to health service is secured (Law et al. 2019). Since 2015, 53 European member states have been working towards a strategy for child and adolescent health, which includes organising services and policy making to support child development (Alemán-Díaz et al. 2018). The European countries participating in the current study have different methods of delivering their health systems. Many countries have a well-developed health system for the diagnosis and

treatment of different health issues, including neurodevelopmental conditions. However, as parents voice in the current paper, the systems are seldom transparent, so are inherently hard to navigate, and are often perceived to be insufficiently funded/organised when the conditions of concern are psychological and/or neurodevelopmental in origin.

Parents frequently reported that there was a shortage of speech and language therapy services, and that there was a need to fight to ensure their child had access to them. Health professionals are aware of this situation and that long waiting lists discourage them from referral to speech and language therapy services (Ruggeroet al. 2012). This practice results in late diagnosis and late treatment, with the potential to lead to extensive life-long negative consequences for the child's development and, understandably, parent's discontentment.

Melvin et al. (2019) noted the value of two–way communication through listening to parents, giving them a voice in the therapeutic journey and sharing information in order to facilitate their engagement with intervention. There is a body of literature that indicates that parents' perceptions of therapy are heavily influenced by their relationship and partnership with the therapists (Davies et al. 2017; Klatteet al. 2019). In the current study, the building of this relationship was part of the code 'finding the right person'.

The parental relationship with the therapist, can influence how engaged they are in therapy. Parents' underlying knowledge, skills and confidence related to the management of their child's language, has only recently been attempted to be measured with a modified version of the Parent Activation Measure—SLT (PAM-SLT-UK; Gibbard et al. 2021, 2024; Insignia Health 2014). Further research into both, parent partnership and parent activation and their role in causing change for children's speech and language, will be critical in the development of speech and language therapists' understanding of how parents can most beneficially (for themselves and their child) collaborate with therapists.

There may also be value in further understanding the knowledge and attitudes of the wider social networks identified as being important to parents (Marshall et al. 2017; Roulstone et al. 2015). Their role in helping parents to find the right person and providing support to parents is important and could be enhanced through improved service signposting. Klatte et al. (2020) provide a realist framework of 'context', 'mechanism' and 'outcomes', which they suggest is a first step to opening the 'black box' of collaborative practice between parents and speech and language therapists. The researchers argued that it is important that we make the process of collaborative practice explicit so that it can be debated and tested, both within the profession and with the families with which we work.

Strengths and limitations

This study acknowledges several limitations that shape the scope and generalisability of the findings. Firstly, concerns around language, translation and potential inter-coder variability in analysis led us to include only one family per country (n = 10). Though these interviews were extensive (35–77 min, median 52 min) and yielded rich qualitative data, the sample homogeneity in terms of educational and socioeconomic background restricts the generalizability of our conclusions. We recognise the inherent diversity within and across parental populations and emphasise the need for future research to incorporate the voices of parents from broader socioeconomic strata, including underserved communities and those with multilingual children.

Secondly, this study did not directly link parental experiences to health and service provision within each country. However, other work within the European COST Action compiled data on health and service provision across the participating countries (Law et al. 2019). This resource lays the groundwork for future research to conduct a more in-depth analysis and explore how our findings resonate with the specific healthcare and service landscapes in each nation.

Conclusion

Across countries, parents recount similar experiences in accessing speech and language therapy services. Major obstacles were identified that lead to the perception of delay in obtaining timely access to services. Often, the link between language difficulties and the right proficiency, identifying that it is speech and language therapy services that children required, was the first hurdle, even before trying to get a referral to them.

The analysis of data from a qualitative research project identified obstacles parents perceived to knowing which services were needed, as well as getting timely access to speech and language therapy services. Collaborative working with parents and therapists could mitigate negative feelings towards services and improve relationships between therapists and parents.

Data availability Due to the multi-national nature of the qualitative data, it is not available to share outside that of the research team and their host organisations.

Code availability Not applicable.

Declarations

Ethics approval Cross-national differences existed in relation to the procedures for applying for ethics. Five countries required ethical review of the project, and this was sought and obtained were required.

Consent to participate Written informed consent was obtained from each of the participants.

Consent for publication Consent for data to be used in publication was obtained from each participant.

Conflicts of interest The authors have no relevant financial or non-financial interests to disclose.

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