

Mothers' Recollections of Early Features of Autism Spectrum Disorders

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Background: Early intervention is recommended for autism spectrum disorders but often this is delayed because children have not received a formal diagnosis. Nonetheless parents are likely to identify features of ASD from an early age. The main aim of this study was to document through thematic analysis how parents described the features that alerted them to the child's difficulties. **Method:** From a population of children diagnosed at a specialist, community-based clinic, 72 parents agreed to be interviewed at home about their recollections of early difficulties which were analysed thematically. **Results:** Two-thirds of parents reported the child's problems were apparent by 18 months with speech and communication difficulties, along with behaviour problems, being the most commonly reported. Statistical analyses identified some relationships between certain features and the age of the child when they became apparent. Clusters of features were also identified. **Conclusions:** It is argued that health visitors and childcare personnel should be knowledgeable about the early signs of ASD and of the strategies required to promote the development of children whose parents report these early features of ASD. They should be proficient in sharing their knowledge with parents so that assessment and intervention can begin earlier.

Key Practitioner Message:

- Most mothers identified early signs of ASD before the child was 18 months of age
- Speech and communication difficulties, along with behavioural problems were the most commonly reported signs although there was variation across children
- Mothers' reports lacked the specific features which screening tools for ASD provide. Such tools can have an educative function for mothers
- Health visitors and GPs need to provide mothers with guidance on strategies they can use to promote the child's development while waiting for diagnostic assessments

Keywords: Preschool children; autism spectrum disorders; parents diagnosis

Introduction

In many affluent countries there has been a reported increase in the numbers of children – boys especially – who are given a diagnosis of an autism spectrum disorder (ASD). In south London, rates among a sample of nearly 60,000 children aged 9–10 years were 116 per 10,000 (Baird et al., 2006) which is nearly double the estimated rate of around 60 per 10,000 children across 14 countries reported by Fombonne (2005).

Debate continues as to whether or not this represents a real rise in these conditions or if it results from better identification, use of broader diagnostic criteria and a greater willingness by doctors to make this diagnosis (Gernsbacher, Dawson, & Goldsmith, 2005). Nonetheless this means that more families are expressing concerns about their child's development to healthcare professionals such as health visitors, GPs or staff in childcare facilities.

Clinical definitions of autism (e.g. ICD-10) are based on abnormal language and social development along

with a restricted pattern of play and interests with an outset prior to 36 months. In addition children may exhibit a range of problem behaviours and develop mannerisms and routines, such as hand flapping or lining up toys. Past research suggest that parents are often aware of the child's problems by 18 months (Gray & Tonge, 2001; Young, Brewes & Pattison, 2003) but often a formal diagnosis is not made until after three years of age with long waiting lists for assessments (Charman & Baird, 2002). This period of uncertainty places extra stress on families as well as preventing them from availing of suitable early intervention strategies. There is accumulating evidence that such interventions can produce developmental gains in the preschool period especially if they are commenced at an early age (Rogers, 1996; Buschbacher & Fox, 2003).

Among the reasons noted for the delay in making a formal diagnosis has been a lack of professionals with the required knowledge and skills relating to ASD, especially in distinguishing them from more general

developmental delays and problems. Hence various screening tools have been devised to detect early signs of autism (Baird et al., 2001). An example is the Checklist for Autism in Toddlers (CHAT) or variants of it (Baron-Cohen, Allen & Gillberg, 1992). More fundamentally though, it could be that parents, but more especially primary healthcare professionals or childcare staff, fail to appreciate the significance of early symptoms and hence could delay making referrals for more specialised assessment.

Various studies have explored parents' reports of the signs that alerted them to their child having a problem; usually from self-completion questionnaires with volunteer samples (Gray & Tonge, 2001). In other studies, the data was based on parental recollections many years later (Young et al., 2005). Other researchers have analysed case files. De Giacomo and Fombonne (1998) reviewed case records of 82 consecutive referrals with a mean age of six years, to a specialist diagnostic service in London. As part of assessment tool used (Autism Diagnostic Interview-Revised: Lord, Rutter & Le Couteur, 1994) reports were obtained from parents about the nature of the abnormalities they had noted in their child's development and these were coded into eight categories. This identified speech and language development as the primary and most common concern followed by abnormal socio-emotional responses, medical problems and delay in reaching milestones.

The present study sought to extend the findings from past research in two important ways. Information would be gathered from mothers through individual interviews conducted in the family home soon after a diagnosis of ASD had been made. The aim was to obtain a richer account of mothers' observations which would equate more closely to the type of reports that mothers may make to healthcare personnel if they are concerned about their child's development. Second, by using a large sample of consecutively referred children who had been diagnosed at a community-based clinic, relationships could be explored between specific features reported by parents and certain child and family characteristics, such as reported age of the child and the presence of a general developmental delay. Hence the main aim of the study was to document through thematic analysis how parents described the features that alerted them to the child's difficulties. Exploratory analyses would be undertaken to determine if these features varied according to the age at which the problem was first identified and if the child exhibited an overall developmental delay.

Method

Sample

All parents with preschool children under 5 years of age, who had been given a diagnosis at a community-based clinic for children with suspected ASD, were invited to participate in the project. This was held in one Health and Social Services Trust within Northern Ireland (population 220,000). The children were consecutively seen at the clinics over a 36 month period and hence interviews were conducted on staggered basis. Of the 90 parents approached, 72 parents (around 80% of those diagnosed) were interviewed; 18 families either declined or proved difficult to contact.

Recruitment

Parents were initially approached by clinic personnel about participating in the study either by phone or letter usually within one year of their child having been given a diagnosis of ASD. Those who were willing or contactable were then telephoned by a university researcher linked with the project. She gave further details of the project over the phone and arranged to visit the parents at home. Parents were again informed about the reasons for undertaking the project and what their participation would involve. They were assured that all information would be confidential to the researchers and that no one would be identified in any reports. They could terminate their participation in the interview at any time with no consequences for access to services. All parents agreed to proceed and duly signed a consent form.

Procedures

A semi-structured interview schedule was prepared based on the project aims. This consisted mainly of open questions relating to the signs that had alerted them to a problem, who in the family had first suggested there may be a problem and what help had been sought. General probes were used to encourage fuller responses ('can you tell me more about that? Can you give me an example of what you mean?') but specific suggestions were not made to avoid biasing parental responses. Detailed notes were taken during the interview as pilot testing had indicated reluctance among parents to be tape-recorded.

Information about the child and family were collected after the interview and the Vineland Adaptive Behaviour Scales (Sparrow, Balla & Cicchetti, 1984) were completed to describe the child's current functioning based on parental responses. If parents raised any concerns about their child during the interview, they were advised to contact the professional staff at the specialist clinic. Also at the end of the interview they were given written contact details for the researcher.

Data analysis

Parents' responses to the interview questions were analysed by thematic content (Attride-Stirling, 2001). The resultant groupings were cross-checked by two independent raters who came to a consensus view on the small number of disagreements (9% of ratings). SPSS was used to analyse the predicted relationships. Given the relatively small sample and the number of relationships tested, these should be treated as exploratory findings that could be further tested in subsequent studies.

Results

Participants

Details about the parent and child characteristics are given in Tables 1 and 2. This data was also used to identify relationship between these characteristics and reports of early features of ASD. For the 72 children, the mean overall standard score on the Vineland Adaptive Behaviour Scales was 68 but these ranged from 48 to 97 with a standard deviation of 9.3. (NB An 'average' child would score 100 for his/her age.)

Table 1. Parental characteristics ($n = 72$)

Parental characteristics	<i>n</i>	%
British/Irish	71	99
Other	1	1
Two parent families	62	86
Single parent families	10	14
Under 30 years	19	26
30–39 years	46	64
40 years and over	7	10
Wage-earner in family	58	81
No wage-earner	14	19
Left school at 15 years	10	14
GCSEs/O Levels	31	44
A Levels	10	14
Higher education	20	28
Owned their home	53	74
Rented accommodation	16	22
Lived with child's grandparents	3	4

Table 2. Characteristics of child with ASD ($n = 72$)

Child characteristics	<i>n</i>	%
Male	65	90
Female	7	10
Aged 2 years at interview	22	31
Aged 3 years	28	38
Aged 4 years	22	31
Only child	9	12
Eldest	9	12
Middle	14	20
Youngest	40	56
Sibling with similar problems	16	22
Member of extended family with similar problems	25	35
Both sibling and member of extended family had problems	8	11
No relatives with similar problems	39	54
Hearing impairment	7	10
Vision impairment	7	10
Epilepsy	9	13

Child's age when problem suspected

Nearly one-third of families (31.9%: $N = 23$) reported that they had identified a problem before the child was one year old; a further 35% ($N = 25$) of families by the time the child was 18 months old and another 22.2% ($N = 16$) by two years of age. In only eight families (11%) was the child aged over two years. Thus two-thirds of parents in this sample had identified the problem by 18 months which is earlier than the mean age reported in most previous studies (Gray & Tonge, 2001).

Identification prior to 12 months tended to occur more frequently for only or first-born children whereas the youngest children in the family were more likely to be identified between 12 and 18 months with middle-children being identified after 18 months ($\chi^2 8.7$; $df 4$; $p < .07$).

In the majority of cases (54%: $N = 39$) it was reported that the mother first spotted the problem; although in eight instances (11%) both parents noticed it; in two cases (3%) it was the father and two (3%) the child's grandmother. However in 21 families (29%) it was a person outside the family who suggested to the parents

Table 3. Numbers and percentages of parents mentioning indicators ($n = 72$)

Indicators	<i>n</i>	%
Speech, language and communication difficulties	49	68.1
Behaviour problem – aggression, temper tantrums	25	34.7
Hearing difficulty	21	29.2
Socialisation – lack of interaction, eye contact, unresponsive	18	25.0
Development delay – motor skills, self-care	13	18.1
Mannerisms, e.g lining up toys, hand flapping	13	18.1
Child had regressed, e.g. in speech	9	12.5

there might be a problem; most commonly a health visitor ($N = 14$: 19%) followed by speech and language therapist ($N = 3$: 4%), community paediatrician ($N = 2$: 3%) and a preschool teacher ($N = 2$: 3%).

Not surprisingly the problem was recognised earlier when family members suspected that something maybe wrong (75% [$N = 38$] of families - had identified it by 18 months) than when professionals had identified it (48% [$N = 10$] by 18 months) ($\chi^2 4.8$; $df 1$; $p < .05$). However, none of the other parent characteristics, such as educational level ($\chi^2 5.91$; $df 6$; $p < .43$), absence of wage-earner ($\chi^2 1.27$; $df 2$; $p < .53$) or single parenting ($\chi^2 1.58$; $df 2$; $p < .45$) were significantly related to age of identification.

Early signs of a problem

Parents were asked to describe what had alerted them to thinking that the child may have a problem. Their responses were grouped into the categories listed in Table 3. Within each category parents gave varied accounts of what this had meant for their child and often reported these in conjunction with other indicators. Eighteen parents (25%) mentioned one indicator; 32 (44%) named two different indicators; 16 (22%) three indicators and 5 parents (7%) four or more indicators.

A difficulty with speech, language or understanding was the most frequently mentioned overall and with a frequency that was comparable in previous studies (e.g. De Giacomo & Fombonne, 1998; Chawarska et al., 2007) Of these 49 parents, nearly all ($N = 47$) specifically mentioned the word 'speech', in terms such as 'delayed speech, lack of speech, slow speech development, no speech, speech was behind, didn't speak much, couldn't speak, speech didn't come.' Six parents alluded to the child's babble: 'he wasn't making sounds, his babble was gibberish'; five mentioned a lack of understanding: viz 'wasn't speaking or understanding' and three referred to a lack of communication: 'does not communicate at all; no communication skills.'

Behaviour problems were the next most frequently mentioned concern with temper tantrums, screaming and aggression among the most commonly mentioned with excessive crying and refusal to eat also noted. Examples parents gave included:

'Hyperactive and aggressive; didn't learn from consequences; cross baby, would bang his head and would not eat; wouldn't lie in pram – too alert; temper tantrums and eating disturbance; he did things he

shouldn't be doing; cry non-stop for 3 to 4 hours; difficult child- cried a lot; squealed constantly.'

Twenty-one parents suspected a hearing difficulty with their child; an aspect that previous studies have not commented on (e.g. Gray & Tonge, 2001). Example comments were: 'Poor hearing; we thought his lack of speech was due to a hearing deficit – he failed a hearing test at 8 months. We got hearing checked and found he had glue ear. Got vents in but speech didn't come.'

Socialisation difficulties were mentioned by fewer parents in this study than in previous ones; for example De Giacomo and Fombonne (1999) reported that 39% of parents had noted these problems compared to 25% here. Examples given included:

'Poor eye contact as a baby; did not play peek-a-boo; didn't like to sit and interact with other children; very unsociable child; withdrawn – in a world of his own; no reciprocal responses.'

Five parents commented on the lack of response they got from their child. Concerns with the child's overall development were mentioned by 13 parents. For example: 'Late walker; milestones late – sitting and crawling; lack of walking – couldn't climb; generally slow; clumsy child; slow to train.'

Specific mannerisms and routines that are seen with children who have ASD were mentioned by 13 parents. Comments included: 'Funny characteristics – rocking and lining objects up; became very frightened when taken out anywhere; couldn't play – would spin shoes and cars; growling; hand-flapping and squawking; repetitive routine and rigid behaviour; piled cushions in the middle of the floor; lines up toys.'

Finally nine parents specifically mentioned that the child had regressed; an aspect that other researchers have noted (Charman & Baird, 2002). Some parents linked this with MMR vaccination. For example: 'He was a very bright child up to two years and then overnight everything changed – blank stares and lost all his words; after MMR he became withdrawn, in a world of his own; he had speech until he took fits and then it stopped; used to interact socially and had words but lost it; at 17 months after MMR, he stopped talking but started walking.'

Twenty-one parents reported that a professional had first suspected that the child may have a problem. This was more likely to happen when the parents reported the child to have developmental delays or socialisation difficulties although the differences were not statistically significant when tested. However it was only families who picked up the child's regression which is not surprising as professionals are less likely to know the child at a young age and be in a position to monitor changes ($\chi^2 4.2$; $df 1$ $p < .05$).

In 24 families ($N = 24$; 34%), it was reported that there were disagreements among the parents as to whether or not there was a problem. This tended to happen when the child's problem was identified at an earlier age. Agreements were highest with speech difficulties and behaviour problems, and less so for the other indicators.

Patterns among early indicators

Although all children in the sample had a diagnosis of ASD, there was wide variation in parents' reports of their recollections of early indications of ASD. This was

reflected somewhat in the varying combinations of indicators as well as the different ways they described difficulties within a category. Exploratory cluster analyses were undertaken of the features reported by the 72 parents in an attempt to identify possible combination of features of ASD in maternal reports. In this sample, three broad clusters of features were identified. The largest cluster accounted for 41 children and was based mainly around speech difficulties (loading .88) in combination with behaviour problems (loading .34) and developmental delays (loading .27). The second cluster focussed mainly around behavioural problems (loading .77) and mannerisms (loading .69) and accounted for 13 children. (These tended to be children who were rated as less developmentally delayed by their parents: $\chi^2 6.7$ $df 2$; $p < .05$). The third cluster included suspected hearing difficulties (loading .83), speech (loading .50) and socialisation problems (loading .44). This accounted for 18 children. However it should be stressed that within each cluster, some parents reported additional indicators to those that defined the cluster which underlines the individual variations found with preschoolers who have ASD.

Inter-relationships with early signs

Analyses were undertaken to determine if each of the indicators listed in Table 3 was linked to parental reports of the child's age when they became concerned. In only two instances were significant effects found.

Speech, language and communication difficulties were significantly associated with an earlier identification of a difficulty. Of the 23 children identified before 12 months, 52% ($N = 12$) were reported to have a difficulty in this area compared to 36% ($N = 9$) of those identified between 12 and 18 months but only 8% ($N = 1$) of those identified after 18 months ($\chi^2 10.7$; $df 2$; $p < .01$).

The other indicator related to age of identification was with the child regressing and losing skills s/he previously had. In seven of the nine instances when this was reported, the child was aged between 12 and 18 months ($\chi^2 8.4$; $df 2$; $p < .05$).

Those children whose overall development was markedly delayed (i.e. below the median of standard score of 63 for the total sample as measured by parental ratings on the Vineland Scales at the time of interview) also made more mention of hearing difficulties than did those with children whose overall development was less delayed ($\chi^2 13.1$; $df 1$; $p < .001$) and they tended to report more speech difficulties ($\chi^2 3.3$; $df 1$ $p < .07$). By contrast parents with children with less developmental delay (i.e. Vineland scores above the median) were more likely to report mannerisms than were parents of children with more marked delays ($\chi^2 3.9$; $df 1$; $p < .05$).

Whose help was sought?

Eighteen parents (25%) reportedly sought advice from both their Health Visitor and GP, 37 (51%) from a health visitor only and 10 (14%) from GP only and seven (9%) from neither. Twenty-four (33%) reported seeking advice from a family member or relative and 20 (28%) contacted a range of other persons such as preschool personnel, speech and language therapists and child-minders.

Discussion

This study had a number of limitations. It relied on maternal recollections which may have been distorted by being given a diagnosis of ASD. Moreover there was no contrast group of parents whose child had not been given a diagnosis of ASD even though their parents had suspected a problem. Nonetheless the study confirmed that most parents in this study had concerns about their child's development by the time the child was 18 months old. These focussed around specific features of the child's development rather than an overall delay, with a lack of 'speech' and difficulties in communication being most often mentioned. In addition a range of other problems were noted especially around behaviour problems and odd mannerisms, and suspected hearing impairments and socialisation difficulties. In broad terms these replicated the findings reported in previous studies such as De Giacomo and Fombonne (1998) and suggest that parental concerns about their child's speech are the most common precursor to a subsequent diagnosis of ASD.

However other studies with samples of older children have noted socialisation difficulties as the defining concern (Howlin & Asgharian, 1999). Social deficits may well become more apparent to parents as children start to attend playgroups and nursery schools. Moreover there is evidence of a change in ASD symptomology as the child ages (Charman & Baird, 2002).

A small but significant number of parents in this study mentioned that their child had regressed and that mostly this had become apparent between 12 and 18 months. Other studies reported a higher incidence of regression – up to 47% of children based on more detailed questioning of mothers (Davidovitch et al., 2000). Hence this is another indication that should alert professionals although it would appear that these children present similarly to other children in terms of the indicators of ASD.

Overall what distinguishes children with ASD from those who may be experiencing a general developmental delay in their language development, is the presence of a variety of other indicators which can vary greatly from child-to-child but which should alert parents and professionals to a potential ASD (Johnson et al., 1992). However the broad descriptions that parents used about their children's difficulties lack the specificity required to make a diagnosis of ASD. In particular they made no mention of certain signs that are particularly associated with ASD such as a failure to imitate, lack of pointing and limited use of conventional gestures, and a lack of imaginative play (Gray & Tonge, 2001). Many, indeed most parents, may not be aware of the developmental significance of these behaviours. Early screening instruments that specify particular ASD related-behaviours have a particular value in this respect (Robins et al., 2001) and they might be used by professionals with concerned parents to help build up a more detailed picture of the child's difficulties and increase parental understanding of the significance of these behaviours as well as assisting in making referrals for further assessment. Future research could explore the value of using these detailed checklists with concerned parents over a period of time to monitor the child's development prior to the formal diagnosis being

made. This would extend the insights being gained from longitudinal studies of changes in symptom expression in the early years (Chawarska et al., 2007) and those that have attempted to prospectively monitor the development of children considered at risk of ASD, e.g. a sibling of a diagnosed child (Landa, Holman & Garrett-Mayer, 2007). Also retrospective analysis of home movies taken of the child pre-diagnosis could overcome some of the problems of relying on maternal recollections in identifying early indicators of difficulties (Werner & Dawson, 2005).

A major rationale for paying greater attention to early signs of ASD is to offer concerned parents early intervention to ameliorate or manage better the child's difficulties. Parents certainly spoke of their frustration at the delays in obtaining assessments and diagnosis and that even when this was did happen, they bemoaned the lack of guidance and advice offered to them (Cassidy, McConkey & Truesdale-Kennedy, 2007). Parents particularly appreciated having access to a support worker who can provide information about ASD and advise on practical strategies to facilitate language, communication and interactive play (Whitaker, 2002). Given that health visitors/public health nurses are the group most likely to be contacted by British parents, it is important that they can offer such support to families or provide immediate referrals to other services which can give advice and guide them on practical actions particularly on enhancing communication and managing the child's behaviour. But at present specialist advice is often dependent on the child receiving a confirmed diagnosis and the longer the waiting times for assessment and diagnosis, the longer families have to wait to be given the help they need. One solution is to disentangle intervention from diagnosis. For example, health visitors and childcare staff working in playgroups and crèches should be knowledgeable about the strategies required to promote the development of these children and they should be proficient both in their use with children, and in sharing their knowledge with parents (Crawford et al., 2003). In so doing, they can address the child's difficulties without conveying a diagnosis. Indeed it is likely that all children would benefit to some extent. Hence a priority is not just an expansion of assessment services but also the dissemination of good practice in response to ASD among primary care professionals and early childhood educators.

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