



Contents lists available at ScienceDirect

Research in Autism Spectrum Disorders

journal homepage: www.elsevier.com/locate/rasd

Growing older with autism – The experiences of adult siblings of individuals with autism



Philippa Moss^{a,*,1}, Vasiliki Eirinaki^{a,2}, Sarah Savage^{a,3}, Patricia Howlin^{a,b}

^a Institute of Psychiatry, Psychology and Neuroscience, King's College London, SE58AF, United Kingdom

^b Faculty of Health Sciences, Brain & Mind Centre, University of Sydney, NSW2050, Australia

ARTICLE INFO

Keywords:

Autism siblings
Sibling experience
Impact on siblings

ABSTRACT

Background: Most studies of siblings of individuals with autism have involved children or adolescents. In the present study we explored the experiences of adults with a brother or sister with autism.

Method: As part of a larger scale, adult sibling study, 56 individuals (37 females, 19 males; mean age 40 years) were asked about their experiences of growing up with a sibling with autism and about their worries for the future.

Results: Most participants (77%) described positive benefits, often related to the impact on their own life or personality (e.g. making them more tolerant or caring) and to the positive characteristics of their sibling with autism. Only 14% could describe no positive aspects. The principal problems described were related to coping with behavioural difficulties (39%) and disruption to family relationships (32%) or social life (23%). There was no association between the level of negative descriptions and individual sibling characteristics, participants' social functioning or mental health. The main concerns for the future, expressed by the majority of participants, focussed on problems of finding appropriate care (77%) and the potential emotional impact on the autism siblings of loss of parents.

Conclusions: Most participants described a mix of positive and negative experiences but current concerns focussed predominantly on future longterm care. Many adult siblings will become increasingly responsible for ensuring the welfare of the individual with autism. Medical and other services need to recognise the importance of this role, and the need actively to involve siblings in care planning and decision-making.

1. Introduction

Early research on the impact of having a brother or sister with autism was often based on the premise, either implicit or explicit, that the experience would be largely negative (see DeMeyer, 1979; Lobato, 1983; McHale, Sloan, & Simeonsson, 1984). Some more recent studies, too, suggest that siblings of a child with autism have a higher risk of emotional, behavioural and relationship problems

* Corresponding author at: Nuffield Hearing and Speech Centre, Royal National Throat, Nose and Ear Hospital, London, WC1N 3JH, United Kingdom.

E-mail addresses: philippa.moss4@nhs.net (P. Moss), Vasiliki.eirinaki@roehampton.ac.uk (V. Eirinaki), sarahsavageblanchard@gmail.com (S. Savage), patricia.howlin@kcl.ac.uk (P. Howlin).

¹ Present address: Nuffield Hearing and Speech Centre, Royal National Throat, Nose and Ear Hospital, 330 Grays Inn Road, London WC1X 8DA.

² Present address: University of Roehampton, Roehampton Lane, SW15 5PJ.

³ Present address: Goldman Sachs, New York, New York.

<https://doi.org/10.1016/j.rasd.2018.10.005>

Received 10 April 2018; Received in revised form 7 August 2018; Accepted 11 October 2018
1750-9467/ Crown Copyright © 2018 Published by Elsevier Ltd. All rights reserved.

than other children (e.g. Jokiranta-Olkoniemi et al., 2016). In contrast, other studies describe better social, behavioural and emotional adjustment among these siblings than among their peers in the general population, while others report little evidence of increased risk (See for example, Ferraioli & Harris, 2009; McHale, Updegraff, & Feinberg, 2016; Meadan, Stoner, & Angell, 2010; Orsmond & Seltzer, 2007; Petalas et al., 2012; Pilowski et al., 2004; Smith & Elder, 2010; Tudor, Rankin, & Lerner, 2018). It is now evident that there is substantial variation in the adjustment and relationships of young siblings of children with autism and recent research in this area has focused on the variables that may affect individual outcomes. These include: age and gender (both of the child with autism and their sibling); characteristics of the autism sibling and presence of the broad autism phenotype in the non-ASD sibling (e.g. Hastings, 2003; Kaminsky & Dewey, 2002; Orsmond, Kuo, & Seltzer, 2009; Macks & Reeve, 2007; Petalas et al., 2012; Tomeny, Barry, & Bader, 2012; Tomeny, Baker, Barry, Eldred, & Rankin, 2016; Verté, Roeyers, & Buysse, 2003; Walton, 2016); family size, socioeconomic status and family support (e.g. Meadan et al., 2010; Orsmond et al., 2009); quality of the sibling relationship (e.g. Burke, Taylor, Urbano, & Hodapp, 2012; Coyle, Kramer, & Mutchler, 2014; Tozer & Atkin, 2015; Tudor et al., 2018); and individual and/or family coping styles (e.g. Hesse, Danko, & Budd, 2013; Ross & Cuskelly, 2006; Tsai, Cebula, & Fletcher-Watson, 2017).

Most studies suggest that siblings' adjustment is negatively correlated with the level of behavioural disturbance shown by the child with autism; the likelihood of siblings showing internalising and externalising symptoms also increases with the number of risk factors they experience (Macks & Reeve, 2007). On the whole, too, higher levels of sibling disturbance are reported in families who are experiencing more stress, have poorer social support networks, or are of lower socio-economic status. Sisters tend to be less negatively affected than brothers; older siblings are often better adjusted than younger ones, and having more than one non-autistic sibling also seems to be a protective factor. However, as highlighted by Macks and Reeve (2007) and Meadan et al. (2010), findings on the impact of many of these variables are inconsistent. For example, Pilowsky, Yirmiya, Doppelt, Gross-Tsur, and Shalev, (2004) found no association between siblings' gender and social adjustment, and birth order has not been a predictor in several studies (eg., Kaminsky & Dewey, 2002; Pilowsky et al., 2004). Hastings (2003) failed to find an association between family support or maternal stress and siblings' social and academic adjustment, and findings on family size and socioeconomic status are also mixed (Meadan et al., 2010). It is likely that methodological limitations (e.g. small sample sizes, samples of different ages, different methods of data collection and different comparison groups) contribute to these inconsistencies and compromise comparisons across studies (Meadan et al., 2010). It is also evident, from most reviews in this area, that the majority of research to date has focused on child or adolescent siblings and there has been relatively little exploration of the impact on adult siblings.

Amongst studies that do involve older siblings, Ferraioli and Harris (2009) concluded that "The majority of siblings of children with ASDs function well as children, adolescents, and adults" and they note that young adult siblings were more likely to aim for a career in the caring professions. However, they also list a number of specific challenges for older siblings, including concerns about the risk of having a child with autism and worries about aging parents. The psychological impact on adult siblings, who face the prospect of taking on a greater caring role as parents age, is noted by other researchers (e.g. Tozer & Atkin, 2015; Tozer, Atkin, & Wenham, 2013). These siblings also tend to have poorer physical health, higher levels of stress and depression, and lower life satisfaction than siblings of individuals with other intellectual disabilities (Hodapp & Urbano, 2007; Tomeny, Ellis, Rankin, & Barry, 2017). Sibling attitudes, too, are more negative, and negative sibling relationship attitudes are, in turn, associated with poorer mental health (Orsmond and Mailick Seltzer, 2000; Tomeny, Ellis et al., 2017; Tomeny, Barry, & Fair, 2017)

2. Background to present study

The present data set arises from a series of studies of individuals with autism and their families (Bailey et al., 1995; Bolton et al., 1994; Fombonne, Bolton, Prior, Jordan, & Rutter, 1997). In these studies, the cognitive, linguistic and behavioural profiles of first-degree relatives of 99 children, randomly selected from clinical case files and with a confirmed diagnosis of autism, were assessed in detail. Diagnostic assessments indicated that 74% of probands' siblings were "unaffected" by autism (i.e. they showed no deficits in social or communication interaction and did not exhibit repetitive or stereotyped behaviours/interests); 20% were identified as having the "broader autism phenotype" (BAP; i.e. they showed subtle communication/social impairments and/or stereotypic behaviours); 6% were diagnosed with ASD. (See Bolton et al., 1994; Bolton, Pickles, Murphy, & Rutter, 1998; Fombonne et al., 1997; Howlin, Moss, Savage, Bolton, & Rutter, 2015). The average age at which sibling status ("unaffected", BAP, ASD) was initially confirmed was 20.4 years (range 8–35 years). Approximately 20 years later, siblings were invited to take part in a follow-up study. In a previous paper (Howlin et al., 2015) we describe the cognitive, social and mental health outcomes of these siblings. In the present paper we focus on the "unaffected" siblings' experiences of growing up with a brother or sister with autism.

2.1. Aims

The main aims of the study were to:

- i provide a descriptive account of older siblings' reported experience of growing up with a brother or sister with autism.
- ii summarise their concerns for the future.
- iii explore the relationship between extent of negative experiences/emotions reported and factors noted as significant in child sibling studies: gender; sibling ages and age-gap between siblings; number of siblings in family; ability level of autism sibling; mental health and social outcome of non-ASD sibling.

Table 1
Sibling characteristics.

Sibling with autism	
Age	Mean 39.3 yrs; sd 8.9; range 20-60
Gender	38 (68%) male; 18 (32%) female
IQ level in childhood	≥ 70 = 43% < 70 = 57%
Non-ASD sibling	
Age	Mean 40.3 yrs; sd 8.4; range 23-58
Gender	37 (66%) female; 19 (34%) male
Adult IQ	Mean 117.6; sd 10.4; range 92-137
Social outcome score (0 = good; 5 = poor)	Median = 0; range 0-5
Mental Health rating (0 = good; 8 = poor)	Median = 0; range 0-8
GHQ score (0 = no problem; 30 poor mental health)	Median = 11; range 0-30

3. Method

3.1. Participant selection

From the families involved in the original studies we identified 152 adult siblings (age 18+) who had been initially assessed as “unaffected” by autism; all had a full-scale IQ ≥ 70 . Three families in which a family member had died since our last contact were not asked to take part. In families with three or more siblings, only the two siblings closest in age to the proband with autism were invited to participate in order to avoid excessive demands on individual families. These restrictions reduced the number of eligible participants to 121. Of these, 32 individuals (26%) declined; 19 (16%) did not respond; 70 (58%) agreed to participate in some form but only 59 (49%) completed direct assessments. Among the 11 individuals who did not provide information directly (and who therefore did not participate in the interviews about their siblings), four lived in America or Australasia and in five cases parents considered that their son or daughter would be upset by being interviewed; another two individuals initially agreed but later failed to respond.

Of the 59 who agreed to direct assessments, we excluded the three youngest individuals (age 19–22) who were still living at home as we wanted to focus on the experiences of siblings who were living independently and/or in their thirtieth year or older. The average age of the final sample was 40 years; the average full-scale IQ was 117 (See Table 1).

Initial contacts with siblings were made via parents, all of whom had agreed to be re-contacted for future research studies. Ethical approval was obtained from the Joint South London Maudsley/ Institute of Psychiatry NHS Research Ethics Committee (reference: 07/H0807/65;19/12/07).

4. Assessments

Full details of all assessments are described in Howlin et al. (2015).

IQ. Cognitive assessments were based on the Wechsler Abbreviated Scale of Intelligence (Wechsler, 1999).

4.1. Social functioning

Assessments of social outcome were based on a modified version of *The Family History Schedule* (FHS; Bolton et al., 1994), a semi-structured interview developed for family studies of autism (1998, Bolton et al., 1994; Fombonne et al., 1997; Pickles et al., 2000; Pinto et al., 2010). This provided information on residential status, employment, friendships and intimate relationships. Outcome in each domain is rated from 0 (no difficulties) to 3 (severely impaired). A composite outcome rating is derived from the total score for the four domains. (See Supplementary Tables 1 & 2).

4.2. Mental health

The FHS also provided information on the presence of psychiatric disorders (OCD, bipolar disorder, depression, anxiety, other psychoses), each rated from 0 (no problem) to 3 (severe/needing inpatient treatment). The total score was used to indicate overall level of psychiatric problems (0 = none to ≥ 15 = severe difficulties; details in Supplementary Table 3). Siblings also completed the *General Health Questionnaire-12* (GHQ-12, Goldberg et al., 1997) a widely used brief psychiatric screen. We used the Likert scoring (0–3), for which a cut-off score of 11 or 12 is an indicator of clinical ‘caseness’.

Most recent level of employment and GHQ-12 scores were compared with data for a similar age group of individuals (n = 11,419; age 41–42 years) provided by *The National Child Development Survey: Sweep Six, 1999–2000* (Bynner, Butler, Ferri, Shepherd, & Smith, 2000)

Table 2
Examples of responses to question: How does it feel to grow up with a sibling with autism?

Main category N(%) siblings reporting ¹	Sub categories % siblings reporting	Examples
Positive emotions/ experiences 7 (13%)	Benefits to own life 3 (5%)	“Made me more tolerant” “Empowering”; “I am a more responsible person” “I had to be independent since young”
	Positive aspects of sibling 6 (11%)	“Fantastic personality” “Great to be with” “Wouldn't want her to change” “Proud to be his brother” “Great respect for him...grateful”
Acceptance 23 (41%)	Always accepted the situation 20 (36%)	“No real problem” “We were protected by parents” “Just got used to it”
	Delayed acceptance 3 (5%)	“Hard when younger; not a problem now” “It's normal now”
Negative emotions/ experiences 52 (93%)	Negative experience 4 (7%)	“Horrible”; “Pain in the arse” “Wrecked all our lives”
	Guilt 2 (3.5%)	“Always felt not doing enough” “Not keeping contact”
	Sadness/worry for sib 13 (23%)	“I feel upset about it as its not fair on her” “Feel sorry for him, what will his life be like growing up - frustrating, restrictive?” “People are ignorant of his autism- this worries me” “Feel sorry for Mum and Dad; its been hard on them”
	Sadness/worry for parents 2 (3.5%)	“As a child I was embarrassed for parents”
	Loss/missing out on family life/restrictions on own life 11 (20%)	“I always felt like only child” “No sibling friendship” “Parents were preoccupied with him”
	Embarrassment/ confusion 10 (18%)	“I was baffled- didn't understand” “Felt embarrassment in front of friends”, “As teenager- I was embarrassed” “Trying to explain to others was difficult”
	Difficulties due to sibs' behaviour/autism symptoms 17 (30%)	“Growing up, was embarrassed when others stared” “Always worried he will say something inappropriate” “Her autism has been a source of sadness and frustration” “Difficult to communicate with her” “Different because disorder was rare at that time” “Hard to cope with his screaming”
Other 2 (3.5%)	“He could be violent, but I had a happy childhood even so”	

¹ Many siblings gave multiple responses hence total % in sub-categories may exceed total in Main Category.

4.3. The experience of having a sibling with autism

Several additional questions were added to the standard FHS to obtain information on the overall experience of growing up with a brother or sister with autism. Siblings were asked one general question: “How does it feel to grow up with a sibling with autism?” and three specific questions: (a) “What were the positive aspects of growing up with a sibling with autism?” (b) “What were the negative aspects?” (c) “Do you have any worries for the future?”

5. Analysis

5.1. Analysis of sibling responses

Siblings' answers to the questions about their brother or sister with autism were recorded in writing at the time of the interview and subsequently transcribed in SPSS by PM & SS. A research assistant (VE) listed the emotion/ experience associated with each answer or part of answer (most responses had multiple parts). Ratings were then checked by PH. Following joint discussion, any disagreements were resolved and composite codes were derived to encompass the many individual categories. Assignment to these composite codes was first completed by VE and responses independently rated by PH. Subsequently, a frequency analysis of the individual categories was conducted. Low frequency but similar problems were combined into a single category. Composite codes containing a very large number of individual items were further subdivided and an “Other” category was added to encompass seven items that did not fit within the existing categories. The final categorisation system is described in Tables 2–5 and further details of the process are described in Supplementary Material, Note 1.

To explore the relationship between participants' experiences of growing up with a sibling with autism and individual variables

Table 3

Examples of responses to question: What are the positive aspects of growing up with a sibling with autism?

Main category % of siblings reporting ¹	Subcategories % of siblings reporting ¹	Examples
Positive effects on own life/personality 31 (55%)	Tolerance/better understanding/more empathy 25 (45%)	“More compassionate about others” “Made me mature quicker, he has made me a nicer more caring person” “Acute awareness of how others respond” “I am now in a helping profession” “Engenders compassion” “I am more open minded towards people-less judgemental” “More accepting of people’s differences,... very open because of him”
Positive characteristics of person with autism 18 (32%)	Better able to manage others’ problems/ understanding of disability 7 (13%)	“Helped with work” “Can deal with difficult people- my communication skills are better as a result” “Reliable” “When he did show affection it was special” “He’s good fun” “She is able to love” “Very honest and open”
Positive effects on family 4 (7%)	Increased family closeness	“Brought family closer together and we are supportive of one another”
No positive aspects 8 (14%)		“None-too low functioning - no interaction”
Other 5 (9%)	No difference from normal. 2 (3.5%) Unclassified. 3 (5%)	“I just saw him as my brother” “it’s normal” “He’s in a good placement”

¹ Some siblings gave multiple responses so % of subcategories exceeds total % in main category.

(age, gender, mental health etc.), an overall rating of “negativity” was constructed based on the balance between positive and negative statements in response to the first three questions. A rating of 0 = no negative statements; 1 = mostly positive (> 1 point difference between the number of positives and negatives); 2 = almost/equal mix of positive and negative statements (≤ 1 point difference between numbers of positives and negatives); 3 = mix of positive and negative statements but more negatives (> 1 point difference between number of negatives and positives); 4 = all comments negative.

5.2. Statistical analysis

Data on siblings’ reported experiences are presented as frequencies (n & % siblings reporting); categorical data are presented as medians; continuous data (age, non-ASD sibling IQ scores) as means. Correlational data (rho) or Mann Whitney U tests were used to test the association between variables. A multiple regression analysis had been planned to explore factors that best predicted ratings of negativity but as all correlations were found to be very low (all ≤ 0.2) this was not conducted.

6. Results

6.1. Participant characteristics

The sample comprised 56 non-ASD siblings (37 female and 19 males). Details of ages, IQ, social outcome ratings, employment level and mental health are provided in Table 1. Prior to this study, the deaths had occurred of four mothers (7%) and five fathers (9%); in one family both parents had died. In none of these families was the sibling the main carer, as the person with autism lived either with the remaining parent or was in residential care.

As reported in our earlier paper (Howlin et al., 2015), non-ASD siblings were generally high functioning. Within the present sub-sample, all were of at least average IQ; social outcomes (independence, job, social relationships) were rated as good or very good in all cases; none was unemployed and they were significantly more likely to be in managerial/professional jobs than in the comparison general population NCDS cohort (42% vs. 15%; $X^2 = 17.9$; $p < .001$). Most (91%) were living independently and 90% reported having had long-term intimate relationships; 76% were or had been married or cohabitating with a partner. However, there were more difficulties related to mental health. Although the median score indicated that many siblings had good mental health, 42% were rated as having (currently or in the past) significant mental health problems. Median scores on the GHQ-12 were also above those of the NCDS sample (11.0 vs 9.0) and 47% had scores at or above the suggested level for clinical caseness.

Details on the probands with autism were limited and we did not have data on severity of behavioural or autistic difficulties in childhood. Most were male and over half had an IQ below 70 when assessed in childhood (see Table 1). Just under half (45%) of autism siblings were younger than their non-ASD sibling, with the median age gap being two years. The median number of children in each family was 3.0 (range 2–4).

Table 4

Examples of responses to question: What are the negative aspects of growing up with a sibling with autism?

Main category % siblings reporting ¹	Subcategories % siblings reporting	Examples
Difficulties due to sibling's behaviour/ autism. 22 (39%)	Aggression/ Unpredictability. 6 (11%)	"Would get upset about simple things" "It was hard to see him self-injure" "Worry he will lash out" "He can be very aggressive"
	Rituals; rigidity etc. 15 (27%)	He was frustrating, repeatedly asking questions related to his obsessions." "Obsessions are so strong- can't stop talking about them, rigid and ritualistic". "Always self centred".
	Lack of social/communication/ other skills. 13 (23%)	"She knows there is something wrong and gets upset, ... she can't communicate"
Impact on family relationships 18 (32%)	Affected family relations; lack of parental support. 15 (27%)	"Felt neglected" "Dad wasn't around much and mum always with brother" "Mother always anxious, family unhappy" "Mum and dad very preoccupied"
	Missing out on sibling relationship. 8 (14%)	"Don't have sibling relationship with him" "He can't be a typical older brother" "We can't be friends like I am with my other brother"
	Restriction of activities; "missing out on normal life". 7 (12%)	"As child- couldn't have people round or go on holidays" "No holidays when growing up"
Impact on social life and relationships 13 (23%)	Isolation; loneliness; bullying by other children 11 (20%)	"Isolating... I was bullied at school due to her autism"
	Embarrassment. 7 (12%)	"I was confused, embarrassed" "Dreaded bringing people home"
	Concerns re parents. 3 (5%)	"Mockery, growing up with people purposefully saying horrible things" "I worry for mum and the parental guilt she experiences"
Worry/anxiety 12 (21%)	Concerns re sib's future. 12 (21%)	"Sorting out long term care was difficult as parents were reluctant to accept this" "I should be seeing her more and take more responsibility"
	Concerns re own life 10(18%)	"it's a source of tension within me but you can only do so much" "I used to worry my own kids would have it" "Difficulties now relate to provision for him" "Giving up time more likely in future"
Guilt/ regret at not doing/being able to do more to help or support 6 (11%)	Effect on relationship. 2(4%)	"Feel have to take on responsibility from parents"
	Anxiety re care arrangements .1(2%)	"It used to be relentless and very tiring"
	Tiredness/exhaustion/ responsibility. 5(9%)	"I resented him...life geared around his disability"
Concerns re own life 10(18%)	Resentment. 1 (2%)	
No problems 1 (2%)		

¹ Many siblings gave multiple responses hence total % exceeds 100%.

6.2. Siblings' reported experiences

Q1. How does it feel to grow up with a sibling with autism?

To this general question about growing up with a brother or sister with autism, responses were split into 3 main categories: (i) Positive emotions/positive impact on life; (ii) Acceptance; (iii) Negative emotions/ experiences. A miscellaneous "Other" category was also added. Almost all siblings (93%) reported some negative experiences or emotions but only 7% expressed strongly negative feelings ("It was horrible"; "wrecked all our lives"). The main problems related to feelings of guilt and sadness (for sibling or parents); limitations on family or social life, and confusion, embarrassment or difficulties caused directly by the siblings' behaviours or autism symptoms (see Table 2). Many siblings (41%) noted that, on the whole, they had grown up accepting the situation, either because they were protected well by their parents or because "we just got used to it"; 5% said it had been hard when they were younger but then they grew to accept it. Positive emotions/experiences were described by 13%, either because of benefits to their own development or the positive characteristics of their sibling (See Table 2 for examples).

Q2. What were the positive aspects of growing up with a sibling with autism?

When asked specifically to describe any positive aspects of having a brother or sister with autism, 77% of siblings reported some benefits; 55% described positive effects on their own lives or development and 32% focussed on the agreeable characteristics of the person with autism; 7% thought the experience had brought the family closer (see Table 3).

Q3. What were the negative aspects of growing up with a sibling with autism?

Only one individual said that there had been no problems. The most common problem (reported by 39%) related to difficulties

Table 5
Examples of responses to question: What are your main worries for the future?

Main category % siblings reporting ¹	Subcategories % siblings reporting	Examples
Long-term future 49 (86%)	Impact of death of parents. 24 (43%) Future care arrangements /quality of support. 43 (77%)	“How will he cope with bereavement when mum dies?” “What will happen when mum passes as she knows about the services.” “What will happen to him when he is older?” “Who will take care of him when he is older?” “I worry about his getting older-there is not much support where he lives and he is very vulnerable” “Will he continue to be looked after and will it be enough?” “Borough not supportive we will have to fight for support...not sure if we can fight in way mum has done, no faith in council support” “What will happen when mum dies as he is very attached?” “It’s a constant worry- I want to see her happy and she is not” “It is difficult as its hard to know if he is happy and I worry that he is unhappy but can’t say so” “He’s quite independent but I worry about his physical health” “I worry about him, sad he will never have the love of a relationship, worry about his medication” “How will I see him enough when mum dies?” “I worry that the responsibility of her care will fall to me” “I will have to be his focal point when parent die, it impacts on my future”
Worries re sibling’s mental or physical health 16 (29%)		
Impact on self/own life 26 (46%)		
No concerns 5 (9%)		
Assume rest of family will help out 4 (7%)		

¹ Many siblings gave multiple responses hence total % exceeds 100%.

caused by siblings’ behavioural or autism-related difficulties. Almost one-third described a negative effect on family relationships, such as parents’ time/attention being taken up with the sibling with autism, or their regret at not being able to have a normal sibling relationship. Many (23%) described limitations on their own lives (not being able to take trips or holidays) and social isolation, often due to embarrassment, or rejection by their peer group. One fifth reported being affected by concerns for their parents or the sibling with autism; 11% described feeling guilty at not doing enough/taking enough responsibility for their sibling. More general worries (about the possibility of having a child with autism; impact on relationships; responsibility for care arrangements etc.) were expressed by 18% (See Table 4).

Q4. Do you have any worries for the future?

Nine per-cent of siblings said they had no particular worries but 21% described one main worry; 36% listed two concerns; 35% noted three or more areas of concern. Most worries centred on the long-term future for the sibling with autism. Many siblings (43%) worried about the impact of parents becoming infirm or dying. This was because of the possible psychological effects on their sibling (grief, bereavement) and/or the fact that parents would no longer be able to be the main caretaker. The potential loss of parents was closely associated with worries about access to, or quality of long-term care, which were described by the majority (77%) of siblings. Just under a third of siblings expressed anxiety about the physical and/or mental well-being of their brother and sister. Many (46%) were also concerned about the possible effects on their own lives should they need to take over greater responsibility for care, although 7% said they assumed other family members would help out with this. (See Table 5).

6.3. Factors associated with greater negativity of experience

As noted above, the degree of negativity expressed by siblings was rated on a 5-point scale (0= no negative experiences/feelings described; 4= no positive experiences/feelings described). The median “negativity rating” was 2.0 indicating similar numbers (i.e. within one point) of negative and positive statements. One sibling reported no negative feelings/experiences and 36 (64%) described equal numbers of positive and negative experiences. Eleven individuals (20%) reported more negative than positive experiences but only 8 siblings (14%) could describe nothing positive. There was no association between this negativity rating and any of the variables studied (i.e. ages of autism and non-autism siblings; age gap between siblings; number of siblings in family; social outcome and mental health ratings of non-ASD sibling) and all correlations were small and non-significant. (See Table 6). There was also no difference in negativity ratings according to the gender of the non-ASD sibling (Mann Whitney $z = -.003$; $p = .98$); gender of the autism sibling (MW $z = -0.33$; $p = .74$); IQ level of autism sibling ($\geq 70 / < 70$; MW $z = -0.08$; $p = .94$; median scores for each sub-group = 2.0).

7. Discussion

In this study we explored the personal experiences of adults in middle adulthood who were raised with a sibling with autism. At the time of the interview, the mean age of participants was 40 years; that of their autism siblings was 39 years. The findings reflect the

Table 6
Correlations between siblings' "negativity rating" and other variables.

¹ Negativity rating and:	<i>rho</i>	<i>p value</i>
1. Age non-autism sibling	-.05	.71
2. Age autism sibling	.02	.89
3. Age gap between siblings	-.08	.56
4. No. of siblings in family	-.03	.85
5. Non-autism sibling overall social outcome rating	-.20	.14
6. Non- autism sibling mental health rating	.02	.89
7. GHQ score	.16	.24

¹ N for variables 1–4 = 56; N for variables 5–7 = 55.

variable outcomes reported in previous studies focusing on child siblings. Thus, almost all participants reported some negative aspects of growing up with a brother or sister with autism, with the main difficulties being related to the sibling's behavioural or autistic symptoms, or to disruption in family and/or social life. Feelings of guilt about not doing enough, or concerns about parents or the sibling with autism were also common. Nevertheless, almost all siblings could describe positive aspects, including pleasure in their sibling's character and beneficial impacts on their own personal development. Current concerns centred mainly on access to and quality of long-term care provision.

These results confirm the view that growing up with a sibling with autism is a very mixed experience (cf. Kovshoff, Cebula, Tsai, & Hastings, 2017). Although almost all participants reported some negative aspects, these were mostly balanced by positive experiences as well. Only eight individuals could describe nothing positive. It was also clear that the majority of siblings was functioning well as adults. All were of above average IQ, most lived fully independent lives, and rates and levels of employment were higher than in the general population. The only area in which siblings had more difficulties than the general population was in mental health (Further details in Howlin et al., 2015), but this was not related to the extent of negative or positive experiences reported.

Recent studies (e.g. Kovshoff et al., 2017; Tudor et al., 2018) highlight the many variables that can affect the adjustment of siblings of children with disabilities and it is clear that much more understanding is required of the multiple and complex interactions influencing sibling outcomes. In the present study we were able to explore only a few of these variables, none of which, including mental health problems or current social relationships, appeared to be related to the level of negativity reported. However, we have no formal data on family functioning or family support networks, or on other individual or demographic risk factors that may have influenced siblings' experiences. Similarly, we lack details of the overall level of disturbance/disability of the siblings with autism, or the quality of the sibling relationship, either in adulthood or as children. Moreover, there was only one family in which both parents had died and we do not know what the future effects on siblings may be when they have to take on the main responsibility as carer or legal guardian.

The study suffers from a number of other methodological issues. Firstly, siblings were recruited from a cohort of families who have continued to be involved in research over several decades and thus they are not necessarily representative of siblings in families who are unable or unwilling to participate in research. Secondly, the IQ level of the siblings with autism was relatively high (43% had an IQ \geq 70), which again raises questions about the representativeness of the sample. Thirdly, data on siblings' experiences were based on responses to a few specific questions (i.e. "What were the negative/positive experiences?") taken from a very detailed questionnaire about their lives as adults and participants were not explicitly asked to elaborate or expand on their initial answers. Moreover, coding of information was not based on a formal, qualitative content analysis but rather on the assignment of responses to specific categories. The "negativity rating" was also an attempt to assess the balance between negative and positive comments at a single point in time; we have no data on the longer-term stability or other qualities of this rating. Finally, the study did not include any comparison group.

Despite these limitations the study adds to existing, mainly child-based literature, by confirming that being an adult sibling of someone with autism has both positive and negative effects. It also suggests that there is little or no direct association between functioning in adulthood and the experiences of having a sibling with autism. Anecdotally, too, several siblings noted that although they had negative experiences as children, these had diminished or disappeared as they grew older. While these are positive findings, the one area of major concern is that the majority of siblings now had serious anxieties for the future. Issues such as the lack of residential provision, inadequate or inappropriate services, problems arranging care when parents were no longer around to offer support, were a major source of worry for many. Currently, none of the siblings was the main carer for the adult with autism but there were concerns that they might have to take on this role if both parents died or became incapable. It is very likely that, with time and with continued cuts to services, more will be obliged to take on responsibility for their siblings' care (c.f. Nuttall, Coberly, & Diesel, 2018) and that worries about the future will increase. Tozer and Atkin (2015) note that, although adult siblings can play a crucial role in the lives of their brothers and sisters with autism, very few siblings have *any* contact with services until well into adulthood. They suggest that professionals responsible for the welfare of individuals with autism should be much more involved with adult siblings, and at a much earlier stage. Tozer and Atkin (2015) also found that siblings were in need of information and support around future care options, and they lacked advice about bereavement support for their brother or sister should parents die.

8. Implications

As the number of older adults with chronic conditions, such as autism, grows, it will become ever more important for professionals to recognise and value the role that siblings can play (Hallion, Taylor, & Roberts, 2018). This study highlights siblings' concerns about future provision for their brother or sister with autism and many may also require support for their own mental health problems. Consequently it is essential that their needs for information and support are fully recognised and that appropriate help is provided long before parents are no longer able to cope. More research is also needed into the practical, financial and emotional impact on siblings when parents die and they are left to take over the main responsibility for their brother or sister with autism.

Declaration

The authors declare no conflict of interests

Acknowledgements

We are most grateful to all the families who gave so generously of their time during the course of the study. We are also indebted to Professors Michael Rutter and Patrick Bolton for their advice and input throughout the study. The research was funded by the Nuffield Foundation.

References

- Bailey, A., Le Couteur, A., Gottesman, I., Bolton, P., Simonoff, E., Yuzda, E., ... Rutter, M. (1995). Autism as a strongly genetic disorder: Evidence from a British twin study. *Psychological Medicine*, 25(1), 63–77.
- Bolton, P., Macdonald, H., Pickles, A., Rios, P. A., Goode, S., Crowson, M., ... Rutter, M. (1994). A case-control family history study of autism. *Journal of Child Psychology and Psychiatry*, 35(5), 877–900.
- Bolton, P. F., Pickles, A., Murphy, M., & Rutter, M. (1998). Autism, affective and other psychiatric disorders: Patterns of familial aggregation. *Psychological Medicine*, 28(2), 385–395.
- Burke, M. M., Taylor, J. L., Urbano, R., & Hodapp, R. M. (2012). Predictors of future caregiving by adult siblings of individuals with intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, 117(1), 33–47.
- Bynner, J., Butler, N., Ferri, E., Shepherd, P., & Smith, K. (2000). *The design and conduct of the 1999–2000 surveys of the National Child Development Study and the 1970 British Cohort Study. Working paper, 1*. Centre for Longitudinal Studies, Cohort Studies.
- Coyle, C. E., Kramer, J., & Mutchler, J. E. (2014). Aging together: Sibling carers of adults with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 11(4), 302–312.
- DeMeyer, M. (1979). *Parents and children in autism*. New York: Wiley.
- Ferraioli, S. J., & Harris, S. L. (2009). The impact of autism on siblings. *Social Work in Mental Health*, 8(1), 41–53.
- Fombonne, E., Bolton, P., Prior, J., Jordan, H., & Rutter, M. (1997). A family study of autism: Cognitive patterns and levels in parents and siblings. *Journal of Child Psychology and Psychiatry*, 38(6), 667–683.
- Goldberg, D. P., Gater, R., Sartorius, N., Ustun, T. B., Piccinelli, M., Gureje, O., ... Rutter, C. (1997). The validity of two versions of the GHQ in the WHO study of mental illness in general health care. *Psychological Medicine*, 27(1), 191–197.
- Hastings, R. P. (2003). Brief report: Behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders*, 33(1), 99–104.
- Hallion, M., Taylor, A., & Roberts, R. (2018). Complete mental health in adult siblings of those with a chronic illness or disability. *Disability and Rehabilitation*, 40(3), 296–301.
- Hesse, T. L., Danko, C. M., & Budd, K. S. (2013). Siblings of children with autism: Predictors of adjustment. *Research in Autism Spectrum Disorders*, 7(11), 1323–1331.
- Hodapp, R. M., & Urbano, R. C. (2007). Adult siblings of individuals with Down syndrome versus with autism: Findings from a large-scale US survey. *Journal of Intellectual Disability Research*, 51(12), 1018–1029.
- Howlin, P., Moss, P., Savage, S., Bolton, P., & Rutter, M. (2015). Outcomes in adult life among siblings of individuals with autism. *Journal of Autism and Developmental Disorders*, 45(3), 707–718.
- Jokiranta-Olkonieni, E., Cheslack-Postava, K., Sucksdorff, D., Suominen, A., Gyllenberg, D., Chudal, R., ... Sourander, A. (2016). Risk of psychiatric and neurodevelopmental disorders among siblings of probands with autism spectrum disorders. *JAMA Psychiatry*, 73(6), 622–629.
- Kaminsky, L., & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry*, 43(2), 225–232.
- Kovshoff, H., Cebula, K., Tsai, H. W. J., & Hastings, R. P. (2017). Siblings of children with autism: The siblings embedded systems framework. *Current Developmental Disorders Reports*, 1–9.
- Lobato, D. (1983). Siblings of handicapped children: A review. *Journal of Autism and Developmental Disorders*, 13(4), 347–364.
- McHale, S. M., Sloan, J., & Simeonsson, R. J. (1984). Sibling relationships or children with autistic, mentally retarded, and nonhandicapped brothers and sisters. *Journal of Autism and Developmental Disorders*, 16(4), 399–413.
- McHale, S. M., Updegraff, K. A., & Feinberg, M. E. (2016). Siblings of youth with autism spectrum disorders: Theoretical perspectives on sibling relationships and individual adjustment. *Journal of Autism and Developmental Disorders*, 46(2), 589–602.
- Macks, R. J., & Reeve, R. E. (2007). The adjustment of non-disabled siblings of children with autism. *Journal of Autism and Developmental Disorders*, 37(6), 1060–1067.
- Meadan, H., Stoner, J. B., & Angell, M. E. (2010). Review of literature related to the social, emotional, and behavioral adjustment of siblings of individuals with autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, 22(1), 83–100.
- Nuttall, A. K., Coberly, B., & Diesel, S. J. (2018). Childhood caregiving roles, perceptions of benefits, and future caregiving intentions among typically developing adult siblings of individuals with autism spectrum disorder. *Journal of Autism and Developmental Disorders* On line Jan 2018.
- Orsmond, G. I., Kuo, H. Y., & Seltzer, M. M. (2009). Siblings of individuals with an autism spectrum disorder: Sibling relationships and wellbeing in adolescence and adulthood. *Autism*, 13(1), 59–80.
- Orsmond, G. I., & Mailick Seltzer, M. (2000). Brothers and sisters of adults with mental retardation: Gendered nature of the sibling relationship. *American Journal on Mental Retardation*, 105(6), 486–507.
- Orsmond, G. I., & Seltzer, M. M. (2007). Siblings of individuals with autism spectrum disorders across the life course. *Developmental Disabilities Research Reviews*, 13(4), 313–320.
- Petalas, M. A., Hastings, R. P., Nash, S., Hall, L. M., Joannidi, H., & Dowey, A. (2012). Psychological adjustment and sibling relationships in siblings of children with autism spectrum disorders: Environmental stressors and the broad autism phenotype. *Research in Autism Spectrum Disorders*, 6(1), 546–555.
- Pickles, A., Starr, E., Kazak, S., Bolton, P., Papanikolaou, K., Bailey, A., ... Rutter, M. (2000). Variable expression of the autism broader phenotype: Findings from extended pedigrees. *Journal of Child Psychology and Psychiatry*, 41(4), 491–502 471–483.20.
- Pilowsky, T., Yirmiya, N., Doppelt, O., Gross-Tsur, V., & Shalev, R. S. (2004). Social and emotional adjustment of siblings of children with autism. *Journal of Child*

- Psychology and Psychiatry*, 45(4), 855–865.
- Pinto, D., Pagnamenta, A. T., Klei, L., Anney, R., Merico, D., Regan, R., ... Almeida, J. (2010). Functional impact of global rare copy number variation in autism spectrum disorders. *Nature*, 466(7304).
- 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(2), 77–86.
- Smith, L. O., & Elder, J. H. (2010). Siblings and family environments of persons with autism spectrum disorder: A review of the literature. *Journal of Child and Adolescent Psychiatric Nursing*, 23(3), 189–195 368-372.
- The National Child Development Survey: Sweep Six, 1999–2000.**
- Tomeny, T. S., Barry, T. D., & Bader, S. H. (2012). Are typically-developing siblings of children with an autism spectrum disorder at risk for behavioral, emotional, and social maladjustment? *Research in Autism Spectrum Disorders*, 6(1), 508–518.
- Tomeny, T. S., Baker, L. K., Barry, T. D., Eldred, S. W., & Rankin, J. A. (2016). Emotional and behavioral functioning of typically-developing sisters of children with autism spectrum disorder: The roles of ASD severity, parental stress, and marital status. *Research in Autism Spectrum Disorders*, 32, 130–142.
- Tomeny, T. S., Ellis, B. M., Rankin, J. A., & Barry, T. D. (2017). Sibling relationship quality and psychosocial outcomes among adult siblings of individuals with autism spectrum disorder and individuals with intellectual disability without autism. *Research in Developmental Disabilities*, 62, 104–114.
- Tomeny, T. S., Barry, T. D., & Fair, E. C. (2017). Parentification of adult siblings of individuals with autism spectrum disorder: Distress, sibling relationship attitudes, and the role of social support. *Journal of Intellectual & Developmental Disability*, 42(4), 320–331.
- Tozer, R., Atkin, K., & Wenham, A. (2013). Continuity, commitment and context: Adult siblings of people with autism plus learning disability. *Health & Social Care in the Community*, 21(5), 480–488.
- Tozer, R., & Atkin, K. (2015). 'Recognized, valued and supported'? The experiences of adult siblings of people with autism plus learning disability. *Journal of Applied Research in Intellectual Disabilities*, 28(4), 341–351.
- Tsai, H. W. J., Cebula, K., & Fletcher-Watson, S. (2017). The role of the broader autism phenotype and environmental stressors in the adjustment of siblings of children with autism spectrum disorders in Taiwan and the United Kingdom. *Journal of Autism and Developmental Disorders*, 1–15.
- Tudor, M. E., Rankin, J., & Lerner, M. D. (2018). A model of family and child functioning in siblings of youth with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48(4), 1210–1227.
- 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(3), 193–205.
- Walton, K. M. (2016). Risk factors for behavioral and emotional difficulties in siblings of children with autism spectrum disorder. *American Journal on Intellectual and Developmental Disabilities*, 121(6), 533–549.
- Wechsler, D. (1999). *Wechsler abbreviated scale of intelligence*. San Antonio, TX: Psychological Corporation.