

CHALLENGES FACED BY PARENTS OF CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDER

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ABSTRACT

Few studies address the daily challenges faced by parents of children diagnosed with autism spectrum disorder. This article reports on a qualitative interview study with 20 parents exploring their experiences, challenges faced, and what has helped them to cope. A thematic analysis of the data identified six core categories: Difficulties changing routine, dealing with challenging behaviours, judgements from others, lack of support, impact upon the family, coping and the importance of appropriate support. The findings emphasise where the parents themselves believe they still require additional support. It raises key strategies and resources that parents have found helpful.

KEY WORDS: Autism, children, parents, challenging behaviours, qualitative study

It is well recognised that caring for a child with a disability contributes to higher levels of stress than caring for a child with typical development (Dyson, 1997). Caring for a child diagnosed with autism can be especially stressful for carers (e.g. Dumas, et al., 1991; Ingersoll and Hambrick, 2011). As there appears to be an increasing number of children receiving a diagnosis of Autism Spectrum Disorders (ASD) (Cox, et al., 1999) and children are now being diagnosed much younger (Charman and Baird, 2002), the continued study of factors relating to difficulties faced by the parents needs to be fully addressed.

Several authors have argued that it is the behavioural problems which are the most important predictors of parental stress in children with disabilities (Baker, et al., 2002; Baker, et al., 2003; Osmond, et al., 2003). Behavioural problems are frequently reported in young people with ASD (Gadow, DeVincent, and Azizian, 2004; Tonge and Einfeld, 2003). These behavioural problems, as well as social and cognitive difficulties, may then present particular challenges for the parents (Koegel, et al., 1992; Weiss, 1991). In a sample of parents of children with autism, Lecavalier and colleagues (2006) found parental ratings to suggest that behaviour problems and stress exacerbated each other over time. Specific problems, such as externalising behaviours were found to be more predictive of parent stress than adaptive behaviours. For example, problems such as the absence of language and behavioural difficulties are likely to lead to increases in stress levels (Bristol, 1984; Pisula, 2007) and regulatory problems (eating, sleeping, and emotion regulation) frequently reported in young children with ASD (Degangi, et al., 2000; Dominick, et al., 2007) are also thought to negatively affect the parents.

Children with autism also display repetitive, non-functioning activities and interests, which present considerable challenges and distress for individuals with autism as well as their families, due to the individuals' intolerance of changes (Dunlap, Dyer and Koegel, 1983). Routines and ritual-behaviours are thought to be significantly more prevalent and marked in individuals with autism relative to age and ability matched controls (Lord and Pickles, 1996; Leekam, et al., 2007). The presence of repetitive behaviours is

reported as significantly stressful by parents and caregivers (De Meyer and Goldberg, 1983; Gabriels, et al., 2005; Koegel, et al., 1992). The extreme distress and catastrophic reactions shown by many in responses to changes in routine are rarely described in non-autistic individuals.

In addition to these problems, parents also have to deal with many other co-occurring difficulties, such as financial and time burden of medical treatment and other therapeutic interventions, restrictions on social activities, parental sense of loss and grief, and changes to family goals and achievements (McCubbin, Cauble and Patterson, 1982; Lecavalier, Leone and Wiltz, 2006). Furthermore, research suggests that there is insufficient support services for parents of children with autism, which might help them cope with stress (Whitaker, 2002).

Few studies enquire directly in to the experiences of parents with autism, and have generally relied on the completion of self-report standardized measures of stress. The strengths of these measures are that generalizable causal relationships can be established in measuring contributions to experience of stress. This, however, relies on the assumption that people can accurately report their experiences using self-report questionnaire measures. Furthermore questionnaire measures cannot capture the complexity and subjective experience of parents, and neither do they draw upon any particular difficulties and stresses in caring for their child. Qualitative research has been recognised as offering a valuable contribution to exploring subjects' experiences in-depth. However, there remain relatively few qualitative studies exploring the parents' experiences of caring for a child with autism (e.g. Tunali and Power, 2002).

Some qualitative studies have explored parent's experiences and understanding of diagnosis. For example, Midence and O'Neill (1999) found parents experiences of diagnosis to be stressful and confusing, with accurate diagnosis reported as being a very lengthy process. Dale and colleagues (2006) explored mothers' understanding and attributions made about their child's diagnosis, and found that most mothers had multiple, complex attributions as to the causes of their child's diagnosis. Similarly, Avdi and

colleagues (2000) observe how parents may hold “multiple, ambivalent and often apparently conflicting meanings” (p. 251) in relation to their child’s diagnosis of autism, and explore how parents draw on different discourses – medical discourse, disability discourse and discourse of normal development – to make sense of their child’s diagnosis.

Research is heavily weighted towards exploration of maternal levels of stress (Pisula, 2006; Tomanik, Harris & Hawkins, 2004) with relatively few that addressed those of the father. Evidence suggests that mothers and fathers in fact have comparable levels of stress (Hastings et al., 2005; Rimmerman et al., 2003). However, there may be some differences in how fathers experience stress. For example, in a study of parents with children with disabilities, Hastings (2003) found that mother’s experience of stress may be affected by the psychological health of other family members, whereas father’s stress is affected more by other factors.

With the aim of exploring parents subjective experiences of having a child diagnosed with autism, a qualitative study was completed which explored parents experiences around current stressors and factors that help them to cope. We report here on results of the study, focusing on the daily experiences of parents, and what challenges they face, as well as what helps parents to cope with challenges and stresses. Given the lack of studies involving fathers, an important feature of the current study was to also explore the experiences of both fathers and mothers.

METHOD

Data was collected by means of individual interviews with 20 parents (14 mothers and 6 fathers). This represented the parents of a total of 14 children diagnosed with autism (8 children) or Aspergers or high-functioning autism (6 children). The ages of the children ranged from 4 to 14 years, with 2 children of adult age (26 and 29 years). Participants were recruited through convenience sampling from people known to one of the authors from previous projects, and through advertising through parent support groups. Participants were recruited from towns and cities in the East of England, as well as in London.

Participants took part in individual interviews averaging approximately 45 to 60 minutes. Four interviews were shorter due to time constraints for parents who presented for interviews as a couple (but interviewed separately). Participants gave their signed informed consent. Semi-structured interviews were conducted by the first and last author (AL and PR). An interview schedule was drawn up, which was used as a guide for topics to cover in the interview. Core questions included:

1. As a parent of a child with autism, what makes things difficult or challenging for you?
2. What makes things easier?
3. What helps you cope with any challenges or difficulties you may face as a parent?

Issues raised by parents were explored further with the aid of probing and follow-up questions.

Interviews were recorded and transcribed verbatim. Transcripts were then analysed using the techniques of thematic analysis (Braun & Clarke, 2006), with the aid of NVivo software for analysing and managing data. Transcripts

were first read in full so as to get an overall sense of data. Themes in the data were identified, informed in part by the focus of questions asked (for example ‘challenges faced’, ‘support resources’), and from what emerged in the data. A list of codes was developed and structured according to themes and subthemes. This was applied to all 20 transcripts, and quotes from the transcripts were selected and assigned to codes. In reporting results, representative quotes are selected to illustrate findings. Data has been anonymized by removing references to people’s names in order to protect confidentiality. The project was given ethical approval by the university’s ethics panel.

RESULTS

Challenges faced

Dealing with challenging behaviours

Almost all of the participants (16 out of 20) cited children’s challenging behaviours as being particularly stressful. Examples given included temper tantrums, repetitive behaviours and aggressive behaviour. Tantrums were described as often being unpredictable and difficult to manage. Some parents stressed how tantrums seemed to them to be atypical, given either the age of the child or the duration of the tantrum. For example a mother stated:

I think it may be when he’s stressed about other things he, so gets really upset and tantrums about things, you know, the full sort of screaming on the floor for half an hour, you know, which for an eight year old is not normal really is it? (Participant 1)

Some parents referred to such tantrums as a frequent occurrence, which at times can feel relentless. For example a mother states:

the tantrums went from zero to sixty in seconds. I mean they just went whoosh! like wild fire. And at one point it was a tantrum all day long with breaks (Participant 19)

Parents of older children reporting tantrums as a feature only of the earlier years. However, parents of older children described their adult children still displaying behaviours atypical in nature, often magnified in response, such as getting upset or angry. For example a mother of an adult child diagnosed with Aspergers, described how her daughter would have hysterics when upset:

She fell over and grazed her knee. She then went in to hysterics, and I had to calm her down, because her knee was bleeding and it was like you were dealing with a 2 year-old (Participant 11)

Other parents referred to challenging behaviours in the form of tantrums and aggressive behaviours at schools. This they related to problems around social interactions. For example a mother stated:

he would gouge children’s eyes out, if he was hanging up his coat at the same time as everybody else (Participant 12)

Such incidents required consultation between parents and the teachers, sometimes in a manner that felt accusatory to parents. Some parents felt that the problem involved bullying

from other children at school. In these cases often parents felt that the school teachers focused too readily on their child as the problem, rather than the bullying behaviour. For example, a father of an adult child diagnosed with autism recalled problems at school:

I suppose in some respects it was a lot easier for the teachers at the time to deal with us and one child then deal with the other 29 children picking on [him]. Which would have meant those 29 and their parents to deal with (Participant 14)

A few parents also spoke about aggression (at times quite violent) which was directed towards siblings and themselves. One couple of an adult child diagnosed with autism described episodes where the violence had escalated to the point police had to be called in to intervene. Another mother of a child diagnosed with high-functioning autism, describes a summer that was particularly challenging where her son became aggressive whilst at home:

[he] would be throwing himself all over the place, and, you know, I didn't want [him] to hurt himself. So I had to restrain him, and used to head-butt me, with the back of his face to my head. And I tried to get out of the way, but, you know, [he] would go on and on and on. Repeat, repeat, repeat. And occasionally I would get one right in the eye (Participant 19)

This mother also described her son as obsessive, using phrases to describe her son as going “on and on and on” about something. This was consistent with reports by other parents, who often attributed the tantrums to being associated with both repetitive behaviours and changes to routine.

Changes to routine

Ten parents cited changes to routine as being a particular challenge, as it resulted in the child's behaviour becoming more difficult, for example ending in tantrums. A typical statement in this regard was:

as long as you are doing things that he understands and is within his; or he wants to do, it its fine and its easy. And its when you get to a problem or task which is different from routine or something he doesn't want to do is where the problems start. (Participant 10)

One mother described how stressful and difficult her son's obsessive and repetitive behaviours were and its impact on everyday life in terms of the limitations it places on any spontaneity. Such that any changes in the normal routine would cause the child to become distraught and often could contribute to the beginnings of new obsession. She stressed the importance of maintaining a routine at all times:

if I don't get [him] on the bus for school, then [he] won't want to go the next day, and then we will have an obsession regarding that. “But I didn't go to school on Tuesday. So I don't go to school on Tuesdays!” It will become - Do you see what I mean? I HAVE to keep the routine. If I let the routine slide, we in trouble, all over again! (Participant 19)

Most parents managed this by planning ahead as much as

possible, and informing the child ahead of time of any changes to routine. Periods of transition and change, for example going to a new school, present particular challenges, as the parent needs to try and prepare the child for the upcoming changes. For example, one mother stated:

it's a change, it's a new school and that's where all the stress is. So there is no excitement for me with [him] starting his school because I am just thinking “oh my God its going to be a nightmare”; I have got to get him in to his new shoes, his new clothes, his new t'shirt and I have had to spend a week just showing him his new uniform, his new pictures of his new school (participant 15)

A few parents (such as the parent quoted above) referred to the use of pictures and picture stories as a useful tool for preparing their child to changes in routine.

Judgements from others

Whilst many of the parents were in agreement that dealing with tantrums was often difficult to manage, most parents regarded public tantrums and the reaction from others as being the most difficult aspect of such challenging behaviour. Eleven parents commented on how the perceived judgements from others were the most gruelling part rather than the behaviour per se. A common perception from the parents was that others tended to judge their children as just “naughty” children, and that they as parents were not effective in their parenting. For example one father said:

if you are out in a shop and something happens and he can have one of his turns, which again is doesn't happen that often, but people look at you and think what are doing? What kind of parent are you? (Participant 17)

Importantly, it was not only cases of parents describing the perception of others but also the more concrete scenarios. For example, parents often discussed incidents or reported that others had expressed comments to them, describing others as “rude”. One mother stated how she finds herself “batteling with public all the time”.

Sensory and social problems

Other challenges associated with child's behaviours which were referred to, included the sensory and social difficulties. Sensory problems associated with noise and touch caused some challenges for parents (mentioned by 6 parents) who had to adapt the environment to suit the needs of the child. One typical example given was the use of ear muffs to reduce the amount of noise that the child experienced.

Their childrens' difficulties with social interactions, was a problem consistently raised by several of the parents (11 out of 20). Their children who were diagnosed with autism found it difficult to relate to others, understand others, or even tolerate the presence of others. Parents described their child as a “loner” or “isolated”, and expressed some concern, even sadness at this difficulty in socialising. For example one mother states:

he's left primary school not really having anyone he's playing with anymore but you know, he's not that bothered. But I kind of worry that he's going to go here and children

are going to start saying to him 'you're weird, you're odd' and he's going to start feeling like there's something wrong with him (Participant 1)

Some parents spoke about the exclusion faced by their child such that they were not invited to birthday parties or other events. However this also interlinked with a negative impact upon the parent's social life, as it could often be problematic for them to have guests in their home. For example one mother stated:

you don't have friends around because you have a son who cannot bear people in the house. Whether they are family members, other family members, or very close friends, other people don't come around because he will make a fuss. He will swear, he will shout, he will get angry (Participant 13)

This may render parents isolated, which was also expressed in how many parents felt unsupported or lacking enough support from others.

Lack of support

Parents referred to their parenting responsibility as consuming of their time. Some parents expressed a sense of exhaustion, with little break. Three parents referred specifically to the difficulty finding a child-minder to look after the child, as the child presented particular challenges that minders were not typically experienced or trained to deal with. This resulted in little respite for the parents. Grandparents were in some cases cited as a resource in this regards, where grandparents could be called on to assist or look after the child for a short period of time. However, this was not always the case and a number of parents described the lack of understanding from grandparents, who did not understand autism and regarded the child's behaviour as a response to bad parenting. For example one mother stated:

His [the child's father] mum said there was nothing wrong with him he is just slow and he, and of many people, and even up to now say there is nothing wrong with him because they want to see some physical disability because you know he looks fine. But they are not there when he is having the tantrums or when he is having his mood swings and when he is going bonkers. (Participant 20)

As with this comment, mothers tended to describe their own parents as more supportive or understanding than the parents-in-law.

Parents also referred to the lack of resources or support from external organisations. This varied between parents, with some parents feeling well-supported by various organisations. Others felt unsupported. There were no clearly identifiable differences in parents' experience of external support depending on location (London or towns in the East of England). A couple of parents attributed their experience of support to their socio-economic circumstances. However, whether there is a "post-code lottery" in terms of resources cannot be substantiated. Some parents referred to lack of information about resources that are available. As one mother stated:

we didn't have any information, we didn't know we could actually go for a statement through the GP or anything. There is no, there's no information at all. You, it's it's all down to you. (participant 6)

The above parent had a child diagnosed with Asperger's and there was some indication that the level of resources and support may vary according to severity of diagnosis with parents of children diagnosed with autism possibly having more resources and support available to them than parents of children diagnosed with Aspergers. For one single parent who was a working mother, she felt that there was not enough support to help her with her son who was diagnosed with autism while she was working. She took the decision in the end not to work, so that she could spend the time taking care of her son. This linked with parents' experience of struggling to find appropriately trained people that could look after their child so that they could get some time to themselves, or get some respite. This may differ with severity of autism.

Parents also expressed deep concern about the dependency of their children on them for care. This posed some anxiety for parents (12 out of 20), particularly for mothers, as they worried about how their children will be able to cope when they are no longer alive or able to look after them. For example a mother explains:

as he gets older I do worry kind of what things will hold for him, you know. When you're a little child, you know, people are understanding of you and what not, but as you get older people, you know, perhaps won't be [pause] and, you know, as an adult or, you know, in years to come, or when I'm gone or [his father is] gone do you know what I mean? Yeah kind of, who'll be there to kind of protect him? (Participant 9)

Impact on family

Twelve parents spoke about the emotional impact that having a child diagnosed with autism has had on them as parents, and as a family. Parents were careful to state love for their child, but it was clear that in many cases there has been a difficult emotional impact on them as a family. This was suggested by 4 mothers who reported having struggled with depression in the past, two of whom were diagnosed with post-natal depression, and one of whom who had felt suicidal during a particularly difficult period in her life as a single mother. One couple spoke of significant health problems that they attributed to stress.

Some parents described feelings of desperation. One mother referred to her experience as a parent and how "it consumes you". Another mother spoke about how at times she feels like a "failure as a parent". A single mother having to cope on her own with a young child, describes her time of despair:

I have been a total wreck crying everywhere. I have been walking down the road crying. You know I used to dread the school holidays (Participant 20)

Another couple of an adult child with autism spoke emotionally of the isolation and desperation that they have experienced, with others having little understanding of what

their experiences has been. She describes:

You feel really really on your own as if that's it, theres never going to be any thing else. You are going to get no help, no support. This is your life. Its (pause) I can only explain it, its like being a beaten wife but you are not you are a beaten mum. That same thing. It's domestic abuse, its domestic violence. That same feeling, that stress. And you are shattered and you are tired and you don't want to get up again. And god forbid, there are times when you wished you had not even had that child because of the strains it puts on you (Participant 13)

As well as the impact on themselves, thirteen parents were also concerned about any possible negative impact on siblings. Parents were concerned that they, by necessity, were more neglectful of their other children. They felt that the other children became jealous or upset about this. For example a father stated:

our children do get quite jealous the fact that [he] gets more attention and favouritism than they do. He doesn't get told off for doing certain things that they certainly would do, but they wont understand that he doesn't understand (Participant 10)

Some parents spoke about how in general the siblings have a reasonable relationship with the child diagnosed with autism, and were understanding, even protective. However, other parents spoke about how the other children are “embarrassed” about the behaviour of their brother or sister. For example one parent described how her daughter was “embarrassed” and “mortified” by her brother who was diagnosed with autism, she goes on to say:

she would be like standing away from us or she would be crying herself but I would say to her 'you know you have to understand that he has autism' and you know she gets left out as all the attention is always on him (Participant 20)

Coping and support

Some parents spoke about how the challenges became easier to deal with over time, as parents learnt how to respond to challenging behaviours or the severity of challenging behaviours (particularly tantrums) diminished as the child got older. Parents also spoke of how their experiences with their child was not always challenging and there were equally moments that were rewarding and uplifting, for example when their child achieved something or a milestone was reached.

Nine parents spoke about how the support of other parents of children diagnosed with autism was an important and valued source of support. Given that so many parents found the judgements and lack of understanding from others difficult, other parents who are experiencing similar issues, provided a source of understanding, support and advice. For example a father stated:

it's a relief to see that there are other people and until you get to that point when you are with other people in your situation who you can talk to about the same sort of things; and that understand, you know, what difficulties you

have (Participant 10)

What parents found particularly helpful, is that ideas and strategies for coping and dealing with challenges could be shared. Parents also made comparisons to the children of other parents. Seven parents commented on how they felt fortunate that their child was not “as disabled” or “as bad” as other children with more severe disabilities. Some parents for example commented on how their child was affectionate and enjoyed cuddles, which they felt fortunate about when comparing to children diagnosed with autism who do not like to be touched or cuddled. One mother commented:

those woman who have a child who is so badly developmentally delayed, and it goes on for the rest of their life, I don't know. It must tear them to shreds. I mean I can be proud of the things that [daughter] has accomplished. And when she does get something, that can be good. But when your child is so developmentally delayed that your whole life – I can have a bit of life to myself. I am conscious how lucky I am (Participant 11)

This can be considered as a strategy for coping, as the comparison to others helps create a sense that the difficulties and challenges faced are not as bad as could be.

Nine participants talked about organisations and professionals who had been very helpful and supportive. Parents who tended to describe schools as unsupportive or lacking in understanding tended to refer to previous “mainstream” schools, who may not have had an understanding or expertise of educating children diagnosed with autism. Once the parents had managed to get their child into a school that had learning support for learners with special education needs, they felt that the school was an invaluable source of support. Parents described such schools as “brilliant” and “fantastic”. Some parents also mentioned organisations such as the National Autistic Society, Mencap and Mind as very helpful source of information and support. Parents also described professionals, such as psychologists and pediatricians as very helpful. This however was not consistent as parents also spoke about lack of resources and support (discussed above).

DISCUSSION AND CONCLUSION

Participants spoke at length about the various challenges they faced being a parent of a child with autism. The majority alluded to how stressful the child's challenging behaviour was for them. This mostly included tantrums as a result of the child's difficulty coping with changes to routine and sensory difficulties. However, it was raised that potentially the most difficult part for them was in fact the social implications of their child's behaviour, both their child's lack of social responsiveness and its impact on them socially. For example, many raised concerns about their children's inability to cope in social situations mirroring that of previous studies (Davis and Carter, 2008; Beck, Hastings and Daley, 2004).

Many parents had learnt ways to deal with or just accept challenging behaviour, but the lack of understanding and even judgements from others often proved the most difficult for parents. This left them feeling judged as ‘bad’ parents or feeling like a failure. Another social implication for parents was the difficulty in finding adequate support, as there

seemed to be few resources that parents could draw on where people were understanding or trained to deal with the challenging behaviours of their child. Many parents then experience some degree of social isolation. An important source of support appeared to be the contact with other parents of children with autism. Through this contact, parents could compare with the experiences of other parents and learn from their successes. This contact also allowed the opportunity to compare their child to the child of other parents, and in some cases make a downward comparison that made them feel more fortunate. The use of social comparison as a means of coping was also found in a recent study of parents of children with Duchenne Muscular Dystrophy (Hodges and Dibb, 2010), although it was highlighted how this social comparison may also be unhelpful as it may elicit negative feelings of frustration or threat.

Although a weakness of qualitative studies is its limited generalizability, the findings do allow us to get a subjective account of parents' experiences, and how they cope with stresses, which can be an indication of shared experiences. This is supported by findings from other research that establishes the stressful nature of caring for a child with autism (e.g. Ingersoll and Hambrick, 2011). It also allows us to get a sense of, not only that challenging behaviours are stressful for parents but rather *what* it is about such behaviours that are the most difficult to cope with. The lack of understanding and support of the lay public, extended family, and even some professionals seem a key stressful component of the challenging behaviour.

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