Impact of challenging behaviour on siblings of people with Autism

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Abstract

Purpose – Despite being largely supportive of their sibling with an autism spectrum disorder (ASD), some siblings without ASD also feel the effects of the disorder particularly in relation to challenging behaviour and lack of empathy. The purpose of this paper is to explore the experiences adults who have a sibling with ASD and intellectual disability (ID) with challenging behaviour.

Design/methodology/approach – Interviews were conducted with 11 capacitous adult siblings of service users who have ASD and ID as well as a history of challenging behaviour. A modified version of the autism Parenting Stress Index was used to assess the impact on those siblings. thematic analysis was utilised to analyse their responses.

Findings – Four main themes emerged from the interviews, which highlighted that challenging behaviour can cause emotional losses and can impact upbringing and the sibling relationship. Despite the siblings making adjustments, they continue to have concerns for the future.

Originality/value – Chronic challenging behaviour can impact on siblings, and it is important to support entire families, and not exclusively parents.

Keywords Intellectual disability, Impact, Challenging behaviour, Autism, Family supports, Siblings

Paper type Research paper

Introduction

Emerson (1995) defines challenging behaviour as “culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities”.

Prevalence

Prevalence studies that have looked at a wide range of challenging behaviours have indicated that such behaviours often coexist and that sizeable minority of people with intellectual disabilities (ID) show severe and multiple forms of challenging behaviour (British Psychological Society, 2004).

Prevalence of challenging behaviour was examined in the total population of people with ID in the UK (Emerson et al., 2001). The authors took their sample from a range of environments; residential facilities, village communities, day services, adult placement services, nurseries, special schools and peripatetic support teams. They found that challenging behaviours were shown by 10–15 per cent of people with ID. Similar prevalence levels were found by in Scotland (Cooper et al., 2009) and in North America (Borthwick-Duffy, 1994).

Impact

Challenging behaviour can both impact on the quality of life of the person exhibiting the behaviour and present difficulties for carers (Emerson, 1995). Doubet and Ostrosky (2015) report four key areas of impact on families.
Choosing activities. The parents surveyed discussed how having a child who is engaged in challenging behaviour changed typical and planned family activities.

Siblings. Parents reported that their attempts to help other children understand their absences from sibling extracurricular activities were compounded by the knowledge that despite the sibling understanding, they still wished they could be there.

Increase in family stress. At home, parents reported that the pressure of repeat incidents of behaviour impacted on their stress levels and that of other family members.

Questioning parental competence. The final theme in the research was that parents reported diminished feelings of competence in relation to their parenting approaches.

Siblings show less satisfaction with their sibling relationship in adolescence, as peer relationships become more important and there is less contact with siblings (Cicirelli, 1994). During adult years, sibling relationships increase in satisfaction and contact (Cicirelli, 1994).

In a study by Orsmond et al. (2009), the authors found that despite decreased contact with their siblings, adult siblings reported the same degree of positive effect in the relationship as adolescent siblings which suggests there may be a stability over time in the closeness of the sibling relationship when one has an autistic spectrum disorder (ASD).

While closeness in relationships between siblings where one has an ASD seems to be stable over time, the sibling relationship can have an effect on the sibling with no ASD. It is apparent that, despite their largely supportive attitude towards their sibling with an ASD, some of the non-autism spectrum disorder (NASD) (or neurotypical) brothers and sisters of those siblings also feel the effects of the disorder due to challenging behaviour and impaired empathy exhibited by their siblings (Hastings, 2003). Some evidence would suggest that NASD children and adolescents who have a sibling with an ASD are more likely to be distressed than their peers whose siblings do not have an ASD diagnosis (Hastings, 2003).

The effects of having a sibling with ASD can also have effects on the NASD siblings’ role in adulthood. Siblings with ASD become more reliant on their non-disabled siblings in later life (Davys et al., 2011). While research suggests there is a willingness to assume the role of primary support for the sibling with ASD (especially among sisters), this can be emotionally taxing for non-disabled siblings as they “worry for the future” as well as struggle to manage other competing demands with this new responsibility such as careers, children and aging parents (Davys et al., 2011).

Gender can influence the feeling of responsibility for the sibling with ASD as female NASD individuals reported their lives were more influenced by their sibling with an ASD than male NASD individuals reported (Hastings, 2003). There is also some evidence that NASD sisters of a sibling with an ASD are significantly more anxious and depressed than NASD brothers of a sibling with an ASD (Orsmond and Seltzer, 2009).

Hastings (2003) reported that the impact of autism on younger siblings and from a male sibling was more severe. Even within the ID population, challenging behaviour exhibited by those with ASD has more impact on siblings than other subgroups. For example, siblings of individuals with down syndrome seem to fare better than those who are siblings of individuals with autism. Compared with siblings of brothers/sisters with autism, siblings of brothers/sisters with down syndrome showed closer, warmer sibling relationships, along with slightly better health and lower levels of symptoms of depression (Urbano and Hodapp, 2007).

Much of the research is applied to child studies. There is limited research on adults’ reflections on growing up with a sibling with ASD; therefore, literature is limited on the opinions and needs of adult siblings of brothers/sisters with ASD and this is why this research is so important.

Study aims

This study set out to gain the perspectives of siblings of individuals with ASD and ID and to learn about how their experiences growing up have impacted them. In particular, the impact of challenging behaviour on siblings was explored.
Methodology

Design

Prior to interviewing the participants, ethical approval was obtained from the research ethics committee for Brothers of Charity, a community service for people with intellectual disabilities in the West of Ireland.

A qualitative approach using in-depth interviewing was chosen as it is less likely to constrain the material that participants contribute to the project. However, as part of the process of development, we modified and used the autism Parenting Stress Index (Silva and Schalock, 2012) to assist us in identifying areas of enquiry and in devising prompts for the interviews. The interview questions were as follows:

- Tell me about who is in your family.
- Overall how would you describe growing up in your family?
- What have been the happiest moments of growing up in the family?
- Who in your family has autism?
- Is x different from other people socially? If so how and does this affect you?
- Is x’s communication different from other people socially? If so how and does this affect you?
- Does x have tantrums/meltdowns? If so how and does this affect you?
- Does x have aggressive behaviour? If so how and does this affect you?
- Does x have self-injurious behaviour? If so how and does this affect you?
- Does x have difficulty making transitions from one activity to another? If so how and does this affect you?
- Does x have sleep problems? If so how and does this affect you?
- Does x have problems with his diet? If so how and does this affect you?
- How close are you and x? Tell me more about this.
- What is your prediction for x’s future? Tell me more about this.
- What help do you think x and the family need to do well in the future? Who do you think should provide this?
- Do you have any questions for me?

We used an iterative approach to develop our interview (Srivastava and Hopwood, 2009). The interview was piloted on the first two participants from each of the three interviewers. As anticipated, some small adjustments were made to the interview questions, for example:

- There needed to be more focus on getting relevant information without leading participants.
- There needed to be a comment before “what were the happiest moments growing up?”
- For each specific question, for example, “socially different”, “communication difficulty”, etc., it was necessary to seek both positive and negative examples.
- We replaced “tantrums/meltdowns” with “Can you remember a time when s/he was very distressed”.
- Before asking about what supports might be useful, we needed to first ask “what supports have you received to help you to live with XXX […]”.

The 11 interviews were carried out by a consultant psychiatrist (4), a senior clinical psychologist (3) and a then psychologist in clinical training (4). Participants were able to conclude the interview whenever they wanted and were offered further support at the end of the interview. They were given contact details for the interviewer in case they have any queries at a later date.
Interviews, which lasted 40 minutes on average (range 20–60), were transcribed verbatim before analysis. Once the data analysis was completed, a triangulation and feedback meeting was offered to the participants and three siblings attended.

**Participants**

Participants were capacitious adult siblings of service users with ASD and ID known to the Brothers of Charity Galway service who present with challenging behaviour, and where the sibling:

1. still lives at home either full time or when not attending term time further education; and
2. left the family home within the last year.

Also, participants were included where their sibling either lives at home full time with or without respite access or has moved out (e.g. to supported accommodation) but spends five days or more per month at the family home. This was to ensure that all interviewees were familiar with their siblings’ current behaviour patterns whilst giving informed consent to discussing current and previous behaviour patterns.

Child siblings were excluded as the interview process may be stressful for a child. We consulted with multidisciplinary team (MDT) members supporting the family prior to inviting siblings to participate but did not interview staff. Where siblings did not have the capacity to take part in the research, they were excluded. We consulted with MDT staff supporting the families to help us decide whether siblings meet our inclusion and exclusion criteria.

After potential interviewees were contacted by the professional involved, they were given at least 24 hours to reflect before being approached to give consent. To increase the reach of the study (Ely et al., 1991), we purposively recruited participants whose siblings had a range of functional abilities, ages, backgrounds and challenging behaviours. The final sample size was determined by continuing to interview participants until the data became “saturated” (Lincoln and Guba, 1985) and little new information emerged during coding. In previous qualitative projects, we have worked on, a total of 10–15 interviews were sufficient to saturate data.

**Data analysis and storage**

Thematic analysis (Braun and Clarke, 2006) suits questions related to people’s experiences, views and perception, and this approach was adopted to analyse the interview transcripts. Specifically, inductive thematic analysis was utilised, where the coding and theme development are directed by the content of the data. Patterns of meaning were identified through a rigorous process of data familiarisation, data coding, and theme development and revision.

We will store data for the period specified by the ethics committee, which is ten years. All data are stored at the community ID team electronic files, and only the researchers have access to it. Community ID team database has data protection registration, and we ensured that we complied with Data Protection Act guidance.

**Ethics and consent**

All sibling responses remain anonymous. All those interviewed were adults who can provide informed consent. Before commencing the project, Ethics Committee approval was sought and granted from the Brothers of Charity Galway.

**Findings**

Using thematic analysis method, we identified four consistent themes. The quotes from various participants are organised under these themes below and a narrative and model are suggested at the end.
Differences – gains and losses

The losses in people’s lives are identified as “being different” where the sibling with ASD often dictates both the mood and activities in the home. This involved not doing things other families do especially in relation to social interaction.

A number of siblings described the family mood being dictated by the ASD siblings’ behaviour, for example, when describing happy times “I suppose when we’re all together and when A was in good form” (P1).

The siblings also noted that compromises and sacrifices were necessary in order to get by “It would have been B first. Which I think my sister and me accepted. I don’t think we begrudged it […] in one way, he’s not independent. We are and sometimes that’s the price you have to pay” (P2).

One prevalent difference they noted was what might be described as a state of hypervigilance in the house “I think that it probably did impact you know. Although we had a standard upbringing […] you would have higher levels of anxiety, than you know other kids” and “having to keep everything secure in the house, locking all the doors […]. He would try and run away a lot” and also “I was kind of always preparing myself, you never kind of switch yourself off, especially like when he’s going through a tough time […] you’re always on alert” (P3).

In general, the losses experienced were associated with negative emotional impacts including fear, anxiety, guilt, frustration and embarrassment. The anxiety was personal to the sibling but also in the broader family. The fear was multi-faceted, including fear of meltdowns, fear of aggression and fear for safety of self and others. It also elicited feeling of care, concern and compassion for many people.

A number of families reported finding it very difficult to relax, and a constant feeling of tension. One sibling described the complexity of going away for a short time “If we went on holidays, and he was in respite and knowing that he’s doing well, we could relax more” (P1).

Family members also described feeling guilty at times. Perhaps when the ASD sibling is distressed or when they feel they should help more “To see him cry, that puts guilt on you but like it’s a natural guilt” (P2) and “I’d like to go abroad for a while, but like I’d feel a bit guilty, coz id be leaving my mother on her own, like” (P4).

On a positive note, some siblings found their experiences as carers from an early age inspiring “I think that I have good patience because of the experience of being his brother. I am now studying social care as a result” (P5), “thank god that I do have him, and he’s made me a better person” (P6), and finally “I did nursing I’m a psychiatric nurse” (P11).

One sibling talked about feeling powerless to affect the impact of ASD on his brother which completely took over his personality “I think he’s a slave to the autism” (P2) and “it was never about myself, it was always – I wish I could take that away from him […] it’s as if […] he’s locked in the autism” (P6).

Impact on upbringing

Many of the siblings described initially described a “normal upbringing”. There was a sense that this may have been because their situation was the only one they had encountered. “I always say it’s the only way I know, I’ve never been exposed to a normal functioning family” (P3) and “at times it was difficult […] I guess just dealt with it anyways, whatever […] didn’t know any different” (P4).

However, when pressed they identified many differences in practices “ […] because I was the eldest, I kinda did grow up a lot quicker than say my friends would have […] as in like I was given a lot more responsibility, a lot more […] I was like a lot more mature, and I kinda […] my parents depended on me a lot and I depended on them. So I was very involved with C growing up” (P3) and “if he was up everyone was up […]” (P11).

There was also a sense of parents compensating in some cases “mum especially always made a point of making sure that we got the opportunities that every other siblings would get. Doing things with friends” and “[They] never took their focus off me either so I was always very much included in everything. Still brought places, they’d still come to all my school plays, sports
days anything like that [...] it was not like we have C to focus on now and I had to take a back seat. I had a great childhood” (P3).

The task of identifying triggers was discussed in detail as this led to family members having to adopt a detective type approach in dealing with incidents “Sometimes when he acts out, there has to be a trigger under it. You can spend all day trying to work it out” (P2).

Impact on sibling relationships

Siblings described questioning their own competence, which led to additional emotional distress at their lack of coping “There are times when I feel useless as I can’t do something” (P7) and “There are times when everyone is stressed and we don’t know what to do” (P8).

Whilst siblings were understanding and even accepting towards their ASD sibling’s aggression, there were times when they reacted angrily “he didn’t have the communication skills or verbal skills to tell us that he was having tantrum” (P3) and “my coping mechanism is to like accept that he will never be normal functioning whatever that even is” (P6) and “He hit my elbow a month ago, and it really hurt. I got angry with him” (P7).

Siblings described having positive relationships whilst clearly outlining that despite the impact of ASD on this relationship was evident “Me and him are very close. I can always direct him if needs be. He looks up to me” (P5), “I care for him in a dutiful kind of way” (P9) and, finally, “I think we get on very well but it’s just a weird relationship” (P2).

Siblings described having to withdraw at times in order to protect themselves physically and emotionally “Yeah, he’s given me a few slaps. I kind of have pulled back”. “You don’t want to isolate him either because that won’t help the relationship either” (P1), “I’d make an excuse not to call out to him” (P1) and “I had to kind of dehumanise him to be able to deal with [...] him trying to hurt me, or trying to hurt himself. So it was almost like I had to numb myself, and then like I’d [...] once that was dealt with [...] I’d go and I’d cry for like 2 days” (P6).

Future directions

Siblings reported their aspirations which at times contrasted sharply with their reality or anxieties due reported failures of care “My vision for X is that there should be a community around him […] and sometimes you ask, is he happy where he is? But where do you put him? Out in the community? I just read an article in the Sunday Times yesterday. So we’re in a catch 22 situation; I don’t trust the community. If we’re in a community care thing, if they’re having staffing crisis where he is and that resulted in reduced staff so he can’t get out […] where’s the roadmap for B? They just deal with crises” (P2) and “I don’t want him to just be given a bedroom and he just watch TV all day, he’s a very intelligent boy. He needs to […] like he does work experience in Charlie Byrnes, or Fat Tony’s like for an hour, like sweeping the floor, like he’s a very bright child. […] well young adult” (P6).

Some siblings reported that the family did not receive sufficient help, which increases their anxieties about what to expect from services in the future “I felt that we could have got more help in June. Mum felt under pressure. Some months there would only be one night respite per month” (P10) and “I have a lot of support from my family, but as in the outside world, there is no support for […] I have never gotten any other support. I’ve kinda had to manage it on my own as well” (P6).

One sibling commented on service shortfalls being a national policy and legislation issue rather than a local service issue “There needs to be a change of mind-set. Change of mind-set from government as well as the [local service]” (P2). There was also a comment on the need to educate the public and “I think the acid test always is when you’re in a shop and have that kid staring at him. Might be 4 or 5 years of age, just notices that there’s something wrong. I had this situation where I was in a shop and this child goes ‘Mummy, is that guy drunk?’ She was putting shoes on her child, she was mortified, she took the shoes off the child, like just didn’t know what, and she said there’s something, the child kept pointing because he B, was making noises and the mother was like just dig me into a hole and get me out of here. She put the child’s shoes on and ran her out of the place” (P2):

Siblings discussed the chronic nature of their concern about their ASD sibling’s welfare and their potential ongoing role as a carer “I try not to think about I’s [sic] future because of the idea of
“growing old and frail and looking after” (P9) and “It worries me for the future. My parents are getting older and I can see it. Like they’ve won the battle but they’ve lost the war. They’ve won a few battles for him but the overall war we’re losing” (P2) and finally “I’m scared of his future. Where he is now, is, I wish I could keep him there forever, because they’re just so amazing and I’m afraid of what services are out there […] but he only has like two years left in the school that he’s in, and I remember like when I was younger, like two years ago, I was like he’ll live with me forever, and like that’s ok, […] no, I’ll take him in, he will be part of my little family, and he’ll live in my house, he’ll have his own room and all that, but that’s not realistic. So I don’t know, I am quite scared of the future” (P6).

Discussion

The present study sought to explore the experiences of adult siblings of individuals with ASD with challenging behaviour. From the 11 transcribed structured interviews, a strong consistent narrative emerged from the data. This narrative is based around four identified themes which is summarised as follows:

First, the theme of differences – gains and losses; while many siblings reported life as being “normal for them”, they also reported many differences from those around them. There have been significant losses as the course of the siblings’ life has been dictated by my sibling’s ASD but there also were gains and positive experiences. Second, the theme of emotional impact was identified; these losses have resulted in predominately negative emotional impacts. Third, in the narrative, lies the theme of adjustment: “However, I have been active in making adjustments to cope and to take some control”. Finally, concern for the future was identified as the fourth theme: “I have thought about the future for my sibling and I see myself being involved but will require a lot of support, both individual and societal”.

Participants reported that their siblings’ challenging behaviour had a significant impact on them, the family unit, their upbringing and their relationship with their siblings. Whilst a number of stressful experiences were discussed, some siblings were able to make adjustments and encounter positive life events shaped by their experiences despite having ongoing worries for the future. Despite these positive experiences, previous research suggests that the struggle to maintain relationships with an ASD family member can have long-term detrimental effects.

As per previous research findings for family members and carers of people with ASD, siblings encountered significant difficulties. Despite these difficulties, participants have been active in making adjustments to cope and to take some control. Participants have been adopting a detective role, interpreting behaviour, trying to understanding communication by getting a greater knowledge and understanding of the condition. People struggled to develop and maintain a connection or relationship with their sibling particularly where there was aggression in relationships, although this sometimes led to withdrawal. Others adopted a role of an advocate.

Sibling attitude can be summarised as “I haven’t really thought much about the future for my sibling but I see me being involved but will require a lot of support. This support will be required for my sibling directly but there is also a need for a societal response”. The individual response will have to meet concerns for future placement whether it is full-time residential or involve respite. The participants see that this may also bring increased responsibility for them. The societal issues that emerged were the need to have social reform, change public perceptions and building social and community supports.

References


Further reading


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