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Children with specific language impairment: parental accounts of the early years

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Abstract

Parent views of specific language impairment have received little attention in the literature, even though speech and language development is the single greatest area of concern for parents. This article examines parental views of events up to, and including, language unit admission for their children. A series of qualitative interviews was conducted with parents. Parents felt that, apart from speech and language difficulties, the children were developing normally. They placed a low value on speech and language therapy, and saw language unit admission as the only intervention that 'worked'. Initially, some children were placed in mainstream school, where their failure to keep up with peers resulted in transfer to a language unit. Parent views provide a unique understanding of the impact of specific language impairment on the child and family. Such information is essential for the early diagnosis and treatment of this condition.

Keywords children • language units • parent views • specific language impairment

Introduction

There is little qualitative data found in the speech and language literature on the views and experiences of parents whose children have specific language impairment. This is surprising, in view of the fact that 20 percent of parents in the UK are concerned about their children's speech and language development at any one time (Hall and Elliman, 2003).

Children with specific language impairment are delayed in language development, but have normal non-verbal cognitive skills and physical abilities. The usual parental role in the diagnosis of this condition is confined to the completion of parent report questionnaires (Fenson et al., 1994; Klee et al., 1998). Such measures assess children's ability to produce and comprehend vocabulary, and use the size of children's vocabulary as a predictor for future language disorders. However, recent comparison of a parent-led measure and a structured screening test administered by health visitors showed that neither method was successful in identifying true cases from non-cases (Laing et al., 2002). Establishing sensitivity and specificity criteria in acceptable ranges is a continuing problem in the screening literature (Capute et al., 1986; Clark et al., 1995; Dockrell, 2001; Glogowska et al., 2002; Law et al., 1998; McGinty 2000). Specific language impairment presents more difficulties because of a lack of consensus about its definition (Conti-Ramsden, 1993; Dockrell, 2001; Urwin et al., 1988). Also, identifying persistent difficulties from transient difficulties has been problematic (Dockrell, 2001; Enderby and Emerson, 1996).

The clinical value of parent report measures is in the strength of their correlation with standardized language production measures (McGinty, 2000). Parental anxiety as a referral criterion has been shown to have a significant association with pass or fail outcomes in tests of both verbal comprehension and expressive language (McGinty, 2000). However, Klee et al. (1998) found that parent report alone tended to overestimate the size of the problem and recommended the use of parent report in combination with appropriate follow-up measures in order to achieve best outcomes (Klee et al., 1998).

Recent studies have added a more qualitative dimension to parent report. A community-based study of speech and language intervention acknowledged the value of in-depth interviews with parents in helping to explain the findings of a randomized controlled trial (Glogowska et al., 2002). The authors highlighted a theme that is commonly found in social research: the meaning that parents attach to events has a powerful influence on the way in which they respond to the trial.

For the most part, the meaning that parents attach to the experience of specific language impairment in the early pre-school years has been unexplored. Parent report measures are developed often through the 'expert panel' approach, which does not use the parents' frames of reference (Laing et al., 2002). The aim of this article is to present a qualitative account of children with specific language impairment from the parents' perspective, and to explore the meaning that parents attached to events during the period from detection of a problem to eventual language unit admission.

Method

Parents of children from two local education authorities (LEAs) on Merseyside participated in a larger qualitative retrospective study to explore parental views of their children's pre- and post-language unit experiences (Rannard, 2001). In this article, only pre-language unit data are reported. Language units in both LEAs were housed in one classroom of a mainstream school. Class size was between eight and 12 children; a teacher, speech and language therapist and classroom assistant provided access to national curriculum subjects within a structured language environment.

The focus of the study was on children who had been integrated into mainstream education from language units, and not those who had been integrated from the language units into special education. Parents were asked to recall the events that had occurred before language unit admission. Initially, the LEAs' administration contacted parents by letter to introduce the study and invite parents to take part. Ethical approval for the study was obtained from Liverpool John Moores University Research Ethics Committee.

In LEA (1), 132 parents and children were identified from the records of the educational psychology department. In LEA (2), the parent partnership officer identified 40 parents. Of the 132 parents from LEA (1) who were invited to participate, 30 had children who were still attending language units and therefore ineligible for the study. One child was in a reading recovery scheme at a school in another LEA, one parent declined to take part, and two parents declined because they did not want their child to be included in a research project. In LEA (1), 33 parents participated and 65 parents failed to respond. Of the 40 parents from LEA (2) who were invited to participate, 18 agreed initially and 22 failed to respond; seven parents took part and 11 parents failed to keep appointments on several occasions. In summary, 40 parents from both LEAs took part in the study.

Characteristics of the children

At the time of the study, all the children had left the language units and were attending mainstream schools in their local areas. Five of the children retained a statement of special educational need: one child had regressed in language ability during a prolonged stay in hospital; one child had mild receptive and expressive problems; one had Attention-Deficit Hyperactivity Disorder (ADHD); and two children had reading difficulties.

Nine of the children were firstborn, 18 were lastborn, and three were only children. The remaining 10 children were second or thirdborn in families with both younger and older siblings. The children ranged in age from 6 years 10 months to 16 years 9 months (mean 9.82, SD 2.39) at the date of interview. Four children were in secondary school (ages 13 and 14; two were 16). The remaining 36 (90%) children were in primary schools. Thirty of the children were male and 10 female, reflecting the general trend of children with learning disabilities. Initially, 15 children had begun mainstream school before transferring to language units. The remaining 25 children had gone to the units at the age of four.

Parent interviews

All of the parents were interviewed in their own homes. A chronological or life-history approach was used, which allowed parents to recount experiences using their own frames of reference (May, 2001). Discovering the meaning that was given to events by parents was important, due to the fact that, largely, such information had been ignored in the literature up to that point. The use of a topic guide retained focus during each interview.

Of the 40 parent interviews carried out in the home, 29 were with the child's mother, nine were with mother and father, one was with a grandmother, and one was with a father. Each interview lasted approximately one hour. All interviews were transcribed verbatim and checked subsequently for accuracy while listening to each tape. A chart of main themes and sub-themes was constructed for each interview, allowing comparison across cases. A second researcher read five randomly chosen transcripts, and independently identified themes and sub-themes. Initial inter-rater agreement was 84 percent, and further discussion resulted in 100 percent agreement.

Results

Children's overall development

Several children were described as 'bright' or 'quick' because they were able to do things at the same level or better than their older siblings. One father commented:

> See, though he couldn't speak he wasn't stupid. In the language unit it ended up he was showing the children how to use a computer. (F5)

Parents gave other examples that they felt showed the children were 'normal' in every other way. One child was reported to be good at jigsaws:

> He was marvellous with jigsaws. They put 16 out on the floor and he sat for about an hour and did all 16. (M13)

Only two of the mothers reported that they had been worried about their children's receptive capabilities in the time before the language unit; one of these children had continuing mild receptive and expressive language problems. In five (12%) of the families there were other family members with a history of communication problems, two in parents and three in siblings. The siblings had also attended language units.

Temper tantrums

Eleven parents (27.5%) reported that their children had severe temper tantrums between 12 months and two years. One mother said:

> By the time he was two they were getting worse, 'cos he couldn't say mum, he never spoke at all, and he'd just, like, walk up to a wall and start banging his head on the wall [or] pavements outside. (M5)

Two of the children were referred to a child and adolescent psychologist, due to the tantrums. Other parents reported a change in behaviour:

> He was the easiest baby to look after all the way through 'til he got to about 18 months and he changed totally. He cried constantly, he never slept, he just changed . . . he was just so angry all the time, really, really angry. (M7)

Parents linked the tantrums to the child's frustration at not being understood when they tried to speak:

> She used to have terrible tantrums, but I can understand what it was, it was frustration. (M14)

> He would fling himself on the ground in frustration . . . I would say, 'I know there's something wrong, but I don't know what to do.' (M7)

Frequently, parents reported that they avoided certain social situations because of the tantrums. One mother 'dreaded' going to the shops or on the bus, and another said:

> I've not been able to go anywhere with him because he performs so much. (M5)

Some children had problems in mixing with other children at nursery due to their tantrums; one child was expelled from two nurseries for this reason.

Age of detection of a speech and language problem

Twenty-eight parents (70%) could remember how old their child was when they first noticed a speech and language problem (see Table 1). In 16 cases the mother noticed; in one it was the father; in four cases, it was both parents; in three cases, members of the extended family noticed; in three cases the nursery which the child attended picked up the problem. In one case, the health visitor noticed when the child was 2 years old.

Table 1: Age of detection by parents/others

Age in months	6–12	12–18	18–24	24–30	30–36	36–42
Children (*n* = 28)	3	7	7	4	5	2

Table 2: Parent descriptions of initial problem

Initial problem	Number of parents	Age of the child when noticed
No sounds	2	8 months
Strange sounds	1	10 months
Non-specific but knew something was wrong	2	12 months
Unrecognizable speech sounds	1	18 months
Single words	1	2 years
Persistent, unrecognizable speech sounds	1	2.5 years
Only sibling could understand	1	2.5 years

Nine parents (23%) could remember what first alerted them to their child's communication problem (Table 2). They used comparison with milestones that had been reached by older siblings, or comparison with children outside the family as a yardstick. Some parents said they 'just knew' something was wrong. One mother described how silent her daughter aged 8 months was:

> If you didn't make any effort to go near her she'd sit there all day not . . . nothing, no crying, just nothing. It was amazing. (M14)

The highest number of detections by parents and others was reported between the ages of 12 and 24 months. One mother said that she had delayed seeking help

> because he was a boy and boys are always slower. I noticed he didn't seem to be interested in talking. But he was perfect in every other way. (M7)

Parents reported that they themselves would get upset because they could not understand what their children were saying:

> You couldn't understand her and we used to sit here and cry. I'd say I'm sorry sweetheart, say it again and of course she'd say it again and I'd say I don't know what you want. So in the end we'd both end up in tears, you know. (M14)

Some mothers said that, as time went on, they avoided going to places where the child's speech was likely to be heard:

> Sometimes we would go out and I would think, I hope nobody talks to him too much . . . because he was constantly getting the wrong responses. Afterwards I mean I used to feel really guilty about it. (M21)

Mothers also reported that sometimes they blamed themselves for the speech and language problem:

> 'Cos you blame yourself. Is it because . . . had I not talked to him enough? (M21)

Speech and language therapy

In nearly all cases, parents were concerned about their children's speech and language development for some time before referral to speech and language therapy was made. Sixteen parents had no recollection when speech and language therapy started, and two children had had no therapy before going to a language unit. Of the remaining 22 children, eight began speech and language therapy between the ages of 2 and 3 years, 11 children at 3.5 years, and three children between 4 and 5 years. An average of two years had elapsed from the time that parents had become aware of a problem to the start of therapy. Parents frequently reported that the reason for this delay was a failure by health professionals to refer the child for assessment by a speech and language therapist.

Thirty-eight parents (95%) felt that clinic-based speech and language therapy had limited effect:

> He did go to speech therapy but it wasn't doing anything at all. He was only going for sort of two weeks over a 6-week period and then having a break and then going back. It was a waste of time really you know. (M20)

> He'd had speech therapy at nursery and before nursery and it never made any difference. (M9)

Two parents reported that speech therapy had made a difference; one of whom (M11) arranged private speech therapy for her son because she felt that therapy lasting three quarters of an hour twice a week in the local clinic was not enough.

Mainstream school prior to language unit

Initially, 15 children (38%) attended mainstream school for periods varying from six weeks to two years. Parents were concerned during that time because they knew that neither their peers nor their teachers would understand what the children were saying. One parent commented:

> When he was in school it was awful because children . . . we used to have to bring

> him home for his dinner, 'cos children used to be, like, laughing at him and asking him to say things and it was, like, in a circle round him making him talk or asking him to say such a thing. (M15)

Parents felt that the time spent in mainstream school before going to the unit – even with speech and language therapy support – was particularly worrying and a waste of valuable time for the child.

Views on special needs education

Six parents said they felt stigmatized initially by having a child in a special unit. One mother said:

> Some of the mothers, they used to say to me: 'What do you mean, a language unit?', and I knew what they were thinking. I used to say, 'Well, it's purely for his speech,' but I knew that some people were thinking, like, he's backward you know, like a stigma. (M8)

Some felt that because their children were normal in every other way, there should be no need for them to go to a language unit:

> Even though we knew his speech was bad, we [were] always, like . . . he shouldn't have to go there. He's a bright boy. Why, why, you know? (M+F10)

> I didn't want him to go. [I] cried because I wanted him to go to a normal school, you know. (M9)

Once the children began to make progress at the unit, the parents felt less concerned:

> I felt a bit strange when the language unit was suggested but when I saw how it worked and how I was involved in decision-making, I changed my mind. (M2)

Children spent between six and 24 months (mean 17.25 months, SD = 5.58) in the language units, and all had to leave by the age of 7. All parents felt that the language units provided a major breakthrough in establishing a means of communication for the children, or 'the key that opened the door'. All parents commented on the marked difference in the children after they had been in the language unit for only a short time:

> In the first eight months he was there he was totally different. He's had no temper tantrums for the last five years. (M5)

> I'm sure the language unit had a lot to do with how he changed back into a happy little boy. (M9)

> He started talking, the temper tantrums stopped and it was as if somebody had took my little boy and given me somebody else's. I just couldn't believe the difference in him. (M5)

Thirty-two parents (80%) did not want their children to leave the units and would have preferred them to continue with what one described as 'better than a private education' (M+F24):

> When he came to leave the unit I was brokenhearted really, because not only did they bring out his speech . . . his learning, his reading, his sums, everything . . . he's just so confident. (M8)

> I'd have been happier if he'd stayed there, 'cos he was coming on so well. (M16).

Discussion

Parents can make a valuable contribution to the assessment of speech and language difficulties. However, parent report measures are used frequently as an addition to standardized measures, and not as valuable information in their own right. Using parent's views in the development of measures is seldom reported; more often such measures are a professionals' interpretation of what parents have said (Laing et al., 2002).

This group of parents were aware of a problem with their children's speech and language development from an early age, in contrast to the widely-held view that it is sometimes necessary to guide parents to accept there is a problem (Hall and Elliman, 2003; Pollard, 1992). In the parents' view, the children's difficulties were confined to language development – their non-verbal abilities were as good as, and sometimes better than, that of their older siblings or others within their social group. In contrast, many authors believe that isolated language problems are rare, and that there is seldom a language problem without an accompanying general developmental delay (Bishop, 1997; Ors, 2002). This gap between parent and professional frames of reference is something to be considered in the development of parent report measures.

Different aspects of the children's specific language impairment had a marked effect on parental behaviour. A quarter of the parents reported severe temper tantrums in their children, similar to earlier studies linking language disorders with a range of behavioural problems including temper tantrums (Silva et al., 1987). As a result, parents avoided taking the children into social situations and reported problems when the children went to nursery or playgroup.

In addition, mothers were reluctant to take their children on the bus, to the shops or anywhere that their child's odd speech sounds could be heard. Others could not understand what their children were saying, and some mothers blamed themselves for the problem, thinking they had not talked to the child enough. All of this was not helped by the fact that health professionals took a long time to refer them to speech and language therapy, which has also been identified as a source of frustration for parents in other studies (e.g. Band et al., 2002).

The majority of parents felt that clinic-based speech and language therapy was ineffective, similar to the findings of Glogowska et al. (2002) who found little evidence for the effectiveness of pre-school speech and language therapy in a recent randomized controlled trial. Parents felt that the children only made progress in speech and language development when they went to the language units.

Most children went to the language units at the age of four, but some were admitted later after a period in mainstream education. Although some parents did not want their children to go to a language unit because of the stigma attached to additional learning needs education, equally, they did not want the children to fail in the mainstream system. The partnership that is reported between parents and language units in this study is not found generally in the wider mainstream system (Band et al., 2002). However, the benefits of this partnership were that parents felt the children's language needs were being met, and that they themselves felt involved in decision-making at the units. As a result, most of the parents did not want the children to leave the units when the time came.

Limitations of the study

Recruitment to the study was low; this was similar to other studies involving children where the reason may be linked to parents' desires to protect their children (Ors, 2002). The perceptions of those who took part in the research may not have been typical of the whole group. These parents may have had more difficulties than those who declined to take part, or may have 'overweighted' certain events and forgotten those with a lesser impact (Miles and Huberman, 1994).

Conclusion

Parents in this study provided valuable information on the wider impact of specific language impairment which formalized testing may not always convey. Giving parents the opportunity to use their own frames of reference in describing events is an important element of the diagnostic process, and is seen increasingly as a necessary part of clinical and evaluative research. As such, it needs to be considered in the future development of parent report measures for specific language impairment.

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