What are the lived experiences of siblings of children and young people with attention deficit hyperactivity disorder (ADHD)? An Interpretive Phenomenological Analysis

Tamzin Messeter
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Tamzin Messeter
Birmingham Educational Psychology Service
Younger brother with ADHD - interest in the experiences of siblings of CYP with mental health difficulties

Experience working with two siblings of children with ADHD on first fieldwork placement

Limited research has considered the impact on siblings of CYP with ADHD
Research aims

To review literature relating to ADHD, sibling relationships and previous research looking at the influence of having a sibling with ADHD

To understand the experiences of children and young people who have a sibling with ADHD

To consider how EPs may use the findings of the research in their practice
Neurodevelopmental disorder

Inattention, hyperactivity, impulsivity

SEND CoP – listed as SEMH need

No biological test for ADHD – diagnosis based on opinion

‘a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development.’ (APA, 2013).

To meet the diagnostic criteria the behaviours must:

• Be uncharacteristic of the developmental age of the child
• Be seen across a variety of situations and settings, for example home and school
• Have started before the age of 12
• Cause difficulties with social and academic performance
• Be present for at least 6 months

No biological test for ADHD – diagnosis based on opinion
Biomedical perspective

Social construct perspective

Bio-psycho social perspective

Intervention?
An overview of the consequences of ADHD for a child or young person. This figure was comprised from several research studies (Johnston and Mash, 2001; Salmeron, 2009; Birchwood and Daley, 2010; Hamed, Kauer and Stevens, 2015)

**Family**
- Interpersonal conflict
- Increased parental stress
- Parental self-blame
- Increased financial pressures

**Social**
- Social failure
- Deviance with peer groups
- Lack of peer understanding at disruptive behaviour
- Anxiety

**Quality of life**
- Reported low self-esteem
- Reported increased bullying
- Lack of motivation
- Feelings of sadness
- Poor life satisfaction

**Academic**
- Lower scores on assessments
- Less likely to achieve qualifications
- More likely to face exclusion
- Difficulties maintaining employment
Sibling relationships

Sibling relationships are unique – longest relationship individuals will experience in lifetime – however they are under researched population.

Research suggests there are a multitude of dimensions by which a sibling relationship can vary:

- Close vs distant
- Harmony vs conflict
- Competitive vs co-operative

Factors which affect nature of sibling relationships:

- Birth order
- Age difference
- Gender
- Parent relationship status
- Family stressors
- Family size
- Sibling with additional needs
Siblings with additional needs:

Positive and negative outcomes reported:

- Greater risk of depression and anxiety
- Increased levels of maturity and empathy for others and their needs
- Increased levels of responsibility and caretaking

Impact on sibling social life:
- Impact on parental time and attention

Number, age and gender of all siblings in family:
- Resources used to support sibling

Nature of disability:
- Sibling information and knowledge on disability

Sibling relationship:

- Extent of caretaking role
Previous research: siblings of CYP with ADHD

<table>
<thead>
<tr>
<th>Type of study</th>
<th>2 x qualitative</th>
<th>5 x quantitative</th>
</tr>
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</table>

Two key areas of finding were grouped across both the quantitative and qualitative research:

- Emotional needs
- Conflict and disruption

Two additional areas were identified from the qualitative research:

- Caretaking
- Coping strategies
Emotional Needs

• CYP with a sibling with ADHD experience emotions which affect their overall happiness and satisfaction with life (Peasgood et al., 2016)
• Higher rates of anxious and shy behaviours and increased anger (Steinhausen et al., 2012)
• Desire to have a ‘normal life’ (Kendall, 1999)
• Feelings of being overlooked within family and rejection from family (King et al., 2016)
• Concern and worry for their sibling
• Not all studies reported these findings, two studies found no differences in psychological functioning between control participants
Conflict and disruption

- High conflict reported in sibling relationships (Kendall, 1999 and Mikami and Pfiffner, 2008)

- Conflict may present through both physical and verbal acts of aggression and may depend on the relationship between siblings.

- Increased level of self-reported bulling from siblings (Mikami and Pfiffner, 2008)

- Differential parental treatment experienced – eg., parents minimising acts of aggression and violence, fewer consequences for bad behaviour
Caretaking

- Daily expectation that siblings would take on role of responsibility or care in the family system (Kendall, 1999; King et al., 2016)
- Expected to play and supervise siblings at home
- Proxy parent role could lead to siblings feeling resentful
- Participants younger than their sibling viewed caring role more positively as it gave them specific role within family (Kendall, 1999)
Coping strategies

• No valid assessment to measure coping strategies but one study required participants to keep a diary for eight weeks (Kendall, 1999)
• Siblings manage reported disruption in 3 key ways:

  • **Retaliation**
  • **Accommodation** ‘I only talk to him about what he wants to talk about’
  • **Avoidance** ‘I just stay out of his way’
Coping strategies

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Limitations of the past research

- Self-report measures
- No ‘gold standard’ for accurately measuring emotions
- Do not look at individual experiences
- Are they assessing correct constructs?
- No positives accounted for
Research questions

How do participants describe characteristics associated with their siblings’ ADHD?

What is it like growing up with a sibling with ADHD?

How do children and young people with a sibling with ADHD experience their sibling relationship?

How do participants describe the positive characteristics of their sibling?
Methodology

Qualitative

‘Soft’ relativist position – prioritising individual experience but seeking to explore any shared experiences

Interpretive Phenomenological Analysis – how do individuals make sense of their life experiences? (Smith, Flowers and Larkin, 2009)

The meaning of the participants’ account is prioritised over the description (Willig, 2013)
I used a face to face, semi-structured interview to elicit detailed views about living with a sibling with ADHD.

With some participants I used the Kinetic Family Drawing as an opener/warm up activity and to understand more about the family system the participant was in. This was not used in the analysis.

KFD – (Burns and Kaufman, 1970)
Session 1 – explanation of study, consent sign and ‘get to know you’ activities

Session 2 – semi structured interview. This was audio recorded

Session 3 (optional) – joint session with participant and sibling
Participants

- **Ben (14)**
  - Twin sister, Rachel has ADHD
  - Rachel takes medication

- **Chloe (11)**
  - Younger brother, Josh (8) has ADHD
  - Josh does not take medication

- **Katy (11)**
  - Younger sister, Georgie (8) has ADHD
  - Georgie takes medication

- **Jess (18)**
  - Younger brother, Tom (14) has ADHD
  - Tom takes medication

- **Taylor (14)**
  - Younger sister, Georgie (8) has ADHD
  - Georgie takes medication

- **Lauren (18)**
  - Younger brother, Tom (14) has ADHD
  - Tom takes medication
How do participants describe the characteristics associated with their siblings’ ADHD?
Anger?

‘issues’

Can’t control it
Am I responsible?

"Cos it isn't just, she don't take her anger out on just me, it will sometimes be other people like her friends, she'll either get angry at them and stuff like that." (Ben)
• ADHD forms part of siblings’ identity

• Allowed siblings to feel part of a group (eg, my sibling has ADHD)

• “she can’t help it!”

• ADHD explains differences

• **CYP with ADHD may notice their differences more as a result of their sibling ascribing them a disability identity**
What is it like growing up with a sibling with ADHD?

- Feeling of powerlessness
- Strategies for coping
- Support

Understanding
Avoidance
<table>
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<tr>
<th>Feelings of powerlessness</th>
<th>Strategies for coping</th>
<th>Support</th>
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<tbody>
<tr>
<td>Failed attempts at resolving conflict</td>
<td>Avoid sibling</td>
<td>Use mother or close peer to talk to</td>
</tr>
<tr>
<td>Leads to feelings of anger, sadness and stress</td>
<td>Be weary of topic of conversation</td>
<td>Mothers offered support for conflict resolution</td>
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<tr>
<td>Vulnerable</td>
<td>Empathising with sibling</td>
<td>Used support for practical solutions rather than emotional support</td>
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<tr>
<td>Desire for difference</td>
<td></td>
<td>At times, offered parents support</td>
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<tr>
<td>Power imbalance in sibling relationship</td>
<td></td>
<td>Feelings of isolation from peers</td>
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</table>
How do children and young people with a sibling with ADHD experience their sibling relationship?

- Challenges and threats to sibling relationship
- Role of responsibility within the family system
Challenges and threats to sibling relationship

- Conflict, arguments, confrontations
- Longing for ‘different’ relationship

Role of responsibility within family system

- Provided caregiving role
- Role extended to school eg, supervision of sibling
How do participants describe the positive characteristics of their sibling?

Georgie: Happy, generous, active, creative, playful, honest, funny

Josh: Kind, generous, playful

Rachel: Nice, generous, imaginative, happy, active, protective

Tom: Funny, active, nice, sensitive, kind, honest
Summary of findings

Conflict within sibling relationship

CYP with a sibling with ADHD make significant accommodations in their own lives due to their siblings’ behaviours

Lack of understanding of ADHD in participants

Influence of adopting a role of responsibility on identity development

It is possible to identify positive features of the sibling relationship
Future research could...

Explore the experiences of siblings younger than their brother or sister with ADHD

- Would this influence the role of responsibility within the family system?
- Are they more likely to display behaviours modelled on their older sibling?

Investigate the cultural differences in attitude towards ADHD in families

- This research was limited to white, British families

Explore the possibility that having a role of responsibility for a sibling with an additional need may influence identity development
### Considerations for Educational Psychologists

<table>
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<tr>
<th>Category</th>
<th>Considerations</th>
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<tr>
<td><strong>Awareness</strong></td>
<td>- Of unique concerns and challenges siblings can face</td>
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<tr>
<td></td>
<td>- Sibling with ADHD may put child at risk of greater emotional reactivity</td>
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<tr>
<td><strong>Intervention</strong></td>
<td>- Specific intervention may not be necessary</td>
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<td></td>
<td>- Identified key adult and pastoral support important</td>
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<td>- Offer opportunities for CYP to talk about their experiences</td>
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<td><strong>Explore increasing knowledge of ADHD</strong></td>
<td>- Previous research suggests increased knowledge of sibling’s condition can lead to improved well-being</td>
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<td>- Information sessions and support groups may be useful</td>
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<tr>
<td><strong>Explore familial factors</strong></td>
<td>- Determine parental expressed emotion (high is linked to ADHD behaviour severity)</td>
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<td>- Consider the sibling in the wider context of their family system</td>
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Thank you for listening

Any questions?

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Please tweet about the Conference using #DECP19

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