



UNIVERSITÀ DI PARMA

ARCHIVIO DELLA RICERCA

University of Parma Research Repository

Typically developing adolescents' experience of growing up with a brother with an autism spectrum disorder

This is the peer reviewed version of the following article:

Original

Typically developing adolescents' experience of growing up with a brother with an autism spectrum disorder / Corsano, Paola; Musetti, Alessandro; Guidotti, Laura; Capelli, F.. - In: JOURNAL OF INTELLECTUAL AND DEVELOPMENTAL DISABILITY. - ISSN 1366-8250. - 42:2(2017), pp. 151-161. [10.3109/13668250.2016.1226277]

Availability:

This version is available at: 11381/2813719 since: 2021-11-18T13:09:35Z

Publisher:

Routledge

Published

DOI:10.3109/13668250.2016.1226277

Terms of use:

Anyone can freely access the full text of works made available as "Open Access". Works made available

Publisher copyright

note finali coverpage

(Article begins on next page)

Typically developing adolescents' experience of growing up with a brother with an autism spectrum disorder

Abstract

Background Researchers studying siblings of people with an autism spectrum disorder (ASD) suggest that growing up with an individual with disability has positive and negative effects.

Method Qualitative content analysis of semi-structured interviews with 14 typically developing (TD) adolescents with a brother with an ASD and their mothers was used to explore the experience of growing up with a sibling with an ASD and identify differences in the relationship with and attitude toward the brother.

Results TD siblings expressed mixed feelings about their brother, a precocious sense of responsibility, concern about the future, friendship difficulties, troubles and the desire to talk about their experience. Most adolescents integrated their positive and negative feelings; however three adolescents displayed rejection, denial or a sense of persecution.

Conclusions Qualitative research into the experiences of adolescent siblings of people with an ASD should be used to develop support programmes to help adolescents manage their relationship with a sibling with a disability.

Keywords: *Autism spectrum disorders; siblings; adolescents; qualitative research; families*

Introduction

Autism spectrum disorders (ASDs) are a group of neurobiological developmental disabilities involving serious impairments such as difficulties with social interaction and communication, repetitive behaviour and restricted interests (American Psychiatric Association, 2013).

Because most people with a formal diagnosis of an ASD live within a family and are cared for by their parents (Connell, Halloran, & Doody, 2014), ASD can have a strong impact on the entire family unit, increasing the risk that other family members will experience psychological difficulties and stress (Maks & Reeve, 2007). In particular, there is evidence that the family of people with an ASD experience depressed feelings, tiredness, a sense of loss of control (Woodgate, Ateah, & Secco, 2008) and feelings of loss (Bayat, 2007). Caring for a child with an ASD represents a big commitment for parents and is associated with a lower quality of life (Davies & Gavidia–Payne, 2009; Green, 2013).

In the last decade there has been growing interest in the typically developing (TD) siblings of individuals with an ASD (Green, 2013; Meadan, Stoner, & Angell, 2010; Smith & Elder, 2010; Thomas, Reddy, & Sagar, 2015). There are several reasons for this. First, researchers studying sibling relationships have underlined the importance of this bond for psychosocial development (Dunn & Kendrick, 1982) and hence it is plausible that growing up with a sibling with impairments in communication and social interaction might affect a child's social and emotional development. Moreover, after parents, siblings are the people who spend most time with an individual with an ASD, and hence their sibling's disability could have considerable impact on their well-being and adjustment. Finally, some studies (Bass & Mulick, 2007; Klein, Feldman, & Zarur, 2002) of sibling-mediated intervention for children with an ASD have argued that "understanding the psychosocial functioning of these TD siblings is important for shaping and individualising future sibling-mediated treatment

programs” (Dempsey, Llorens, Brewton, Mulchandani, & Goin–Kochel, 2012, p. 1393).

Research on the TD siblings of people with an ASD has yielded mixed findings, indicating both the negative and positive effects of growing up with an autistic sibling, and that it has little influence on the psychosocial adjustment of TD children.

Wintgens and Hayez (2003) identified suffering in siblings of children with an ASD that was due to the behavioural oddities of their sibling, and reported that they showed a greater need for care, often displayed a precocious sense of responsibility, relational rejection and embarrassment about their sibling with a disability in the presence of strangers and friends. Other studies have reported that TD siblings of autistic people have difficulty in forming a satisfying relationship with their sibling and in accepting his or her lack of social and communication skills (Harris, 2008; Lyons, Leon, Roecker Phelps, & Dunleavy, 2010; Moyson & Roeyers, 2011). They display higher rates of behavioural and emotional problems than children in general. In particular, Ross and Cuskelly (2006) identified physical aggression as a key source of stress in this kind of sibling relationship and a common source of internalising behavioural symptoms and emotional problems. A qualitative study of 14 TD siblings of autistic children, aged between 5 and 29 years (Benderix & Sivberg, 2007), also documented several stressors, such as a precocious sense of responsibility, feeling sorrow, exposure to the sibling’s with a disability frightening behaviour, physical violence, insecurity and anxiety. In another qualitative study, Petalas, Hastings, Nash, Reilly, and Dowey (2012) emphasised that living with a sibling with an autism spectrum disorder had a negative and stressful impact on the daily lives of 12 TD adolescents. These authors cited the unpredictable behaviour of the person with an ASD, the failure of attempts to interact with him or her and embarrassment in social situations as the main stressors.

These and other studies reported, however, that growing up with a sibling with an ASD could also have positive effects. TD siblings display higher levels of empathy, tolerance

and patience (Benderix & Sivberg, 2007; Moyson & Roeyers, 2011), have more positive self-concepts, greater social competence and more positive views of the behaviour of people with an ASD than the general population (Macks & Reeve, 2007; Verté, Roeyers, & Buysse, 2003). When they are older they help their sibling to manage his or her developmental problems (Ross & Cuskelly, 2006). In their qualitative study Petalas et al. (2012) concluded that living with a brother with a disability is a positive experience that could help siblings learn to avoid judging others and accept them as they are.

As the presence in the family of an individual with an ASD can have both negative and positive effects on his or her siblings, there has been research into adjustment and internalising and externalising symptoms in the TD siblings. The findings are controversial. Whilst some studies have reported more behavioural dysfunction and more emotional problems in this group (Constantino et al., 2006; Hastings, 2003), many investigations have found that the prevalence of internalising or externalising behaviour was similar in siblings of people with an ASD and a sample of the general population (Hastings, 2007; Verté et al., 2003). In particular, Dempsey et al. (2012), in a quantitative study based on parents' and teachers' reports of internalising and externalising behaviour in 486 TD siblings of children with an ASD, reported that there was only a small difference relative to the standardised sample. Similarly, a study based on the self-reports of 94 siblings of children with an ASD (Hastings & Petalas, 2014) concluded that this population showed rates of behavioural and emotional problems similar to those in regular British samples.

Taking into account demographic and environmental variables such as gender, birth order, family size (Kaminsky & Dewey, 2002; Macks & Reeve, 2007), severity of the ASD diagnosis (Smith, Elder, Storch, & Rowe, 2015) and maternal depression (Orsmond & Seltzer, 2009), various researchers have concluded that the presence of an individual with ASD is not in itself a risk factor for siblings. "The impact of having a brother or a sister with

ASD may depend on a number of factors, such as where the sibling comes in the family, the social and economic standing of the family and a sibling's own personal qualities and characteristics" (Connell et al., 2014, p. 2). Given an otherwise optimal developmental environment the siblings of children with an ASD may be as well adjusted as their peers without a sibling with a disability. However, qualitative research, which can provide in-depth data on the feelings and needs of these siblings and capture the particularities of the experience of living with a sibling with a disability, offers another approach to identifying the emotional and behavioural issues that are specific to this population (Green, 2013). For example, Moyson and Roeyers (2011) used a focus group to investigate the overall quality of life of seventeen 6-to-14 year-old siblings of individuals with an ASD. Like an earlier qualitative study (Benderix & Sivberg, 2007), they set out the factors they considered important to a good quality of life for these siblings. These included forbearance, acceptance, dealing with the outside world and social support. Moyson and Roeyers (2011) emphasised the highly individual nature of the experience of having a sibling with a disability, and the importance of considering that experience holistically: "positive and negative experiences are inextricably linked to the sibling relationship" (p. 51). In another qualitative study (Angell, Meadan, & Stoner, 2012) semi-structured interviews were used to collect data on the experiences of 12 siblings of children with an ASD, aged between 7 and 15 years. Three themes emerged: descriptions of the sibling subsystem, cohesion between and among the siblings, and adaptability to a family with an ASD child. In accordance with the systems theory, the authors found a dynamic, recursive relationship among these issues. A recent study (Connell et al., 2014) described the experience of growing up with a brother with an ASD. This sister's story provides an insight into the difficulties faced by the TD sister of a brother with an ASD at various developmental stages, including the challenge of accepting the presence of a child with an ASD in the family. This sister's account emphasised the

extent to which her brother's disability made her feel socially disengaged, and the debilitating effects of the unpredictability of his behaviour.

The above-mentioned studies considered the experiences of TD siblings of individuals with an ASD in childhood, adolescence and adulthood. Very few qualitative studies have focused specifically on adolescent siblings. Petalas et al. (2012) and Green (2013) emphasised the importance of studying this population, because adolescents need to spend less time with their family, to fit in with their peers and to be able to better understand their sibling's diagnosis. Adolescent siblings of children with an ASD may feel guilty, due to their common desire to spend more time outside of the family and their loyalty to their sibling. Disability in the family also makes for embarrassment in peer interactions.

Masha and Boucher (2006) studied the feelings, thoughts and the subjective experiences of 14 TD adolescent siblings (aged from 11 to 18 years) of teenagers with ASD. As in the studies described above, they found that growing up with a sibling with ASD had both positive and negative effects. In particular, the TD adolescents were concerned about their sibling's uncontrolled behaviour, the embarrassment this caused in social and public contexts, and the ways in which their sibling's disability interfered with their personal life, depriving them of privacy and making it difficult for them to maintain friendships. A more recent qualitative study of 12 TD adolescent siblings (aged from 14 to 17 years) of brothers with an ASD (Petalas et al., 2012) described their experiences of living with their brother. The authors concluded that the brother's disability had a negative impact on the whole family. The TD adolescent siblings displayed varying degrees of acceptance and perceptions of their brother, but they were worried about their future.

The literature discussed above emphasises the importance of qualitative research and makes it clear that there have been few studies that specifically investigate the adolescent siblings of children with an ASD. The primary aim of this study was to extend the small body

of evidence on this important, under-researched topic by describing and analysing the experience of growing up with a brother with an ASD in a sample of TD adolescent siblings. As well as documenting the main features of this experience – as in earlier research – we aimed to identify differences among siblings with respect to their relationship with and attitude to their brother with a disability. Semi-structured interviews were used to collect the adolescent siblings' experiences and their mothers' perspective. The interview data was subjected to content analysis.

Method

Research design

The present study was designed to explore the experience of growing up with a sibling with an ASD in TD adolescents. A qualitative analysis step by step process was used to identify the main themes that characterise their relationship with and attitude toward the brother. To achieve this understanding, a content analysis was carried out from the transcript interviews, in order to identify common topics and elements of differentiation among the participants.

The study was designed and carried out according to the Ethical Code of the Italian Association of Psychology (AIP) and the American Association of Psychology (APA).

Participants

Fourteen adolescents ($M_{\text{age}} = 16.07$ years, $SD = 2.46$ range: 12–20; 9 males and 5 females) with an adolescent brother with an ASD and their mothers ($n = 13$; $M_{\text{age}} = 47.57$ years, $SD = 3.84$, range 40–52) participated in the study. In three cases, the TD adolescent was a younger sibling of the brother with an ASD and in 11 cases he or she was an older sibling. The number of children in the home ranged from two to four ($M = 2.43$, $SD = 0.76$, mode = 2). All the participants were from two-parent families (Table 1).

<< Please insert Table 1 about here >>

The inclusion criteria for the study were that the family included:

- an adolescent with a formal diagnosis of an ASD;
- a TD adolescent sibling without an intellectual disability or psychiatric diagnosis;
- a mother without a psychiatric diagnosis.

Based on the principles of convenience sampling we included all the siblings who met the criteria. All 14 adolescents with an ASD ($M_{\text{age}} = 14.64$; $SD = 2.53$, range 12–20 years) were male, had received a diagnosis of an ASD from a multidisciplinary diagnostic clinic and were living in the family home. They had all been diagnosed with moderate-to-low functioning ASD (verbal ASD: $n = 7$; non-verbal ASD: $n = 7$). Their age at diagnosis ranged from 2.5 to 4.5 years and in all cases this initial diagnosis had been made by a qualified and experienced practitioner. Diagnoses were confirmed in the day care centres for ASD where the participants were recruited, as reported by the mothers and by the directors of the centres. Two of the adolescents with an ASD had an additional diagnosis of intellectual disability, one had comorbid epilepsy, one comorbid diabetes, and one comorbid obesity. The mothers reported that they had never received psychotherapeutic or medical treatment for psychiatric symptoms and they also reported that none of the TD adolescent participants had received a formal psychiatric diagnosis.

All the participants were Caucasian and resided in northern Italy. The participants were recruited through two local ASD day care centres. The first author contacted the directors of the day care centres, explained the aims and participation criteria for the study and asked for assistance in recruiting participants. The families were initially contacted by the day care centre directors, who briefly explained the purposes of the research and relayed contact details of the families who expressed an interest to the researchers. The fourth author contacted these families and told them about the research. All the families contacted at this

stage agreed to participate in the study. All the participants gave informed consent. The mothers and TD siblings who were aged 18 years or older gave written informed consent. The TD siblings who were less than 18 years old gave oral informed consent and in addition both parents gave written permission for their participation.

Semi-structured interviews

Drawing on the literature review, the research group developed two semi-structured interview protocols designed to elicit information from the TD adolescent siblings and mothers of a child with an ASD. The sibling interview protocol (Table 2) consisted of questions on several different themes: (1) perception of the brother with ASD (e.g., “How would you describe your brother to someone who does not know him?”); (2) self-perception (e.g., “How do you see yourself?”); (3) awareness of the brother’s disability and contribution to the management of his condition (e.g., “Would you know how to describe autistic disorder to someone who does not know him?”); (4) perception of the sibling’s own future and that of the family (e.g., “How do you see your future?”); (5) the impact that having a brother with an ASD has had on the sibling’s social life (e.g., “Do you invite your friends to your home?”); (6) need for psychological support (e.g., “Would you like to talk to someone about how you feel?”).

<< Please insert Table 2 about here >>

The mother interview protocol (Table 3) was designed to meet two objectives, firstly to provide further insight into the experience of growing up with a brother with a disability and secondly to enable us to compare the perspectives of the mothers and siblings. It included questions on the following themes: (1) the TD child's reaction to his or her brother’s disability and changes in their understanding over time (e.g., “When did your [son/daughter] know about [his/her] brother’s disability?”); (2) the TD child’s overall experience of having a

sibling with an ASD and his or her reaction to their disruptive behaviour (e.g., “How does [he/she] react to his/her brother’s crises?”); (3) perception of the family’s future (e.g., “How do you see your family’s future?”); (4) the role of the TD son or daughter in the family (e.g., “How do you see your [son/daughter]’s role in the family?”); (5) the impact of the son with ASD on the TD son or daughter’s social life (e.g., “Does your [son/daughter] invite [his/her] friends home?”); (6) qualities of the TD son or daughter that were valued or appreciated (e.g., “What do you like about your [son/daughter]?”); (7) psychological support for the TD siblings of people with ASD (e.g., “Do you think that your [son/daughter] needs psychological support?”).

<< Please insert Table 3 about here >>

Procedure

The interviews were conducted by the fourth author over a three-month period in the ASD day care centres through which the participants were recruited. Interviews with the mothers lasted 43 minutes on average (range: 37–49 mins) and interviews with the TD sibling lasted 35 minutes on average (range: 22–48 mins). All of the participants completed the interviews.

Before beginning the interview, the researcher asked the participants to speak freely and emphasised that their data would remain confidential and anonymous. The adolescent siblings were interviewed separately from their mothers. All the interviews were audio-recorded.

Qualitative analysis

First, the interviews were transcribed verbatim.

Qualitative content analysis based on the stage-by-stage analysis process described by Burnard (1991) was used to codify and categorise the interview texts. The analysts read the transcribed material several times, in order to immerse themselves in the data and the

subsequent analysis was a gradual, step by step process. This method of analysis was selected because the third author was qualified in it and it has previously been used in research with siblings of people with an ASD (Benderix & Sivberg, 2007).

The whole research group participated in the analysis and discussion of the results. The group consisted of two clinical psychologists with many years of experience of working with people with an ASD, a developmental psychologist with expertise with adolescents and a doctoral student trained in qualitative research. One of the clinical psychologists was also trained in psychoanalytical psychotherapy and the other was trained in systemic psychotherapy. The authors' preconceptions were derived from their experiences in the fields of developmental disability and vulnerable families.

Analysis of the sibling interviews consisted of the following stages. (1) The entire research group read all the interview transcripts several times at a group meeting and discussed their preliminary thoughts and perspectives; these comments were transcribed separately for each interview. (2) The third and the fourth authors re-read the transcripts independently, focusing specifically on the themes of interest to identify the most interesting material. In particular, for each sentence pronounced by the participants, the researchers made marginal notes on the content that emerged. (3) The researchers jointly compared and discussed the content highlighted in the previous stage of the analysis, making any necessary adjustments, in order to improve the validity of the analysis and minimise researcher bias. Disagreements about interpretation were resolved by discussion. (4) Next, the research team identified the categories or themes that emerged from the material and the preliminary comments and discussion (see step 1). Following this, all the transcripts were re-read by the third author to ensure that the themes were grounded in the data. (5) The research team then compared the themes recorded for the different interviews in order to identify commonalities and differences. These were documented on a new sheet. (6) Finally, the transcripts of the

interviews with siblings that had generated themes not shared by everyone were re-read to verify the differences between these siblings and the sample as a whole.

A similar procedure was used to analyse the mothers' interviews. Steps (1), (2), (3) and (4) were carried out as described above, after which the researchers compared the interviews of the mothers of the TD siblings who had shown particular differences from the others, in order to verify and confirm these differences from another point of view.

Finally, all the interviews were re-read to check that no topics had been forgotten or ignored. The interpretation of the data was developed jointly by the research team and, as is typical for qualitative research, the authors' preconceptions will have influenced their interpretation.

Results

The following themes emerged from the content analysis: the TD siblings' attitude toward their brother, the TD sibling's perception, precocious responsibility, concern about the future, friendship difficulties, troubles and talking about their brother.

Attitude to a brother with an ASD

The adolescent siblings of boys with an ASD showed both a negative and positive attitude toward their brothers. Most of the TD siblings (11) described their brother as a "sick" or "problematic" person. They described him as someone for whom they had to make many sacrifices, someone with whom it was difficult to communicate and someone they both wanted and did not want to spend time with. Brothers with an ASD were seen both as playful and affectionate as well as strange and disruptive. The TD siblings described their brother as someone who needed help, someone to protect and manage, but also someone with whom they could play and quarrel.

Most of the siblings expressed both annoyance and empathy toward their brother. All the TD siblings emphasised that their perception of him had changed over time. At great personal cost, they had learned to appreciate their brother and find positive aspects in their relationship with him.

Three siblings displayed attitudes and perspectives that differed from this general pattern. E, a 16-year-old older sister, described her brother as “an insufferable person, very troublesome, smelly!” She spoke about him with anger and annoyance. In contrast, B, a 19-year-old brother, described his sibling as “a normal younger brother I can spend time with and have fun with.” He talked about him with affection. Finally, D, a 17-year-old older brother, characterised his brother simply as “a sick person who is very demanding and requires many sacrifices”.

The mothers' interviews corroborated and extended the findings from the sibling interviews. They described their TD children as showing acceptance, protection and empathy towards their brother. They mentioned the jealousy and rivalry typical of sibling relationships, but added that the TD adolescent expressed discomfort, shame, worry and annoyance at his or her brother's limitations. The mothers emphasised that their TD children found it difficult to cope with having a sibling with an ASD. One mother said: “He would have preferred a different brother”. E, B and D's mothers corroborated the attitudes their children had displayed in their interviews. D's mother reported that D's response to his brother was a mixture of anger, shame and worry and that, over time, he had become more distant from his brother and had gradually come to see him more and more as a hindrance. E's mother corroborated her daughter's rejection of her brother and the difficulty E had in accepting the family's inevitable sacrifices. Finally, B's mother said that her son behaved like a normal older brother to the boy with an ASD and that he struggled to understand why his brother was considered a person with disability.

TD siblings' self-perceptions

The siblings' interviews included questions about how the siblings perceived themselves and how they thought friends and parents perceived them. Overall, the siblings expressed positive perceptions of themselves, which they thought were shared by their friends. In particular, they described themselves as nice people, smart, funny, helpful and patient, kind and altruistic. It is interesting to note that E claimed to be “smiling, but never when I am at home!” In contrast, the siblings felt that their parents saw them as lazy, listless and headstrong, but also as kind, patient, helpful and responsible.

Both the adolescents' self-descriptions and their mothers' descriptions emphasised the following characteristics: availability, altruism, sensitivity, a strong sense of responsibility, a sense of duty and openness to others. They described their children as “a wonderful person and who is available to the whole family”, “a source of support and protection for the whole family”, “an essential presence for everyone, but someone who needs their independence”. Once again, the descriptions of E, B and D were distinct from the others. E's mother described her daughter as “a teenager who is jealous of her space” and she was unable to cite any positive qualities for her daughter. D's mother described her son as “a reflexive boy, very intransigent with everyone and himself; he shares his father's hypocrisy and intolerance”. Finally, B described her son as “a true father to the whole family, a person who is fully committed to ensuring that problems are always solved and making the family's situation as normal as possible”.

A precocious sense of responsibility

In several instances, the siblings' self-descriptions – which were confirmed by their mothers – suggested a precocious sense of responsibility. This was one of the main qualities the

mothers saw in their TD children. Most of the TD siblings reported that they acted as a support to their family in several contexts, such as when their parents were tired or when there was a crisis with their brother. They mentioned having to give up their own plans to stay with their brother. Their mothers' accounts corroborated this picture; they confirmed that the TD child had had to learn from an early age to help the family look after their brother, and to make sacrifices for everyone's benefit. One mother said: "Over time he has learned to mask his concern in order not to create more problems for us as parents, he has learned to pander to his brother to keep him calm". Even though the mothers said they appreciated their TD children's sense of responsibility ("their sense of responsibility increases the effectiveness of their actions"). They were nevertheless aware that this precocious sense of responsibility could cause them to worry too much and could cause problems for them at school and in relationships with their peers. Most of the siblings claimed that having had to take care of their brother from an early age had made them stronger; however, they also worried about what would happen in the future.

Concern about the future

The concern that the siblings of people with an ASD have about the future was a recurring theme, both in the sibling and mother interviews. Only one adolescent stated clearly that he wanted to take care of his brother in the future. Another boy described the distress the issue of his own and his brother's future caused him: "I believe that my brother will have to stay with my parents, but it makes me feel bad to talk about it with them". Most of the siblings said they would continue to be a point of reference for their brother, but they wanted to lead their own, independent life.

On this issue E, B and D once again expressed divergent attitudes that were consistent with their other answers. E stated that "I will see my brother only if I meet him by chance

when I go to visit my parents. Nothing more”. D was so obsessed by the idea that he would have to take care of his brother in the future that he had repeatedly raised the issue with his mother. Finally, B, notwithstanding the fact that his brother had been diagnosed with a low functioning ASD, said that in the future he saw his brother “with his new family, with a wife and children”.

Overall, the mothers were aware of their children’s concerns. They said they hoped that their child with an ASD would get a place in a specialist residential facility so that their TD children could be free and autonomous, yet be near their brother. Only two mothers claimed they saw their family as “a united family with all the children together in a common project” in which even the child with an ASD would find his place, and as “a united family without stress”.

Friendship difficulties

The presence in the family of a boy with an ASD was a source of distress for almost all the siblings interviewed when it came to managing their relationships with their friends. They reported that they did not invite their friends home if their brother was present, because they were afraid that he would have a crisis. They also said that they only spoke to their friends about their brother if they were asked about him. One sibling said: “When I found out a classmate had a brother with an ASD I felt more at ease, because I could invite him home and I knew he understood me”.

The mothers also highlighted the difficulties their TD children had in their relationships with their friends. They confirmed that their children were embarrassed and ashamed of their brother in front of their friends. When they invited friends home, which was rare, “He introduces them to his brother immediately, so that there won’t be any surprises”. One mother said that her son was bullied because of his brother’s disability. In general,

however, the mothers reported that they had noticed that over the years their TD children had become less ashamed of their brother.

As with the other issues E, B and D's accounts of their peer relationships diverged from those of the rest of the sample. E's mother said that her daughter often invited friends home and simply acted as if her brother did not exist, which embarrassed her friends. D said that because of his brother he would never invite friends home and his mother confirmed that he felt his brother's presence was a social stigma. Finally, B's mother said that her son would like to invite friends home, in spite of his brother, but that he was "very isolated and has problems at school".

Talking about having a brother with an ASD

The final theme that emerged from the interviews was the difficulty that siblings – and their families – had in discussing their brother. As we mentioned above, the TD siblings avoided discussing their brother with their friends unless they were asked specific questions. The mothers stressed that their TD children almost never asked questions about their brother. They reported that in most cases their TD children had become aware of their brother's diagnosis gradually, simply through family life. If the children did not ask questions, their parents did not raise the issue; this demonstrates the families' shared difficulty in talking about the family member with an ASD.

There were, however, some exceptions. B's mother claimed that her TD son often wondered why his brother had an assistant at school. D also often posed questions to his parents; his mother reported that he asked questions such as "Why is that? What's wrong? What problems will there be in the future?" In particular, she claimed that D often asked his parents who would take care of his brother in the future, expressing his wish to distance himself from a family and social situation that he found very painful and overwhelming.

Whilst the TD siblings had difficulty talking to friends and parents about their brother, they expressed a strong desire to talk to other siblings of people with an ASD or to talk to experts on this disability. In particular, they wanted to have the opportunity to share their experiences of living with their brother, in order to improve their relationship with him, to know how to behave with him, to find a balance between their positive and negative feelings and to get more information about ASD. One TD sibling said: “I’d like to tell my brother’s story to see if it is like the others”. Another mentioned the need to “build a network of adolescent friends who have the same problem in their family”. Only E, among all the siblings, said that she did not want to talk to anyone about her brother and did not need any support.

All the mothers agreed that their TD children needed to share their experiences with others, yet, with one exception, they reported that their TD children had not received any psychological support. D’s mother said that her son had asked her several times if he could see a psychologist to deal with the burden of his family's situation.

Discussion

This study has provided rich information on the experience of adolescent siblings of people with an ASD, an important yet under-researched topic. It has identified some important differences in the attitudes TD siblings have towards their brother with an ASD. Common elements of the TD sibling experience included mixed feelings about their brother, a precocious sense of responsibility, concern about the future, difficulties in relationships with friends and a need to talk about him. Three adolescents in our sample found it more difficult to live with a brother with ASD.

The main objective of the study was to explore the TD adolescent siblings’ experiences of growing up with a brother with an ASD, through their own accounts and from

their mothers' perspective.

The interviews revealed that overall the siblings had mixed feelings about their brother and their relationship with him. First, most of the siblings stressed the difficulty of living with a brother with a disability and who is disruptive and has behavioural problems that are often a source of distress in social and public situations; their accounts of the difficulties this caused for them were corroborated by their mothers. Discomfort, shame, embarrassment, anger and concern about the future were the feelings most frequently mentioned by siblings and their mothers. Over time, however, the experience of living alongside their brother has resulted in the TD siblings developing positive attitudes and feelings such as empathy, tenderness and a desire to take care of their brother and becoming aware of the importance of helping and supporting the family as a unit. Although most of the siblings' attitudes to their brother with an ASD fluctuated between positive and negative, almost all of them appeared to have achieved a certain emotional balance, albeit with difficulty and at great personal cost. Interestingly, many of the siblings said that, over time they had learned to appreciate their brother. This finding is in line with other qualitative research stressing that TD children and adolescents have a mixed perspective on the experience of having a sibling with an ASD (Benderix & Sivberg, 2007; Connell et al., 2014; Petalas et al., 2012). Our data suggests that the majority of the participants had developed a complex, realistic view of their brother, encompassing both positive and negative feelings. Like other studies (Connell et al., 2014; Dempsey et al., 2012) we found that in most cases the TD siblings had a peaceful relationship with their brother with ASD. It could be argued that having a broad perspective on the experience of having a brother with an ASD could be an important protective factor.

The aspects highlighted by the data are even more important if contextualised to the adolescent population. The sibling interviews in this study, as in the study by Petalas et al.

(2012), revealed that siblings of individuals with ASD feel they need more information about their brother's condition, are concerned about their own future and suffer because they do not feel able to invite friends home. These issues are particularly important for adolescent siblings. In fact, they are projected towards their future outside of the family and involved in meaningful relationships with their peers (Jackson & Goossens, 2006). As siblings reach adolescence, they become more aware of the difficulties of their sibling with ASD and want to understand the extent of his or her capabilities and disability. This is related to concerns about future autonomy and the desire to compare one's own experience with that of other adolescent siblings of people with ASD. Our data suggests that the siblings of people with an ASD should be encouraged to participate in discussion groups with their peers and to pursue an open, constructive dialogue with their parents about what will happen in the future. Our findings also indicate that there is a need for further investigation into the specific experiences of adolescent siblings of people with an ASD.

The second aim of this study was to identify the differences in adolescent siblings' relationships and attitudes to a brother with an ASD. Content analysis of the interview data revealed that three of the siblings in our sample, two boys and one girl, offered more unusual accounts of their experience. By her own account and that of her mother, E strongly rejected her brother, whereas on several occasions B appeared to deny the existence of his brother's disability and didn't seem to see the problems his brother's disability caused. Finally, D felt that growing up with a brother with an ASD was a form of persecution, that he had been condemned to make sacrifices, particularly with respect to his social life, and that he might have to pay a heavy price in the future for having a brother with ASD.

These three adolescents' specific reactions to their brother's disability were suggestive of considerable suffering, although this was manifested differently in each case. E expressed anger and contempt for her brother and tried to distance herself from him now, and for the

future. B's response was one of denial. Like a father, he had taken responsibility for normalising the family context, ironing out the problems and making everything seem all right. However, the interview with his mother revealed that he was very isolated at school and had few friends. Finally, D appeared obsessed by the impact that his brother's disability had and would have on him and felt persecuted. He perhaps suffered the most out of the three siblings who displayed less typical responses. He ruminated, he judged himself and others and he worried about the future. He did not keep his suffering to himself or try to deny his problems; instead, he attempted to face up to the situation. D's mother reported that he always asked a lot of questions about his brother and about the future as if he was trying to control the family's situation. Research on expressed emotion (Brown, Birley, & Wing, 1972) provides an interesting perspective on these adolescents' responses to having a sibling with an ASD. In families where there is a child with an ASD, high levels of expressed emotions (criticism and over-involvement) are associated with poor adjustment (Greenberg, Seltzer, Hong, & Orsmond, 2006). In our sample, one-sided perceptions of one's relationship with a brother with an ASD, whether negative (E and D: criticism) or positive (B: over-involvement) were associated with greater suffering and social maladjustment, according to the mothers' reports. This suggests that difficulty in acknowledging both the positive and negative aspects of the relationship with a sibling with a disability may be a risk factor.

Although the extant literature suggests that the siblings of people with an autism spectrum disorder are generally well adjusted (Dempsey et al., 2012; Hastings & Petalas, 2014), the three cases discussed above reinforce the need to provide more support for this population. This suggests that the siblings of people with ASD would benefit from being involved in support groups or programmes (O'Brien, Duffy, & Nicholl, 2009). Almost all of the siblings interviewed, including D, said they would like to be involved in a self-help group, where they would be able to share their experiences and learn how to improve their

relationship with their brother. Psychological support would be even more useful to those siblings, such as E and B, who deny that they need it.

The study has some limitations. First, it is based on a small, non-homogeneous sample. The majority of participants were the older brothers of a sibling with an ASD. Other authors have reported on samples with a similar birth order and gender profile (Hastings, 2003) which indicates that these variables may be significant factors in this research area. The characteristics of the sample may limit the transferability of the findings. Second, the age range of the TD siblings (12–20 years) was quite broad, so given that each stage of adolescence has specific characteristics (Blos, 1962) there is a need for caution when generalising from this sample to the adolescent population as a whole. Research on more homogeneous or more representative samples of adolescents would be needed. Third, the study relied exclusively on data obtained from semi-structured interviews. The interview protocols contained some leading questions, which may have influenced the content of the participants' responses. Freer accounts of the experience of growing up with a sibling with ASD would be valuable, as would research combining various methods to provide a more detailed and more robust evaluation of adolescents' feelings towards their sibling with an ASD. Finally, in order to improve the reliability checks of the data analysis process, a further independent check of the themes that emerge in the study would be advisable.

These limitations notwithstanding, our study provides useful insights into adolescents' experiences of growing up with a brother with an ASD, and could be used to develop support programmes to improve their well-being. Such programmes should focus on issues common to the target population, providing opportunity for discussion with other adolescents in a similar family situation and providing information on ASDs. Support programmes could also be used to help the adolescent siblings of children with a disability plan for the future, including how to retain some personal autonomy whilst helping and supporting their family.

Our data also showed that there is a need to address the specific needs of a subgroup of adolescents who are more distressed by the presence of a sibling with a disability in their family, by providing personalised interventions.

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Association.
- Angell, M. E., Meadan, H., & Stoner, J. B. (2012). Experiences of siblings of individuals with autism spectrum disorders. *Autism Research and Treatment*, 2012, 1–11.
doi:10.1155/2012/949586
- Bass, J. D., & Mulick, J. A. (2007). Social play skill enhancement of children with autism using peers and siblings as therapists. *Psychology in the Schools*, 44, 727–735.
doi:10.1002/pits.20261
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, 51(9), 702–714. doi:10.1111/j.1365-2788.2007.00960.x
- Benderix, Y., & Sivberg, B. (2007). Siblings' experiences of having a sibling with autism and mental retardation: a case study of 14 siblings from five families. *Journal of Paediatric Nursing*, 22(5), 410–418. doi:10.1016/pedn.2007.08.013
- Blos, P. (1962). *On adolescence: A psychoanalytic interpretation*. New York, NY: Free Press.
- Brown, G. W., Birley, J. L. T., & Wing, J. K. (1972). Influence of family life on the course of schizophrenic disorders: A replication. *British Journal of Psychiatry*, 121, 241–258.
doi:10.1192/bjp.121.3.241
- Burnard, P. (1991). A method of analysing interview transcripts in qualitative research. *Nurse Education Today*, 11, 461–466. doi:10.1016/0260-6917(91)90009-Y
- Connell, Z. O., Halloran, M. O., & Doody, O. (2014). Living with a brother who has an autism spectrum disorder: a sister's perspective. *British Journal of Learning Disabilities*. doi:10.1111/bld.12109

- Constantino, J. N., Lajonchere, C., Lutz, M., Gray, T., Abbacchi, A., McKenna, K., & Todd, R. D. (2006). Autistic social impairment in the siblings of children with pervasive developmental disorders. *American Journal of Psychiatry*, *163*, 294–296.
doi:10.1176/appi.ajp.163.2.294
- Davis, K., & Gavidia–Payne, S. (2009). The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities. *Journal of Intellectual and Developmental Disability*, *34*(2), 153–162.
doi:10.1080/13668250902874608
- Dempsey, A. G., Llorens, A., Brewton, C., Mulchandani, S., & Goin–Kochel, R. (2012). Emotional and behavioural adjustment in typically developing siblings of children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorder*, *42*, 1393–1402. doi:10.1007/s10803-011-1368-9
- Dunn, J., & Kendrick, C. (1982). *Siblings: Love, envy and understanding*. Cambridge, MA: Harvard University Press.
- Green, L. (2013). The well–being of siblings of individuals with autism. *ISRN Neurology*, ID 417194, 1–7. doi:10.1155/2013/417194
- Greenberg, J. S., Seltzer, M. M., Hong, J., & Orsmond, G. I. (2006). Bidirectional effects of expressed emotion and behaviour problems and symptoms in adolescents and adults with autism. *American Journal of Mental Retardation*, *111*(4), 229–249.
doi:10.1352/0895-8017(2006)111[229:BEOEEA] 2.0.CO;2
- Harris, H. (2008). Meeting the needs of disabled children and their families: Some messages from the literature. *Child Care in Practice*, *14*, 355–369.
doi:10.1080/13575270802267796
- Hastings, R. P. (2003). Brief report: Behavioural adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders*, *33*, 99–104.

doi:10.1023/A%3A1022290723442

- Hastings, R. P. (2007). Longitudinal relationships between sibling behavioural adjustment and behaviour problems of children with developmental disabilities. *Journal of Autism and Developmental Disorders*, *37*, 1485–1492. doi:10.1007/s10803-006-0230-y
- Hastings, R. P., & Petalas, M. A. (2014). Self-reported behaviour problems and sibling relationship quality by siblings of children with autism spectrum disorder. *Child: Care, Health and Development*, *40*(6), 833–839. doi:10.1111/cch.12131
- Jackson, S., & Goossens, L. (2006). *Handbook of adolescent development*. New York, NY: Psychology Press.
- Kaminsky, L., & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry*, *43*, 225–232. doi:10.1111/1469-7610.00015
- Klein, P. S., Feldman, R., & Zarur, S. (2002). Mediation in a sibling context: The relations of older siblings' mediating behaviour and younger siblings' task performance. *Infant and Child Development*, *11*, 321–333. doi:10.1002/icd.261
- Lyons, A. M., Leon, S. C., Roecker Phelps, C. E., & Dunleavy, A. M. (2010). The impact of child symptom severity on stress among parents of children with ASD: The moderating role of coping styles. *Journal of Child and Family Studies*, *19*, 516–524. doi:10.1007/s10826-009-9323-5
- Macks, R. J., & Reeve, R. E. (2007). The adjustment of nondisabled siblings of children with autism. *Journal of Autism and Developmental Disorders*, *37*, 1060–1067. doi:10.1007/s10803-006-0249-0
- Mascha, K., & Boucher, J. (2006). Preliminary investigation of a qualitative method of examining siblings' experiences of living with a child with ASD. *British Journal of*

Developmental Disabilities, 52, 19–28. doi:10.1179/096979506799103659

Meadan, H., Stoner, J. B., & Angell, M. E. (2010). Review of literature related to the social, emotional, and behavioural adjustment of siblings of individuals with autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, 22(1), 83–100. doi:10.1007/s10882-009-9171-7

Moyson, T., & Roeyers, H. (2011). The quality of life of siblings of children with autism spectrum disorder. *Exceptional Children*, 78, 41–55.
doi:10.1177/001440291107800103

O’ Brien, I., Duffy, A., & Nicholl, H. (2009). Impact of childhood chronic illness on siblings: a literature review. *British Journal of Nursing*, 19(22), 1358–1365.
doi:10.12968/bjon.2009.18.22.45562

Orsmond, G. I., & Seltzer, M. M. (2009). Adolescent siblings of individuals with an autism spectrum disorder: Testing a diathesis-stress model of sibling well-being. *Journal of Autism and Developmental Disorders*, 39, 1053–1065. doi:10.1007/s10803-009-0722-7

Petalas, M. A., Hastings, R. P., Nash, S., Reilly, D., & Dowey, A. (2012). The perceptions and experiences of adolescent siblings who have a brother with autism spectrum disorder. *Journal of Intellectual and Developmental Disability*, 37(4), 303–314.
doi:10.3109/13668250.2012.734603

Ross, P., & Cuskelly, M. (2006). Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual and Developmental Disability*, 31, 77–86. doi:10.1080/13668250600710864

Smith, L. O., & Elder, J. H. (2010). Siblings and family environments of persons with autism spectrum disorders: A review of the literature. *Journal of Child and Adolescent Psychiatric Nursing*, 23, 189–195. doi:10.1111/j.1744-6171.2010.00240.x

- Smith, L. O., Elder, J. H., Storch, E. A., & Rowe, M. A. (2015). Predictors of sense of coherence in typically developing adolescent siblings of individuals with autism spectrum disorder. *Journal of Intellectual Disability Research*, 59(1), 26–38. doi:10.1111/jir.12124
- Thomas, S., Reddy, N., & Sagar, J. V. (2015). Psychosocial issues of siblings of children with autism spectrum disorder. *International Journal of Advanced Research*, 3(4), 119–124. Retrieved from https://scholar.google.it/scholar?as_q=Psychosocial+issues+of+siblings+of+children+with+autism+spectrum+disorder&as_epq=&as_oq=&as_eq=&as_occt=any&as_sauthors=&as_publication=&as_ylo=&as_yhi=&btnG=&hl=it&as_sdt=0%2C5
- Verté, S., Roeyers, H., & Buysse, A. (2003). Behavioural problems, social competence and self-concept in siblings of children with autism. *Child: Care, Health and Development*, 29, 193–205. doi:10.1046/j.1365-2214.2003.00331.x
- Wintgens, A., & Hayez, J. Y. (2003). Le vécu de la fratrie d'un enfant souffrant de handicap mental ou de troubles autistiques: résilience, adaptation ou santé mentale compromise [The experience of siblings of a child with mental disability or autism: resilience, adjustment or compromised mental health]. *Neuropsychiatrie de l'enfance et de l'adolescence*, 51, 377–384. doi:10.1177/1049732308320112
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research*, 18(8), 1075–1083. doi:10.1177/1049732308320112

Table 1. Demographic information on participating families

Identifying code	Age (in years) and gender	Mother's age in years	Age in years, gender and functional level ^a of the sibling with ASD	Number of children in the home	Marital status of parents
B	19, M	50	17, M, l	3	Married
A	14, M	40	12, M, m	2	Married
E	16, F	50	12, M, l	4	Married
F	14, F	47	17, M, l	4	Married
C	20, F	47	16, M, l	2	Married
S	14, M	50	20, M, m	2	Married
T	12, F	45	15, M, m	2	Married
G	17, M	52	12, M, m	3	Married
D	17, M	51	14, M, l	2	Married
R	13, F	47	12, M, m	2	Married
N	18, M	50	12, M, m	2	Married
M	16, M	43	15, M, l	2	Married
P	15, M	42	14, M, m	2	Married
O	20, M	52	17, M, l	3	Married

^al = low functioning; m = moderate functioning

Table 2. Sibling interview protocol.

1. How would you describe your brother to someone who does not know him?
2. For you, your brother is...?
3. How do you see yourself?
4. How would your friends describe you? (give me at least three characteristics)
5. How would your parents describe you? (give me at least three characteristics)
6. How do you see your future?
How do you see your family's future?
7. Would you know how to describe autistic disorder to someone who does not know your brother?
8. Are you able to manage your brother's behaviour?
9. Do you help your parents' to manage your brother?
10. Do you invite your friends to your home?
Do you speak about your brother with them?
11. Would you like to talk to someone about how you feel?

Table 3. Mother interview protocol.

-
1. Can you tell me how you explained to your [son/daughter] that [his/her] brother was autistic?
When did [he/she] learn about [his/her] brother's disability?
From whom?
Did your [son/daughter] ask a specific question or did you tell them on your own initiative?
How did your [son/daughter] react?
 2. How does your [son/daughter] find living with an autistic brother?
 3. How does [he/she] react to his/her brother's crises?
How does [he/she] feel?
What difficulties has [he/she] had to face?
Over time, has there been any change?
 4. How do you see your [son/daughter]'s role in the family?
 5. How does the fact that [he/she] has a brother with a disability affect your [son/daughter]'s relationships with friends?
Does [he/she] speak about him with friends?
Does [he/she] invite [his/her] friends home?
 6. What do you like about your [son/daughter]?
 7. How do you see your family's future?
 8. Does your [son/daughter] get any psychological support?
(yes) what kind?
(no) Do you think that [he/she] needs it?
-