

'You know what boys are like':

pre-diagnosis experiences of parents of children with autism spectrum conditions

Abstract

Background

The importance of early identification and intervention for children with autism spectrum conditions (ASC) has been established. However, there are often considerable delays from initial concern (by parent or professional) to diagnosis. Little is known about parents' experiences of primary care in the pre-diagnosis period.

Aim

To identify feasible improvements to the management of primary care consultations with parents of children who might have ASC.

Design and setting

UK-based qualitative interview study.

Method

Semi-structured interviews with a diverse qualitative sample of 24 parents of children, aged between 3 and 11 years, who were diagnosed with ASC.

Results

Three types of parental concern emerged: first, parents who had no concerns about their children's development before their diagnosis; secondly, parents who reported that they had some concerns but had not raised them with health professionals (passive concern); and thirdly, parents who had raised concerns about their children with health professionals (active concern). The passively concerned parents could not pin down exactly what it was about their children's development that concerned them. Many of the actively concerned parents had been prematurely reassured by health professionals that there was nothing wrong. This left them feeling isolated and alone. Actively concerned parents who already had a child diagnosed with ASC did not experience a delay in diagnosis.

Conclusion

Health professionals should acknowledge parents' concerns carefully; contrary to intentions, early reassurance may result in parents feeling that their concerns have not been heard. Parents may be the best resource in identifying ASC.

Keywords

autism; consultation; diagnosis; doctor-patient relations; parents; primary care.

INTRODUCTION

The prevalence of autism spectrum conditions (ASC) is increasing and is estimated to be 1% of the child population.¹ It is not clear whether this represents an increase in ASC or more effective methods of identification. The importance of early identification and intervention, in improving children's social skills and quality of life, has been established.²⁻⁴ Diagnosis of ASC can be challenging: while the main characteristics of ASC are held to be difficulties in three areas — communication, social interaction, and social imagination — the condition manifests differently across the spectrum,⁵ and there is no universally accepted diagnostic tool. Observation or interview instruments, such as the Autism Diagnostic Observation Schedule and the Autism Diagnostic Interview-Revised⁶ are in use, albeit with widespread variation in their use.⁷ Evidence suggests that early diagnosis can be made reliably;⁸⁻¹⁰ however, considerable delays remain from initial concern (by parents or professionals) to diagnosis.^{11,12}

Research suggests that clinicians are beginning to identify ASC earlier, leading to better parental satisfaction.¹³ The role parents play in the identification of ASC has also been considered,^{12,14} and while diagnosis remains imprecise, and a matter of clinician judgement, parents have been identified as the best resource in identifying ASC.¹⁵ Proposed National Institute for Health and Clinical Excellence (NICE) guidelines, currently under development,

recommend that professionals always take parental concerns about behaviour or development seriously, even if these concerns are not shared by others. However, parents often face a frustrating period of uncertainty and worry and find themselves trying to convince doctors that their children need specialist assessment.¹⁴ A tendency for doctors to minimise or dismiss parental concerns has been reported in several studies.¹⁵⁻¹⁷

GPs are usually the first point of contact for parents, and their response to parental concerns plays a significant, but little considered, role in the diagnostic process. The present study aimed to identify feasible improvements to the management of primary care consultations with parents of children who might have ASC.

METHOD

Using a qualitative design, a maximum variation sample of 24 parents from across the UK, were interviewed by one author, in 2007-2008. The sample was recruited through a combination of support groups, snowballing, and online forums. Three interviews were conducted with both parents present, the remainder with one parent. The parents had children, aged 3-11 years, diagnosed with ASC. Three parents had two children diagnosed with ASC. This sub-sample was part of a larger project, and further analyses and extracts from the larger study can be seen at www.healthtalkonline.org.

The interviews were conducted in

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How this fits in

Early diagnosis and intervention is beneficial to children with autistic spectrum conditions. Parents can be a good resource for identifying ASC. This research suggests that parents may feel their concerns are not heard in GP consultations. Suggestions are presented for reassuring parents without dismissing their concerns.

people's homes after informed consent was obtained. They were semi-structured and had two parts: a narrative section in which participants were asked to tell their stories; and then a semi-structured section in which the chronology of the diagnostic journey was explored in depth. The interviews lasted between 1 and 3 hours and were recorded and transcribed verbatim. The data were analysed thematically using the organisational support of NVivo 2. The transcripts were read carefully and then coded by one researcher. A second researcher independently coded the first few interviews and results were compared, differences discussed, and the coding framework revised and further developed. Links across codes were made using a mapping technique,¹⁸ and several key themes emerged as links were made across the codes and categories subsumed or expanded using a constant comparison approach. One theme was the significance to parents of the pre-diagnosis period.

Critical distance from the data was maintained through the involvement of the second researcher and second author, as well as presenting the findings at both regional and national GP conferences.

The study had NHS multicentre research ethics committee approval from Anglia and Oxford.

RESULTS

The subsample considered in this analysis included participants from a range of socioeconomic groups and geographical (including urban and rural) locations in the UK. Demographic details of the sample are presented in Table 1. Extracts from the data are included, with the interview identifiers in parenthesis.

Three categories of parental concern were labelled from the analysis: no concern, passive concern, and active concern. The first category is self-explanatory; parents said they were not concerned about their children's development before a health

professional or teacher raised concerns. Passive concern includes a small group of parents who recalled being worried about their children's development but did not seek advice or help from their GP or health visitor. The actively concerned parents were worried about their children and reported asking for help from their GP or health visitor.

Of the three parents with two diagnosed children, two were categorised as 'no concern' for their first child and 'active concern' for their second. The third parent was actively concerned about both children. The third category included parents who discussed some passive concern initially but then actively sought help. The demographic characteristics of parents in each category are mixed.

No concern pre-diagnosis

Several parents told the interviewers they had not been concerned about the child's development. One child was diagnosed just before his second birthday; others in this group were diagnosed between the ages of 5 and 8 years. This suggests that once the children began school, the differences were identified more easily. These parents expressed surprise when a health visitor or member of school staff suggested they take their children to the GP to investigate delayed development or unusual behaviours. For example, one mother thought that her son had hurt himself when a student teacher suggested she take her son to the GP. Some described how content, undemanding and, in a couple of cases, developmentally advanced their children had seemed. A few parents in this category recalled recognising something different about their children but this was interpreted as an example of the child's 'eloquence' or advanced development. One father commented: 'Well I think initially we thought we had a gifted child' (12), while another mother said 'I just, we just as a family thought [um] that he was just a normal, very active, inquisitive little boy, you know, who was just a bit different, a bit of a loner'. (21)

Passive concern

Some parents said that they were concerned about their children's development but did not raise their concerns with health professionals. One couple in this group described shifting over time, from being passively concerned to becoming actively concerned. This couple talked about feeling concerned when their son was 18 months old but they didn't seek help until he was aged 2 years and it

Table 1. Demographic details of the sub-sample

Category	n
Age, years	
21–25	1
26–30	1
31–35	7
36–40	9
41–45	3
46–50	3
Sex	
Male	6
Female	18
Marital status	
Married/cohabiting	15
Separated/divorced	3
Single	1
Occupation	
Full-time employment	9
Part-time employment	5
Full-time carer	8
Student	2
Ethnicity	
White British	20
Other (mixed race British, Black Caribbean)	4

became more apparent to them, in comparing his development with his older sister and peer group, that he had developmental issues. The children of the remaining parents in this group were diagnosed aged 4–5 years.

Some parents remembered feeling concern for several months. For example:

'And it wasn't until he got to about 18 months old that I realised that he wasn't really joining in with other children, wasn't talking at all, and [um] by then our second child was on the way as well and just thought he is so easy, so easy going and so content with his own thing. I did suspect there was something wrong.' (1)

In retrospect, parents offered reasons for not seeking advice from their GP or health visitor. For example, they were new parents and so did not know to ask, or worked full time and so did not interact with the children as much as they would have liked:

'So yes, sometimes there are little signs there. Sometimes when you have got a busy life and, you know, you work full time and you know you don't have as much time with the children as you would like [um] you don't always pick up on the signals early enough but intuitively I felt there was something that wasn't quite as it should be but I really couldn't put my finger on it.' (16)

'Just watching him play with the other children, you realised that something wasn't right [...] But because we were new parents, we didn't know, we never knew there was anything wrong.' (20)

Others said they were unable themselves to articulate their concerns about their children's development:

'I thought "I'm not going to my GP and tell him I have got a naughty boy".' (3)

Not being able to define their concerns militated against these parents raising the issue with health professionals.

Active concern

Parents in this group described becoming concerned and asking their GP or health visitor for advice when their children were aged between 9 months and 3 years. A few parents described how their children regressed and lost skills such as speech. Others said that they compared their child's development with siblings, or their peers, and it was very apparent to them that there

was something different by the time they were 12 months old (or for a few, even earlier). The early signs were delayed developmental milestones such as smiling, crawling, or babbling. Later signs included severe tantrums, anxious behaviours, and a lack of eye contact. These signs are described in the following extracts:

'When he got to the age of about a year he was still developing normally, crawling, walking, etc, and then his speech didn't really come on very well at all. [Um] We had some concerns about it, he wasn't really babbling and the normal baby talk that you get and I spoke to the health visitor and continued to do so. They didn't think there was anything too much to worry about.' (6)

'We first got concerned about him when he was about 6 months old. He didn't smile at people, you know, other children were beginning to babble and say words. He didn't say anything at all really. He just seemed to be very much in his own world. That sounds such a cliché but we could just put him in his bouncer and he would happily sit there all day and not murmur and he didn't get hungry or get thirsty, you know, even as he got older he would never ask for things, we would have to tell him, you know do you want something to eat, do you want something to drink. He would never ask for anything. I mean I knew straight away I could just tell. Even though I didn't have any other children first, I just knew there was something weird about him so to speak.' (7)

'We have known probably since he has been about 9 months old that [name] was autistic because he had very strange and unusual behaviours that we couldn't explain and nobody could explain and in the beginning everybody wanted to tell us that it was just normal for a child to be like that but we knew that there was something wrong.' (19)

Some GPs referred the children straight away for assessment and these children were diagnosed within a relatively short space of time. The remaining parents experienced a delay of between 6 months and 5 years. These parents were told that there was nothing to worry about and their children would grow out of it:

'Then [er] he moved to another ... a nursery school and they didn't actually tell me there was, they sort of mentioned to me that he wouldn't sleep in the afternoons. He would disturb the other children and so I took him to my GP and said, "You know the nursery

school have suggested I bring him to you because he won't rest in the afternoon". And she was, "Like oh well my daughter is four, and she won't rest in the afternoon either". (8)

'When he was 10 months I remember going to the health visitor because he was nipping and biting and he was really hard going. He pulled the stair gates off the wall. He could launch himself over it. He climbed up furniture. He was really, really dangerous. But the health visitor just said, "No, you know what boys are like". (15)

Parents who felt that their concerns were not fully engaged with described a range of emotions including distress, anger, humiliation, and frustration. Their relationship with their GP and other health professionals was affected by what they perceived to be a lack of engagement with their concerns, particularly as the lack of action or acknowledgement by the GP or health visitor left them feeling isolated and alone:

'And then like I say it was just really a case of trying to get somebody to [um] listen to us. We went through all the usual routes, you know we went to see the doctors and the regional health visitors and they just didn't seem to latch on the fact that this kid had a problem. They just thought he was underdeveloped but there were certain traits with him that we knew "no it is not underdeveloped there is something psychologically incorrect with this kid". And we sort of felt on our own for a while, didn't we?' (9)

'But it leaves you that way that you think, well I if I go to the doctor he is just going to pooh pooh things. Or treat you like with this funny little grin on their faces as if to say, "Oh aye there is nothing wrong with you really". (15)

'I feel like I was let down. That is what I do. I do feel like I was let down. I feel like they should have listened to me more.' (5)

It was not clear why some other children were referred and diagnosed within a few months. It could reflect geographical differences in provision, or different approaches of health professionals and parents, characteristics, and relationships. It was apparent that those parents who had another, older child already diagnosed with ASC experienced a fast-track referral, with the second child often going through a

lighter assessment process than their sibling. The combination of the parents' experience, and the history of the older child, facilitated a faster diagnostic journey. For example, one mother noticed her younger son making a distinctive movement with a pencil in front of his eyes, in a similar way to his older brother who had been diagnosed 2 years before: 'I contacted our paediatrician who was absolutely fabulous and said "bring him in". (1). Positive relationships with their health professionals were reported by parents who did not experience a delay in diagnosis:

R2: 'Yes, all the professionals we were involved with ...'

R: 'Were absolutely superb.'

R2: 'But all the professionals we dealt with, I mean particularly those at [assessment centre] were so supportive to us and so fantastic.' (14)

DISCUSSION

Summary

This analysis has categorised parents' concern relating to their children's development. GPs and other health professionals need to remain attuned to parental concerns. Contrary to intentions, early reassurance may result in parents feeling that their concerns have not been heard. This has some resonance with existing research in other health areas.¹⁹ As Caronna *et al* suggest:¹⁵

'The paediatric provider's willingness to share that uncertainty with families is critically important to preserve and strengthen the relationship between family and clinician.'

The experiences of those (few) parents with a child already diagnosed with ASC reflect this; these parents felt that their GP or paediatrician listened to their concerns about their second child and acted on them, and they talked positively about their healthcare providers.

In most cases when parents present to a GP or health visitor with concerns about their child's development, reassurance will be appropriate. The challenge for the health professional is to listen adequately, explore sensitively, and safety-net appropriately, so that parents feel listened to and opportunities for diagnosis are not missed. As illustrated above, parents may struggle to articulate exactly what is different or unusual about their child. A combination of sound clinical knowledge of diagnostic

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Ethical approval

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Competing interests

The authors have declared no competing interests

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features of ASC and sensitive questioning may be needed to build a picture of the child's behaviour away from the surgery and to get to the root of a parent's worries. Asking parents to write down examples of behaviour that strike them as odd and to collect information from other adults (relatives, carers at nursery or school) will contribute usefully to this picture.

There is sometimes a concern that lack of definitive reassurance will lead to unnecessary worry in parents of unaffected children. In these situations, formulations such as *'Nothing you have told me makes me worried that your child has a problem but I can see that you are concerned. Why don't we meet in X weeks and meanwhile can you keep a note of ...'* can serve to reassure without dismissing.

Another factor that may lead to delay in diagnosis is a feeling of therapeutic nihilism; nothing can be done so there should be no hurry to give diagnostic labels. In fact, as discussed earlier, there are a number of benefits, both material (in terms of access to educational and financial support) and psychological, that may follow on from diagnosis.

Strengths and limitations

The strength of this study is that qualitative studies of parents' experiences of autism diagnosis have not been reported before. This analysis has identified three categories of pre-diagnosis parental concern that have not emerged in existing research and has highlighted easily implemented changes to practice. The main limitation of the study is that the data are retrospective and cannot include the parents who may be

unjustifiably concerned. Parents are recalling experiences, and so inconsistencies and gaps may remain. It was not possible to observe the consultations (which are few and far between) and nor was it possible to interview health professionals about their perspective on these consultations, which might have been different from the parents.

Comparison with existing studies

Existing studies have largely focused on identifying the early signs of autism, rather than exploring parental experiences of the pre-diagnostic period. The growing recognition of parental expertise in identifying problems with their children's development or behaviour has consequences for research and practice.

Implications for clinical practice

To provide the best service to parents and patients, GPs and other health professionals need a good working knowledge of the features of ASC and the services available to people with this diagnosis: online resources such as the Royal College of General Practitioners' e-learning module on ASC may help here. Listening skills that lead to parents feeling heard are vital to avoid negative parent experiences, which may have far-reaching consequences for the parents' relationship with their health professionals.

Not feeling heard can leave parents feeling isolated and have implications for the doctor-patient relationship.

Parents, particularly those with more than one child, may be the best resource in identifying ASC.

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