A qualitative analysis of what is it like growing up with a sibling with Autism

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Abstract

This is a qualitative study into the perspective experiences of typically developing children’s relationships with their autistic siblings. Previous research is often inconclusive and focuses on the negative attributes of these relationships. Five children in two focus groups between the ages of 6 and 15 participated in this study. Independent interviews were carried out on the parents of the siblings to gain an understanding of their family. The study used thematic analysis to identify key emergent themes for analysis and interpretation. This research lends support against traditional views of what it is like growing up with a sibling with a disability. The analysis suggests the experiences show no significant differences in their interactions compared to ‘normal’ sibling pairs. Siblings express worries over bullying and anger but are accepting, supporting and understanding of their siblings autism and have an unconditional admiration for their sibling.

KEY WORDS: AUTISM, RELATIONSHIPS, SIBLINGS EXPERIENCES, THEMATIC ANALYSIS, PARENT EXPERIENCES
Introduction

The History of Autism

Manfred Bleuler, when referring to the withdrawn behaviours of schizophrenia first used the term autism in 1911. Autism is considered a rare condition with a prevalence of 2-4 per 10,000 yet an annual rise in the diagnosis of autistic spectrum disorder (ASD) shows how it is much more common than previously believed. Autism is second in frequency only to mental retardation among the serious developmental disorders (Newschaffer, Croen, Daniels et al, 2007: 235). Leo Kanner (1943: 217) adopted the term ‘autism’ to describe a group of children ‘who have come into the world with an innate inability to form the usual, biologically provided affective contact with people’. Autism is recognised as a disorder in the DSM-IV by the American Psychiatric Society (1994) and the International Classification of Disease, 10th Revision. Under the classification as a Pervasive Developmental Disorder (PDD), it defines autism by the presence of deficits or unusual behaviours with three domains (see appendix one).

Aetiology of Autism

Autistic Spectrum Disorder is defined based on observations and descriptions of behaviour and since there are a lack of specific biological markers or biological tests (Abrahams & Geschwind, 2008) autism diagnosis relies on observable characteristics. Although autism is one of the most complex neurobiological disorders, there is insufficient research to suggest a strong genetic component (Hollander, 2011), and therefore no single cause can be defined.

Empirical evidence for the aetiology of autism is weak and society offers explanations that are more plausible. In 2009, Grether, Anderson, Croen, Smith & Windham found that autism is associated with an advanced age of parents and Mandell, Wiggins, Carpenter, Daniels, DiGuiseppi & Durkin (2009) also found that more educated mothers are likely to have children with ASD diagnosis’s due to a greater knowledge of developmental milestones or a greater ability to advocate with clinicians and educators for diagnosis. Even exposure to environmental toxins have been linked to developmental delays in children (Gillberg & Wing, 1999).

Sibling relationships

Children’s relationships with their brothers and sisters are an important aspect of their daily life; in essence, siblings usually grow and develop with each other. Edwards, Mauthner, & Hadfield, (2005: 499) listened to accounts of children’s everyday lives with their brothers and sisters who commented on protection from being alone and that their siblings gave them a strong sense of identity.

In 1969, Bowlby discussed the significance of siblings being subsidiary attachment figures. For young children the family is their main social environment and their main opportunity to learn about other people.

Sibling relationships when one sibling has autism

It can be suggested that the characteristics mentioned in the DSM-IV such as a lack of emotional reciprocity, restricted and repetitive behaviours and preoccupations with restricted patterns of interest are likely to affect sibling
relationships. Bunk & Schaufeli (1999: 260-267) argued that humans have developed innate mechanisms to expect reciprocal altruism in inter-personal relationships. Recent research on sibling relationships when one child has autism has shown that typically developed siblings have a cognitively immature understanding of the causes of autism than would be expected, based on their overall level of cognitive functioning (Glasberg, 2000: 143). Research also shows that the time siblings spend together is not qualitatively comparable to interactions between typical siblings (Harris & Ferraioli, 2009). Mothers of children with autism report outcomes that are more negative for their typically developing children than the mothers of typical siblings (Hastings, 2003:99). Poor adjustment outcomes have also been observed in comparison to the siblings of children with other developmental disabilities (Rossiter & Sharpe, 2001:65). Research has also associated children with siblings with autism to have an increased risk for depression and anxiety (Rossiter & Sharpe, 2001:65).

Current research on sibling relationships when one child has autism

Although research has looked at the effects of autism on typically developing siblings (McHale et al. 1986: 399) (Bagenholm & Gillberg 1991: 291) research is often inconclusive and focuses on more negative attributes (Rivers & Stoneman, 2003: 383), (Kaminsky & Dewey, 2001: 399). Few studies have investigated how developmental disabilities in children affect siblings, particularly from the subjective perspective of the typically developing sibling.

Method

Method rationale

Philosophical Background:

Psychological theorists often make a number of philosophical assumptions when they approach their discipline. Sarter (1988: 52) states that philosophy ‘is inquiry into the nature of reality through rational or intuitive thought... the traditional goal of philosophy is wisdom and understanding of truth’.

German philosopher Dilthey’s (1926) work was concerned with distinctions between human sciences (Verstehen) and the natural sciences (Erklärung). He believed that the human sciences are distinguishable from natural sciences because of ‘fundamental differences in attitude toward their respective phenomena of research’. He stated that the natural sciences investigate objects from the outside to the inside, whereas human sciences depend on a perspective from the inside to the outside; ‘The most important concern in the human sciences is that of meaning’. However, many psychologists believe that to study something it must be measurable and quantifiable and for this reason, many research psychologists belong to a school of thought called empiricism, which dominated much of the early history of modern psychology.
For some years, psychologist theorists have criticised traditional scientific methods and have had an increased interest in qualitative methods. Qualitative research is used as a means to understand and explore the social world and reality of nature and was influenced by the work of Lincoln and Guba (1985: 15). They described qualitative research as a paradigm with a worldview, ‘a way of breaking down the complexity of the real world’. Hermeneutics is the theory and practice of interpretation, it ‘refers to the art, theory and philosophy of the interpretation of meaning of an object’ (Schwandt, 1997:62). Gadamer (1960) elaborated the concept of philosophical hermeneutics to uncover the nature of human understanding as a method of interpreting texts. Gadamerian phenomenology also highlights the importance of researcher influence on their studies ‘understanding belongs to the being of which is understood’.

Methodological Aims

1. To understand the relationships between siblings where one has a diagnosis of Autism.
2. To use literature to investigate the previous understandings of the effect autism has on both those diagnosed and their siblings.
3. To look at the siblings own understanding of their brother/sisters disorder and discuss its impact on them.
4. To explore the subjective experiences and feelings of typically developing siblings with a brother or sister with autism through focus group interviews.
5. To interview a parent of the siblings to gain a greater understanding of the autistic siblings behaviour and characteristics, and to also explore their perception of the sibling’s relationship.
6. To use thematic analysis to identify the key themes for analysis and interpretation.

Methods and Decisions

Considering the use of Quantitative Methods alone

Quantitative research is an objective and empirical investigation via mathematical techniques; it uses numerical values to look at the relationship between variables to either prove or disprove a hypothesis (Neil, 2007). Described by Bryman (1988) as ‘Hard and reliable’.

An advantage of carrying out quantitative research into the area of sibling relationships would be to test or make confirmations about theoretical notions and concepts. However, there is little research about sibling relationships from the subjective experience of the typically developing sibling.

Considering the use of Qualitative Methods alone

Qualitative methods have become increasingly common in psychology since the 1980s, described as a ‘rich and deep’ methodology (Bryman, 1988) with emerging theories and concepts.
Qualitative research is idiographic, studying the individual as a whole, emphasising the perspective of their ‘world’ and everyday lives. It is unethical to rely on statistics and data analysis to measure an individual’s perspective in-depth as it would be too structured and restricted for the purpose of this study. ‘The rich use of data gathering methods such as the in-depth interview and focus groups encourage the emphasis on the individual’s perspective’ (Denzin and Lincoln, 2002:1).

The descriptive detailed attributes of qualitative methods allow the research to be on a personal level, providing more insight for the researcher so they can feel and understand from a personal perspective (Wilde, 1992: 234). An advantage of qualitative research is that is follows an ethos for equality, the researcher assumes a learning role rather than a testing one conducting research among participants rather than on them.

Field and Morse (1985) suggest that qualitative methods should be used when there is ‘little known about a domain’ which is relevant for this study.

For a visual representation of how I reached this decision, see ‘Decision tree diagram’
Fig 1: Decision Tree

Need to carry out research to explore the relationships between siblings when one child has autism-exploring both parent and sibling experiences.

Quantitative Research
- Empirical based, observes and measures numerically. It is objective and designed to test or prove a hypothesis (Nykiel, 2007). Is deductive (Frankel and Devers, 2000).

Mixed Methods Research
- Brings together the benefits of both approaches, greater validity (Bazeley, 2004). Triangulation (Denzin, 1978)

Qualitative Research
- 'Emphasis on the individuals experience' (Denzin and Lincoln, 2008) Explores personal understanding and knowledge of their worlds. Is inductive.

Empirical based, observes and measures numerically. It is objective and excludes personal experiences and interpretations of the individual's world.

Which method/approach?

Ethnography/Participant Observations
- Subject to researcher bias, no insight into thoughts and personal life experiences of participant.

Qualitative Interviews
- Kvale (1983, p.174) 'World of the interviewee with respect to interpretation of the meaning of the described phenomena.' Rich, insightful data. Could lead to new findings.

Conversation Analysis
- Would be specific to a particular topic, no real insight or understanding would be achievable.

Narrative Analysis
- Is participant led, may lead to unstructured responses and may deviate from the topic being researched.

Discourse Analysis
- Lacks personal experience and understanding.
Method Decisions Finalised and Summarised

As this research is not looking for causal explanations, testing a hypothesis or aiming to make any predictions from the analysis it is unnecessary to consider quantitative methods. It seems more logical to use qualitative methods to engage in dialogue with the participants to fully understand or at least to an extent, perceive their worlds.

Summary of aims for the method

The aims of this method are to carry out focus group interviews with the siblings of autistic children and semi-structured interviews with their parents, to explore what it is like growing up with a sibling with autism using thematic analysis.

Rationale and implications for Semi-Structured Interviews with parents:

This method will use semi-structured, open-ended interviews with the parents of the siblings, based on previous research.

According to Smith, (1995) the use of semi-structured interviews is useful to gain a detailed picture of participants' beliefs, perceptions or accounts of a particular topic (Schwandt, 1997).

In 1984, Burgess described semi-structured interviews as ‘conversations with a purpose’ a more humanistic way of interviewing as it ‘allows them space to talk’ (Rapley, 2004:25). Within semi-structured interviews, the interviewer can openly ask questions on the given topic whilst still having a level of control (Rapley, 2004:26) and steer the participant in order to create new emergent ideas and findings (Wengraf, 2001).

Rationale and implications for Focus Group Interviews with the siblings

Focus groups are a type of group interview that rely on communication between the research participants to generate data.

As well as being a quick and convenient way to collect data from several people simultaneously, the group interaction is part of the method to encourage the children to talk to one another by exchanging anecdotes and commenting on each other’s experiences. Gibbs, (2007) describes the key features of focus groups as ‘organised discussions’.

Participants can provide mutual support in expressing feelings that are similar to others in the group (Boulton & Kitzinger, 1994: 150). A limitation with focus groups is that participants may be influenced by others opinions and may fear the implications of what they say.
## Participants: Table 1: Details of the Interview Participants

<table>
<thead>
<tr>
<th>Name of autistic child</th>
<th>Age of Autistic child</th>
<th>Autism Diagnosis</th>
<th>Name of sibling interviewed</th>
<th>Age of sibling interviewed</th>
<th>Number of siblings at home</th>
<th>Number of family members at home</th>
<th>Ethnicity of siblings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tracey Beaker’s Dad</td>
<td>40-45</td>
<td>High functioning autism</td>
<td>Tracey beaker</td>
<td>11</td>
<td>4</td>
<td>6</td>
<td>White British</td>
</tr>
<tr>
<td>Jack’s Mum</td>
<td>40-45</td>
<td>Classic autism</td>
<td>Jack</td>
<td>15</td>
<td>2</td>
<td>4</td>
<td>White British</td>
</tr>
<tr>
<td>Isla’s Mum</td>
<td>35-40</td>
<td>Asperger’s Syndrome</td>
<td>Isla</td>
<td>7</td>
<td>4</td>
<td>6</td>
<td>White British</td>
</tr>
<tr>
<td>Cody’s Mum</td>
<td>35-40</td>
<td>Classic autism</td>
<td>Cody</td>
<td>6</td>
<td>3</td>
<td>5</td>
<td>White British</td>
</tr>
<tr>
<td>Natalie’s Mum</td>
<td>30-35</td>
<td>High functioning autism</td>
<td>Natalie</td>
<td>11</td>
<td>3</td>
<td>4</td>
<td>White and Black British</td>
</tr>
</tbody>
</table>
Participant recruitment

The selected sample of interviewees was an opportunity sample recruited from local support groups for the families of autistic children.

Aspirations Greater Manchester is a voluntary organisation and The National Autistic Society runs the Trafford Thursday Night Project. I individually contacted both organisations and asked if they had any families with siblings that would be willing to help. I attended sessions at both centres and left letters with details of the study and its outcomes on the notice boards at the workshops (see appendix 5).
### Table 2: Details of visits to the workshops

<table>
<thead>
<tr>
<th>Dates Visited workshop</th>
<th>Workshop visited</th>
<th>Aim of the visit</th>
<th>Outcome of visit</th>
</tr>
</thead>
<tbody>
<tr>
<td>26/04/2011</td>
<td>Aspiations (ASGMA) Family Groups</td>
<td>To visit the workshop for the researcher to meet the members, volunteers and families and to tell them about the aims and method of this study.</td>
<td>Introduced myself to the members of the family group and the volunteers that run the organisation. Informed and discussed my future research with parents about the methodology of the study and left letters with more information and the date of interviews.</td>
</tr>
<tr>
<td>10/12/2011</td>
<td>Aspiations (ASGMA) Family Groups</td>
<td>To carry out the focus groups and interviews.</td>
<td>Method was unsuccessful due to a limited number of families attending the workshop due to weather conditions.</td>
</tr>
<tr>
<td>28/01/2012</td>
<td>Aspiations (ASGMA) Family Groups</td>
<td>To carry out the focus groups and interviews.</td>
<td>Weak results as the participants were out on a swimming trip. A focus group of 3 participants was completed with interviews with 3 parents.</td>
</tr>
<tr>
<td>2/2/2012</td>
<td>National Autistic Society (NAS) Trafford Thursday Night Project</td>
<td>To visit the workshop for the researcher to meet the members, volunteers and families and to tell them about the aims and method of this study.</td>
<td>Introduced myself to the members of the family group and the volunteers that run the organisation. Informed and discussed my future research with parents about the methodology of the study and left letters with more information and the date of interviews.</td>
</tr>
<tr>
<td>9/2/2012</td>
<td>National Autistic Society (NAS) Trafford Thursday Night Project</td>
<td>To carry out the focus groups and interviews.</td>
<td>Carried out focus group interviews with 3 siblings and individually interviewed the parents of the siblings.</td>
</tr>
</tbody>
</table>
Investigative Materials

- An Olympus Digital Voice Recorder
- Set of interview prompts for the interviews with the parents (See appendix 3)
- Set of interview prompts for the focus group interviews with siblings (See appendix 4)
- Ethics Forms (See appendix 6)
- Consent Forms (See appendix 7)

Procedure

I chose to volunteer at the workshops before carrying out my study as it would give the parents and children a chance to familiarise themselves with me and vice versa.

On the day of the interviews at both family workshops, I arrived early and thanked the participants for their help. After going through the formalities, the parents helped me to gather the children in a room away from everyone else. Once the children were settled, I got them to introduce themselves to me and each other using their pseudonym names and then started recording by asking the first question ‘So how old are you all’. After the first general questions, I asked ‘Do you know if your brother/sister has autism’; the following questions were determined by the children’s responses. Once all the topics were covered, I thanked the children for their time and help and then began the interviews with their parents independently. At the end of the interviews, I thanked the parents for their participation and for allowing me to carry out interviews with their children and reiterated their right to withdraw their data if they wished to do so.

Procedure for analysing qualitative data

The interviews were transcribed using the Jefferson transcription system (Jefferson, 2004: 13) and coded and analysed for emergent key themes. The analysis will use current literature to explore and understand the children and parents perceptions of their sibling relationships.
Table 3: Symbols used in the interview transcripts

|------------------------|-------|
| Main technique used when discussing a particular interview transcript (I4, FG1, 22) (I5, CM, 23) | I4 = Interview 4  
I5 = Interview 5  
IM = Isla’s Mum  
JM = Jack’s Mum  
TBD = Tracey Beaker’s Dad  
FG1 = Focus Group one  
CM = Cody’s Mum  
NM = Natalie’s Mum  
FG2 = Focus Group two  
22 = Line number referenced |
| (=) | Indicate where one speaker takes over the conversation from another speaker without a pause |
| () | The start of conversation overlap |
| () | The end of conversation overlap |
| (.) | Pauses in conversation |
| (0.5) | Indicate different lengths of pause |

Ethical Considerations

This research follows the ‘Code of Ethics and Conduct’ according to the British Psychology Society (2009: 10) and its ethical principles. As this research is carried out on children under the age of 16, it is important to follow the United Nations Convention of the rights of the child (1989). Parents of the participants were required to provide consent for themselves and their children and were informed of their rights as participants. The consent forms also clarify that any information they provide would be anonymous but not confidential. The children will also use pseudo names for themselves, their family members and schools to maintain anonymity. All participants will be told that they can pursue the findings of the research and may have a copy of the study once completed. It was also important to consider the emotional vulnerability of the participants as well as their physical vulnerability. Levels of emotional and physical vulnerability were taken into account due to the personal nature of the questions.
Results and Analysis

Rationale for Thematic Analysis

‘Thematic analysis is a process of encoding qualitative information’ (Boyatzis, 1998) and is a widely used method for identifying, analysing, and reporting themes within data (Roulston, 2001). ‘A theme captures something important about the data…meaning within the data set’ (Braun and Clarke, 2006).

According to Bernard and Ryan (2005), identifying themes takes place ‘before, during and after data collection’. This process uses inductive reasoning (Braun & Clarke, 2006) by which themes and categories emerge from the data through the researcher’s careful examination and constant comparison. Thematic analysis can highlight similarities and differences across different data set’s and can generate unanticipated insights, a phenomenological approach where the emphasis is on attempting to understand the psychological conceptions of participants (Smith, 1995).

Analysis of the Interviews

Through analysing the interview transcripts, six main themes were identified; a) perceptions of normality, b) acceptance, c) coping strategies, d) distressing symptoms, e) knowledge and support and f) learned helplessness which will all be fully expanded on in the discussion.

These themes were identified through coding and extracting thematic maps (Braun and Clarke, 2006) as demonstrated in Figure 2, Figure 3, and Figure 4.

Fig 2: Positive and negative themes from the parent interviews
Fig 3: Positive and negative themes from the sibling interviews

Fig 4: Combined themes from the sibling and parent interviews
Theme A: Perceptions of Normality

Subtheme One: Comparisons to ‘normal’

‘But I knew it was something, she wasn’t like other children.’ (I1, IM, 26).

‘Emma gets angrier than an average person would’ (I1, IM, 200)

‘…but he has autism instead and it makes him different to me’ (I7, FG2, C, 167)

Subtheme Two: What defines ‘normality?’

‘He’s got very low learning ability but on looking at him he appears normal, its only when you spend time with him that you realise he’s got autism.’ (I5, CM, 9)

‘They have just recognised that Aaron is a bit different. But what is normal? I mean we’ve all got a bit of autism in us’ (I6, NM, 177)

‘Well I dunno, I dunno what would happen in a normal family, (1) is every family like that I dunno.’ (I1, IM, 199).

Subtheme Three: Autistic child as ‘different’

‘I used to say to my husband ‘Is something wrong?’ (I2, JM, 25).

‘That’s what made us first realise something wasn’t you know right.’ (I3, TBD, 38)

Subtheme Four: Normal as a social expectation

‘Very rarely, he talks about something normal’ (I4, FG1, J, 290)

Subtheme Five: Perceptions of ‘normal’ sibling relationships

‘…they don’t really have anything in common. But I think for any boy with 3 sisters that would happen’ (I3, TBD, 65).

‘It’s just normal. They’re very close and sometimes they can argue and sometimes they get on like a house on fire so it’s just like a normal family.’ (I6, NM, 265)

‘I think it’s a pretty normal sibling relationship’ (I5, CM 190).

‘Well, like most sisters’ (I1, IM, 143).
Theme B: Acceptance

Subtheme One: Acceptance through society

‘It’s more social skills for me, if he can fit in socially.’ (I5, CM, 40).

Isla’s mum found acceptance towards autism through going to support groups ‘...and it’s things like that, that kind of make you think, yeh, yeh everything is okay’ (I1, IM, 34).

Parents have also demonstrated acceptance through being open about their child’s disability ‘we’ve never kept it a secret from any of our children, any of our family for that matter,’ (I1, IM, 144).

‘people stare at him but I don’t think they understand… That he (2) he can’t help it’ (I6, FG2, N, 43).

‘I don’t want him to have it, if he didn’t have autism…’ (I6, FG2, C, 123) because other people do not accept it ‘cos they might laugh at us cos James is different.’ (I6, FG2, C, 183).

Subtheme Two: Unconditional acceptance

‘Never, I wouldn’t change it for the world. For me autism is what defines Alan, (.) it’s makes him, (.) him and we all love him, you know, (2) for that.’ (I2, JM, 93) (I2, JM, 97) (I3, TBD, 103).

Tracey Beaker and Jack both state how they would not change anything about their brothers (I4, FG1, J&TB, 297).

Jack chose to discuss news that an operation could ‘cure’ autism; he went on to say how he would not want his brother to have it, ‘...I like my brother how he is.’ (I4, FG1, J, 312).

Subtheme Three: Parents encouraging sibling acceptance

‘We try to help them understand this and over time they have’ (I1, IM, 59)

‘...make allowances for Emma, she will say ‘Oh well Emma has some problems”’ (I1, IM111).

Subtheme Four: Acceptance through understanding

‘So as Isla is maturing she is understanding about Emma a lot more and is much more accepting towards her behaviours,’ (I1, IM, 145).

‘Even though they argue, (.) they’ve got like a bond I think.’ (I2, JM, 74)

When Jack was asked if he was aware that his brother had autism he laughed and replied ‘Well it’s obvious like’ (I4, FG1, J, 32) connoting Jacks awareness and
acceptance of autism. Jack also continues to discuss how he welcomed his brother into his friendship group at school (I4, FG1, J, 168).

**Theme C: Distressing Symptoms**

**Subtheme One: Anger**

‘It’s probably one of our biggest problems at the moment about how angry she is’ (I1, IM, 193).

‘I wish she didn’t have it, cos I don’t like a sister that has lots of issues and always yells’ (I4, FG1, I, 46).

Cody expresses how he dislikes his brother having autism because of his anger problems (I7, FG2, C, 123).

**Subtheme Two: Anti-social behaviour**

‘He’s been swearing a lot, which is an autism trait, coming from a family that we don’t allow swearing, it sets a bad example to my younger son,’ (I5, CM, 15)

**Subtheme Three: Isolation**

‘I worry that she gets upset and wouldn’t have anyone to talk to’ (I4, FG2, I, 130).

‘He finds things hard (3) and it makes him want to do things alone, like play on his own (. ) so I feel sorry for him’ (I4, FG2, TB, 61).

As a way of helping her son to cope with the demands of his autistic brother, Jack’s mum invites his friends over (I2, JM, 65).

**Subtheme Four: Bullying**

Siblings worry about getting bullied because of their autistic sibling ‘Well, I’m worried that if people find out that he’s got autism that they might come and tease me about it’ (I7, FG2, C, 133). Jack also explains how he used to think that he could catch his brothers autism and worries that people at school may think that too (I4, FG2, J, 326).

‘Oh it’s terrible. I mean absolutely terrible, she used to put things in Isla’s cot, things like balls and sharp stones (. ) things that she thought would hurt her, she was just horrible to her and she carried on being horrible to her’ (I1, IM, 92).

‘If the bullying doesn’t stop he’s moving, because I’m not having that…’ (I6, NM, 154).

‘I worry about him, like at school and what people are like with him, I think he gets bullied sometimes’ (I7, FG2, N, 14).
Theme D: Coping Strategies

Subtheme One: Siblings distancing themselves from stressful situations

‘At the minute, Hamish will say it’s not James he doesn’t like, its autism.’ (I5, CM, 102).

Another way for siblings to cope with their brothers and sisters is by moving away from them (I6, NM, 144) and (I2, JM, 60).

Subtheme Two: Siblings implementing care roles

‘She looks after him more than looking up at him as an older brother; she takes on an extra role, my role if you know what I mean…” (I6, NM, 121).

Subtheme Three: Help from external sources

‘You can share stories and I think you know, at least you think I’m only going through the same rig-moral as other parents now’ (I6, NM, 220)

‘we do get a support worker from the council … what tends to happen is the support worker will play with Isla and Tom and I will then have some time for Emma,’ (I1, IM, 173).

Parents also use resources such as the internet (I6, NM, 194).

Subtheme Four: Routine and structure

Natalie’s mum has found that routine and structure help her to cope with the demands of her son (I6, NM, 235).

Cody’s mum also find’s that separating her family, makes everyday tasks more manageable (I5, CM, 153).

Theme E: Knowledge and Support

Subtheme One: Lack of support and knowledge

‘I didn’t know what it, it was, (1) but I knew it was something’ (I1, IM, 25).

Parental anger towards the education system for a lack of support ‘they didn’t understand him, they didn’t understand his needs’ (I6, NM, 55) because of this she expressed her opinion towards improving knowledge about autism (I6, NM, 171).

‘I never had even really heard of it’ (I5, CM, 76)

‘I found I was doing all the research myself’ (I5, CM, 187).

‘We knew he wasn’t normal (.) but no one seemed to pin point what it was, so in that respect no’ (I2, JM, 35)

Subtheme Two: External support
‘It’s mainly other people that help… talking to other people and they help you, (.) you know, what you’re entitled too, extra help and things like that’ (I2, JM, 32).

Tracey beaker’s dad emphasises the mutable behaviours of autism and how it can affect knowledge ‘not everything can prepare you for everyday tasks that you wouldn’t expect to face every day.’ (I3, TBD, 20)

Subtheme Three: Lack of sibling knowledge and understanding

Many of the siblings had varying definitions of autism; ‘[I dunno really] (2) I used to think I could catch it (laugh)’ (I4, FG1, J, 326) (I7, FG2, C, 198)

‘I didn’t know what it was’ (I7, FG2, C, 200).

‘I might just have them trained by their twenties. Or they might all be in Australia.’ (I5, CM, 201).

Subtheme Four: Siblings wanting to support

‘[Well, I always] (3) want to look after Martin when he’s angry or sad (.) but I don’t know what to do’ (I4, FG1, TB, 84).

One parent explained how her children have learnt to support each other (I1, IM, 138). ‘I just help by getting him some friends (.) and making him have someone to talk to’ (I4, FG1, J, 94).

Theme F: Learned Helplessness

Subtheme One: Parent learned helplessness

‘It isn’t easy. Some days can be better than others but I suppose that’s all part of the package really’ (I1, IM, 157)

‘I’m sure there’s days when I don’t do it right, (.) like any mum.’ (I5, CM, 167)

‘She’s just our daughter (1) like any daughter.’ (I1, IM, 213)

Subtheme Two: Sibling learned helplessness

Many siblings want to help ‘I don’t know what he’s thinking (.) and I feel like I should help and be a good sister but I don’t know how to.’ (I4, FG1, TB, 88) but have had to develop ways to accept this ‘He just gets annoyed and then he goes off up to his room and gets really [stressed so I just leave him alone].’ (I4, FG1, TB, 174).
Discussion

During the thematic analysis of the parent interviews and the sibling focus group interviews, six core themes became apparent. These were identified as a) perceptions of normality, b) acceptance, c) coping strategies, d) distressing symptoms, e) knowledge and support and f) learned helplessness.

It is important to consider the autistic child in relation to this study, current research has shown that all children are a part of and operate as a family system and cannot be understood in isolation (Bowen, 1966). Consequently, the behaviour of both the autistic and non-autistic sibling can have an effect on other members of the family. A study by Olivia (2005: 253-270) found that when children have a good relationship with their siblings, they also have good relationships with their parents and friends.

A number of factors mediate the effects of the child with autism on the typically developing sibling. Several of these factors relate to the typically developing child’s family environment, such as the number of siblings in the family (Kaminsky and Dewey, 2002: 225), marital stress and the availability of social support (Hastings, 2003: 99).

In society, the process of labelling someone as ‘abnormal’ or ‘special needs’ draws upon the exceptionally different construct of a child and consequently everyone else in society is perceived as ‘normal’. According to Burman (2008:22) ‘the normal child is a fiction or myth...No individual or real child lies at its basis...It is an abstraction, a fantasy...’

A predominant theme throughout the analysis was the inconsistent ideologies of what defines normal, yet all interviewees agreed that their autistic sibling or child is ‘abnormal’.

One parent believes that her son appears ‘normal’ in appearance but says his autism is only noticeable after spending time with him (I5, CM, 9). Some interviewees make comparisons of their children to other children and identify that something ‘is wrong’ (I2, JM, 25). One sibling recognises that his brother’s autism makes him different to him (I7, FG2, C, 167).

Research by Hwang and Charnley (2010: 7), looked at the understanding of Korean children’s experiences of living with an autistic sibling and found that they had a daily struggle with the labelling of their sibling as ‘unusual’ or ‘abnormal’. Cody is worried that if people at school find out, they might tease him (I7, FG2, J, 133). Jack chooses not to tell his friends at school for fear they may think they can catch it (I4, FG2, J, 326).

It is interesting to see that Jack chooses to invite his brother into his friendship group, ‘I just help by getting him some friends...’ (I4, FG1, J, 94), acquiring a caring sibling role. According to Howlin (1988: 395), the ‘burden of care’ falls more heavily on girls but other research suggests that the sexual distinction has declined (Gath & Gumley, 1987: 715).
Hwang and Charnley (2010: 8) found that siblings of autistic children were more accepting and supportive. This can be seen in this analysis as siblings become accustomed to public hostility, ‘people stare at him but I don’t think they understand… that he (2) he can’t help it’ (I6, FG2, N, 43).

One sibling identifies how his perceptions of normality are intertwined with everyday social skills ‘very rarely, he talks about something normal’ (14, FG1, J, 290), implying that his brother’s autism makes it difficult for them to create a reciprocal understanding. A study by Milevsky & Levitt, (2005: 299) found that children with siblings have a better social understanding of others’ feelings, emotions and perspectives.

Another consistent finding is a theme of acceptance; generally, it appears that all children are accepting of their sibling’s autism. Research by Erikson et al (1999) found that when siblings focus positively on their siblings abilities it enables them to avoid any negative aspects of it, which they also found helped them to engage in a continual process of understanding (I4, FG1, I, 268) (I4, FG1, TB, 293).

It appears that society can affect tolerance towards autism, yet it is discussed whether this is due to a lack of understanding ‘people have called him spacka…people haven’t understood and don’t even know what the word is but they have just recognised that Aaron is a bit different.’ (I6, NM, 176).

Several studies have shown that if parents demonstrate their acceptance of the impaired child, siblings tend to react similarly (Grossman 1972) ‘Never, I wouldn’t change it for the world…and we all love him…’ (I2, JM, 93). Parental openness and communication aids sibling adjustment and understanding about the child’s impairment (McHale et al 1986: 413). ‘We try to help them understand this and over time they have’ (I1, IM, 59).

We can also see how Cody is not accepting of his brother’s autism (I6, FG2, C, 123) mainly because other people would not accept it ‘cos they might laugh at us cos James is different’ (I6, FG2, C, 183). Cody’s worries relate to a study by Burke (2010: 1681), who referred to the experiences of siblings of disabled children as ‘disability by association’. He argued that the experience of childhood disability becomes the property of the family as each member shares the experiences of the other. In schools, many children are conditioned to ‘normalise’ their behaviours and to conform to society (Goodley, 2010) which could explain Cody’s worries.

Another major effect on chid siblings is the behavioural problems they become accustomed to; anger was a major factor affecting the lives of the siblings of autistic children. Mascha and Bouche (2006: 19) found that the most negative aspects of living with a sibling with autism are acts of aggression, excessive anger and tantrums. ‘It’s probably one of our biggest problems at the moment’ (I1, IM, 193). Most siblings are victims of their siblings violence ‘he’ll just batter me…but I’m used to it’ (I7, FG2, C, 128) and succumbed to it on their everyday experiences ‘…I don’t like a sister that…always yells’ (I4, FG1, I, 46).
Not only are sibling’s victims of their brothers and sisters violence but they also express their concerns about their siblings being bullied. ‘I worry about him...I think he gets bullied sometimes’ (I7, FG2, N, 14). Parents also expressed their concerns over their children being bullied (I6, NM, 154).

Despite this, the interviewed children generally portray loving and caring relationships with their siblings and this illogical and unpredictable behaviour portrays how autism changes over time (Shattuck et al, 2007). Sibling relationships must also change with it and learn to cope with this. This type of behaviour can negatively influence the sibling relationship; ‘...make siblings less willing to engage in activities with their brother or sister with an ASD’ (Orsmond & Seltzer, 2009: 1053).

In order to deal with the added strains of having an autistic sibling, many of the siblings and parents have developed coping strategies to help them, (I6, NM, 144) (I2, JM, 60). Some siblings cope by helping more and taking the strain off the family as a whole. Schachter, Shore, Feldman-Rotman, Marquis & Campbell (1976: 418) propose that siblings share out traits amongst themselves in order to limit competition for parents’ attention. This could explain why non-autistic siblings would take on a role of caring for the autistic sibling, ‘She looks after him...she takes on an extra role, my role if you know what I mean.’ (I6, NM, 121). Mandleco, Olsen, Deychels & Marshell (2003) found that when sibling role demands become too extreme, it can have negative outcomes including role strain and the stress of trying to fulfil multiple role obligations.

Another way of improving the living experiences of a sibling with autism is by sticking to routines and rituals. Parents find this to be a good way of coping with everyday strains on the family (I6, NM, 235) (I5, CM, 153). Wiggs (2010: 14) found that structure in daily living improves the quality of the child/parent relationship as well as relieving stress for the parent.

Throughout the interviews the analysis showed that many children support their autistic siblings with homework and by finding them friends (I4, FG1, J, 94) (I1, IM, 138) but others cannot because they lack the knowledge to be able to (I4, FG1, TB, 84) (I7, FG2, C, 200). Children with more support show low signs of loneliness and depression and have more self-esteem and happiness (Milvesky, 2005). Through the interviews with the parents, they expressed how they lacked knowledge and support prior to diagnosis and did not know what autism was (I1, IM, 25) which consequently influenced their ability to help their children understand their siblings.

It seems that siblings’ understanding of autism develops with age (Glasberg, 2000: 153). ‘So as Isla is maturing she is understanding...’ (I1, IM, 145) and parents often underestimate the understanding siblings have of the disability (I1, IM, 111).

Throughout the interviews, both the siblings and parents demonstrate learned helplessness (Rivers & Stoneman, 2003: 394). The emotional ties between siblings are often described as second only to the ties between children and
parents. This could explain why children have more learned helplessness than their parents who are more instinctively inclined to keep trying to help.

The analysis also shows how support groups are a major aspect of these family lives. (I6, NM, 194) (I2, JM, 45). Kaminskey and Dewey (2002) found that siblings of autistic children who attended support groups exhibited fewer internalizing or externalizing behaviours than those siblings who did not.

During the analysis, it was observable that Tracey Beaker and her dad demonstrated autistic characteristics, research by Rutter (1968: 1) shows that autism is 50 times more common in the siblings of autistic children. Girls are less likely to be identified with autism (Gould & Smith, 2011) as they can mask the symptoms (Attwood, 2007). Often, typically developed children imitate their autistic siblings to get more attention (Sigman, Gamliel & Yirmiya, 2007).

**Critical Evaluation**

The main weakness of this study is how limiting the sample is; the participants consisted of schoolchildren, from nuclear families, making it hard to draw any generalised conclusions. The sample is also more susceptible to demand characteristics, as some of the children were shy, they did not have as much involvement as others. Another problem with the recruitment of the sample is that all participants are members of family support groups and would generally be more inclined to help which may not be representative of all families. An additional weakness is the reliability of the diagnoses of the autistic child, who all attend mainstream schools. Perhaps they only have a ‘mild’ form of autism and may not be representative of all children on the spectrum.

The main strength of this study is that the interviews took place in a natural environment adding to the ecological validity of the study. As the analysis relied on the subjective experiences of the children, the analysis is more valid and reliable than if the study only looked at the perceptions of the parents.

**Further Research**

For future research, it would be interesting to explore the experiences of sibling relationships when both siblings have autism, as this seemed quite common amongst families at the support groups. It would also be interesting to revisit the normative ideas of what childhood is and explore how, if it has, changed due to an increase in the prevalence of autism.
Conclusion

This research lends support against traditional views of what it is like growing up with a sibling with a disability. Many would assume there are a number of negative attributes that may affect the relationships of siblings without autism. However, the analysis conducted in this study suggests the siblings show no significant differences in their interactions compared to ‘normal’ sibling pairs, challenging the research by Harris & Ferraioli, (2009). Siblings tended to express positive experiences when asked about their relationships with each other.

In my reflexivity, (see appendix 2) I will discuss the process of carrying out this study, from my perspective as a researcher.
References


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