

Autistic parents' views and experiences of talking about autism with their autistic children

Autism
2021, Vol. 25(4) 1161–1167
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DOI: 10.1177/1362361320981317
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Abstract

Little is known about how parents talk about autism with their autistic children, particularly among families in which both a parent and child are autistic. Using an online survey, we gathered quantitative and qualitative data from 34 autistic parents (most of whom had told their children about their diagnosis) to address this knowledge gap. There was considerable overlap between the views and experiences of the autistic parents in this study and the largely non-autistic parent samples in previous research. Specifically, parents emphasised the importance of being open and honest about the diagnosis, disclosing the diagnosis as early as possible, individualising discussions to children's needs and framing the diagnosis positively. There were, however, areas in which the views and experiences of the current sample differed from previous research on non-autistic samples. First, our sample of autistic parents outlined the benefits of their own experiential expertise, which they felt resulted in heightened understanding and empathy with their children. Second, our sample tended not to express concerns about disclosure potentially having a negative impact. Finally, our participants did not express a want or need for professional support with disclosure. Instead, they reported feeling well equipped to support their children using their own knowledge and lived experience.

Lay abstract

Previous research examining how parents talk about autism with their children has tended to focus on parents who are not autistic themselves. We collected information on this topic from 34 autistic parents of autistic children (most of whom had told their children about their diagnosis). We found similarities, but also differences, between the views and experiences of autistic parents in this research and those reported in previous research (in studies of largely non-autistic parents). Similarities include the following: it is important to be open and honest about the diagnosis; the diagnosis should be introduced/discussed as early as possible; discussions should be tailored to each individual child's needs; and we should not overlook the challenges associated with autism, but it is important to focus on positive aspects too. Differences include the following: autistic parents used personal experiences in conversations about autism, which was felt to result in increased understanding and empathy with their children; autistic parents overwhelmingly focused on more positive aspects of an autism diagnosis; our sample did not express concerns that discussions could have negative consequences too (e.g. making children more anxious); and autistic parents did not want or need professional support to talk about autism with their children (instead, they felt confident in using their own knowledge/experiences to guide discussions).

Keywords

autism spectrum disorders, diagnosis, disclosure, family functioning and support, parents

There has been limited research on parents' decisions to disclose their children's autism diagnosis to them (see Smith et al., 2018). In one of the largest studies on this topic, Crane et al. (2019) used an online survey to elicit the views and experiences of 558 parents in the United Kingdom (UK). Just over two-thirds (68%) of parents had told their children about their autism diagnosis. Of

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those who had not disclosed, the majority planned to do so in the future. Despite few parents receiving support or guidance about disclosing an autism diagnosis to their children, those who had disclosed tended to be satisfied with the process and felt confident in talking to their children about being autistic. Parents highlighted the importance of openness and honesty when talking about autism, as well as the need to tailor discussions to individual children's needs (also see Smith et al., 2019). Furthermore, parents mentioned challenges and concerns about such discussions, including expressing fears it could lead to bullying or stigma from peers or an increase in their children's anxiety (see also Smith et al., 2018). Parents expressed a desire for greater input from professionals to ensure that the disclosure was a positive experience and was framed in a way that their children would understand.

This research provided important insights into parents' experiences of talking about autism with their children, yet the majority of Crane et al.'s (2019) participants were not autistic themselves ($n = 451$, 80.8%). It has been well-documented that family members of autistic people have elevated rates of sub-clinical autistic characteristics (the 'broader autism phenotype') (see Rubenstein & Chawla, 2018) and possibly undiagnosed autism (Pohl et al., 2020). Indeed, a child's diagnosis can sometimes act as a precursor to diagnosis for a parent, facilitating the realisation that they may be on the autistic spectrum and could benefit from a formal diagnostic assessment themselves (e.g. Crane et al., 2018). While Crane et al. (2019) included the perspectives of autistic parents within their online survey sample, data from these parents were neither examined as a discrete group nor did the survey permit a detailed exploration of their family circumstances and if/how being autistic themselves influenced the way they discussed autism within their families. This is important, since close connections between autistic family members (e.g. in feeling better understood; Crompton et al., 2020) and the benefits of autistic-led support (e.g. in promoting a positive autistic self-identity; Crane et al., 2020) have been well-documented. Yet there has been limited research on autistic experiences of parenthood and, to our knowledge, none focusing on their experiences of talking about autism with their children.

The aim of this research was to investigate autistic parents' views and experiences of talking about autism with their autistic children. Specific aims were to (1) identify whether autistic parents disclosed their children's diagnoses to them and, if so, how; (2) determine parental satisfaction with diagnostic disclosure and any support they have received, or would like to have received; and (3) understand better the nature of discussions about autism within families.

Method

Participants

An online questionnaire was advertised to autistic parents in the United Kingdom (UK) who had at least one autistic child. We limited our sample to the United Kingdom due to differences across countries in terms of diagnostic and support services and general attitudes towards autism. We employed opportunity sampling via social media platforms, targeting organisations for autistic people but also parent support groups. In total, 119 people engaged with the survey and 85 (71.4%) cases were removed during data cleaning. Fifty-seven of these cases were ineligible: 36 parents (30.3%) were not autistic, 4 (3.4%) did not have at least one child on the autism spectrum, and 17 (14.3%) were not UK residents. A further 17 cases (14.3%) did not complete any questions and a further 11 cases (9.2%) completed demographic questions only.¹

Data from 34 autistic parents were included in analyses. As shown in Table 1, our participants tended to be females (88.2%), formally diagnosed as autistic (79.4%) and from white ethnic backgrounds (94.1%). The characteristics of their children are presented in Table 1. Parents who had more than one autistic child were asked to respond to the survey in relation to their oldest autistic child. Most of our participants' children were male (61.8%), educated in mainstream schools (79.4%), and, on average, received an autism diagnosis at the age of 8 years.

Materials

The online survey was adapted from that developed by Crane et al. (2019). It comprised six sections, featuring both open and closed questions (with additional open-text boxes provided throughout to enable participants to expand on their responses to the closed questions). Sections 1–3 used closed questions to collect information about the parents, their families and their autistic children: to characterise our sample and establish whether parents had disclosed their own diagnosis to their children (response options: 'yes', 'no' and 'it's complicated'). Section 4 established whether the parents had disclosed their children's autism diagnosis to them (response options: 'yes, I told them', 'yes, someone else told them', 'yes, I think they know but I haven't actually told them' or 'no, they do not know/do not understand'). If their children knew they were autistic, parents were then asked about their satisfaction with the diagnostic disclosure (on a five-point scale), and were asked whether there were any particularly positive/helpful or negative/unhelpful aspects of these discussions (via open questions). Section 5 centred on support regarding disclosure, asking parents if they had received any support (response options: 'yes' or 'no'). If parents had received support, they were asked to rate their satisfaction with this support (on a five-point scale). If they had not, they were asked whether they would

Table 1. Parent and child characteristics ($n = 34$).

Characteristics			
Parent data	Age (years)	Mean (SD)	42.12 (6.81)
		Range	27–55
	Gender	Male	2 (5.9%)
		Female	30 (88.2%)
		Non-binary	2 (5.9%)
	Autism diagnosis	Yes	27 (79.4%)
		No, I self-identify as autistic	7 (20.6%)
	Ethnicity	White (including British, Irish or any other White background)	32 (94.1%)
		Mixed (e.g. White and Black Caribbean/African, White and Asian or any other Mixed background)	1 (2.9%)
		Prefer not to say	1 (2.9%)
	Number of children in household	Mean (SD)	2.34 (1.19)
		Range	1 to 7+
	Number of autistic children	1	20 (58.8%)
2		11 (32.4%)	
3		3 (8.8%)	
Child data	Gender	Male	21 (61.8%)
		Female	11 (32.4%)
		Other gender	2 (5.9%)
	Age at diagnosis (in years)	Mean (SD)	8.26 (3.74)
		Range	2–16
	Age at time of study (in years)	Mean (SD)	11.53 (3.87)
		Range	3–18
	Diagnosis	Autism	7 (20.6%)
		Autism spectrum disorder/condition	17 (50.0%)
		Asperger's syndrome/disorder/high-functioning autism	6 (17.6%)
		Pathological demand avoidance (PDA)	1 (2.9%)
		Self-identified	3 (8.8%)
	Other diagnoses	None	12 (35.3%)
		Physical disability	6 (17.7%)
		Behavioural condition	5 (14.7%)
		Affective condition	11 (32.4%)
		Learning disability	4 (11.8%)
Parent-reported language	Other	6 (17.7%)	
	Language use is completely typical	15 (44.1%)	
	Difficulties mainly with 'pragmatic' (i.e., social) language	18 (52.9%)	
Education	Little or no spoken language	1 (2.9%)	
	Mainstream	27 (79.4%)	
	Special school/unit	3 (8.8%)	
	Not applicable/other	4 (11.8%)	

SD: standard deviation.

have found this useful (response options: 'yes', 'maybe' and 'no'). Section 6 focused on day-to-day conversations about autism. If parents discussed autism with their children, they were asked to share (via an open question) what they tend to talk about, providing an example if easier. Participants were then asked about the terminology they tended to use when discussing autism (e.g. 'autistic', 'has autism'), selecting options adapted from Kenny et al. (2016). A series of open-ended questions followed, asking participants to explain: any particularly positive aspects of discussions with their

children; anything that they felt could have been done better/differently; if/how their experience as an autistic person has influenced the way they talk to their children about autism; and any advice they would give to other parents (autistic or non-autistic) when discussing autism with their autistic children. Finally, participants were given the opportunity to add anything further that they felt was pertinent regarding discussions about autism within their families (via an open-text box). [see Supplementary material for a copy of the survey.]

Table 2. Parental experiences of disclosing an autism diagnosis to their children.

		Yes (<i>n</i> = 32, 94.0%)			No (<i>n</i> = 2, 5.9%)
		I told them (<i>n</i> = 29, 85.3%)	Someone else told them (<i>n</i> = 2, 5.9%)	I think they know (<i>n</i> = 1, 2.9%)	
Satisfaction with diagnostic disclosure	Satisfied	21 (72.4%)	1 (50%)	0 (0%)	n/a
	Neither satisfied nor dissatisfied	6 (20.7%)	0 (0%)	1 (100%)	n/a
	Dissatisfied	2 (6.9%)	1 (50%)	0 (0%)	n/a
Received support?	Yes	3 (10.3%)	0 (0%)	0 (0%)	0 (0%)
	No	26 (89.7%)	2 (100%)	1 (100%)	2 (100%)
Usefulness of support	Useful	3 (100%)	0 (0%)	0 (0%)	n/a
	Not useful	0 (0%)	0 (0%)	0 (0%)	n/a
Desire for support?	Yes	3 (12%)	0 (0%)	0 (0%)	0 (0%)
	Maybe	7 (28%)	1 (50%)	0 (0%)	0 (0%)
	No	15 (60%)	1 (50%)	1 (100%)	2 (100%)

Procedure

Ethical approval was obtained from the Department of Psychology and Human Development at UCL Institute of Education. The survey (powered by Qualtrics) was open for 8 weeks, between May and June 2019.

Data analysis

Quantitative data are presented descriptively (providing total numbers and percentages). Qualitative data (collected throughout, and at the end of, the survey) were analysed within an essentialist framework (reporting the experiences, meaning and realities of the participants), using thematic analysis (Braun & Clarke, 2006, 2019). Specifically, one researcher (J.D.) familiarised themselves with these data, reading and re-reading survey responses while identifying patterns. Then, extracts of these data were assigned ‘codes’, which were organised into broader analytical themes. An inductive or ‘bottom-up’ approach was used to generate the themes, meaning that they were generated in response to the data, as opposed to trying to fit them into pre-defined themes; an approach aligned with the exploratory nature of the work. Themes were identified at a semantic (rather than a latent) level (i.e. without making assumptions regarding the wider structures or theories that may have shaped participants’ responses). Themes were then reviewed by J.D., in collaboration with L.C. and E.P., merging or separating them as required, and ensuring that there was internal coherence within a theme and strong distinctions between themes.

Results

Quantitative data

Diagnostic disclosure. As detailed in Table 2, the majority of parents (*n* = 32, 94%) had disclosed their child’s autism diagnosis to them, with many themselves telling their

children about their diagnosis. Over half of parents were satisfied with the way the diagnosis was disclosed. Parents who received support on the diagnostic disclosure found the support useful, yet most parents did not receive any support in this regard (nor did they want it). When asked whether children knew about parents’ diagnoses, 25 (73.5%) did, two (5.9%) did not and seven (20.6%) said ‘it’s complicated’.

Autism terminology. When presented with a list of terms used to talk about autism within the family, the three most commonly selected terms (not mutually exclusive) were autistic (*n* = 19, 73.1%), on the autistic spectrum (*n* = 7, 26.9%) and Aspie (*n* = 6, 23.1%; data from eight parents were missing). No autistic parents in this sample reported using person-first language (i.e. person with autism).

Qualitative results

We identified four themes in the open-ended data: (1) open, honest discussions about being autistic are part of our everyday lives; (2) shared understanding: ‘I tell them I get it’; (3) discussions should be framed positively; and (4) tailoring discussions to children’s specific needs.

Theme 1: open, honest discussions about being autistic are part of our everyday lives

Parents emphasised how their children had ‘the right to know’ (Participant 16; henceforth P16) about their diagnosis so they ‘understand why [they] behave the way [they] do’ (P23). While some parents were cautious about telling their child about their diagnosis at a young age in case they ‘wouldn’t understand’ (P12), many felt it was important to tell them early on: ‘I’m so glad I told him when he was young rather than waiting for some time he was “ready”’ (P25). Parents explained that this gave them ample time to discuss the diagnosis, starting from a blank slate: ‘If you

start when they are young, they have no baggage and are coming to the concept totally fresh. So you can frame it how you want' (P25).

Parents that chose to disclose their own autism diagnosis highlighted the importance of being 'transparent', both about their own diagnosis: 'I am very open about being autistic' (P30); and their child's diagnosis: 'I am always open and honest about her neurology, she is wonderful and there is no need to hide that' (P24). Parents believed that this honesty empowered their children, providing 'an explanation for why he struggled' (P7) and bolstering mental health: 'they are much happier now they have some understanding' (P29). Parents explained that talking about autism was not a one-off event, but part of their everyday dialogue: 'we talk about it all the time' (P16). They added that these discussions were often not planned: 'we don't need to have big or heavy discussions about it very often' (P21); but were guided by their children: 'My son asked us questions but wasn't pushed to ask any' (P21).

Parents who chose not to disclose their own diagnosis or had more complicated circumstances also reported value in having an open dialogue with their children:

While I don't feel able to speak of autism directly . . . I find other ways to discuss autistic difficulties. I am very open about my own difficulties and spend a lot of time modelling that it's ok to not cope with some things (P13).

Theme 2: shared understandings: 'I tell them I get it'

Parents spoke of how they used their own lived experiences to guide their discussions: 'I tell them I get it and give personal examples of my struggles and the strategies I've used' (P16); reporting that this created a sense of shared understanding: 'we can talk about stuff neurotypicals just don't get or understand' (P23). Parents added that conversations about autism were often light-hearted and involved humour: 'Many families joke about it like "oops, I was being extra autistic when I took that thing literally, huh!?"' (P13). Together, they explained how this contributed towards a comfortable dialogue surrounding the diagnosis: 'We understand each other. . . which certainly helps to build trust and keep communication lines open so even the most difficult things can be discussed' (P34). Parents also felt that their own diagnosis gave them a better basis for discussion than professionals: 'We are all autistic [in our family] and probably know more about how to live and deal with it than the professionals doing the diagnosis' (P20).

Theme 3: positively supporting children to make sense of themselves as 'different'

Participants reported viewing autism as a 'difference' and felt 'negative language such as "disorder" was unhelpful' (P21). They noted how they used the idea of 'difference' to help guide discussions with their children, highlighting

that it is okay to be different to others: '[I] explain that everyone's brain works differently and not everyone thinks the same. . . Different brains think differently which is what makes the world so interesting and people so clever in different ways' (P30). Parents also emphasised (both implicitly and explicitly) the concept of neurodiversity: 'I try and talk about the differences between us so he understands people are different and that is normal' (P25). Parents discussed the importance of focusing on their children's strengths and encouraging them to 'look at themselves in a positive light' (P12). Parents added that this did not mean overlooking challenges, but framing these in a positive way: 'It is mostly all positive and when it is not, we look at how we can find something positive out of a bad situation' (P12). Parents highlighted the importance of autistic role models in supporting this process: 'He likes science, so comparing [him] to Einstein and other scientists made him feel good about himself despite the difficulties of a big and busy brain' (P34).

Theme 4: tailoring discussions to children's specific needs

Parents commented that discussions should be 'tailored' and 'relevant' to their children's own interests and experiences: 'Whatever you use/however you speak to them/about them, I believe it needs to be relevant to them, something they can relate to' (P34). Parents added that language should also be adjusted according to their children's understanding and preferences: 'People should not get hung up on terms and should use what the young person prefers' (P11). Similarly, parents emphasised how discussions should be 'age appropriate', that is, 'Find and use appropriate resources that explain autism in an age appropriate way, that highlights traits that are true for your child' (P34) and, where possible, child-led: 'My son would talk openly to me about his difficulties and I would support him accordingly' (P3).

Discussion

This study is, to our knowledge, the first to focus exclusively on autistic parents' views and experiences of talking about autism with their autistic children. Overall, there was considerable overlap between the views and experiences of the autistic parents in this study and the largely non-autistic parent sample in previous research (e.g. Crane et al., 2019; Smith et al., 2018) as well as published guidance for talking about autism within families (see Smith et al., 2019). Parents emphasised the importance of being open and honest about the diagnosis, disclosing the diagnosis as early as possible, individualising discussions to meet the needs of the specific child, and ensuring discussions focus on framing the diagnosis as positively as possible. These general areas of good practice will be useful for parents and/or professionals who are involved in disclosing an autism diagnosis to children (see also Smith et al., 2019).

There were, however, key areas in which the views and experiences of the current sample differed from previous research on largely non-autistic samples. First, our sample of autistic parents noted the benefits of their own experiential expertise and felt this resulted in heightened understanding and empathy with their children. This aligns with research on interactions with autistic family and friends more broadly, highlighting how enhanced understanding and empathy among autistic people results in them feeling more comfortable and at ease (Crompton et al., 2020). Second, autistic parents in this study tended not to express concerns about disclosure potentially having a negative impact (as per Crane et al., 2019; Smith et al., 2018). Instead, they focused on helping their child to make sense of themselves and their differences in a positive way. Together, these factors may result in the third key area of divergence: that many of our autistic parents did not express a want or need for professional support with diagnostic disclosure (cf. Crane et al., 2019; Smith et al., 2018). Instead, they felt well equipped to support their children using their own knowledge and lived experiences.

Recent research has reported the challenges autistic mothers experience in communicating with (non-autistic) professionals regarding their autistic children: noting how they feel misunderstood and that they struggle to know what information to share, leading to anxiety and conflict (Pohl et al., 2020). Autism professionals rarely share experiential/insider expertise (though see Moore et al., 2020) and encounters with professionals (e.g. during the diagnostic process) tend to focus on the negative (rather than positive) aspects of autism, even when professionals make a conscious effort to focus on a person's strengths (Crane et al., 2018). Importantly, our sample of parents emphasised that they did not intend to overlook the more challenging aspects of autism when talking with their children, but were conscious of the need to be sensitive in how they framed these challenges – an approach very much aligned with the neurodiversity movement (see Kapp, 2020). Since having a positive autistic self-identity is related to better mental health outcomes (Cooper et al., 2017), autistic parents could play a crucial role in the design and development of neurodiversity-based psycho-education programmes for autistic children and parents.

This study is not without its limitations. First, our sample of autistic parents, which largely comprised females from white ethnic backgrounds, was not representative of the broader UK population – as is the case with most online survey research with the autistic community (e.g. Crane et al., 2019). Second, we recruited our sample largely via autistic organisations, which may have biased our sample towards those who were more accepting of their autistic identity, and thus engaged in more positive discussions about autism with their children. Third, we did not determine whether other family members (e.g. another parent) were autistic, neither did we determine the relationship between parent and child (e.g. biological, foster

and adoptive); all of which may have influenced the way autism was discussed within the family.

Nevertheless, this research is, to our knowledge, the first to exclusively examine autistic parents' views and experiences of talking about autism with their children. While these results align with previous research on largely non-autistic samples (e.g. Crane et al., 2019; Smith et al., 2018), and reinforce several key recommendations about how best to discuss autism with autistic children for autistic people (e.g. Smith et al., 2019), they also uniquely highlight the benefits of autistic parents' experiential expertise when engaging in discussions about autism. Growing up in family environments that are particularly accepting of difference and foster a positive sense of self-worth may well serve to guard against poor outcomes later in life for autistic people (e.g. with respect to mental health) and is a worthy avenue for future research.

Acknowledgements

We would like to thank the autistic parents who took part in this research, as well as the small group of autistic parents who reviewed an early version of the survey and provided really helpful feedback.


Funding

The author(s) disclosed receipt of the following financial support for the research, authorship and/or publication of this article: Research at the Centre for Research in Autism and Education (CRAE) is generously funded by the Pears Foundation.

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Supplemental material

Supplemental material for this article is available online.

Note

1. While there appears to be a large amount of excluded data, it should be emphasised that the majority of those who were excluded were actually not eligible to complete our survey: either because they were not autistic themselves or because they did not have an autistic child. Anecdotally, during recruitment, we noted that there was some confusion with our request for 'autistic parents of autistic children', with some people focusing on 'autistic parents' or 'parents of autistic children', but not the specific combination of these that we were looking for in this study.

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