

The impact upon a family of having a disabled child

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This research seeks to explore the impact of having a disabled sibling, with a focus on autism. This impact has often been overlooked, meaning there is a lack of research focused on siblings despite the challenges they face. The sample comprises five individuals from different families; four of the participants have a sibling with autism, and one participant has a sibling with Down syndrome. The study has taken an interpretivist approach using interviews and open-ended questionnaires to collect qualitative data. The chosen paradigm was the most appropriate when collecting and analysing experiences of individuals with disabled siblings. It employed mixed methods: semi-structured interviews were conducted, and each participant completed an open-ended questionnaire. The data were analysed using a thematic approach to identify six themes. The results showed that all the respondents agreed that their disabled sibling has impacted their life, but the overall impact was mixed, showing positives and negatives, although, more negatives were found. There was a detailed discussion on the participants' experiences. It is recommended that there should be further research conducted on siblings and more support given.

There is a growing body of research which considers the experiences of siblings and their families who must cope with difficult challenges which are not fully understood by professionals (Opperman & Alant, 2003).

EMOTIONAL IMPACT ON SIBLINGS

The sibling relationship is the longest relationship one is likely to have, and siblings have a unique bond (Batchelor

2019). Siblings grow up together, so they have important influences on each other's development (Anet al. 2017; Black et al. 2017). As a result, there are negative emotional impacts on siblings, such as adjustment, anxiety and depression. Factors which are important in adjustment are knowledge, coping strategies and social support (Batchelor 2019). Sibling adjustment is not fully understood, as some siblings find it challenging to adjust but some adjust well (Smith et

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IMPACT

al. 2015; Van der Merwe et al. 2017). However, individuals with siblings with autism and intellectual disabilities reported more adjustment difficulties in comparison to those with typically developing siblings (Shojaee et al. 2018). It is suggested that siblings struggle with finding meaning and managing and understanding the impact of autism when it is more severe (Smith et al., 2015).

There is a heightened frequency of anxiety and depression in individuals with a disabled sibling (Frith, 2008). It was reported that having a sibling with autism can contribute to anxiety and depression for any gender and age, but adolescent girls are the most vulnerable for reporting depression (Bitsika et al., 2015). Interestingly, female siblings of children with autism are seen to cope better than their male counterparts (Smith et al., 2015). However, the impact that having a sibling with autism has on an individual depends upon a range of factors (Turns et al., 2016). For example, some emotional and behavioural difficulties are linked to family context (Tomeny et al., 2016).

There is a lack of research on this complex concept, and it cannot be caused by one thing alone. It is clear that it is difficult for a child to have a disabled sibling, and this can cause emotional and behavioural challenges and affect sibling relationships (Aytekin, 2016). Feelings of loneliness and isolation have been reported by adolescents and adults (An et al., 2017; Batchelor, 2019).

PERCEPTIONS OF THEIR DISABLED SIBLING

The perceptions of siblings of individuals with disabilities relate to the view they have of their disabled brother or sister. The sibling's experience is a lifelong process, but past studies on siblings focused on childhood, so there is a paucity of knowledge regarding the interplay between sibling relationship, old age and disability (Avieli et al., 2019). Avieli et al.'s study itself only looked at physical disabilities.

Sibling perceptions may change over time (Van der Merwe et al., 2017) but similar concerns have been seen to persist throughout their lives. Siblings have reported being obsessed with the idea of what will happen if their parents die (An et al., 2017). Adult concerns focus mainly on the long-term care ahead (Moss et al., 2019), and adolescents also report

this concern for the future (Corsano et al., 2017).

The birth order of siblings may affect perceptions, as it has been argued that the second child is more affected when the third child has a disability (Black et al., 2017). Older siblings report fewer negative behaviours, because typically-developing younger siblings may surpass their sibling with autism and take on a caregiving role for their older sibling, leading to negative feelings (Braconnier et al., 2018). Siblings of a child with autism who is older than them report poor peer relationships and greater adjustment problems compared to siblings of typical children or children with a different disability (Bitsika et al., 2015). Siblings of individuals with a disability perceive their disabled sibling as less active and emotionally stable than themselves, but do not show differences in showing feelings (Trubia et al., 2016).

LIFE CHOICES/ CAREGIVING ROLE

Siblings face the strain and stress of becoming future carers, which impacts their life and the decisions they will make growing up (Smith et al., 2015). This parental role and this sense of responsibility increases with age as there are worries about their sibling's future and their parents' ability to care for them as they get older (Ferraioli & Harris, 2009; Turns et al., 2016). Additionally, siblings of children with autism are caregivers during childhood, moving on from this to become primary caregivers in adulthood which is called parentification (Nuttall et al., 2018).

PARENT IMPACT ON THE SIBLING

Parentification links to a concept called the spillover effect which explains the transfer of stress from one family subsystem to another, so in this case parents to siblings (Turns et al., 2016). There is not much research on this, though there is a discussion on how parents may decrease the sibling's feelings of neglect by such

means as one-on-one time and role splitting (Bitsika et al., 2015). However, disabled children require different kinds of investments which may affect non-disabled children (Black et al., 2017) and make this unachievable. Having a disabled sibling is difficult, as those in that position cannot spend as much time with their parents yet they need support too (Aytekin, 2016).

SUPPORT

The support siblings receive is minimal and there is limited research into siblings of children with autism (Braconnier et al., 2018). However, it is agreed that there is a need for support for individuals with disabled siblings (Aytekin, 2016; Roberts et al., 2016; Corsano et al., 2017; Shojaeeet al., 2018). It is argued that this need for sibling support has been acknowledged in legislation, but the implications for non-disabled siblings remain unclear (Naylor & Prescott, 2004). The Special Educational Needs Code of Practice (DfE/DfH, 2015) mentions the need to support the child and their parents to facilitate their development and achievement. However, there is no mention of siblings, only parents, throughout this document. Parents are the focus of research and there is a lack of sibling inclusion even though siblings desire to be included in services offered to families (Arnold et al., 2012). This is because siblings will become responsible for their sibling's care, so they need to be involved in planning and decision-making (Moss et al., 2019).

Siblings may experience being ignored and neglected by their parents and professionals (Aytekin, 2016; Batchelor, 2019). Research on the importance of intervention for siblings shows that this would be more beneficial for siblings who have difficulties adjusting, and siblings of children with severe needs (Roberts et al., 2016). However, there has not been much research on support for siblings of disabled children (Aytekin, 2016). Support should be focused on the child's life span, in view of findings which suggest that the

The impact upon a family of having a disabled child

sibling's attitudes change (Van der Merwe et al., 2017). Parents spend more time with their child with autism and there is a lack of support for siblings, but how a sibling copes depends upon the family, severity of the child's diagnosis, age and maturity (Turns et al., 2016).

POSITIVE IMPACTS

Most research has discussed the positive and negative impacts of having a sibling with a disability (An et al., 2017; Van der Merwe et al., 2017). Positives focus on aspects which contribute to the sibling's life and personality, for example by making them more tolerant and caring (Moss et al., 2019). This also includes increased self-confidence and emotional development (Bitsika et al., 2015). Adults report that having a sibling with a range of disabilities makes them realise the preciousness of family and being healthy (An et al., 2017).

Interestingly, siblings report that taking on a caregiving role gives them a positive appreciation for their sibling with autism (Braconnier et al., 2018) and they enjoy teaching and caring for them (Turns et al., 2016). Siblings who provide a lot of support for their sibling and have low levels of stress and depression have positive attitudes regarding their relationship with their sibling (Tomeny et al., 2017). Individuals who have more positive experiences with their sibling with autism use coping strategies (Ferraioli & Harris, 2009; Turns et al., 2016). Siblings report more positive sibling relationships than their parents did, which may be because parental stress impacts their assessment of their children's relationship (Braconnier et al., 2018).

IMPACT OF DIFFERENT DISABILITIES

There are common themes regardless of the disability, such as having mixed feelings about one's sibling, a sense of responsibility, and concerns about the future (Corsano et al., 2017) such as becoming a caregiver (Bitsika et al., 2015;

Avieli et al., 2019).

However, there are differences, such as siblings of an individual with autism reporting fewer positive relationships compared with siblings of an individual with other intellectual disabilities (Tomeny et al., 2017). Siblings of individuals with autism report more stress than siblings of individuals with Down syndrome, but research on this is limited (Shivers et al., 2019). It has been reported that siblings of children with a range of disabilities are unable to accept their sibling (An et al., 2017). It seems that differing findings are focused on the disability's characteristics, as siblings of children with autism have reported their sibling's aggressive behaviour (Braconnier et al., 2018).

Individuals who have siblings with cancer showed similar results and were labelled the forgotten child, with poor psychological adjustment because parents focus on the patient, making siblings feel like a burden (Batchelor, 2019). This is seen in individuals who have siblings with autism, as their parents spend more time with the disabled sibling (Turns et al., 2016). This is because children with disabilities require different kinds of investments which may affect non-disabled children (Black et al., 2017). Again, siblings of disabled children often go unnoticed and neglected by parents and professionals (Aytekin, 2016; Batchelor, 2019). The family context can have an impact on the effect of having a disabled sibling (Trubia, et al., 2016; Avieli et al., 2019).

METHODOLOGY

It was decided to obtain the data through semi-structured interviews and open-ended questionnaires because qualitative research focuses on the participants' perceptions of their situation (Bell, 2010). The data were coded and analysed to see whether they support or contradict current literature and answer my research questions. Through evaluating the data, six main themes were found. There is discussion about the impact of having a disabled sibling. This is referenced back

to current literature, seeking to conclude whether the research answers the primary research question of the impact upon a family of having a disabled child.

DISCUSSION AND FINDINGS

LIFE CHOICES

One of the key findings to emerge from the data is the impact on participants' life choices. All five participants believe that their sibling has impacted their life choices whether positively or negatively. When discussing the impact on life choices, two participants had mainly negative answers, two had positive answers and one had a combination. Those who pointed out negative impacts on their life choices discussed their worries about the future and being unable to do certain things because of their sibling. This echoes literature suggesting that siblings face the strain and stress of becoming future carers which impacts their life and their decisions growing up (Smith et al., 2015). One participant discussed in their interview and questionnaire the impact this had when they moved out of the family home. They said,

'It has affected my life choices as when I moved out I made sure I didn't move too far away because I felt bad.'

This shows that their life choices were constricted as they felt they could not move far from the family home.

On the other hand, three participants discussed positive impacts on life choices, such as their sibling inspiring them to work in the field of special needs, but this is not seen in the literature. One participant reported finding the students they work with less challenging thanks to living with their sibling, as most people do not have this experience.

CAREGIVING ROLE

Another key finding was the caregiving role that siblings take on. Four participants reported that they had had to take on a caregiving role, while one said that they

must do now they are older. This links to literature which suggests that the parental role and responsibility that siblings take on increases with age due to worries about the future (Ferraioli & Harris, 2009; Turns et al., 2016). One participant described this in their interview and questionnaire:

'I've never had to take on a caregiving role, but I feel like I have since getting older.'

The other four participants discussed taking on parental roles such as personal care and preventing the sibling from harming themselves. This echoes existing literature which suggests that siblings of children with autism are caregivers during childhood on the way to becoming primary caregivers in adulthood (Nuttall et al., 2018). One participant who is older than their sibling with autism, discussed this:

'I have had to take on a caregiving role for my sibling such as babysitting. It's watching he doesn't swallow anything or hurt himself.'

PERCEPTIONS OF DISABLED SIBLING

Another key finding was the perceptions that the participants have of their disabled sibling. In both the interview and questionnaire all the participants said that their perception of their sibling has changed. They all feel that now it is more positive as they have learned more about their siblings and their disability. This links to findings in the literature that sibling perceptions may change over time (Van der Merwe et al., 2017). One of my participants said that when they were younger and lived at home, they had less patience because they were with their sibling a lot. In their questionnaire they reported that

'It has changed the older I have gotten; I have researched more about autism and I learn more about him every day.'

Interestingly, the same participant reflected in their interview:

'That's not like my perceptions changed on him. It changed on his autism.'

This indicates that their perception of their sibling has altered as they have learned more about autism.

Two participants who have older disabled siblings said that knowing their siblings their whole lives has given them more positive views. The existing literature suggests that when a typically developing sibling is younger, they may surpass their sibling and take on a caregiving role for their older sibling, leading to negative feelings towards them (Braconnier et al., 2018). My findings contradict this, as my participants with older disabled siblings showed more positive sibling feelings. One of my participants described this in their interview:

'Yes, because when I was younger I didn't really understand it. I just thought he was normal and then I was like he's not quite like me and my brother.'

There were some negative findings, as when four of the participants discussed worrying about their sibling and at first struggling to accept the situation, despite being able to accept it more now. One interviewee said,

'You're more sad for yourself than him because he doesn't know that he'll never have friends or never be able to speak – he's blissfully happy and in his own little world.'

When prompted, the participant said that their sibling has complex needs and does not have the understanding to know about their autism or that they cannot do certain things. This indicates feelings of sadness about their sibling's development and a sense of grief.

EMOTIONAL IMPACT

When discussing the emotional impact, four of my five participants believed that their sibling had a negative impact on their mental health, though one

said more so when they lived at home. This supports existing literature which suggests that there is a heightened frequency of anxiety and depression in individuals with a disabled sibling (Frith, 2008). One participant described in their interview how it impacted them:

'It did a bit because it's quite sad that he can't do that for himself and you have to watch him.'

This suggests that this participant believes that their sibling has impacted their mental health and, again, indicates feelings of sadness about their sibling not having typical development.

In contrast, one participant, whose disabled sibling is older and does not live at home, believes that having a disabled sibling has no impact on their mental health:

'No, I wouldn't say it has because I've known him from birth, and I've known that growing up he's needed some extra care. I think it's just been normal to me.'

This echoes literature suggesting that, the impact of having a disabled sibling may depend upon a range of factors (Turns et al., 2016).

Another theme which emerged from my data yet is not seen in the literature is the reaction to the diagnosis, which was discussed by two participants. One participant mentioned in their interview that they used to pray that their sibling did not have autism, but they now accept him, which links to the perceptions of their sibling changing. The other participant recalled that their heart broke when they found out their sibling has autism because of how hard life would be. This is not explored in the literature, maybe because siblings of disabled children are neglected by parents and professionals (Aytekin, 2016). It could be that siblings of disabled individuals are not thought to struggle with this life-changing situation, in light of the fact that two participants discussed feeling

like a burden. Therefore, researchers may not think about conducting research in this area.

POSITIVE IMPACTS

Another key finding was the positives of having a disabled sibling, which links to perceptions and life choices as well as the overall impact. All five participants discussed positives such as improvements in their personality including becoming more caring, understanding of others and enjoying spending time with their sibling. This links to Moss et al.'s (2019) contention that the positives of having a disabled sibling contribute to the sibling's life and personality. One participant discussed this:

'I've grown up a lot quicker than I should have and I'm very responsible. I can look after a child with complex needs.'

There was a focus on the participants enjoying spending time with their siblings and caring for them. Some individuals enjoy caring for their sibling with autism and teaching them (Turns et al., 2016). One participant reported,

'He's always happy to see me and I like spending time with him.'

Another key finding was how the participants viewed the overall impact of their sibling; positively or negatively. The participants were asked about the overall impact and if this was positive or negative. The answers given were mixed: one participant said their overall experience was negative, two said positive, one said it had been negative but now was more positive, and one said mixed. One sibling who is older than their sibling with severe autism said that they found it difficult growing up. As Smith et al. (2015) suggest, siblings struggle with finding meaning, managing, and understanding the impact of autism when it is more severe. One participant described how they had been affected:

'I'd say negatively because it has made me sad for him and it has been really hard.'

DOES THE DISABILITY ALTER THE IMPACT?

The final theme to emerge from the data was whether or not the impact varied according to the disability. Interestingly, throughout the study the participant who has a sibling with Down syndrome had more positive answers. The literature suggests that siblings of individuals with autism reported more stress than siblings of individuals with Down syndrome (Shivers et al., 2019). This participant recalled, 'I don't think I needed support when I was younger because it was made so normal.' A participant with a sibling with severe autism, however, reflected that 'it is hard and if you could have a choice you would choose for him not to be that way'. This links to the literature, as siblings struggle with finding meaning, and managing and understanding the impact of autism when it is more severe (Smith et al., 2015).

CONCLUSION

The research has indicated positive and negative impacts on my participants. There was agreement that life choices were impacted but also discussions that this was positive. In general, participants have had to take on a caregiving role and their perceptions have grown more positive, despite still experiencing challenges. There was agreement by and large about their siblings impacting their mental health, and where this was not the case their disabled sibling was older and did not have autism. Additionally, the data revealed themes that are not discussed in the literature, such as diagnosis and working in the special educational needs field. Positives included improvement of personality traits and enjoying spending time with their siblings. The overall impact was mixed, hinting that the degree of severity may have an impact. Lastly, the type of disability implied an impact in this study, but other factors may alter the impact. ■

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