

Young People's Experiences of having a sibling admitted to a Child & Adolescent Mental Health inpatient unit

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Declaration and signature of candidate	
<p>I confirm that the thesis submitted is the outcome of work that I have undertaken during my programme of study, and except where explicitly stated, it is all my own work.</p> <p>I confirm that the decision to submit this thesis is my own.</p> <p>I confirm that except where explicitly stated, the work has not been submitted for another academic award.</p> <p>I confirm that the work has been conducted ethically and that I have maintained the anonymity of research participants at all times within the thesis.</p> <p>Signed: _____ Date: _____</p>	

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List of Abbreviations:

CAMHS	Child & Adolescent Mental Health Service
CBCL	Child Behaviour Checklist
CCAT	Crowe Critical Appraisal Tool
IPA	Interpretative Phenomenological Analysis
NHS	National Health Service
NICE	National Institute Health and Care Excellence
SMI	Severe Mental Illness
UK	United Kingdom

Thesis Abstract:

Paper one is a literature review of eight published studies. It reviews research on the experiences of young people who have a sibling experiencing mental health difficulties. The findings identified that young people would like more information on their sibling's difficulties and highlighted the lack of research with this population. This is despite clinicians and researchers identifying a need to better understand young people's experiences. Furthermore, generalisability of the findings was often limited by the fact that data was gathered from parents and not the young people directly.

Paper two is an empirical study using the qualitative methodological approach, Interpretative Phenomenological Analysis. It explored the experiences of young people who had a sibling admitted to a mental health inpatient unit. 5 brothers of adolescent females were interviewed. Interviews were analysed using interpretative phenomenological analysis. Findings suggest young people experience changes in their family relationships as a result but have trouble expressing their own emotions and may use avoidance strategies to manage this. They also worry about not being able to support their sister enough and what their future may look like with mental health difficulties.

Paper three is an executive summary. This was written as an accessible document for clinicians working in Child & Adolescent Mental Health Services to help disseminate the findings from the empirical study. The rationale for the research, method, findings, limitations of the research and recommendations are summarised.

What is the impact of having a sibling with emotional difficulties during adolescence and childhood?

Abstract:

When individuals experience emotional difficulties, such as anxiety or depression, the whole family can be affected, including siblings. However, little is known how siblings are impacted when a young person is experiencing difficulties.

In this review, research into the experiences of siblings of young people with emotional difficulties is reviewed. A systematic search of electronic databases found eight relevant articles.

Findings suggest that siblings are at increased risk of developing emotional difficulties, but this may be overlooked by professionals. Siblings describe wanting further information on how to support their brother or sister. However, much of the data was sourced from parents with only two studies interviewing siblings.

Further research into the impact of having a sibling with emotional difficulties is needed, with data collected directly from the sibling for a more accurate understanding. Clinicians need to be aware of how these difficulties can affect siblings and how to support them.

Introduction:

The sibling relationship is unique, often being one of the longest and closest relationships a person may have. Growing up, siblings may spend a lot of time with each other and may consequently develop an enhanced awareness of how the other is feeling. As children grow, their sibling can offer support and guidance, as well as increased opportunity for social and emotional development (Brody, 2004; Voorpostel & Blieszner, 2008; Pike, Kretschmer, & Dunn, 2009).

Many mental health difficulties emerge during adolescence (World Health Organisation, 2017). Young people may also experience ongoing emotional difficulties, such as anxiety and depression, which impacts on their day-to-day functioning (Ogundele, 2018) and can require specialist treatment. It is reported that young people in the UK are increasingly experiencing emotional difficulties (Royal College of Nursing, 2017). As over half of the children in the UK live with at least one sibling (Office for National Statistics, 2017), it can be assumed therefore that there are many siblings living with a brother or sister experiencing emotional difficulties. Understandably, this can have a significant impact on the family environment and the sibling relationship, such as having to help their parents to care for their unwell sibling or becoming distant from their sibling (Sin, et al., 2012). Unfortunately, as families report long delays in accessing specialist support (Care Quality Commission, 2017), the young person's mental wellbeing can deteriorate during this wait which may cause additional stress to family members.

The term emotional difficulties include a broader range of difficulties that young people often experience such as anxiety and depression (Ogundele, 2018) and those more frequently seen by specialist Child and Adolescent Mental Health Services (CAMHS) (Children's Commissioner, 2016). It is unknown how this group of siblings experience their brother or sister's difficulties. It is important to learn more about how siblings are impacted by this and ensure they are receiving the support that they need. However, little is known about the impact of being a young person who has a sibling with emotional difficulties.

There has been considerably more research exploring the impact of having a brother or sister with a chronic physical health condition or life-limiting illness, such as cystic fibrosis or cancer (e.g. Knecht, Hellmers, & Metzger, 2015). A previous meta-analysis found these siblings experience negative psychological effects and impaired functioning (Sharpe & Rossiter, 2002) and highlight the need for professionals to be aware of the increased risk to siblings (e.g. Giallo, et al., 2014). Support offered through psychoeducational groups has been found to be beneficial in improving sibling wellbeing with this population (Lane & Mason, 2014; Williams, et al., 2003; Lobato & Kao, 2002; Gursky, 2007).

Qualitative research has shown that adult siblings of those with severe mental illness (SMI), such as Bipolar Affective Disorder and Schizophrenia, report stigma from others for having a brother or sister with mental health difficulties (Corrigan, Miller, & Watson, 2006). They may also worry about their unwell sibling becoming a burden to them if they need to become their main carer when their parents pass away (Greenberg, Kim, & Greenley, 1997; Friedrich, Lively, & Rubenstein, 2008; Seeman, 2013). Areemit and colleagues (2010) also found that young people reported a negative impact on their own quality of life, and an increased sense of responsibility because of their brother or sister having an Eating Disorder. More recently, research has been conducted with siblings of young people experiencing a first episode of Psychosis who also report the significant impact it has had on them and describe needing to support their parents (Sin, et al., 2012).

Despite this, support specifically for siblings of young people appears to be unavailable. A 2015 Cochrane review (Sin, et al., 2015) aiming to evaluate the effectiveness of psychoeducational interventions for siblings of individuals with SMI was only able to find one suitable trial. A survey of mental health professionals found that 90% felt siblings should receive emotional support (Rethink, 2006), and best practice guidelines advise that the whole family is involved in treatment, with support offered to all members (Department of Health & NHS England, 2015). Evidence also suggests that siblings of young people with emotional difficulties would like to be kept involved and more informed of their brother or sister's diagnosis and prognosis. Some siblings report feeling excluded from discussions

about their sibling's difficulties despite wanting to be included and wanting to be provided with information (Gettings, Franco, & Santosh, 2015; Rethink, 2006). Due to a lack of research involving siblings as participants, it is difficult to conclude how best to support and offer this information to this group of young people.

The limited research into siblings has largely focussed on either young people with physical illness or adults with emotional difficulties. These findings cannot be easily generalised to siblings of young people with emotional difficulties. There is, however, an increasing awareness of the needs of young people who have a sibling experiencing Psychosis or have an Eating Disorder. Previous research (e.g. Sin, et al., 2015; Areemit, et al., 2010) has reviewed the literature on the impact of specific diagnoses (e.g. Psychosis and Eating Disorders) on siblings. The NHS has commissioned specialist mental health services for First Episode Psychosis and Eating Disorders. Their remit includes work with family members (NHS England, 2016, 2015). However, the impact of a sibling's emotional difficulties in young people is not well established.

Rationale for review

A review of the current literature into the impact of siblings of young people with emotional difficulties will be beneficial. Research to date has largely focussed on siblings of adults with emotional difficulties, or siblings of young people with physical health conditions. With reports of emotional difficulties in young people on the increase, it can be assumed therefore that siblings are more likely to be living with a brother or sister who is experiencing emotional distress. It is important to understand how young people experience this to ensure services are meeting the needs of the whole family.

Aim

The aim of this review is to collate and review existing research relating to siblings of young people with emotional difficulties to help answer the question: 'what is the impact of having a sibling with emotional difficulties during adolescence and childhood?'

Methodology:

Search strategy

Initial scoping searches were conducted during February and March 2018. This included searching the PROSPERO database to ensure there were no existing systematic reviews that had already been conducted in this area. As no relevant reviews were found, a thorough review of the current literature around sibling experiences was conducted during June 2018. The database host 'Health Databases Advance Search' (HDAS) was used to search for relevant literature from: EMBASE, PsycINFO, AMED, HBE, PubMed, BNI, HMIC, CINAHL and Medline. Additionally, Science Direct and EBSCO databases were searched. Grey literature was searched via the British Library 'EThOS' service for access to unpublished theses. Hand searching of the reference lists of relevant articles was also conducted.

All published research available from the databases up to 9th June 2018 was included in the search. No restrictions were placed on the country the data was collected in. This allowed for the broadest range of data to be included in the initial search.

Articles found were screened firstly by title, then abstract and, finally, the full text was read to assess for suitability. Articles were excluded if they did not meet the inclusion criteria. Articles not published in English were excluded during the search as it was not possible to have these accurately translated.

Search terms

Keywords were developed to build an efficient search strategy. The primary concepts of 'siblings', 'emotional difficulties' and 'experience' were expanded to ensure a comprehensive search was employed. The search terms were entered, initially as 3 separate searches using the Boolean operator 'OR', and then combined using the Boolean operator 'AND'. Where the database allowed, search terms were 'exploded' using the thesaurus function.

- Sibling/s OR brother/s OR sister/s
 - AND

- Mental health OR emotional difficulties OR depression OR low mood OR anxiety OR self-harm OR personality disorder
 - AND
- Experience OR impact OR quality of life OR wellbeing OR functioning OR coping

Although the research question is centred on young people's experiences, age was not included in the search terms to ensure articles were not missed and instead were screened out in the following stage of the process. The process is shown in figure 1.

Inclusion / exclusion criteria

The following criteria was applied to the search results:

Inclusion:

- A focus on siblings;
- Index sibling to be a young person, defined as being under the age of 18;
- Dominant focus is on emotional difficulties or mental health problems.

Exclusion:

- Participants are adults;
- Dominant focus of research is physical illness, behavioural or neurodevelopmental disorders e.g. Attention Deficit Hyperactivity Disorder (ADHD), Conduct Disorder or Autism Spectrum Disorder (ASD);
- Siblings not focus of research;
- Not exploring experience or effect on siblings – e.g. looking at parent experience;
- Looking at the effect of 'severe mental illness' (SMI) on siblings e.g. Schizophrenia, Anorexia Nervosa, unless possible to separate data by diagnosis;
- Exploring the effect of death and bereavement on a sibling.

An upper age limit of 18 years was set as health and social care services typically transfer care of a person to adult services once the young person turns 18 and are then legally classed as an 'adult' (Department for Education, 2018).

Search results

The initial search produced 3709 articles, of which 1162 were duplicates and 161 were found to be not published in English. A title and abstract screen were conducted on the remaining 2386 articles. Articles were excluded at this stage if they did not contain reference to the keywords, included an adult sample or the focus was on the impact of learning disability or autism, death/bereavement, and physical health conditions. This left 65 articles. Reference lists were hand searched for additional articles not already selected. This found an additional 17 articles, bringing the total to 82.

The full text of 82 articles were then retrieved and read in full to assess suitability. Following this 74 were excluded as they did not meet the inclusion/exclusion criteria as described previously. Eight studies were therefore selected for review. This included a range of methodologies: 2 qualitative, 4 quantitative methodologies, a systematic review and a mixed methods design (as defined by National Institute Health and Care Excellence, 2014).

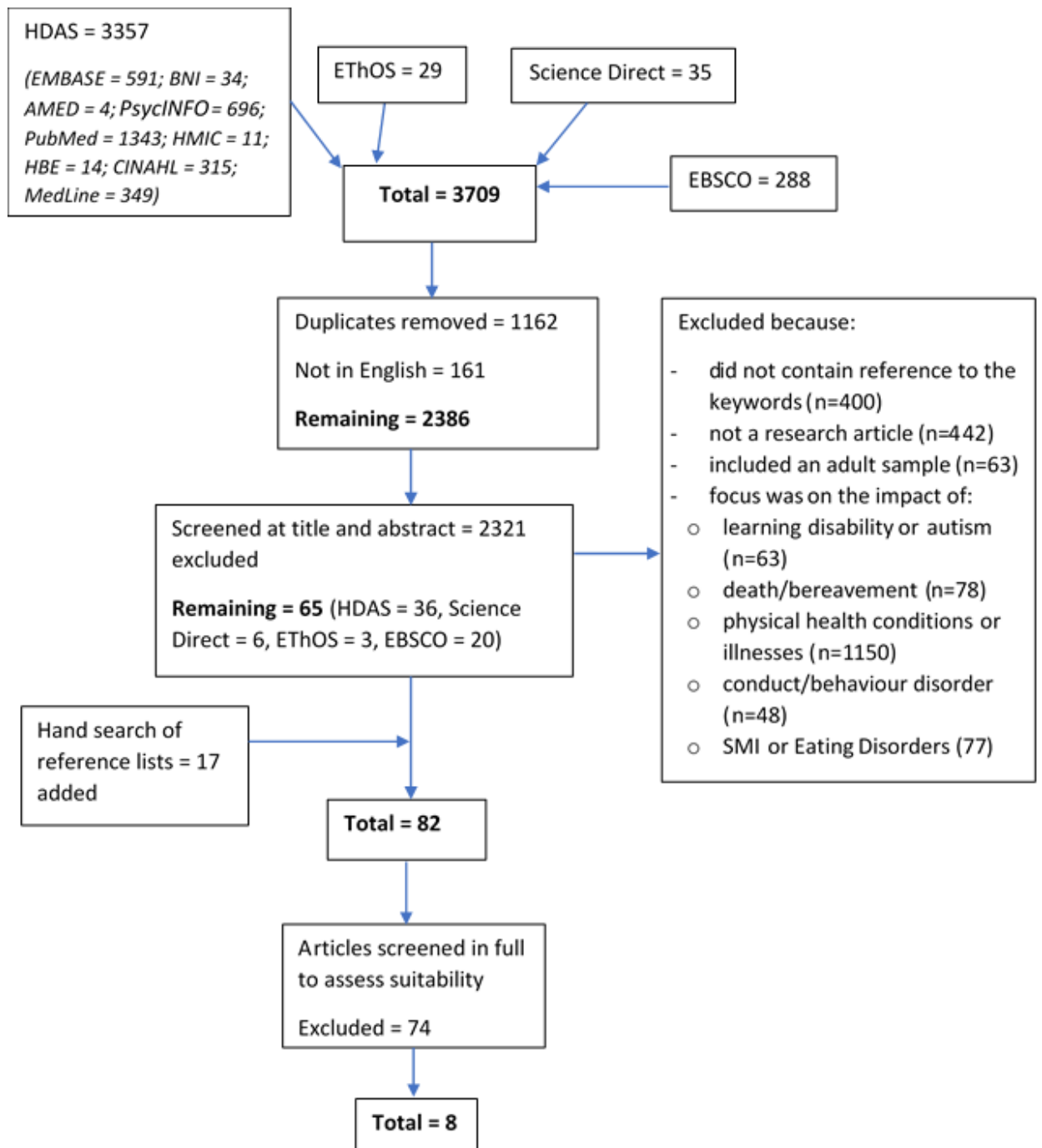


Figure 1: Data search process

Critical appraisal

As different methodologies were used by the final 8 articles selected for review it is important that a critical appraisal tool be consistent in appraising each methodology and allowing for comparison as necessary. The Crowe Critical Appraisal Tool, version 1.4 (CCAT; Appendix 1) (Crowe, 2013) was selected for this

reason. It has good construct validity and reliability between raters and can be used across methodologies (Crowe & Sheppard, 2011).

The CCAT appraises each article on 8 key categories that should be present in all research designs with guidelines for each. The reviewer is asked to rate each category on a 6-point scale, from 0 - 5 with 5 being the highest. There is no standardised method for scoring, instead reviewers are asked to consider the points present in each category and make their own judgement in deciding on a score. As a rough guide, articles were given a score of '5' if all guidelines described were met and '0' if none were met. Scores are then summed to give a total out of 40. Crowe (2013) advises that this is converted into a percentage for ease.

Synthesis

A narrative approach to synthesising the articles by themes was used (Cronin, Ryan, & Coughlan, 2008; Snilstveit, Oliver, & Vojtkova, 2012). Firstly, an overview of each individual article was developed before synthesising the data found across the articles by different thematic categories. The findings were synthesised by aspects of the study design and quality before grouping by the major themes found across the articles, and those which help to answer the research question and aim of the literature review.

Results:

Eight articles were selected for review. This included a range of research designs including a systematic review, mixed methods, qualitative and quantitative methodologies. A summary of the included articles is found in Table 1 and described in further detail below.

Table 1: Summary of included articles

Authors (year)	Aim	Sample	Diagnosis of index sibling	Methodology / study design	Analysis	Key findings
Liegghio (2017)	Explore how siblings experience their brother or sister's mental health difficulties and how these experiences shape their sense of self and family.	7 siblings (mean age 15.4 years; SD = 2.76).	Anxiety, First Episode Psychosis, Attention Deficit/Hyperactivity Disorder, depression and Bipolar Affective Disorder ¹	Qualitative: Semi-structured interview	Grounded theory	Siblings experience their brother or sister's mental health issues negatively with it being a source of worry, stress and burden. Suggested there was a tendency to not talk openly about mental health in the family.
Fox, Barrett, & Shortt (2002)	Explore the nature of sibling interaction and relationship variables for children diagnosed with an anxiety disorder and their sibling compared to control sibling pairs.	36 children with clinically diagnosed anxiety disorder and their siblings (mean age 10.4 years; SD = 2.75). 15 control children and their sibling (mean age 10.3 years; SD = 2.99).	Anxiety disorder	Cross-sectional self-report questionnaires and an observed discussion between sibling pairs. Parents completed measures on child's behaviour and their own mental health. Children completed questionnaire on sibling relationship and anxiety.	MANOVA and discussion was analysed using discriminate function analysis	Siblings of children diagnosed with an anxiety disorder rated more conflict, less warmth and more control in their relationships compared to control sibling pairs.
Dia & Harrington (2006)	Examine the psychosocial functioning of children who have a sibling with an anxiety disorder.	65 siblings (mean age 9.9 years; SD = 3.2) of children receiving treatment.	Anxiety disorder (78%) and anxiety and depression (22%)	Cross-sectional – parent self-report questionnaire on child behaviour and demographics.	Regression analysis	Compared to the general population, the sibling sample were more likely to have elevated scores that were in the clinical range.

¹ Attempts were made to clarify how many siblings had each diagnosis. Further information was not received but was included as focus is on having a sibling with a mental health issue, and not a specific diagnosis.

Authors (year)	Aim	Sample	Diagnosis of index sibling	Methodology / study design	Analysis	Key findings
Ma, Roberts, Winefield, & Furber (2015)	Synthesise published data on the prevalence of psychopathology in siblings of children with mental health problems.	Systematic literature search found 39 studies that met inclusion criteria ² .	Affective and anxiety disorder	Systematic literature search	Narrative synthesis	Siblings of children with affective disorders had significantly higher rates of affective disorders compared to control siblings.
Deal & MacLean (1995)	Investigate the psychological adjustment of young people who have emotionally unwell siblings and explore how they perceive their relationship with this sibling.	15 younger siblings (mean age 11.4 years; SD = 2.6) of previously hospitalised young people. 15 younger siblings of never hospitalised young people.	Depressive disorders (n=5), depression with comorbidities (n=4), conduct and adjustment disorders (n=6)	Cross-sectional mixed-methods: Parent and participant completed questionnaires on child behaviour, self-perception, depression, anxiety and sibling relationship. Participant interviewed about sibling relationship.	Multivariate analysis of variance (MANOVA)	Siblings of previously hospitalised young people experienced more psychological distress and viewed their siblings more negatively than controls. Parents reported more internalising behaviours compared to controls.
Kelvin, Goodyer, & Altham (1996)	Explore the temperament style of siblings of young people with anxiety or depression compared to control sibling pairs.	31 siblings of 29 clinically unwell young people (58% aged over 12). 40 community control siblings (80% aged over 12).	Depressive disorders (72.4%) and anxiety disorder (27.6%)	Cross-sectional self-report questionnaires and diagnostic research interview. Participants completed questionnaires on temperament and functioning.	Regression analysis	Younger siblings are at increased risk of developing mental health difficulties and have poor functioning compared to controls.

² A range of diagnoses were included but results were categorised by diagnosis. Therefore, this article was included as data specifically referring to emotional difficulties was able to be reviewed separately.

Authors (year)	Aim	Sample	Diagnosis of index sibling	Methodology / study design	Analysis	Key findings
Litzfelner (1995)	Investigate siblings' perceptions of how they and their family are affected by their brother or sister's mental health issues.	4 siblings of children receiving outpatient treatments (age 13 – 19 years).	'severe emotional disability' ³	Qualitative: Focus group methodology	Thematic analysis	Siblings spoke positively about the future for their sibling and felt their family lives were normal. They spoke about the impact of aggression shown by their sibling on their lives and wanting further information on their sibling's difficulties.
Hudson & Rapee (2002)	To see if parents of anxious children will be over-involved in helping their anxious child during a task compared to when helping their non-anxious sibling.	37 children with anxiety and their siblings. Control group of 20 children and their siblings. Age 7 – 16 years.	Anxiety disorder	Cross-sectional mixed methods: questionnaires on anxiety, depression and behaviour completed. Interaction between parent and child observed during a puzzle task.	Within-participants t-tests and analysis of variance (ANOVA)	Parents were more involved with both their children on a puzzle task compared to control sample. Siblings also reported higher levels of anxiety compared to control sample.

³ Attempts made to clarify details on the sibling's difficulties with the researcher, but further information was not received.

Overview of research quality

Study design:

Two studies used a qualitative design (Litzelfelner, 1995; Liegghio, 2017) whilst four used quantitative research designs (Dia & Harrington, 2006; Hudson & Rapee, 2002; Kelvin, Goodyer, & Altham, 1996; Fox, Barrett, & Shortt, 2002). Deal & MacLean (1995) used a mixed methods research design whilst a systematic review was completed by Ma, et al., (2015).

Of the two qualitative studies, Litzelfelner (1995) collected data from a focus group of 4 siblings of children receiving outpatient treatment for 'emotional disability'. Transcripts were analysed using thematic analysis. Liegghio (2017) completed semi structured interviews with 7 siblings of young people with a range of emotional difficulties. Grounded theory was used to analyse the interviews.

Of the quantitative research, all were cross-sectional studies whereby participants completed a range of self-report questionnaires covering behaviour and mood. Kelvin, Goodyer, & Altham (1996) also completed a diagnostic research interview with participants. Fox, Barrett, & Shortt (2002) observed a discussion between siblings that was later coded to measure the sibling relationship on 4 variables. Hudson & Rapee (2002) similarly coded interactions between parent and child during a puzzle task.

Deal & MacLean (1995) also used a cross-sectional design with self-report questionnaires. However, participants were also interviewed about the sibling relationship. Details on the qualitative method used was not reported.

Ma, et al., (2015) completed a narrative synthesis on literature published between January 1990 and July 2011.

Sample characteristics:

Sample sizes ranged from 4 to 65 individuals. Litzelfelner (1995) and Liegghio (2017) interviewed siblings of young people with emotional difficulties. The quantitative and mixed-methods studies collected data from a parent. Aside from one quantitative study Dia & Harrington (2006) study, participants included sibling pairs

and a parent (Hudson & Rapee, 2002; Fox, Barrett, & Shortt, 2002; Kelvin, Goodyer, & Altham, 1996; Deal & MacLean, 1995). The qualitative and quantitative design studies were conducted in English-speaking, Western countries and published between 1995 and 2017. Studies were conducted in the United States of America (Deal & MacLean, 1995; Dia & Harrington, 2006; Litzelfelner, 1995), Australia (Hudson & Rapee, 2002; Fox, Barrett, & Shortt, 2002), United Kingdom (Kelvin, Goodyer, & Altham, 1996) and Canada (Liegghio, 2017). The systematic review by Ma et al. (2015) included studies from these countries as well as Spain and the Netherlands.

Three of the quantitative studies and the mixed-methods study included a control sample of siblings and sibling pairs (Deal & MacLean, 1995; Hudson & Rapee, 2002; Fox, Barrett, & Shortt, 2002; Kelvin, Goodyer, & Altham, 1996). Dia & Harrington (2006) had no control group data as only parents were asked to complete questionnaires on their child and these scores were compared with the published norms for the questionnaire.

The studies used young people and their siblings who were recruited from clinical populations. Although most relied on self-report details about the diagnosis or difficulties the index child was experiencing, Kelvin, Goodyer, & Altham (1996) and Hudson & Rapee (2002) completed a diagnostic research interview to assess siblings and their unwell brother or sister using standardised diagnostic criteria (DSM-IV; American Psychiatric Association, 2000). Fox, Barrett, & Shortt (2002) also completed a diagnostic interview but only for the index child and not with the control sample so there may have been some control participants with existing difficulties not accounted for. Dia & Harrington (2006) excluded siblings who were found to have a professional diagnosis of mood or anxiety disorder so that they could assess the level of internalising and externalising behaviours present in a non-clinical sample.

There are some limitations in generalising findings. For example, Hudson & Rapee (2002) excluded single-parent families from participating in their study. Currently, almost 1 in 4 UK families are single-parent (Gingerbread, 2018). Dia & Harrington (2006) and Fox, Barrett, & Shortt (2002) requested that the sibling closest in age to

the index child be included as participants. Deal & MacLean (1995) only used younger siblings of the index child. The rationale for having such exclusion criteria is not sufficiently explained and represents a gap in the research as the impact on older siblings, or siblings from single-parent households are not discussed.

Data collection and analysis:

Dia & Harrington (2006) only collected data from the parent whilst the majority of studies only collected questionnaire data from siblings. First hand qualitative accounts may increase the reliability of this data, for example, parental self-report may not be an accurate reflection of sibling behaviour. Data from multiple perspectives should be collected that is combined to produce the most valid information (Ma, et al, 2015).

Different methods for assessing the emotional difficulties of the index child were used. Four of the five quantitative studies (Dia & Harrington, 2006; Fox, Barrett, & Shortt, 2002; Hudson & Rapee, 2002; Deal & MacLean, 1995) included the 'Child Behaviour Checklist' (CBCL; Achenbach, 1991) which measures the level of 'internalising' (e.g. anxiety, low mood) and 'externalising' (e.g. aggression) behaviours present. This provides an overview of the level of emotional difficulty experienced by the young person. The questionnaire is completed by the parent and this may result in an under, or over-reporting of behaviours and therefore not a true representation of how siblings are feeling. Research into the CBCL has also found that parents typically reported fewer internalising symptoms than what was reported by their child (Rey, Schrader, & Morris-Yates, 1992).

Statistical analysis used in the studies included analysis of variance (ANOVA) (Hudson & Rapee, 2002) and multivariate analysis of variance (MANOVA) (Deal & MacLean, 1995; Fox, Barrett, & Shortt, 2002) and regression analysis (Dia & Harrington, 2006; Kelvin, Goodyer, & Altham, 1996). Regression analysis was used to explore the variables associated with increased risk of internalising and externalising difficulties for siblings of young people with existing emotional difficulties. The cross-sectional nature of these studies is only able to provide

information on one point in time however, and correlational analysis does not allow readers to infer cause or effect.

Quality of studies:

The quality of the studies, as assessed by the CCAT, vary from 60% to 88% suggesting all studies have met some criteria in each section (see appendix 1 for details of basic criteria). The final scoring is shown below in table 2. The systematic review (Ma, et al, 2015) was rated the highest at 88% as detailed information was presented on each stage of the process and clearly explained. Of the quantitative studies, the exploratory study by Dia & Harrington was rated the poorest (60%). The article did not include details on ethical issues to do with recruitment. Litzelfelner's (1995) qualitative study was also rated poorly, due to only containing brief detail on ethical issues and providing little information on the sample.

All studies failed to report enough information on ethical matters although there is nothing to suggest that studies were conducted unethically despite this. Of the eight studies included, only Kelvin, Goodyer, & Altham (1996) provide acknowledgement of other contributors, which included a leading pharmaceutical company. This is important to document as can lead to bias and a conflict of interest (Crowe, 2013).

Many of the studies do not include information on the study design, such as how the sample size was chosen or why a particular methodology and analysis was selected: the type of qualitative analysis used is not even disclosed by Deal & MacLean (1995). Although the methodology selected by researchers on the whole can be considered appropriate in answering their research questions.

In the systematic review by Ma and colleagues (2015), the reviewers were unable to come to a conclusion after reviewing existing literature due to the variable quality of methodology used in the studies. This suggests that the poor quality of some of the included articles is not unusual. Articles have also scored highly in some categories yet poorly in others (e.g. Liegghio, 2017) and each have their own strengths and limitations, as summarised in table 3 below.

	Hudson & Rapee (2002)	Deal & MacLean (1995)	Dia & Harrington (2006)	Fox, Barrett, & Shortt (2002)	Kelvin, Goodyer, & Altham (1996)	Lieghio (2017)	Litzelfelner (1995)	Ma, Roberts, Winefield, & Furber (2015)
Preliminaries	4	3	2	4	4	4	3	4
Introduction	4	3	3	5	4	5	4	5
Design	3	3	3	4	4	4	3	4
Sampling	3	3	4	4	5	4	3	5
Data Collection	3	4	4	5	4	5	4	5
Ethical Matters	1	1	1	3	1	4	2	3
Results	3	3	3	4	3	4	3	4
Discussion	4	5	4	4	4	4	4	4
Total (/40)	25	25	24	33	29	34	26	34
%	63	63	60	83	73	85	65	85

Table 2: CCAT scores

	Strengths	Limitations
Hudson & Rapee (2002)	Introduction and abstract are clear & succinct.	Single parent families excluded but no rationale provided.
Deal & MacLean (1995)	Findings are summarised well in discussion.	Qualitative data and analysis are not provided.
Dia & Harrington (2006)	Discussion provides good summary of results.	Information should be included on participants who declined.
Fox, Barrett, & Shortt (2002)	Preliminary statistics reported & checked for confounding variables.	No explanation over how sample size was chosen
Kelvin, Goodyer, & Altham (1996)	Detailed information given on chosen measures.	Information on sampling method is vague.
Lieghio (2017)	Methodology is very detailed.	Further information on participant demographics needed.
Litzelfelner (1995)	Data is interpreted and applied to clinical situations.	No information on analysis used or sample characteristics.
Ma, Roberts, Winefield, & Furber (2015)	Clear rationale provided & detailed methodology.	Potential research bias not discussed.

Table 3: Strengths and limitations of studies

Narrative synthesis

The findings of these studies relevant in answering the aim of this literature review can be grouped into the following themes: influence of family variables, increased risk to sibling, resilience, relationship impact and emotional impact.

Family variables:

The results of the studies indicate that birth order and family structure can play a role in how a sibling adjusts to having a brother or sister with emotional difficulties.

Across the articles, the effect of birth order on sibling experience has been mentioned. In their review, Ma and colleagues found younger siblings were more likely to develop emotional difficulties if their older sibling was unwell, compared to having an unwell younger sibling. They reflect that this relationship has also been observed in the general population, where prevalence rates suggest that younger children have higher rates of emotional difficulties than older children (Ma, et al, 2015).

Other studies (e.g. Hudson & Rapee, 2002) only included the younger sibling of young people with emotional difficulties so comparisons cannot be made.

Researchers also comment on the effect of a family history of mental health difficulties and current family environment. Hudson & Rapee (2002) noted that mothers had higher self-reported levels of anxiety compared to fathers. Mothers were also found to be significantly more involved with their child than mothers in the control group during a puzzle task. This overinvolvement is hypothesised to be “central to the development of anxiety disorders” in children (p. 548). Although, the authors found that mothers were as involved with their non-anxious child as they were with their clinically anxious child suggesting the difference was not due to their child’s difficulties.

Increased risk to sibling:

Studies that included the index child and their sibling reflected on the increased levels of emotional difficulties present in the sibling (Dia & Harrington, 2006; Kelvin,

Goodyer, & Altham, 1996; Hudson & Rapee, 2002; Ma, et al, 2015). Many of these young people had scores on self-report measures that placed them in the clinical range for anxiety or depression but were often not receiving support for this.

Dia & Harrington (2006) found siblings had high internalising behaviours compared to the general population, suggesting an increased risk of depression and anxiety. Regression analysis found a positive relationship between total CBCL score and length of time the index child had been receiving treatment for their anxiety disorder suggesting risk to the young person increased the longer the index sibling was unwell.

Ma, et al. (2015) reviewed existing literature on the prevalence of psychopathology in siblings of children with mental health problems. They concluded that siblings of children with affective disorders had significantly higher rates of affective disorders compared to control siblings.

Kelvin, Goodyer, & Altham (1996) explored the different temperament styles of depressed and anxious children compared with their siblings. Community control participants were also recruited and matched for age and gender with the index sibling. All participants were interviewed to determine presence of any mental health difficulties. This allowed prevalence of mental health difficulties in siblings of children with depression and anxiety to be compared with a community sample and population norms. The researchers found that the sibling group had three times the expected prevalence rate for depression, attention deficit and hyperactivity disorder, conduct and anxiety disorders. Regression analysis found a significant correlation between level of 'emotionality' temperament and comorbidity in siblings who had an unwell brother or sister.

Resilience:

Although the research suggests that siblings have high levels of emotional difficulties, not all the sibling participants were found to have poor functioning. As Kelvin, Goodyer, & Altham (1996) note that not all siblings with potentially diagnosable mental health difficulties had impaired functioning suggesting they were managing well despite symptomology.

Relationship impact:

The studies suggest that the sibling relationship may be impacted negatively because one sibling is experiencing emotional difficulties.

Fox, Barrett, & Shortt (2002) found siblings rated more conflict in their relationship with their anxious brother or sister compared to the control sibling pairs. Siblings interviewed by Litzelfelner (1995) also spoke about the aggression they had witnessed from their sibling and this being one of the most difficult behaviour to observe from their sibling. Deal & MacLean (1995) also found that 80% of siblings reported frequent episodes of physical aggression from their unwell sibling, compared to only 20% in the control sample.

Deal & MacLean (1995) also found that participants perceived their relationship with them as less positive and identified less with their sibling compared to the matched controls. However, they hypothesise that by not identifying with their unwell siblings they are attempting to alleviate any worries they have about going on to develop similar difficulties. It may also be an attempt to reduce the emotional impact on them by distancing themselves, physically and emotionally, from their unwell sibling. As one sibling described:

"It doesn't really affect my life much because I spend a lot time at work and school and stuff, but when I'm home it does."
(Litzelfelner, 1995, p. 268).

Siblings also describe an altered relationship with their parents as a result of having a brother or sister with emotional difficulties. As one of the siblings in Liegghio's study states:

"Me and my mom, we sort of get along now... It sort of hurt our relationship" (p. 5).

Additionally, Deal & MacLean (1995) found siblings perceived a lack of parental support and parental favouritism to their unwell sibling. The authors reflect on the possible long-term negative effect this may have.

Quantitative research also supports these findings. Fox, Barrett, & Shortt (2002) found that anxious children were statistically less warm and more controlling towards their sibling during an observed discussion compared to the control sibling

pair. However, it is not known if these differences are directly linked to the index child's anxiety difficulties or other variables such as the home environment.

Emotional impact:

Several of the studies found siblings described feeling worried as a result of their brother or sisters emotional difficulties. Deal & MacLean (1995) stated that siblings of unwell adolescents described feelings of guilt and a sense of responsibility towards their older brother or sister. One sibling in Liegghio's (2017) study described their brother as a "burden" (p. 4). Another sibling stated:

"It stresses me out a lot...If I could choose to be anywhere, it would be anywhere but home because home, there's always problems, or there'd just be issues with my brother and I could hear all about it and then I have to get involved. So it's like stressful, and then like I can't focus properly and do my own stuff, like, for school, for example." (p. 4).

However, siblings also describe not having the support they need. Siblings spoke about the tendency for the family to conceal or not talk about their sibling's mental health difficulties. This left them with added burden as they felt they had no support, or guilt at requiring extra support.

"I would feel bad if I had to say, "Oh, yeah. I'm going to counselling because of my brother." Like, it's not because of him, but it's because of the overall stress. But, I don't know. I wouldn't want to call it "counselling" 'cause then it seems like there's a huge problem, and maybe there is but I don't know – I'd feel weird or even, like, bad." (Liegghio, 2017, p. 6).

Discussion:

The articles found during this literature review have helped to begin to understand how young people with a sibling experiencing emotional difficulties may experience and, be impacted by, the difficulties.

Critical overview of literature review

This literature review aimed to answer the question: ‘what is the impact of having a sibling with emotional difficulties during adolescence and childhood?’

Unfortunately, little research was found that included this population in its sample and therefore the results are limited. The included studies often had insufficient information on the young person’s emotional difficulties although every effort was made to gather further information on the sample where possible. This may have resulted in a large variance in the types of emotional difficulties included. As the studies were conducted in different countries and participants recruited via several different methods, the findings must be interpreted with caution as the negative emotional and relational impact to siblings reported by this review may not be representative of all siblings of young people with emotional difficulties. For example, siblings of young people admitted to a mental health inpatient unit may have different experiences compared to young people treated by community outpatient clinics.

Clinical implications:

This review raises important clinical questions for professionals working with families and young people and for researchers when thinking about the impact a sibling with emotional difficulties can have on young people.

Psychoeducation

The researchers conclude that professionals should ask about how siblings are managing in assessment sessions. Farnfield (2017) states that siblings should be included in treatment and believe the difficulties observed in the index child may provide a function in the family, and their difficulties should be seen in the family context and not in isolation. Litzelfelner (1995) concludes that accessible information should be provided for family members and siblings should be included in thinking about the strengths present in their family so that the focus on the young persons emotional difficulties is shifted.

As mirrored by research with siblings of children with physical illnesses, siblings of children with emotional difficulties also report wanting further information on their brother or sister's difficulties. Litzelfelner (1995) found siblings described worrying about the future and the possible genetic risk to their brother or sister's difficulties was made worse by not having an understanding of their sibling's difficulties. Psychoeducational groups have been successful with siblings of children with physical illness (e.g. McKenzie Smith, et al., 2018; Gursky, 2007) and perhaps should be considered for siblings of young people experiencing with emotional difficulties.

As mentioned previously, a review into psychoeducation specifically for siblings was only able to identify one suitable trial (Sin, et al., 2015). However, it has been suggested that one of the barriers to this may be because the young person does not identify as having a sibling with a mental health problem or emotional difficulties. This would then result in the young person not viewing themselves as a 'carer', although they may offer support to their sibling. Combined, this can further exclude them from receiving support (Rethink Mental Illness, 2013; Sin, et al., 2012).

Clinical practice

As has been highlighted by the articles, it is paramount that clinicians include siblings where possible when working with young people and their families. They are at an increased risk of also developing emotional difficulties and may be already experiencing increased anxiety due to having a brother or sister experiencing emotional distress.

One option is for clinicians to ask about the wellbeing of siblings when assessing a young person (Dia & Harrington, 2006; Liegghio, 2017). This family-focused approach to including all family members and recognising that they can all be affected may help to improve wellbeing for all family members (Kilmer, et al., 2010) as well as reduce the emotional burden that siblings have described because of having a brother or sister with emotional difficulties. It would also be important for clinicians to consider what sibling relationships were like prior to the onset of the

emotional difficulties to ascertain if this has been affected. This would therefore guide what therapeutic impact is offered such as systemic family therapy or individual support for the sibling is thought to be more suitable.

Future research

As the findings from this review suggest there may be a relationship between birth order and how a sibling's difficulties are experienced, this would be pertinent to explore further to generate a hypothesis on why there may be a relationship between these two variables.

In those siblings who appear to be adjusting well despite having an unwell brother or sister, future research should focus on what qualities this group have that allow them to develop resilience as this can be replicated to help support other families to adapt well to having a young person experiencing emotional difficulties (Kilmer, et al., 2010; Deal & MacLean, 1995).

Further research should aim to seek the perspectives of young people about what intervention they would find valuable when their sibling has emotional difficulties. A range of interventions have been trialled with siblings of young people with physical illnesses or learning disabilities that aim to increase understanding and offer support, but little is known about what would be most helpful in this population. Psychoeducational groups aimed specifically at siblings may be valuable, but these should be piloted in the first instance to ensure the needs of these siblings are met. Other sources of support may come from pastoral support or mentoring offered in schools or through third-sector organisations. It may also be that including siblings, either informally or formally, as part of the initial assessment process is sufficient at meeting the needs of most siblings, but further research is needed to evaluate if this approach has beneficial long-term outcomes for siblings and the family.

Conclusion:

This review highlights the need for further research with siblings of young people with emotional difficulties. Although the included studies were of reasonable quality, the full extent to which siblings are impacted by, and their experience of, their brother or sister becoming unwell with emotional difficulties is not known. It appears that siblings are negatively impacted and may be experiencing significant difficulties themselves. The cross-sectional nature of much of the included research is unable to infer cause, or impact.

Qualitative research is required to learn more about how siblings experience this and what support they feel would be helpful. Qualitative research would provide an opportunity to gain an understanding of the sibling experience as well as research exploring factors associated with positive adjustment to sibling emotional difficulties.

Clinical trials including siblings are needed to test out approaches that may offer better support for siblings given that research suggests they are at increased risk of developing emotional difficulties. Although this can be for many different reasons, it is important that siblings are not forgotten about in clinical practice. For example, research exploring the feasibility and consequences of including siblings in the assessment and intervention process would be helpful. This may result in early detection and intervention of sibling difficulties, improving prognosis for siblings.

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Appendices

Appendix 1: Crowe Critical Appraisal Tool

Category Item	Description of item <input type="checkbox"/> Present, <input type="checkbox"/> Absent, <input type="checkbox"/> Not applicable	Score [0-5]
Preamble		
Text	1. Sufficient detail others could reproduce <input type="checkbox"/> 2. Clear/concise writing <input type="checkbox"/> ; table(s) <input type="checkbox"/> ; diagram(s) <input type="checkbox"/> ; figure(s) <input type="checkbox"/>	Preamble score
Title	1. Includes study aims <input type="checkbox"/> and design <input type="checkbox"/>	
Abstract	1. Key information <input type="checkbox"/> 2. Balanced <input type="checkbox"/> and informative <input type="checkbox"/>	
Introduction		
Background	1. Summary of current knowledge <input type="checkbox"/> 2. Specific problem(s) addressed <input type="checkbox"/> and reason(s) for addressing <input type="checkbox"/>	Introduction score
Objective	1. Primary objective(s), hypothesis(es), or aim(s) <input type="checkbox"/> 2. Secondary question(s) <input type="checkbox"/>	
Design		
Research design	1. Research design(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Suitability of research design(s) <input type="checkbox"/>	Design score
Intervention, Treatment, Exposure	1. Intervention(s)/treatment(s)/exposure(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Precise details of the intervention(s)/treatment(s)/exposure(s) <input type="checkbox"/> for each group <input type="checkbox"/> 3. Intervention(s)/treatment(s)/exposure(s) valid <input type="checkbox"/> and reliable <input type="checkbox"/>	
Outcome, Output, Predictor, Measure	1. Outcome(s)/output(s)/predictor(s)/measure(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Clearly define outcome(s)/output(s)/predictor(s)/measure(s) <input type="checkbox"/> 3. Outcome(s)/output(s)/predictor(s)/measure(s) valid <input type="checkbox"/> and reliable <input type="checkbox"/>	
Bias, etc	1. Potential bias <input type="checkbox"/> ; confounding variables <input type="checkbox"/> ; effect modifiers <input type="checkbox"/> ; interactions <input type="checkbox"/> 2. Sequence generation <input type="checkbox"/> ; group allocation <input type="checkbox"/> ; group balance <input type="checkbox"/> ; and by whom <input type="checkbox"/> 3. Equivalent treatment of participants/cases/groups <input type="checkbox"/>	
Sampling		
Sampling method	1. Sampling method(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Suitability of sampling method <input type="checkbox"/>	Sampling score
Sample size	1. Sample size <input type="checkbox"/> ; how chosen <input type="checkbox"/> ; and why <input type="checkbox"/> 2. Suitability of sample size <input type="checkbox"/>	
Sampling protocol	1. Target/actual/sample population(s): description <input type="checkbox"/> and suitability <input type="checkbox"/> 2. Participants/cases/groups: inclusion <input type="checkbox"/> and exclusion <input type="checkbox"/> criteria 3. Recruitment of participants/cases/groups <input type="checkbox"/>	
Data collection		
Collection method	1. Collection method(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Suitability of collection method(s) <input type="checkbox"/>	Data collection score
Collection protocol	1. Include date(s) <input type="checkbox"/> ; location(s) <input type="checkbox"/> ; setting(s) <input type="checkbox"/> ; personnel <input type="checkbox"/> ; materials <input type="checkbox"/> ; processes <input type="checkbox"/> 2. Method(s) to ensure/enhance quality of measurement/instrumentation <input type="checkbox"/> 3. Manage non-participation <input type="checkbox"/> ; withdrawal <input type="checkbox"/> ; incomplete/lost data <input type="checkbox"/>	
Ethical matters		
Participant ethics	1. Informed consent <input type="checkbox"/> ; equity <input type="checkbox"/> 2. Privacy <input type="checkbox"/> ; confidentiality/anonymity <input type="checkbox"/>	Ethical matters score
Researcher ethics	1. Ethical approval <input type="checkbox"/> ; funding <input type="checkbox"/> ; conflict(s) of interest <input type="checkbox"/> 2. Subjectivities <input type="checkbox"/> ; relationship(s) with participants/cases <input type="checkbox"/>	
Results		
Analysis, Integration, Interpretation method	1. A.I.I. method(s) for primary outcome(s)/output(s)/predictor(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Additional A.I.I. methods (e.g. subgroup analysis) chosen <input type="checkbox"/> and why <input type="checkbox"/> 3. Suitability of analysis/integration/interpretation method(s) <input type="checkbox"/>	Results score
Essential analysis	1. Flow of participants/cases/groups through each stage of research <input type="checkbox"/> 2. Demographic and other characteristics of participants/cases/groups <input type="checkbox"/> 3. Analyse raw data <input type="checkbox"/> ; response rate <input type="checkbox"/> ; non-participation/withdrawal/incomplete/lost data <input type="checkbox"/>	
Outcome, Output, Predictor analysis	1. Summary of results <input type="checkbox"/> and precision <input type="checkbox"/> for each outcome/output/predictor/measure 2. Consideration of benefits/harms <input type="checkbox"/> ; unexpected results <input type="checkbox"/> ; problems/failures <input type="checkbox"/> 3. Description of outlying data (e.g. diverse cases, adverse effects, minor themes) <input type="checkbox"/>	
Discussion		
Interpretation	1. Interpretation of results in the context of current evidence <input type="checkbox"/> and objectives <input type="checkbox"/> 2. Draw inferences consistent with the strength of the data <input type="checkbox"/> 3. Consideration of alternative explanations for observed results <input type="checkbox"/> 4. Account for bias <input type="checkbox"/> ; confounding/effect modifiers/interactions/imprecision <input type="checkbox"/>	Discussion score
Generalisation	1. Consideration of overall practical usefulness of the study <input type="checkbox"/> 2. Description of generalisability (external validity) of the study <input type="checkbox"/>	
Concluding remarks	1. Highlight study's particular strengths <input type="checkbox"/> 2. Suggest steps that may improve future results (e.g. limitations) <input type="checkbox"/> 3. Suggest further studies <input type="checkbox"/>	

Manuscript Format

1. Manuscripts should allow for 'blind/anonymised' refereeing and **must not** contain author names or any identifiable data.

2. Manuscripts **must** be typed in double spacing throughout, including quotation, notes and references in the following order:

- Title Page: to contain the title of the paper, word count, suggested running head (short title for your paper), key words, author names, affiliations and contact details for the corresponding author.
- Abstract: on a separate sheet, the title to be repeated followed by a summary of not more than 150 words. The suggested running head should also be present. *For tips on optimizing your abstract for search engines please click [here](#).*
- Practitioner Points: two to six bullet points of no more than 180 characters each (including spaces), up to a total of 480 characters.
- Organisation of the text: see copy of Journal for the format currently in use.
- Figures, tables, etc.: All figures and tables should be numbered with consecutive arabic numerals, have descriptive captions and be mentioned in the text. They should be kept separate from the text but an approximate position for them should be indicated. These will need to be uploaded separately. Please supply figures in the format in which they were created, if possible.
- References (in text): These should be indicated by the name and date e.g. 'Carr (2009)'. If more than two authors are listed, cite the reference as 'McHugh et al. (2010)'. Quotations should include page numbers. Websites should also be cited in this way, with a full reference appearing in the References section (see below). Please check all websites are live and the links are correct at time of submission.
- References: Should be listed at the end of the paper in alphabetical order according to the first author and be complete in all details following the APA style of referencing.
 - **Articles**: Altschuler, J. (2015). Whose illness is it anyway? On facing illness as a couple. *Journal of Family Therapy*, 37(1), 119-133.
 - **Chapters**: Burnham, J. (2012). Developments in the Social GRRRAAACCEEESSS: visible-invisible and voiced-unvoiced. In I.B. Krause (Ed.), *Culture and Reflexivity in Systemic Psychotherapy. Mutual Perspectives* (pp 139-163). London: Karnac.
 - **Books**: Burck, C., & Daneil, G. (2010). *Mirrors and Reflections. Process of Systemic Supervision*. London: Karnac.
 - **Web pages** (no author or date identified): Counting the cost: caring for people with dementia on hospital wards. (n.d.) Retrieved from

http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1199. [Cite in text as ("Counting the costs", n.d.)]

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3. The word limit, excluding abstract and practitioner points will vary depending on the type of paper you are submitting. Please refer to the 'Advice to Authors' section below.

4. Style: Whilst Journal style is generally formal, originality in presentation does not necessarily preclude publication if clarity and readability is thereby enhanced. Sexist language forms are unacceptable.

Your manuscript will be returned to you if you fail to conform to these requirements.

ADVICE TO AUTHORS

Writing is a very enjoyable and satisfying way of being involved in the world of family therapy. The exchange of ideas and experience is important both for the development of our chosen field and for the development of the individual practitioner. We intellectually sustain ourselves by creating a healthy and vibrant literature. Family therapy needs to develop authors and *The Journal of Family Therapy* wants to hear from you.

These are the types of papers that are regularly submitted to the *Journal of Family Therapy*:
(The word count for all these papers does not include tables and figures.)

Systematic reviews (up to 6000 words).

Systematic reviews are welcomed. For systematic reviews and meta-analyses please ensure that you have used the PRISMA checklist and include a flowchart as part of your submission. Please complete and supply AMSTAR for systematic reviews which are narrative reviews not meta-analyses.

Suggested headings for systematic reviews are:

- background or context;
- objective;
- search strategy;
- inclusion criteria;
- data extraction and synthesis;
- main results; discussion and conclusions.

Please ensure that you include the standard points for practice.

You should provide the PROSPERO number in the methods section of the paper, or explain in your covering letter if you have not registered your review with PROSPERO.

Literature Review (3,000–5,000 words)

These are much sought after by the readership. Such a paper would have:

- A brief general introduction
- A description of the way in which the themes in the literature are organised by the author for review. This may include conceptual and definition problems.
- The review
- An overview of the review process including gaps in existing knowledge
- Future directions

Additional Notes to Authors:

- JFT has an international readership, so spell out details that might be unfamiliar to the non UK field.
- JFT welcomes the linking of previous literature in a substantive, explanatory sense and therefore advises authors to reference other papers where possible.

PAPERS EXCEEDING THE SPECIFIED WORD LIMITS (including references) WILL BE RETURNED TO THE AUTHOR

Young people's experiences of having a sibling admitted to a Child & Adolescent Mental Health inpatient unit

Abstract:

Siblings play an integral role in one's social and emotional development. However, when a sibling begins to experience mental health difficulties, family life can be affected. Little research has explored the experiences of young people whose siblings are admitted to hospital because of their mental health difficulties.

Semi-structured interviews were undertaken with 5 males aged 12-18, who had sisters in hospital. Interviews were analysed using Interpretative Phenomenological Analysis. 5 superordinate and 13 subordinate themes were developed, describing the impact of the hospital admission, changes to relationships, opening up, contact with professionals and thoughts about the future.

Participants wanted their sister's to be the priority but described emotional avoidance, guilt at not being able to keep their sister safe and worries about adding to their parent's stress.

Clinicians should ensure they include all family members in assessment and treatment. Age appropriate information and support should be provided for siblings of inpatients.

Practitioner points:

- Include siblings of young people where possible in assessment and treatment;
- Offer a space for siblings to talk openly and ask questions about their brother / sister being in hospital;
- A debrief for young people following a sibling's suicide attempt or deliberate self-harm.

Keywords:

Siblings, young people, mental health, CAMHS, inpatient, experiences

Introduction:

Mental health, like physical health, can refer to a range of symptoms that all individuals will experience in their lifetime. Good mental health enables an individual to manage day-to-day stresses healthily and engage in routine activities (World Health Organization, 2019). Whilst feeling worried, sad or stressed, at times, is considered a normal and healthy aspect of everyday life, there can be times when this may interfere with daily functioning (Mind, 2018; Mental Health Foundation, 2019). Experiencing mental health difficulties is common with approximately 1 in 4 adults in the UK experiencing mental health problems each year (McManus, et al., 2016).

The mental health of young people has become a priority for many in the UK due to reports of a significant increase in the number of young people experiencing mental health problems (NHS Digital, 2018). Adolescence is often described as a tumultuous time due to the changes associated with puberty. It has also been described as a period of 'storm and stress', a term coined by the psychologist Stanley Hall in the 1900s, later updated by Arnett (1999) to describe the increases in parental conflict, mood disruption and risk behaviours often observed during adolescence. For some young people, they may also experience significant mental health difficulties (Mental Health Foundation, 2019). Self-harm, associated with mental health problems, is also on the increase in young people (National Institute for Health and Care Excellence (NICE), 2011). An accurate figure is unknown but a recent survey by The Children's Society (2018) suggests that of 14-year-olds in the UK, 1 in 5 girls, and almost 1 in 10 boys had self-harmed in the previous year. This follows from an earlier study which reported a 68% increase in the number of 13 – 16-year-old girls presenting to hospital following self-harm between 2011 and 2014 in the UK (Morgan, et al., 2017).

The increased awareness and prevalence of mental health problems in adolescents has resulted in the UK government providing extra funding to improve the wellbeing of children and young people (Department of Health and Social Care, 2015). However, as often reported in the media, many people continue to describe difficulties in receiving specialist support as referrals to Child and Adolescent Mental Health Services (CAMHS) increase (Newlan, 2018; Tyler, 2019). The long delay in accessing specialist help can mean that young

people experience a further decline in their mental health. Without timely access to services, this deterioration could lead to increased risk to self, or others, which can result in intensive treatment being required through a hospital admission (Matthews-King, 2018). In recent years, there are often reports of bed shortage due to the increasing demands on these specialist places (e.g. Pickover, 2017). This can result in adolescents being admitted to hospitals many miles away from their friends and family (Frith, 2017). Despite the government pledging to ensure that children are admitted to hospitals close to home (Department of Health and Concordat signatories, 2014), the most recent figures state that in October 2018, over a quarter of all under-18s admitted to an open mental health ward were placed more than 50 kilometres away from their home (NHS Digital, 2019). This can make it harder for the young person to maintain contact with their community team, become isolated from the support of their friends and family (Campbell, 2018; Edwards, et al., 2015), and result in poorer outcomes on discharge, such as increased suicidality (Lear & Pepper, 2016).

For the young person's family, inpatient treatment can also cause additional stress (Blizzard, et al., 2016). The family life cycle can be disrupted by the temporary absence of the young person (Corrigan, et al., 2006; Abrams, 2009). Families may need to readjust their expectations in light of this and adapt to having a family member away from home earlier than anticipated (Sergeant, 2009). The onset of mental health problems can be a significant life event for the young person and their entire family (Griffiths & Sin, 2013). Studies suggest that positive family engagement improves outcomes on discharge such as improved wellbeing and reduced risk of readmission (Green, et al., 2001; Brinkmeyer, et al., 2004). However, the increased travel time can impair how successfully a family can engage with any intervention offered by an inpatient unit (Edwards, et al., 2015; NICE, 2016).

Research with parents of young people experiencing mental health difficulties suggests that they can experience emotional strain and isolation (Whitlock, et al., 2016), and would like enough information on how to support their adolescent (Rodríguez-Meirinhos, et al., 2018). If their child is admitted to hospital for the first time, qualitative research conducted by Clarke & Winsor (2010) found parents reported feeling alone, stigmatised and struggling to adjust their expectations for their unwell child.

In the UK, approximately half of all young people currently live with at least one sibling (Office for National Statistics, 2017). They play an important role in all areas of a child's development, such as emotional support and cognition (Brody, 2004). Relationships between siblings are unique. Starting from birth, they are often the longest relationship an individual may have with another person (Pike, et al., 2009; Sin, et al., 2008). Siblings may spend a significant amount of time together growing up – sharing a physical environment and experiencing life events together. Young people may also self-disclose information about stressful experiences to their sibling if they have a warm relationship (Howe, et al., 2001). It can be assumed therefore that many siblings have an exclusive and detailed understanding of their brother or sister, yet the importance of this relationship is often overlooked (Bank & Kahn, 1975).

As families are a system, it can be assumed that if one member of the system is experiencing distress it will have a subsequent effect on other family members (Kozłowska & Elliott, 2017). Little research has explored impact on siblings whose brothers or sisters are experiencing mental health difficulties. Research has begun to look at the experiences of siblings whose brothers or sisters have been diagnosed with an Eating Disorder, such as Anorexia Nervosa. One qualitative study found sibling's quality of life is impaired compared to control sibling pairs (Areemit, et al., 2010).

Previous research has explored the role of older siblings as carers for their brother or sister diagnosed with difficulties such as Schizophrenia. These siblings often reported feeling burdened by their unwell brother or sister and accepting that they would need to take on the role of carer when their parents had passed away (Friedrich, et al., 2008; Hatfield & Lefley, 2005). They also worried about the stigma their sibling's diagnosis could bring (Ewertzon, et al., 2012), and the possibility the symptoms could be hereditary (Stalberg, et al., 2004).

In the UK, Early Intervention in Psychosis services (EIP) have been commonplace for around a decade. Their aim is to treat those experiencing a first episode of psychosis as soon as possible to improve long-term prognosis (Neale & Kinnair, 2017). As they work with young people, many service users will live with siblings when their mental health difficulties first appear. Sin and colleagues have looked at the impact this has on siblings and the support

EIP services can provide as they found siblings were often overlooked by professionals despite offering support to families (Sin, et al., 2005). Siblings reported feeling that their family were more resilient and supportive of each other as a result (Sin, et al., 2008), but were significantly affected by their sibling's psychosis and wanted accessible information and support (Sin, et al., 2012).

Research with young people has largely focussed on the impact of having a sibling with a chronic physical health condition. Meta-analyses of studies exploring children who grow up with a chronically unwell sibling has found they are at risk of negative psychological effects, such as anxiety and depression compared to those with well siblings (Barlow & Ellard, 2006; Sharpe & Rossiter, 2002). There are several hypotheses as to why this may be. Siblings may take on a care-taking role which brings additional stresses. Young people also report wanting to be told more about their siblings' diagnosis and prognosis as they often worry about the outcome for their sibling (Craft & Craft, 1989). Educational groups for this population have shown to be effective in informing children and offering support (e.g. Lobato & Kao, 2002).

Research with similar populations suggests that siblings with a brother or sister experiencing psychosis, or chronic illness, are negatively affected (Barlow & Ellard, 2006). However, research has not focussed on young people whose sibling's mental health difficulties have led to a hospital admission. It is imperative professionals better understand the needs of this group of people especially given the increase in young people experiencing mental health difficulties in the UK as more siblings may be placed in this situation. Additionally, research suggests that parents are negatively affected (Clarke & Winsor, 2010) which, may have a subsequent impact on any children living at home.

Research Aims

The aims of this study were to:

- Explore young people's experiences of having had a sibling admitted to an inpatient mental health unit;
- Understand how professionals can support, and include, siblings in routine clinical practice.

Research Question

What are young people's experiences of having a sibling admitted to a Child & Adolescent Mental Health inpatient unit?

Methodology:

Ethics

Ethical approval was obtained from the Staffordshire University Ethics Committee Board in February 2018 (Appendix A) and from the NHS Health Research Authority North-West Research Ethics Committee in June 2018 (Appendix B: IRAS, confirmation of ethical approval).

Recruitment

The research methodology, Interpretative Phenomenological Analysis (IPA) is described as being more concerned with the depth of the data generated, as opposed to breadth (Smith, et al., 2009). As such, no minimum sample sizes are dictated however for doctoral level research 6 – 8 participants is recommended (Turpin, et al., 1997). However, due to time restraints, it was agreed to conclude recruitment in March 2019.

Purposive sampling was used to recruit a homogenous sample of 5 participants.

Recruitment was conducted through an NHS adolescent mental health inpatient unit in the West Midlands region between July 2018 and March 2019.

Posters were placed in the family visiting room on the inpatient unit (Appendix C: Participant recruitment poster, and information sheets were also handed out to families who met the inclusion criteria by the unit Family Therapist (Appendix D: Participant information sheets.

The inclusion criteria set out by the study was:

- Aged between 12 and 18 years;
- Able to speak English fluently;
- Has a sibling currently admitted to a CAMHS inpatient unit;
- To have been living with their sibling prior to the inpatient admission.

An age criterion was set as this age group are more likely to have been living at home with

their sibling prior to their admission to an inpatient unit. This study focussed on young people's experiences in the time leading up to the admission and it was therefore considered important that the participant was living with them at the time. Additionally, there is a lack of research with under-18s who are living with a sibling with mental health difficulties (Barnett & Hunter, 2012; Griffiths & Sin, 2013). The age criterion was also chosen as compared to younger children, those aged 12 and above are often able to engage in more meaningful conversation about their experiences as they can consider the impact of different contexts on self and others take different perspectives and demonstrate a greater ability for abstract thinking (Choudhury, et al., 2006). The interview approach would not need to be adapted significantly for this age group compared to when interviewing much younger children. This is also important as IPA is focussed on giving meaning to someone's experience through the language they communicate (Smith, et al., 2009). Additionally, it was felt that the richness of participants descriptions may be lost if interviews were translated from another language. Therefore, only English-speaking participants were eligible to participate.

Participants

Participants were White-British males aged between 12 and 18. The final sample of participants is described below in table 1. Some identifying information has been altered to ensure anonymity.

Table 1: Participant details

Barry (aged 12)
Barry has two older sisters, with the eldest having moved out. 'E', the second eldest was admitted to hospital for the second time following deterioration in her mood. Barry states he argued a lot with 'E' prior to her becoming unwell.
Tristan (aged 13)
Tristan has one older sister, 'L' who admitted to hospital following a suicide attempt. He describes having a 'normal' sibling relationship with 'L' before she became unwell.
John (aged 13)
John has two older sisters, with the eldest having moved out. 'N', the second eldest was admitted to hospital following a suicide attempt. There have recently been changes in the family set-up and John describes arguing a lot with 'N' whilst growing up.
Peter (aged 18)
Peter has one older sister and a younger sister, 'P'. 'P' was admitted to hospital for further assessment. Peter describes a difficult relationship with his older sister but a close relationship with 'P'.
Gary (aged 16)
Gary has one younger sister, 'A'. 'A' was admitted to hospital following a suicide attempt. Gary describes a close relationship with 'A' prior to her becoming unwell.

Procedure

Participants were made aware of the research via the methods described above. If families were interested in participating, they then contacted the researcher via telephone or email to go through any further questions and obtain verbal consent before arranging a suitable time and location for the interview to occur.

Prior to beginning the interview, participants and parent were given the opportunity to ask questions and the researcher ensured that participants understood the research fully.

Informed consent was obtained from all participants (Appendix E: Consent forms). For participants aged under-16, informed consent was obtained from a parent or carer and

assent obtained from the participant. For participants aged over-16, informed consent was obtained from the participant only. The sibling currently in hospital was also made aware of the research as part of the consent process.

A semi-structured interview schedule was developed and used in all interviews (Appendix F: Semi-structured interview schedule). Participants were aware that their interviews would be audio recorded so that they could be later transcribed for analysis and consented to this prior to the research interview beginning. To ensure that participants felt comfortable and safe during the interview process, participants were reminded that they could stop the interview at any time and time was spent at the end of the interview for a verbal debrief and 'check-in' with participants to ensure they felt safe and well.

The interview schedule was developed in accordance with the IPA guidelines (Smith, et al., 2009) and in conjunction with the academic supervisor. The average interview length was 38 minutes, with interviews lasting between 25 and 62 minutes.

Interviews were audio recorded and later transcribed verbatim by the researcher.

Interviews were anonymised at this point, ensuring any identifiable information was altered.

Analysis

IPA was chosen as a methodological approach. Data was analysed using the process described by Smith, Flowers and Larkin (2009). Each transcript was first read several times, and the audio-recordings listened to multiple times. The researcher's initial thoughts and exploratory comments were noted (Appendix G). Transcripts were then uploaded to NVivo data analysis software (QSR International Pty Ltd. Version 12, 2018). This is software developed specifically for qualitative analysis, allowing transcripts to be coded and analysed. Each transcript was coded line-by-line using NVivo. These codes related to the content, the language used (linguistic) and interpretation (conceptual) of the transcript (Appendix H). Emergent themes were noted and listed chronologically. These themes were then arranged into clusters of similar or related themes and superordinate and subordinate themes generated by hand (see appendix I).

Epistemology and Reflexivity

IPA is a phenomenological approach concerned with the meaning people attach to experiences through the language they describe it with. It is described as an idiographic, rather than nomothetic, methodology as it attempts to understand individual experience. This can lead to unique insights in a subject that little is known about which can result in further research. IPA was therefore chosen as the phenomenon under investigation is under-researched.

IPA allows for a constructivist approach, meaning there is no one objective truth as there are multiple interpretations to be made (Hugly & Sayward, 1987). Interpretations are therefore led by one's own values and experiences of the world. IPA researchers are said to engage in a double hermeneutic process as they make sense of how the participant is trying to make sense of their experience.

Although it is difficult to remove all one's preconceptions, IPA believes researchers should attempt to bracket these off (Langdridge, 2004). A reflective journal was used during the data collection and analysis process. Additionally, a regular IPA peer supervision group was attended by the researcher. This was facilitated by an experienced IPA researcher and attended by other doctoral level students using IPA methodology as well as individual supervision. This allowed the researcher to become aware of their biases and judgements and instead able to focus on what the participants are saying.

The researchers own experiences of working in CAMHS inpatient units and family therapy clinics, and of having their own siblings, may have influenced how the participant's experiences were interpreted during analysis as these experiences will have influenced how the researcher constructed meaning from the participant's interpretation of their experience (Willig, 2016); i.e. their experiences will be viewed through the researcher's unique perspective, giving more meaning to certain aspects according to what the researcher may have expected to find.

Results:

Five superordinate themes were generated, with 13 subordinate themes as illustrated in

table 2 below. Each theme will be discussed with extracts from the data to illustrate each theme. The full table of extracts can be found in appendix J.

Table 2: Themes

Superordinate Themes	Subordinate Themes	Themes present in participant(s)
1. "a shock to the system"	a. "a punch in the face out of nowhere"	Barry, Peter, John, Tristan
	b. "acted nonchalant"	All
	c. "I wanted to help her"	Tristan, Peter, Gary
2. Relationship changes	a. "a lot more open with each other"	All
	b. "we kind of get along a lot better now"	All
	c. "I worry about her"	All
3. The future	a. "Like this forever"	Barry, Gary, Tristan, Peter
	b. Setbacks	Gary, Barry, John
4. Contact with professionals	a. "who was taking care of her?"	Peter, Tristan, Barry
	b. "Someone to talk to"	All
5. Opening up	a. "emotionally shut myself off"	All
	b. "I'm not the one who needs the attention"	Peter, Gary, John
	c. Stigma	Barry, Peter, Gary, John

Theme 1: "a shock to the system"

1a "a punch in the face out of nowhere"

John, Barry, Peter and Tristan spoke about the shock in becoming aware that their sister was so unwell that they required a hospital admission. They were aware that their sister had been receiving support from professionals but did not know what was discussed. They then felt the hospital admission was more of a shock as they had not realised their sister was in crisis, as Peter described:

"It's like, it's like having several gentle hits as opposed to one smack. Like you'd rather the gentle hits that hurt a bit and increase a bit but it's manageable because you understand what's happening versus a punch in the face out of nowhere that takes you back and sort of like well where's this come from? And all of a sudden you're defenceless against it." (Peter)

1b "acted nonchalant"

Following their sister's admission to hospital, all the participants spoke about the effect it had had on their parents and their home life. Peter described his older sister as becoming more demanding of his mother's attention which was adding to the tension at home. Whilst Barry and John's elder sisters had moved out of the family home and were less aware of the impact their sister's difficulties were having at home.

“Dad drank quite a bit which he doesn't do that much now [...] but he hated it because obviously it's his youngest child at the end of the day [...] Then obviously the older one kicked off about the fact he was drinking.” (Peter)

“I can remember my older sister when she still lived there. She just like went to her Nanna's because she was really upset. It was like quite upsetting.” (Barry)

John, Barry and Tristan appeared to be aware that their parents were struggling with the stress of the situation although it was not shared with them.

“My dad acted nonchalant, but I could tell he was very worried, but he was just trying to put on a brave face in front of me. And then like that night we didn't really talk about it, we were just trying to act normal.” (Tristan)

Gary described home as quiet and conversation revolving around his sister because of her being admitted to hospital.

“Quiet. So, like all we really talk about is ‘A’ like, it's kind of strange not having ‘A’ in the house cause we just sort of, even though we didn't talk to her much anyway”

1c “I wanted to help her”

Tristan, Peter and Gary described a sense of helplessness in relation to helping their sister, especially with their suicidal thoughts. They described wanting to have been with their sister to try to prevent or change how they were feeling.

*“I feel I could have been next to her, should have been trying to comfort her.”
(Tristan)*

“I wanted to help her as well. But I can't.” (Peter)

*“I don't think we found the option that suited her best, so we didn't know what to do.”
(Gary)*

Theme 2: Relationship changes

2a “a lot more open with each other”

All the participants spoke about how their relationship with their parents had improved and allowed them to talk more openly about their sister's situation which they found helpful.

"We're a lot more open with each other and we've spoken about a lot of different things we'd never normally speak to each other now over these few weeks and we, and we've, every night we've sat down together and talked about the situation and we never would have normally done that." (Gary)

"I'd say it's actually brought me and my Mum closer." (Peter)

2b "we kind of get along a lot better now"

The participants spoke about a greater closeness with their sister since they had been admitted to hospital. This was because they were more aware of what they were going through, or it had made them realise how much they cared about their sister.

"we kind of get along a lot better now." (John)

"it was more that I knew what she was going through, so I was being like, a lot like gentle around her." (Barry)

"it's not changing the way we act towards one another, but there's a greater understanding [...] I feel like I've sort of grown to know her emotionally more." (Peter)

2c "I worry about her"

Although participants described a greater closeness with their sister, they also spoke about being worried about their sister a lot of the time especially in relation to their self-harm and suicidal thoughts.

"Sometimes it's like bad news and I just, I worry about her more now." (John)

"I just like get really upset when I find out that she's like she doesn't want to live and stuff." (Barry)

"I think please for the love of God don't say she's going to hurt herself with something, out of fear and it's just constant worry." (Peter)

All the participants spoke about feelings of guilt that they have not done enough to support their sibling.

"well last time she did it, the other day, erm, when my mum was like away for a few

hours she was looking for like the medicine and I was in the house as well, and I didn't know... I kind of feel like that was my fault and I should have like been with her." (John)

"But after she did it [overdose], she said no one supported her on that Friday and no one made her feel any better. I didn't know what to do. [...] I wasn't really sure what else to do." (Gary)

Theme 3: The future

3a "like this forever"

The participants shared their thoughts about what their sister's future may be like. They worried they may never get better.

"it's not nice to know that things might never get better, but hopefully I can know in my head that things will never get worse and it won't go back to how she was." (Gary)

"I was feeling like she's going to be like this forever. She was gonna stay like this, be antisocial. Be that forever. She'd stay completely like that. But when she started opening up, being more social, it relieved me a lot because I knew she was getting better." (Tristan)

"I think that like when she's older she'll probably like struggle to like live on her own and stuff. So like mum thinks that she'll always be living with them and I think she will too." (Barry)

Peter had watched a YouTube documentary on his sister's difficulties but was unsure if he wanted to research it further for fear of what he may learn.

"that's the only sort of information source I have really had on it and I think I'm on the fence of whether I want to know or whether I don't. So, if I do know I find out more about it I realise how unwell she is. Whereas if I don't then I'm sat wondering about things and yeah, you can't find a medium cause no matter where you sit you're not happy." (Peter)

3b Setbacks

John, Barry and Gary spoke about finding it difficult when their sister has a setback and what this may mean for their sisters' recovery.

"it's sad seeing her dip up and down and it's hard to, because we thought those the first two weeks she was just getting better every day [...] But now it's back down to, she's just not talking anymore. Don't know what to do." (Gary)

"I feel like she's getting better... but it kind of happened again didn't it? I don't know what's the cause of that..." (John)

Theme 4: Contact with professionals

4a "who was taking care of her?"

Peter, Tristan and Barry shared that they did not know what to expect when they first visited the hospital but wanted to know who was taking care of their sister whilst she was not with them.

"I wanted to know who was taking care of her and who they were and how nice they were and stuff like that." (Tristan)

"it was weird because it was like an unfamiliar place." (Barry)

Peter and Tristan worried that the hospital would be like the images described in books and television.

"I was thinking they'd all be like – have you ever read 'Grandpa's Great Escape'? I was thinking they'd all be like that." (Tristan)

"I didn't know what I expected. I think in my head, I had it like, some people are going to be walking around in like these white coats and you know, so like you're in American horror movie type thing where it's all going on." (Peter)

4b "Someone to talk to"

Barry, John and Tristan spoke about their experiences of attending family therapy sessions whilst their sibling was an inpatient. Barry and Tristan also spoke about how they initially did

not know what to expect when they attended family therapy.

“the appointments they were a bit like weird at first, because I didn’t really know what was going on but like now its fine.” (Barry)

“At first I was apprehensive because I was like are they going to be nice, mean, supportive or cruel but after the first meeting, it was much better because it was like a weight had been lifted from my shoulder and I knew the people who were looking after her were nice and supportive.” (Tristan)

Peter in contrast spoke about the lack of space to talk with professionals on the unit about how the family were managing and felt this could be any member of staff.

“I think just having something there, someone to talk to, whether it's a mentor or do you know what I mean? That sort of thing, because there is nothing in place to help the family.”

Gary spoke about his previous experiences of having family meetings with professionals which he found unhelpful.

“It wasn't nice at all. Yeah. Having someone criticise everything you do in your life. It wasn't nice, but we tried to change. But eventually the old habits came back, and it, and it didn't really help.”

Theme 5: Opening up

5a “emotionally shut myself off”

The participants described how they were managing the situation and their feelings around their sister’s admission to hospital. There was a sense that the participants were using distraction to manage their emotions or were disconnected from them.

*“Cause otherwise I just sort of, I think I had emotionally shut myself off from it. Sort of detached from it a bit and just accepted factually what it was. Not on impact.”
(Peter)*

“I just have to like occupy myself to, to try and not think about it. And that’s why I

don't want to go back to school because I'll be so bored that's all I could think about." (Barry)

"I had just turned 18 - I went out. Got absolutely leathered for about five out of seven nights of the week I think at one point [...] Well, it was quite weird actually because I always sort of, I started to understand why some people drank." (Peter)

5b I'm not the one who needs the attention"

Peter, Gary and John spoke about not wanting to detract from the care their sister was receiving. There was a sense that they viewed their sister as the current priority and their willingness to adjust their behaviour to support them however, this also resulted in them feeling unable to seek support.

"That someone's around me because they pity me or whatever, But, I don't want to be pitied because of that. And in that sense as well, it's not my problem. I'm not the one who needs the attention [...] I'm not in a bad state myself. So, in that sense that's just not talk about it. Keep it to myself." (Peter)

"Um, I think the reason I wasn't involved was because I wasn't the main problem - if that sounds right [...] And me and my dad kind of just said, okay, we'll do what they want us to do and that's what we'll do. We'll carry on with it." (Gary)

5c Stigma

Barry, Peter, Gary and John spoke about not wanting others to know of their sisters' difficulties for fear of how others would react, or because their sisters did not want other people to know.

"I don't really want my teachers knowing because it's just a bit awkward." (Barry)

"I don't think my friends would be very sympathetic with it. They wouldn't really understand." (Gary)

"it's why I don't like to talk about it. I don't want to be talked to by person because they feel like they have to me, it's not what I want. So, in that sense, I'd rather deal with it myself then talk to someone about it because it's just, I don't want to." (Peter)

Systemic Synthesis

The participants appear to go through a linear process in response to their sister's hospital admission, as illustrated in figure 1. This can be seen similarly to the stages of grief model (Kubler-Ross & Kessler, 2014) as the participants came to terms with their sister's emotional difficulties. The 'shock' can be seen similar to denial and anger stages seen in grief as participants realise how unwell their sister has been. The stage of depression is similar to the 'emotionally shut off' that was described, leading to bargaining as they renegotiate their roles in their family system. This is then concluded with acceptance as they begin to think about the future and accept how things will need to be different moving forward. Families may oscillate between stages or repeat the process depending on new crises emerging. For example, following setbacks in their sibling's recovery, participants may return to the 'shock' stage and experience heightened worry.

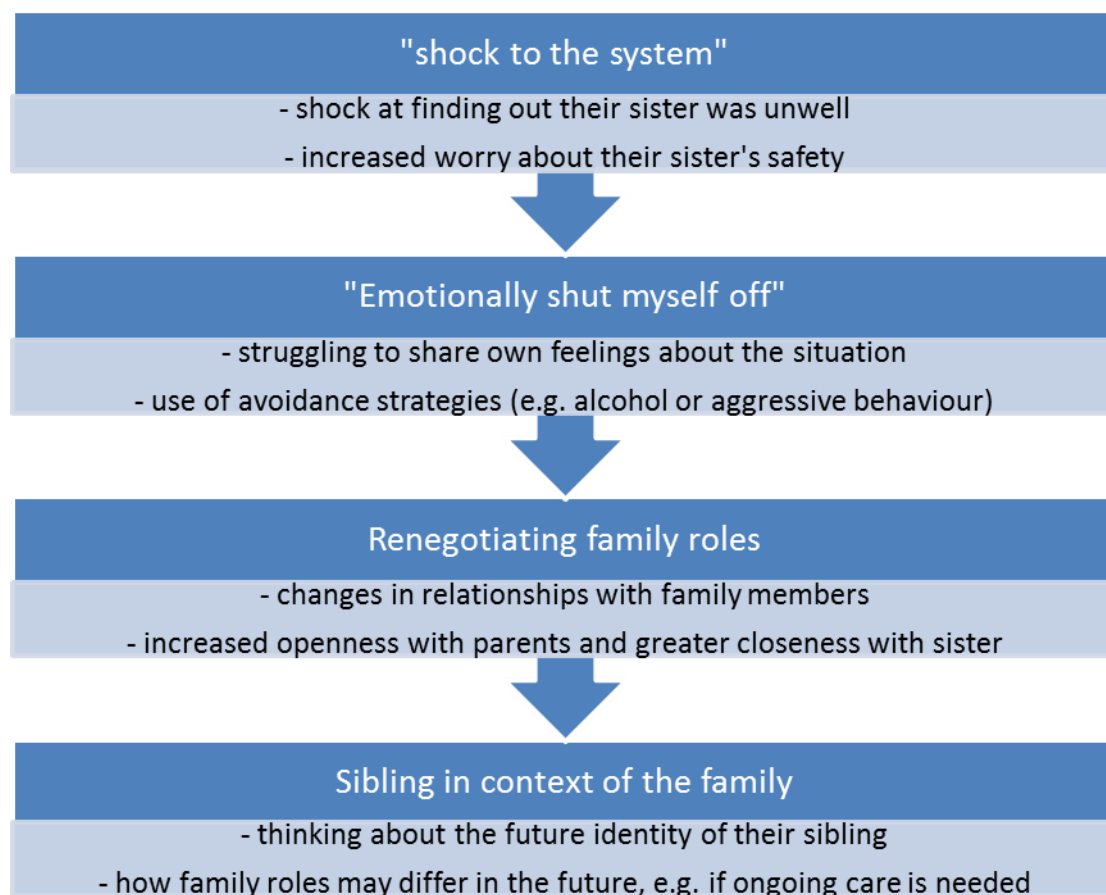


Figure 2: linear process

Discussion:

This study aimed to explore young people's experiences of having a sibling admitted to a mental health inpatient unit, and to then better understand how professionals can support and include siblings in routine clinical practice. The main themes found were around the shock of finding out that their sister required hospital treatment, the subsequent change in their relationship with their sister and parents, and thoughts about what their sister's future with mental health difficulties may look like. Participants also described a sense of helplessness in being able to support their sister especially if they voiced suicidal thoughts. The participants shared how they were managing their own feelings and expressed that to ensure their sister remained a priority, they should manage their feelings on their own. They also described apprehension around visiting the inpatient unit and attending appointments due to not knowing what to expect.

In this study, participants described their sister as being the current priority in their family. They appeared accepting of the extra attention they required and did not report feeling neglected by their parents. This is in contrast with research by Blasko (2008) who found that adults who had a sibling with mental health problems believed they were emotionally neglected when they were younger. Research has also shown that perceived differences in parenting between siblings is associated with poor emotional functioning later in life (Brody, 2004). The increased focus on the young person experiencing mental health problems can result in the needs of the siblings being missed which can result in any difficulties they are facing being ignored (Kilmer, et al., 2008) which may impact the young person long-term. Participants in the present study appeared to recognise and acknowledge the reason for the extra attention their sibling required at this time which may negate against any long-term negative effects.

Participants spoke about the impact that their sister's admission had had on them, their family and home life. Some participants in the current study did speak about using alcohol or aggressive behaviour to manage their own emotions. This has also been shown in previous research which has focussed on the ways young people manage adverse situations. Kozłowska & Elliott (2017) assessed siblings of children being treated at a mental health service in Australia. They found that 13 of the 16 siblings used at-risk self-protective

strategies, such as affect inhibition, that had not been detected by their parents. Although such strategies may be helpful in the short-term, research suggests that the long-term use of such strategies may be detrimental to their own wellbeing.

The participants also shared their difficulties in opening up to others about how they were managing the situation and cutting off from their emotions. Research suggests that female adolescents are more likely to use social support to manage difficulties, and less distraction (Hampel & Petermann, 2006; Patterson & McCubbin, 1987). This may help to explain why the male participants in this study struggled with sharing how they were feeling with others.

The participants described that although they felt they were able to have more open and honest conversations with their parents, they worried about adding to their current stress and not wanting to burden them. They expressed a desire that their sister remain the priority as they were the one who was unwell, and they did not want to be an extra burden to their parents. Additionally, the younger participants interviewed showed great maturity in understanding the extra stress their parents were under. This is likely because of their experiences; however, this may have been at the expense of their own emotional needs (Kinsella, et al., 1996; Marsh, et al., 1993).

Participants described a feeling of guilt in not being able to help their sibling especially with their suicidal thoughts. Research with young females whose sisters had eating disorders suggests that the well-sibling can become the secondary victim because of this guilt and may feel burdened with caring for their unwell sister (Latzer, et al., 2015). In contrast, participants seemed to view their sister's difficulties as outside of their control. This perspective may lead to the participants experiencing lower burden (Greenberg, et al., 1997) as they viewed their sister's difficulties more empathically than if they felt they were doing it on purpose.

Nonetheless, they also recognised that they needed to support their family in making changes to assist in their sister's recovery. Although not directly explored, the participants described a caring and understanding view on their sister's difficulties and wanting to protect them (as described in themes 1c and 2c). Previous research suggests that a caregiving role is present even before their sibling receives a diagnosis (Sanders, et al.,

2014). Although in the present study all participants were male, this finding may also apply to females with siblings in hospital.

Although this has focussed on the negative aspects of having a sibling admitted to hospital, participants also spoke about the increased compassion they had for their sister as a result. Research also suggests that having a sibling with mental health problems can increase resilience and promote positive psychological change (Sanders & Szymanski, 2013). They also felt that their parents were more open and honest with them since the admission to hospital and viewed this positively.

Those participants that had shared with their school what was happening had viewed this positively. Others felt a reluctance to share the situation with their peers due to anxiety about how others would respond or because their sister did not want others to know. Unfortunately, research reported by the charity 'Time to Change' (2015) suggests that 70% of young people experiencing mental health problems experience negative responses from their peers. This can prevent young people from accessing peer support and having a space to talk about what is going on for them.

A significant finding shared by all the participants was in their experiences of their sister's suicidal thoughts and behaviour. Those whose sisters had taken an overdose described having lots of mixed feelings about the incident. They worried that they would be unable to protect their sibling from making a suicide attempt and communicated their guilt in not being able to protect them. Little research has explored the views of young people whose sibling has made a suicide attempt. Research by Buus and colleagues (2014) in Denmark explored the experiences of parents whose children had made a suicide attempt or died by suicide. They described it as a 'double trauma' – the trauma of the suicide or suicide attempt and the following impact on the whole family's wellbeing. A review exploring published literature on children and their parents following an admission to a paediatric intensive care unit by Nelson and Gold (2012) found almost 84% of parent's experienced Post-Traumatic Stress Disorder symptoms following the admission. The memory of their sibling's overdose seemed for some of the participants a difficult experience to process suggesting that the traumatic impact on parents may also apply to siblings and further research into this would be helpful.

These findings also support family systems theory (Bowen, 1974), whereby each member of a family have certain roles and respond to one another according to their relationship agreements. This causes predictability and balance, however, a difficulty with one member in the family has a subsequent impact on all members in the system as the family system's roles change and can cause dysfunction in the long-term as family members take on new responsibilities. It may also be that the sibling's difficulties reflect an issue within the family system, for example poor communication or issues that do not enable family life cycle transitions. The admission to hospital may then facilitate change. For example, participants shared that because of their sibling coming into hospital, they had an enhanced awareness of their sister's needs and improved communication with their parents, perhaps suggesting this was a difficulty prior to the hospital admission.

Limitations

This study has several limitations. Firstly, only one type of family set up was explored. The participants were all White-British males who all had sisters currently in hospital. It is not known therefore if the experience of females or those with brothers in hospital would be different. Participants had one or two sisters. Those from larger families may have different experiences where research suggests the sibling subsystem in a family has greater significance (Bank & Kahn, 1975). It would therefore be valuable to explore if young people are affected similarly in larger families.

Although no siblings refused to participate in the study, many adolescents admitted to hospital during the recruitment period had no siblings matching the age criteria (12 – 18 years old) or had no siblings. Conversely, some adolescents did have siblings who were the right age however parents shared that they would not be suitable as they had their own mental health difficulties or had a learning difficulty. This suggests that the sample of participants recruited for this study does not represent many of the diverse family scenarios present in CAMHS inpatient units. Similarly, all participants, except one, came from two-parent families. However, in the UK today families are varied, for example with the presence of multi-family households (Office for National Statistics, 2017). Additionally, looked after children are more likely to experience mental health difficulties than those not in the care system (gov.uk, 2018) and more likely to require specialist mental health treatment but

were not represented in this study. Our findings cannot be generalised to this population.

In designing the semi-structured interview schedule, service users or their siblings were not consulted. However this would have provided valuable feedback, such as the wording of questions.

There are several ethical considerations to consider when reviewing the findings from this study. Due to the age group of the participants, and that they, and their families, were approached by a professional who worked on the unit that their sister was receiving treatment, they may have felt obliged to participate. Although every care was taken to ensure participants were under no obligation to participate, there may have been some power issues between the researcher and participants. This may have also impacted on the responses participants gave, for example, feeling they were unable to describe how they really felt. Participants were also recruited from the same inpatient unit and so findings may not be generalisable to other areas of the country.

Clinical Implications

The findings from this study illustrate that young people with siblings admitted to a mental health hospital are impacted by this. Although the participants felt they would manage in the long-term, some were beginning to use unhealthy coping mechanisms, such as alcohol, to manage emotions. They had also perceived their parents as becoming overwhelmed and worried about adding to their stress. Research suggests that the combination of these two things may result in the young person going on to develop their own emotional difficulties such as anxiety or depression (Kozłowska & Elliott, 2017). Clinicians working in CAMHS, and those working in inpatient settings, need to be more aware of the possible impact a young person's difficulties can have on their siblings.

Clinicians in CAMHS should offer psychoeducation to the whole family. This may not be suitable for all however, as some in this study also mentioned finding it difficult to know everything about what their sister was experiencing. Information would need to be delivered in a person-centred way which would be age appropriate and offered at a pace led by the young person. This could also be delivered in a group setting. Group interventions for

siblings of children with physical illnesses have been found to be beneficial in lowering anxiety (Gettings, et al., 2015; Gursky, 2007). Peer support or ensuring young people have alternative close relationships in which to seek support is important when young people worry about adding to their parent's emotional burden. Research supports the protective ability of close relationships and promoting healthy adaptive functioning (Namysłowska & Siewierska, 2010). Young people may therefore find it helpful to meet others who have siblings in similar situations and seek peer support.

When parents had been approached about this study, they were often eager for their child to participate so that they would have the opportunity to talk individually and privately about their experiences even if it was for a research study. Although time constraints for staff may make this difficult to do so routinely, other members of the ward multi-disciplinary team may be able to support young people in having a space to talk openly about their experience. This may be the sibling's key worker or named nurse.

Participants who had been involved in family therapy had found these sessions helpful in giving them a safe space to learn more about their sibling's difficulties and hear from the professionals involved in treating them. One participant had not had any family therapy sessions during his sister's admission and had felt that having a place to talk about the impact of his sister becoming unwell would be helpful. This supports the need for family therapy sessions to be offered routinely as those who are unable to receive this can feel isolated.

Participants also shared their initial reservations about attending the ward due to not knowing what to expect. An alternative patient admission leaflet or webpage could be developed which includes photos of the ward.

During assessment, clinicians should ensure that they ask about the experiences of all members in the family and not just the young person who has been referred for treatment. Questions about birth order for example can be helpful in learning more about the family story (Kozłowska & Elliott, 2017). It may give an indication of how other family members may be impacted due to age, birth order and life experience (e.g. Lawson & Mace, 2010).

Future Research

Further research is needed to better understand the perspective of young people whose siblings are receiving inpatient mental health treatment. The participants in this study were all male and had sisters receiving inpatient treatment. Research exploring the views of females or those with brothers receiving treatment would be invaluable to gain a broader understanding.

The participants in this study were all from White-British backgrounds and had one or two sisters. The experiences of young people from less conventional family backgrounds, such as step-families, larger families or looked-after children would also be beneficial. Care giving expectations may also be different in those from other cultural backgrounds (e.g. Namkung, et al., 2017).

Research should also continue to gain the experience of the young person directly as much previous research involving siblings of young people with mental health difficulties or with physical health difficulties does not (Knecht, et al., 2015).

Although suggestions have been made as to how clinicians working with young people can support their siblings, a pilot study would be recommended to test out these hypotheses and to converse with the young person to find out more about if, and what type of support they would find most helpful as the needs of siblings are likely to be different to those of their parents (Amaresha, et al., 2014).

As participants appeared to find their sibling's suicide attempts most difficult, research exploring the long-term effects of a suicide attempt would be beneficial to enable services to offer support to the whole family following a suicide attempt. Not all adolescents will be admitted to a CAMHS unit following an attempt as admission is decided on an individual basis (NICE, 2004; 2019) and the family may therefore not receive appropriate support in processing such a significant event.

Conclusion:

This study aimed to explore young people's experiences of having a sibling admitted to a

mental health inpatient unit, and to then better understand how professionals can support and include siblings in routine clinical practice. The results from this qualitative study suggest that young males are impacted when their sister is admitted to hospital. The experience can bring the relationship with their sibling closer due to a greater understanding of their difficulties and result in increased concern for them. When their sibling has made suicide attempts, it is important that the young person is given space to talk about this and ask any questions they may have as our study showed that young people find this difficult to move on from and this causes increased worry and guilt towards their sibling. Participants did not feel included in community treatment, but this was for several reasons, for instance, due to it not being age appropriate or the family not having made them aware that their sister was receiving CAMHS treatment. For some, this made the hospital admission feel more unexpected as a result and more difficult to come to terms with than those who were already aware that their sister was experiencing difficulties.

Further research is needed in this population, especially looking at other family set-ups, different genders and cultural backgrounds to see if hospital admission is experienced differently. Clinicians need to ensure that siblings are routinely included and asked about how they are coping, especially at assessment. Some young people may find it beneficial to have the opportunity to ask questions and share their experience with others to ensure that they have ongoing support and a forum to discuss concerns.

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Appendices:

Appendix A: Staffordshire University, confirmation of ethical approval



INDEPENDENT PEER REVIEW APPROVAL FEEDBACK

Researcher Name Sumeet Sangha
Title of Study Young people's experiences of having a sibling admitted to a Child & Adolescent Mental Health inpatient unit.
Award Pathway DClinPsy
Status of approval: **Approved**

Thank you for forwarding the amendments requested by the Independent Peer Review Panel (IPR)

Action now needed:

You must now apply to the Local NHS Research Ethics Committee (LREC) for approval to conduct your study. You must not commence the study without this second approval.

Please forward a copy of the letter you receive from the LREC to ethics@staffs.ac.uk as soon as possible after you have received approval.

Once you have received LREC approval you can commence your study. You should be sure to do so in consultation with your supervisor.

You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

When your study is complete, please send the the IPR coordinator (Dr Peter Kevern) an end of study report. A template can be found on the ethics BlackBoard site.

A handwritten signature in black ink that reads 'P M Kevern'.

Signed: Dr Peter Kevern
University IPR coordinator

Date: 21.2.18



Health Research Authority

North West - Preston Research Ethics Committee

Barlow House
3rd Floor
4 Minshall Street
Manchester
M1 3DZ

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

13 June 2018

Miss Sumeet Sangha
Staffordshire University
Leek Road
Stoke on Trent
ST4 2DE

Dear Miss Sangha

Study title:	Young people's experiences of having a sibling admitted to a Child & Adolescent Mental Health inpatient unit.
REC reference:	18/NW/0332
Protocol number:	N/A
IRAS project ID:	229205

Thank you for your letter of 25th May 2018 responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales) NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Independent Peer Review approval]		21 February 2018
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [REC provisional opinion feedback]		14 May 2018
Contract/Study Agreement template [trust agreement]		21 February 2018
Copies of advertisement materials for research participants [Participant recruitment poster]	1.3	09 February 2018
Copies of advertisement materials for research participants [Poster Info for YP IP]	1.2	09 February 2018
Copies of advertisement materials for research participants [Poster info for YP in hospital]	1.4	14 May 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [professional indemnity]		14 July 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [professional indemnity]		14 July 2017
Interview schedules or topic guides for participants [Interview schedule]	2	03 April 2018
IRAS Application Form [IRAS_Form_30052018]		30 May 2018
IRAS Checklist XML [Checklist_30052018]		30 May 2018
Letter from sponsor [Letter from sponsor]		04 April 2018
Other [Supporting letter to REC chair]		25 May 2018
Participant consent form [Participant consent form]	2.6	25 May 2018
Participant consent form [Over 16s consent form]	1.3	25 May 2018
Participant consent form [Parental consent form]	1.2	25 May 2018
Participant information sheet (PIS) [Under 16s PIS]	1.6	15 May 2018
Participant information sheet (PIS) [Over 16s PIS]	2	15 May 2018

Participant information sheet (PIS) [Parent information sheet]	2.6	15 May 2018
Research protocol or project proposal [Research proposal]	4	21 March 2018
Summary CV for Chief Investigator (CI)		23 March 2018
Summary CV for student		23 March 2018
Summary CV for supervisor (student research)		16 March 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

18/NW/0332

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



pp

Professor Carol Haigh
Chair

Email: nrescommittee.northwest-preston@nhs.net

Enclosures: "After ethical review – guidance for researchers" [\[SL-AR2\]](#)

Copy to: *Dr Yvonne Melia*
Ms Louise Alston, North Staffordshire Combined Healthcare



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales



Miss Sumeet Sangha
Staffordshire University
Leek Road
Stoke on Trent
ST4 2DE

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

13 June 2018

Dear Miss Sangha

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title: Young people's experiences of having a sibling admitted to a Child & Adolescent Mental Health inpatient unit.
IRAS project ID: 229205
REC reference: 18/NW/0332
Sponsor: Staffordshire University

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?

You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of a assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed [here](#).

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?

You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Dr Yvonne Melia

Tel: 01 782 295734

Email: Yvonne.Melia@staffs.ac.uk

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **229205**. Please quote this on all correspondence.

Yours sincerely

Kelly Rowe
Assessor

Email: hra_approval@nhs.net

*Copy to: Dr Yvonne Melia, Staffordshire University, Sponsor contact
Ms Louise Alston, North Staffordshire Combined Healthcare, Lead NHS R&D
contact*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Independent Peer Review approval]		21 February 2018
Contract/Study Agreement template [trust agreement]		21 February 2018
Copies of advertisement materials for research participants [Poster info for YP in hospital]	1.4	14 May 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [professional indemnity]		14 July 2017
HRA Schedule of Events [Validated SOE]	1.0	12 June 2018
HRA Statement of Activities [Validated SOA]	1.0	12 June 2018
Interview schedules or topic guides for participants [Interview schedule]	2	03 April 2018
IRAS Application Form [IRAS_Form_30052018]		30 May 2018
Letter from sponsor [Letter from sponsor]		04 April 2018
Other [Supporting letter to REC chair]		25 May 2018
Participant consent form [Consent form 16+]	1.4	12 June 2018
Participant consent form [Consent form under 16s]	2.6	25 May 2018
Participant consent form [Parent consent form]	1.3	12 June 2018
Participant information sheet (PIS) [PIS 16+]	2.1	06 June 2018
Participant information sheet (PIS) [Parent information sheet]	2.7	12 June 2018
Participant information sheet (PIS) [PIS under 16]	1.7	06 June 2018
Research protocol or project proposal [Research proposal]	4	21 March 2018
Summary CV for Chief Investigator (CI) [CV for CI]		23 March 2018
Summary CV for student		23 March 2018
Summary CV for supervisor (student research)		16 March 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Recruitment flow chart]		
Summary, synopsis or diagram (flowchart) of protocol in non technical language		

Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

Assessment criteria

Section	Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	PIS and ICF have been updated as a minor amendment following REC review in order to comply with HRA standards
3.1	Protocol assessment	Yes	Applicant has confirmed that North Staffordshire Combined Healthcare NHS Trust will be the only site in the study as others are mentioned in the Protocol.
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The statement of activities will act as agreement of an NHS organisation to participate. No further agreements expected.
4.2	Insurance/indemnity arrangements assessed	Yes	No comments
4.3	Financial arrangements assessed	Yes	No application for external funding has been made. The statement of activities confirms that there are no funds available to sites from the sponsor.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical	Not Applicable	No comments

Section	Assessment Criteria	Compliant with Standards	Comments
	Trials Regulations assessed		
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England and Wales

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

Participating NHS organisations will be recruiting sites; identification of patients will be by clinical care team at site. Consent may be taken at site but this will be done by an external researcher who may also conduct interviews at site.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. Where applicable, the local LCRN contact should also be copied into this correspondence.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS, the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net or HCRW at Research-permissions@wales.nhs.uk. We will work with these organisations to achieve a consistent approach to information provision.

Principal Investigator Suitability

This confirms whether the sponsor position or whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and Wales, and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A local collaborator is expected at participating NHS organisations in order to identify patients and arrange any access/facilities for external researchers.

GCP training is not a generic training expectation, in line with the [HRA/HCRW/MHRA statement on training expectations](#).

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Do you have a brother or sister who is in hospital with a mental health problem?

If you are aged 12 - 18 and were living at home at the time your brother or sister was admitted to hospital, we would like to speak to you.



Image taken from: <https://nps.ac.uk/wp-content/uploads/2016/08/Case-Report-Based-Interview-1473310438193.jpg>

We are interested in young people's experiences when their brother or sister is unwell and as a result has been admitted to a mental health unit.

We want to learn more about how you felt when your brother or sister was admitted to hospital and any impact this may have had on you.

Further information can be found by emailing Sumeet Sangha at s025081g@student.staffs.ac.uk or call/text xxxxxx.

What are young people's experiences of having a sibling admitted to a CAMHS inpatient unit?

You may be aware that we are recruiting brothers and sisters of patients on the unit to talk to us for our study. Siblings often have a special relationship with each other. We are interested in their story so we can learn more about what support siblings may need when a family member is admitted to a mental health inpatient unit.



Your brother or sister may be approached about the study. If they decide to take part we will not share any information about you with them. Everything they tell us will also be kept confidential from you and the people involved in your care. After the interview, we will write up our findings but we will not use anyone's real name so that readers will not know who participated.

If you have any questions or concerns about the study please contact the researcher, Sumeet Sangha, by email: s025081g@student.staffs.ac.uk or call/text: xxxxx or you can speak to staff on the unit.

Appendix D: Participant information sheets

Under 16's participant information sheet

Under16-years-old



I'm interested but I have some questions...

Why do you want to talk to me?	What would I do?	What is this for?
<p>We are interested in young people's experiences when their brother or sister becomes unwell with a mental health problem and has needed to go into hospital.</p>	<p>If you are interested, the researcher will contact you by phone to arrange a time to talk to you in person about your experiences. The interview will also need to be audio recorded so it can be transcribed by the researcher using secure software.</p>	<p>This research project is being undertaken to fulfil the requirements of the Doctorate in Clinical Psychology.</p>
How long will it take?	Do I have to take part?	Will I get paid?
<p>The interview will take around 1 hour but you can stop for a break at any time. We can also offer refreshments.</p>	<p>No - it is up to you if you would like to take part. We will also ask your parents to sign a consent form stating that they are happy for you to participate. If you decide not to, you and your family will not be disadvantaged in any way. You can also change your mind at any point by contacting the researcher. After the interview you have up to a month to withdraw your data.</p>	<p>Unfortunately we are unable to pay you for your participation.</p>
<p>Under 16's Participant Information Sheet IRAS Reference Number: 229205</p>		<p>Version 1.7, 06 June 2018</p>

Will people know I took part?

We won't tell anyone you participated. Your information will be stored securely and be made anonymous so that nobody can trace your interview back to you. Data is required to be kept at the university for 10 years. Personal information will be destroyed at the end of the study.

Is what I say confidential?

The information you share with the researcher will not be shared with your family or any other professional working with your family. We will only need to break this if you say something that makes us concerned.

Are there benefits to participating?

Being involved in this research is unlikely to benefit you or your family directly but it may help other young people going through similar situations by informing professionals about your experiences.

Could there be side-effects?

Talking about your experiences can make you upset or you may have concerns. We will give you details of services that you can contact for additional support.

Who do I contact?

You can contact Sumeet Sangha (researcher) at xxxxx or s025081g@student.staffs.ac.uk.

If you feel your questions have not been answered or have concerns, you can contact the academic supervisor who is overseeing the research: Dr Yvonne Melia at 01782 295734 or Yvonne.Melia@staffs.ac.uk.

If you are unhappy or have further concerns and wish to make a complaint you can contact the Patient Advice & Liaison Service (PALS) for North Staffordshire Combined Healthcare NHS Trust. The service is open Monday – Friday, 9am – 5pm:
Tel: 01782 275031; **Freephone:** 0800 389 9676; **Text:** 07718 971 123
Email: patientexperience@northstaffs.nhs.uk

Over 16-years-old

I'm interested but I have some questions...

Why do you want to talk to me?	What would I do?	What is this for?
<p>We are interested in young people's experiences when their brother or sister becomes unwell with a mental health problem and has needed to go into hospital.</p>	<p>If you are interested, the researcher will contact you by phone or email to arrange a time to talk to you in person about your experiences. The interview will also need to be audio recorded so it can be transcribed by the researcher using secure software.</p>	<p>This research project is being undertaken to fulfil the requirements of the Doctorate in Clinical Psychology.</p>
How long will it take?	Do I have to take part?	Will I get paid?
<p>The interview will take around 1 hour but you can stop for a break at any time. We can also offer refreshments.</p>	<p>No - it is up to you if you would like to take part. If you decide not to, you and your family will not be disadvantaged in any way. You can also change your mind about participating at any point by contacting the researcher. After the interview you have up to a month to withdraw your data.</p>	<p>Unfortunately we are unable to pay you for your participation.</p>

Will people know I took part?

We won't tell anyone you participated. Your information will be stored securely and be made anonymous so that nobody can trace your interview back to you. Data is required to be kept at the university for 10 years. Personal information will be destroyed at the end of the study.

Is what I say confidential?

The information you share with the researcher will not be shared with your family or any other professional working with your family. We will only need to break this if you say something that makes us concerned.

Are there benefits to participating?

Being involved in this research is unlikely to benefit you or your family directly but it may help other young people going through similar situations by informing professionals about your experiences.

Could there be side-effects?

Talking about your experiences can make you upset or you may have concerns. We will give you details of services that you can contact for additional support.

Who do I contact?

You can contact Sumeet Sangha (researcher) at or s025081g@student.staffs.ac.uk.

If you feel your questions have not been answered or have concerns, you can contact the academic supervisor who is overseeing the research: Dr Yvonne Melia at 01782 295734 or Yvonne.Melia@staffs.ac.uk.

If you are unhappy or have further concerns and wish to make a complaint you can contact the Patient Advice & Liaison Service (PALS) for North Staffordshire Combined Healthcare NHS Trust. The service is open Monday – Friday, 9am – 5pm:
Tek 01782 275031; **Freephone:** 0800 389 9676; **Text:** 07718 971 123
Email patientexperienceteam@northstaffs.nhs.uk



Young people's experiences of having a sibling admitted to a Child & Adolescent Mental Health inpatient unit

INFORMATION SHEET FOR PARENTS AND CARERS

We are conducting a research study exploring the experiences of siblings of young people admitted to a Child & Adolescent Mental Health services (CAMHS) inpatient unit. You have been approached as the parent of a young person currently in hospital due to mental health problems and we would like their sibling to participate in our study.

Please read this information carefully and talk to your child to see if they would like to talk about their experiences of when their brother or sister was admitted to hospital. If there is anything that is not clear or if you would like to know further information please contact the researcher on the details provided below. If you and your child decide not to participate then your family's treatment will continue as usual.

Why are we doing this research?

A lot of research has focused on the impact of physical illness on siblings, and not on the impact of mental health difficulties. We also know that having a child in hospital can be a stressful and worrying time for the whole family. We would like to focus specifically on siblings of young people admitted to hospital with mental health problems to learn more about their experiences and influence the support offered to siblings in the future and to consider what support they might need from services.

Who is organising this research?

The research is being undertaken to fulfil the requirements of the Doctorate in Clinical Psychology being completed by the researcher. The study is sponsored by Staffordshire University.

Why have you asked me and my child?

Your child has been asked as they are aged 12 – 18 and currently have a sibling in a CAMHS inpatient unit.

Do they have to take part?

No! It is entirely up to your child if they would like to take part. If they do decide to participate they will be given an information sheet which provides more detail about the research and what is involved.

If your child is under 16 we will ask you to sign a consent form if you are happy for them to participate. We will still seek consent from your child before proceeding with the interview and will not go ahead if they do not wish to participate.

You and your child are free to change your mind at any point about participating in the research. The treatment you and your family receive will not be impacted either way. You and your child

can request for your data to be removed from the research up to a month after the interview date.

What will happen if my child does take part?

If they decide to proceed, they will meet with the researcher in person at a suitable time and location for them. This can be at Staffordshire University campus or your local CAMHS building, and we can organise a parking permit if necessary. You are welcome to attend with them but we will ask you to wait outside during the interview.

We will speak for around an hour but they can leave the conversation at any time and have regular breaks. We will ask them questions about what they remember around the time their brother or sister was admitted to hospital. They will be asked to speak as openly and honestly as they feel comfortable to do so. No extra tests will be involved. This interview will be audio recorded so that it can be transcribed later by the researcher.

If your child discloses anything that makes the researcher concerned about their safety or the safety of somebody else, then this will be shared with your child's clinical care team (at The Darwin Centre) who will discuss it with you.

Who will know my child participated?

The people in our research team will know they are taking part. All information that is collected about your child during the research will be kept strictly confidential. They will be given a pseudonym which will be used instead of their name so that they cannot be identified.

Information will be stored securely and be anonymised so that the interviews cannot be traced back to your child. All personal information will be destroyed at the end of the study. Research data is required to be kept at the university for 10 years.

Who has checked the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect participant's safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by Staffordshire University REC and the NHS North West - Preston Research Ethics Committee (reference 18/NW/0332).

What happens after my child has participated?

The interview will be transcribed and saved securely electronically. We will collect all the information together and analyse it before writing it up as a research paper. The findings may also be used for teaching or conference presentations, and the findings may be disseminated to services working with siblings of young people with mental health problems. If you would like a summary of the findings, please mention this to the researcher.

Will the study help my family?

It is unlikely to help your family directly, but we hope that the information will be used to better support young people in similar situations in the future.

Who do I contact if I have additional questions or concerns about the research?

If you have any questions or concerns regarding the research please contact the researcher on the details below or alternatively the academic supervisor at Staffordshire University who is overseeing the research: Dr Yvonne Melia at Yvonne.Melia@staffs.ac.uk or 01782 295734.

If you remain unhappy and wish to make a complaint you can contact the Patient Advice and Liaison Service (PALS) for North Staffordshire Combined Healthcare NHS Trust on the details below. The service is open Monday – Friday, 9am – 5pm:

Tel: 01782 275031 or *Freephone:* 0800 389 9676

Email: patientexperience@northstaffs.nhs.uk

Text: 07718 971 123 (charged at your provider's rate)

Where can I get further support?

If you would like any further support because of any questions or concerns you may have about your child please discuss this with your GP or you can contact some of the organisations below:

Young Minds – national charity for young people experiencing mental health difficulties. Parents helpline: 0808 802 5544 (free phone Monday – Friday's 9:30am – 4pm) or <https://youngminds.org.uk/find-help/for-parents/>

MindEd – information on mental health issues for parents worried about their child:
www.minded.org.uk

ReThink – advice line: 0300 5000927 (free phone Monday – Friday's 9:30am – 4pm) or <https://rethink.org/carers-family-friends/brothers-and-sisters-siblings-network/information-for-parents>

Mind – national charity supporting people with mental health difficulties. Information line: 0300 123 3393 (free phone Monday – Friday's 9am – 6pm) or <https://www.mind.org.uk/>

Thank you for reading this. If you think your child would like to take part you or your child can contact the researcher on the details below to discuss it further.


Sumeet Sangha

Email: s025081q@student.staffs.ac.uk Tel: xxxxxx

Appendix E: Consent forms

Under 16's consent form

Participant Identification Number.....


North Staffordshire
STAFFORDSHIRE Combined Healthcare
UNIVERSITY NHS Trust

PARTICIPANT CONSENT FORM

Participant under 16 years old

Title of Project: Young people's experiences of having a sibling admitted to a Child and Adolescent Mental Health inpatient unit.

Name of Researcher: Sumeet Sangha

Please initial box:

1. I have read the information sheet (dated version 1.7, dated 06 June 2018) about the study, had the chance to think about the information, ask any questions and am happy with the answers given.
2. I agree to my interview with the researcher to be audio recorded so it can be later transcribed.
3. I agree for my anonymous quotes and data to be used in the final study report, research publication and teaching as appropriate.
4. I understand that I choose whether to take part or not, and that I can stop at any time, without giving a reason and without it affecting the care me and my family receive now or in the future.
5. I understand that information collected during the study may be looked at by people from Staffordshire University, the regulatory authorities, or the NHS Trust where it is relevant to my taking part in the research.
6. I agree to take part in this study.

Name of Researcher Date Signature

Name of Participant Date Signature

Under 16s Participant Consent Form
IRAS Reference Number: 229205

Version 2.7, 12 June 2018
1 copy for participant; 1 copy for researcher file

Participant Identification Number.....



PARTICIPANT CONSENT FORM

Participant aged 16 - 18

Title of Project: Young people's experiences of having a sibling admitted to a Child and Adolescent Mental Health inpatient unit.

Name of Researcher: Sumeet Sangha

Please initial box:

1. I have read the information sheet (dated version 2.1, dated 06 June 2018) about the study, had the chance to think about the information, ask any questions and am happy with the answers given.
2. I agree to my interview with the researcher to be audio recorded so it can be later transcribed.
3. I agree for my anonymous quotes and data to be used in the final study report, research publication and teaching as appropriate.
4. I understand that I choose whether to take part or not, and that I can stop at any time, without giving a reason and without it affecting the care me and my family receive now or in the future.
5. I understand that information collected during the study may be looked at by people from Staffordshire University, the regulatory authorities, or the NHS Trust where it is relevant to my taking part in the research.
6. I agree to take part in this study.

Name of Researcher

Date

Signature

Name of Participant

Date

Signature

Participant Identification Number.....



PARENTAL CONSENT FORM

Parent of participant under 16 years old

Title of Project: Young people's experiences of having a sibling admitted to a Child and Adolescent Mental Health inpatient unit.

Name of Researcher: Sumeet Sangha

Please initial box:

1. I have read the information sheet (dated version 2.7, dated 12 June 2018) about the study, had the chance to think about the information, ask any questions and am happy with the answers given.

2. I agree to the interview with the researcher to be audio recorded so it can be later transcribed.

3. I agree for my child's anonymous quotes and data to be used in the final study report, research publication and teaching as appropriate.

4. I understand that my child does not have to take part, and can stop at any time without giving a reason and without it affecting the care my children and I receive now or in the future.

5. I understand that information collected during the study may be looked at by people from Staffordshire University, the regulatory authorities, or the NHS Trust where it is relevant to my child taking part in the research.

6. I agree for my child to take part in this study.

Name of Researcher

Date

Signature

Name of Parent/Carer

Date

Signature

Appendix F: Semi-structured interview schedule

Interview Schedule

Setting up the interview:

Today I'm interested in talking to you to find out about your experiences of having your brother/sister in hospital because of their mental health. It won't be like a therapy or counselling session. I won't be able to offer any support after this interview but I can provide you with details of services who may be able to offer further support if you would find this helpful. **[Provide leaflet for participant with service details]**

Take as much time as you need to think and respond to my questions, there are no right or wrong answers. It may feel you are doing a lot of talking but that's because I want to understand your experience as much as possible.

The interview will take around an hour. You can take a break or stop the interview at any time by asking me. Do you think you would be ok with letting me know? If not, we can think of an alternative way together.

Confidentiality – will only break confidentiality if I am concerned about yours or someone else's safety. If I am concerned I may share this information with the professionals at the unit where your sibling is who may decide to talk to your parents. I would always let you know first if I was going to do this.

Any questions?

Background information:

- To start with, I just want to think about you and your family. Can you tell me who lives at home with you? It's up to you if you decide to use their real names, but I'll change them when I write this up to make it anonymous
 - o Names / age / birth order / gender:
 - o Ethnicity?

Before:

- Can you think back to before your sibling became unwell, what were things like for you?
 - o How are things at home?
 - o Your relationship with your sibling?

Start of illness:

- Can you tell me what 'mental health' means to you?
 - o Can you describe how you first heard about mental health problems?
- Thinking about your sibling, can you tell me when you first learned they were having problems?

Prior to admission:

- If you can think back to around the time they became very unwell, just before they came in to hospital, can you describe how things were for you?
 - o Can you describe how you coped at the time?
 - o How are things at home?
 - o Your relationship with your sibling?

In hospital/present:

- If we could move forward and think about how things are now your sibling is in hospital. Can you describe how things are for you?
 - o Can you describe how you cope?
 - o How are things at home?
 - o Your relationship with your sibling?

- Looking back now, can you describe how your family and professionals have involved you in your sibling's mental health care?
 - o Can you tell me about any information you were given?
 - o Being in a therapy or treatment session?

- Can you talk about how open you felt people were with you?
 - o Can you describe how that felt for you?

Ending and debrief:

How do you feel at the end of the interview?

Signposting?

Questions?

Appendix G: Initial comments on transcript example

Does he feel A is like mum - needs meds to not get angry?

R: So, you said you think it's quite a touchy subject, but you said that if you did ask your mum about it you think she'd be happy to talk about it?

G: Totally. Like I just don't want to bring it up, but I'm sure if I do she would be happy talking about it. Like now that A's in here she's talked about a lot more because it's something we can relate to. [R: Yeah] she knows she's been through it herself so she knows maybe how to help A.

R: Yeah. So things are starting to change a little bit?

immediate effect of admission, closer with parents

G: Yeah like definitely. We've become a lot more open as a family about talking about things. We've spoken about things we'd never tell each other at all. We really opened up cause we have to, we spend a lot of time with each other over these last few weeks. It's really hard.

R: It's a bit a trek to get here too, isn't it?

- visiting every night.

G: Yeah. It's about half an hour. So we've got every uh, every night doing that. I'm just sitting there for a few hours and really talk about a lot of things you've never spoken about before. Quite honest with each other.

R: What's that been like?

- mature response

G: it's good. I wish, I wish that was always happens in life. I wish it was always like that. Hopefully from now it will stay like that.

R: Yeah, definitely. So thinking back to A, when did you first learn or were you told that she was having difficulties?

family trying hard but feeling helpless

G: Um, she, she was very down and stayed in her room a lot and every time she got back from school she would just stay in bed. And so we knew something was wrong and she wanted help and we've had like counselling for families, but we said we were going to do things to change and get better as a family, but it slowly stop again. And so about a year or two ago, A first said she was struggling with mental health. So, and we've done various things and talked to various people to help her with that, but it just didn't really get better and like we don't know what to do really.

R: What was that like for you? So she was able to say, I'm struggling and you know, you as a family, tried to get support, put things in place. But...

- lots of change - contradictions - what's it like to live like that?

G: well I tried to help her. It's not, like as much as I can, but because she was saying to me like it would have been a lot better if you came in my room and talked to me for in the evenings, but we do but and when we do that, she doesn't want us to talk to us. So it was very difficult to help her cause we didn't, she wants one thing in her head but she says something else and she didn't, she doesn't like the counsellor and she doesn't like people telling her that she's doing things wrong and she doesn't like changing her lifestyle. I think it was very hard for to change how she lives.

Appendix H: NVivo coding example

The screenshot displays the NVivo software interface. On the left, a transcript window titled "1B - 'Barry' transcript" contains a conversation between two individuals, B and R. The transcript text is as follows:

B: She was, she was talking to me when I like went in to her, but it was like really upsetting. Because under her bed she's got a big drawer thing and under her bed she'd have like tissues of blood. From when she was like self-harmed

R: What was that like for you?

B: Erm, I can remember my older sister when she still lived there. She was just like went to her Nanna's because she was really upset. It was like quite upsetting.

R: Did you speak to anyone about that?

B: No, because everyone in the house already knew.

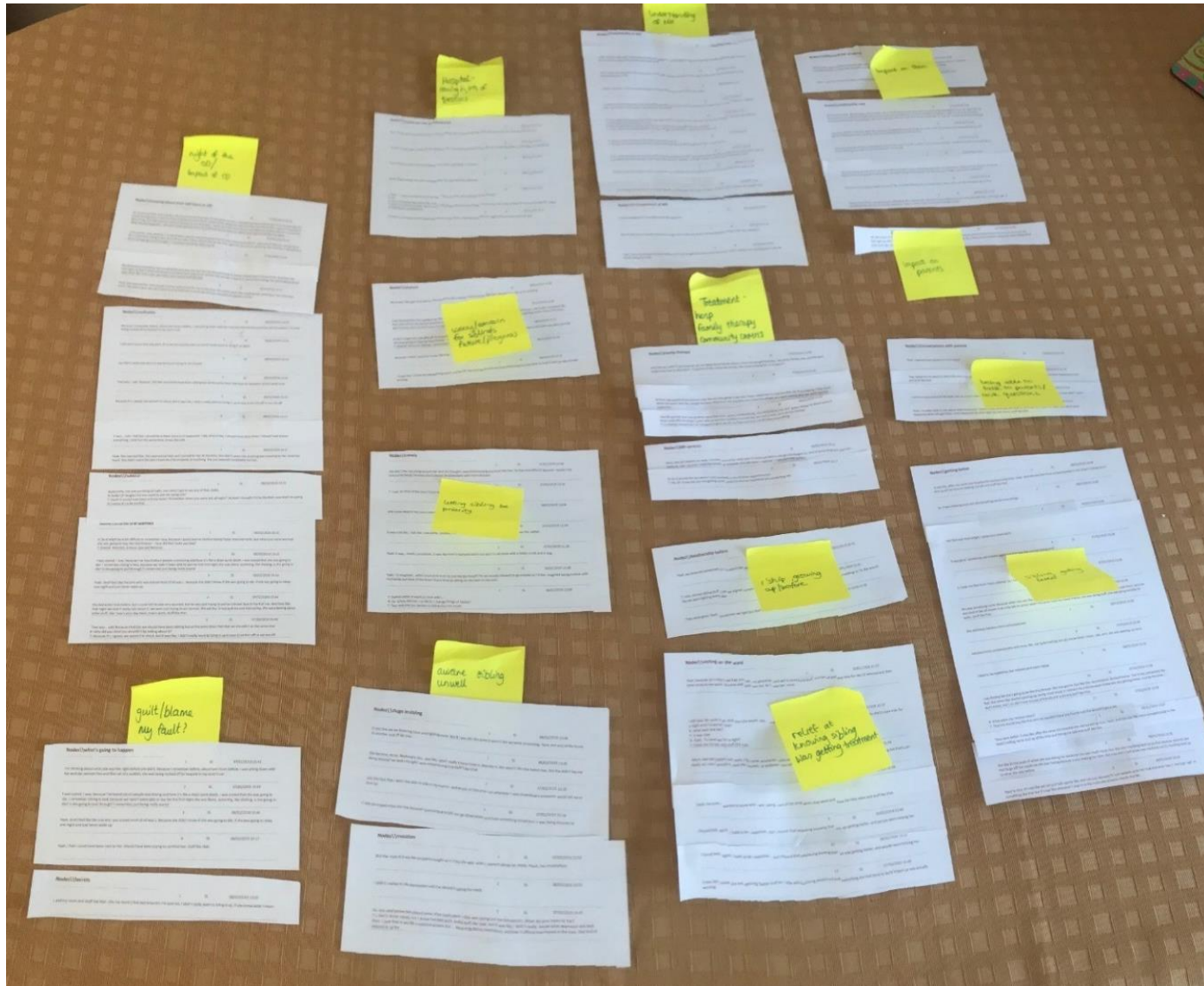
R: Ok. So what was your relationship like with 'E' at that point?

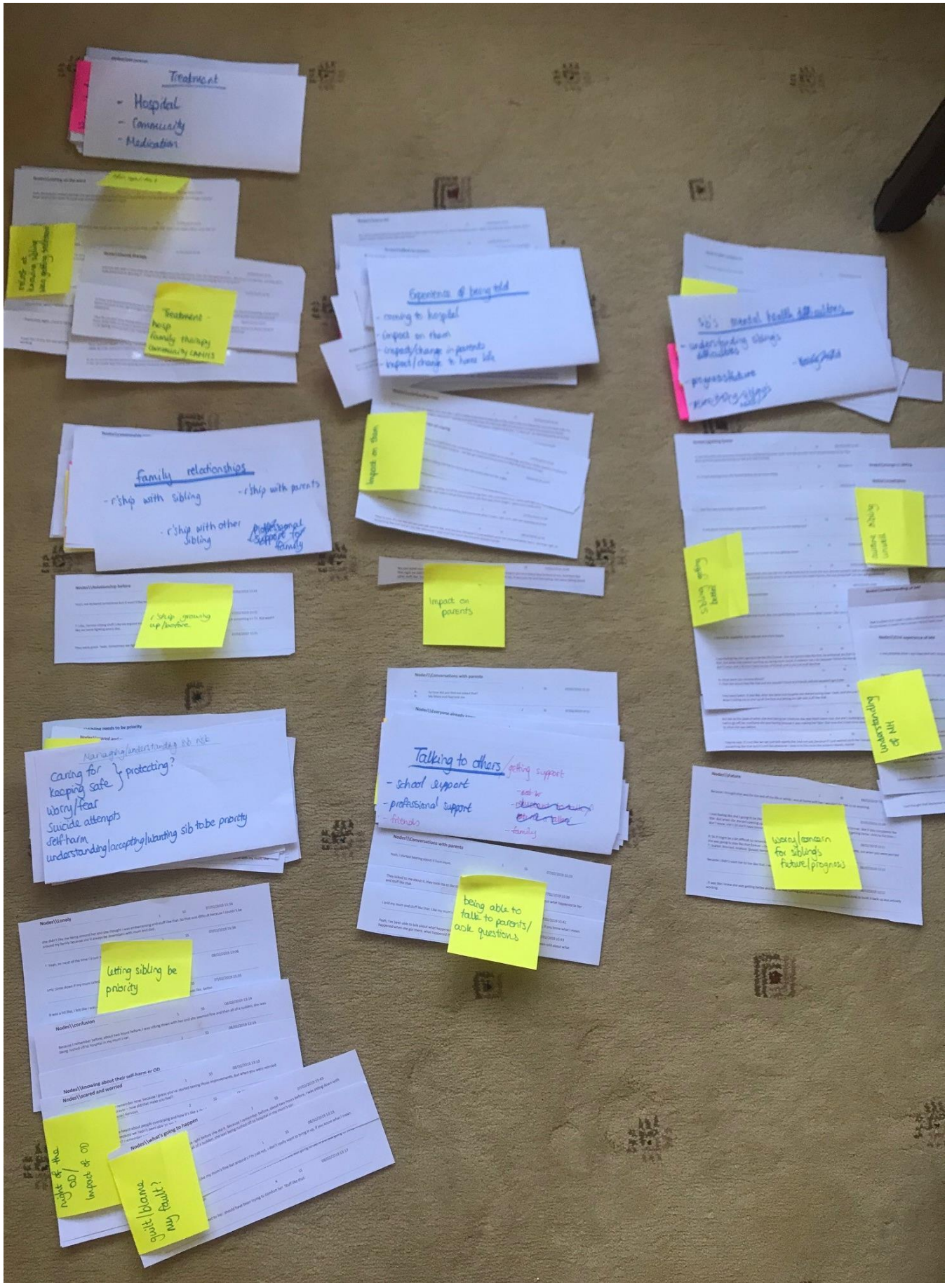
On the right side of the interface, a coding tree is visible. The root node is "Coding Density". Below it, several nodes are listed, each with a colored bar indicating its density or frequency:

- change in sibling
- MH services
- MH symptoms
- relationship now
- Not wanting others to know
- Too young to understand
- keep my cover
- knowing about their self-harm or OD
- Multiple episodes
- Understanding of MH
- Impact of learning about siblings MH problems
- Different ways of coping
- Lonely
- Conversations with parents

At the bottom of the window, there is a search bar with the text "Code At" and a prompt "Enter node name (CTRL +O)".

Appendix I: Examples of developing themes





Treatment

- Hospital
- Community
- Medication

Wish at times sibling was getting better

Treatment - help family therapy community support

Experiences of being ill

- coming to hospital
- impact on them
- impact/change in parents
- impact/change in how life

Sib's mental health difficulties

- understanding sibling's attitudes
- professional knowledge
- hospital

Family relationships

- r'ship with sibling
- r'ship with parents
- r'ship with other sibling
- Professional support for family

Impact on them

r'ship growing up positive

Impact on parents

Cap limits

Parental ability to deal

Managing/understanding sibling

Caring for keeping safe } protecting?
worry/fear
Suicide attempts
Self-harm
understanding/accepting/wanting sib to be priority

Talking to others/getting support

- school support
- professional support
- friends
- family

Understanding understanding of NHS

Worry/concern for sibling's future/progress

Letting sibling be priority

being able to talk to parents/ask questions

Wish of the day/OD/impact of OD

quite blame my fault?

Appendix J: Themes and extracts

1. "a shock to the system"		
Subordinate theme	Ppt	Quotes
1a. "a punch in the face out of nowhere"	Peter	But it had more of a shock to the system that I anticipated it would.
	Peter	when this sort of all kicked off, it sort of brought to light how much, how much of a part she plays in my life and your Mum's and everyone's life around us.
	Peter	I was told bits and pieces so like I was, I was given like the corner pieces of the jigsaw but not enough to make the whole picture itself. Obviously like through a school and parents point of view like it's not my responsibility to deal with her care. It's non, I think the fact that there were points where I was none the wiser about things. It just, I think that is why it was, I'd rather have known from the beginning. And like seen it build, which, you know what I mean. I don't mean I want to see it...
	Peter	It's like, it's like having several gentle hits as opposed to once smack. Like you'd rather the gentle hits that hurt a bit and increase a bit but it's manageable because you understand what's happening versus a punch in the face out of nowhere that takes you back and sort of like well where's this come from? And all of a sudden you're defenceless against it
	Peter	I wasn't told much about it until it was further along and sort of the point where it couldn't be hidden I suppose is the point where I was I right, we have to say something because realistically we can't hide what's going on anymore. So he needs to know, sister needs to know. So I think that's the point where I sort of got told was where that either I was going to figure it out and question it or I was going to be told and told to sort of talk about but you know what I mean?
	John	Well the first time I did know about it an' all that and she had all the therapy, she had – I can't remember what they called but... I can't remember if she got put on medicine or anything like that but err... like I said no one really spoke to me about it and I just kinda stayed out the way...
	John	Uhm, yeah they've emailed my teachers to say if I act differently to send me up and all that so I can talk to someone. So... yeah...
	Tristan	No, all I knew was she was getting some medicine and her boyfriend was comforting her.
	Barry	I don't really know what, I know she gets help from CAMHS. And like her CAMH worker is pregnant now so she like got a bit upset about that. But I don't really know what social services are.

	Barry	I don't really know about CAMHS because they never really spoke to me.
	Barry	Erm, I didn't really know it was... it was like... I didn't really think much of it because they were just like helping her and I was glad.
	Barry	They could ask like how they are because that's like never happened with me. But like I've only been to one CAMHS appointment
	Barry	She still really hasn't got it. But before she's discharged, she's not going to be discharged until like she has all the stuff out in place like school and social services and stuff.

1b. change in the family	Barry	Well my older sister doesn't really know what's going on because and she's not really that bothered because she's got other things to worry about.
	Barry	Erm, mum and dad managed to cope. I don't know how. But, like, by then my oldest sister had moved out. And before that she was living with her boyfriend's family. And then they bought a house.
	Barry	My dad, he just gets stressed out. But he doesn't really show it.
	Barry	Because he's always just like huffing and puffing (laughs) It's just like really annoyed.
	Barry	Erm, I can remember my older sister when she still lived there. She was just like went to her Nanna's because she was really upset. It was like quite upsetting.
	John	Erm... I try to help mum more because she's got kind of worse. Well not worse but like... yeah... like same as me.
	Gary	Quiet. So, like all we really talk about is 'A' like, it's kind of strange not having 'A' in the house cause we just sort of, even though we didn't talk to her much anyway it was still like
	Gary	'A's not at home and that's what's making, and it's not helping all of us and we miss her a lot. And even though we see her every day she isn't, doesn't really talk much here or she doesn't like speaking to us at the moment really.
	Peter	It's not me that needs the care, but it's still, because obviously so much changes so fast, it's, I think it would help people to discuss it more. Just say this is happening and this is happening at home.
	Peter	I'm not as fussed. There are always arguments at home about, because like the older sister she's a bloody nightmare. she wants my mum's attention. You'd think she was about six or seven. The way she wants my mum's attention.

Peter

Dad drank quite a bit which he doesn't do that much now. Still has the occasional but who doesn't, erm yeah but he hated it because obviously it's his youngest child and the end of the day and it was like... Then obviously the older one, kicked off about the fact he was drinking.

Peter

Because even though it's, you're fine, it's an oddity. Like no one likes change course they don't, it's just awkward. But I think helping people accept the change should be more important because it has an effect on everyone around you. And obviously when someone and you've lived with their entire life is taken away from it all of a sudden, it's like, it's like on a seesaw. It changes the balance, so you can move one weight and all of a sudden, it's swinging around.

Peter

it was just escalating, and it just grew and grew and grew and it was just, like there was never like massive fall outs per se. It was just constant tension and it was just... So no one liked what was going on, but no one wanted to openly talk about it. It was, because I think for everyone it was like if we talk about it, we accept that it's happening, and we don't want to accept that it's happening. So it was just easier to just argue about something else.

Peter

I know she struggles with it quite a bit so, cos obviously as a parent feels I should be able to help. Obviously, she's at a stage where she can't, which is horrifying for a mother but it's horrendous cause you can see that as well.

Peter

Cause obviously P's in a state where, well you know, that she's, like considered taking her own life and all sorts and you can see in my Mum's sort of eyes, I don't know how to explain it, but you see it in her eyes that she's, almost, feels guilty

Peter

I think it became a lot more real for my Mum. There's always the inkling. [R: Yeah.] Cause you just know sometimes don't you? But I think it became a lot more real for my mum And I think that was quite difficult for her. So I ended up speaking to her about that quite a lot.

Peter

And then obviously I saw impact it was having on my Mum and that destroyed me cause you know, cause she's my Mum. It's not natural sort of what's happening in any way is it obviously otherwise you wouldn't need to treat for it.

Peter

So I mean within the first couple of weeks I didn't stay home because I didn't like the tension. I didn't like that she wasn't there. And if I wasn't there, I didn't know she wasn't there.

Peter

If she's here and she's not home where she should be and but at the same time...

Peter

Tense, it was sort of sort of the elephant in the room type situation, constantly. So, I mean within the first couple of weeks I didn't stay home because I didn't like the tension

	Peter	I think Mum, I think it was a weird one for my Mum about being open with me because she was being open about it with me. So it's an odd one. Like for her in a way. Cause she's seeking support even through just me listening because it helps doesn't it, you know? And um, I think for her that was quite an odd one, to be to be open with me because I'm her child is yeah, it's almost like a role reversal almost isn't it? So that was an odd one for her.
	Tristan	Yeah, I'd imagined... when mum isn't in or its just me by myself I'm not usually allowed to go outside so I'd like imagined being outside with my friends but most of the time I'd just end up sitting on my own on the sofa.
	Tristan	My dad acted nonchalant, but I could tell he was very worried, but he was just trying to put on a brave face in front of me. And then like that night we didn't really talk about it, we were just trying to act normal. We eat tea. It was just me and him eating. We were talking about other stuff, like: how's your day been, how's work, stuff like that.
	Tristan	I still saw her quite a lot. And then she would, like, every two times a we- not two times a week, once every two weeks she'd come over for a night and I'd see her then
	Tristan	Yeah, because on Friday's we'd go and see my grandma and we'd come here and pick her up and stay here for like 20 minutes and then other times in the week I'd come over and see her. So I saw her more.

1c. "I wanted to help her"	Tristan	I feel I could have been next to her, should have been trying to comfort her. Stuff like that.
	Tristan	Yeah. She seemed fine. She seemed normal, well normal for her at the time. She didn't seem like anything was pressing on her mind too much. She didn't seem like she'd been hurt by anybody or anything. She just seemed completely normal.
	Peter	I wanted to help her as well. But I can't.
	Peter	Well, there was nothing, it wasn't something that was physically attacking. It was something inside our own head that was attacking her. It's like how do you fight that? Because you can't. Yeah.
	Peter	So it was, cause obviously it was at the point then if she continues to stay at home, she could seriously hurt herself or someone else possibly because of her condition. Uhm, and I think that was the hardest thing to accept for my mum.
	Peter	she's not where she should be and she's not where she should be because of how she is so, so it was similar to be situation where you don't want to accept it. When I saw the effect and then my Mum told me the next sort of day after I think that essentially that she considered killing herself that night. And to be honest all that went through my mind was that if she had of hurt herself that I'd hurt them. Cause obviously like, they'd have been the cause.

	Gary	It was a shock that it happened, but it was almost like expected in a, in a horrible way. Cause it, she was feeling, we knew that she was feeling low for such a long time. I think we're just grateful she survived it really. We knew that things need to change from here we can't slack again with what we do and the structures, we need to set up.
	Gary	yes, she once - two months or so before it, she, she ran off and saying that she was going to kill herself and we, so we called like the non-emergency thing and uh, went to the hospital and she had, uh, talked to some doctors and signed up for the CAMHS thing. But I think it took a very long time to get an appointment and she needed it that night. She didn't need it six months later. She needed it to now. And that, it really put her down because she felt very low that she wasn't going to see someone for a while. I think that was very difficult on her. I think the reason she did such a serious step further is that she just wanted help now and I think it was just a massive cry for help. Like she says that she wasn't actually intending to kill herself. She was just trying to get someone to quickly help her
	Gary	Err, it was, it, it was a shame that, that she couldn't get her to stop her from having to go such serious lengths to get to have some support. But I think she could have got support. She just didn't see the support she was getting as the support she needed.
	Gary	Yeah, she was definitely had a lot of options, but I don't think we found the option that suited her best, so we didn't know what to do

2. Relationship changes		
Subordinate theme	Ppt	Quotes
2a. "a lot more open with each other"	Peter	Yeah. So it's a lot happier now because I think everyone's sort of coped now. Everyone sort of accepted it and come to terms with what's going on and now obviously she's starting to come home again. It's starting to normalise a bit and it's going quite nicely.
	Peter	Really it improved after the first couple of months like she was here because it was like, it was sort of normalized a bit,
	Peter	me and my Mum - I'd say it's actually brought me and my Mum closer. Yeah because obviously I spoke to her a lot about it. My dad, I have an odd one with my dad. We just get on, I think we're just that similar that yeah, we get on, but not so similar that we annoy each other
	Peter	But I speak to my Mum quite a lot. Yeah. Like without fail every day sit down and chat about things. Just cos y'know have a cup of tea or something.
	Tristan	They talked to me about it, they took me to like counselling sessions and to meet her and they talked to me about what happened to her and stuff like that
	Tristan	Yeah, I've been able to talk about what happened. I haven't been told why she does it, why she did it. But I've been told about what happened when she got there, what happened the first night she was there, stuff like that.
	Barry	No, because everyone in the house already knew.
	Barry	I think sometimes Mum and Dad are helpful and like honest and stuff.
	Barry	But like other times they do tell me. Uhm and that's like, they tell me most of the time but sometimes they don't.
	Barry	Sometimes I'm glad that they don't tell me because like I manage to make them tell me and then I wish I didn't know
Barry	I think sometimes Mum and Dad are helpful and like honest and stuff.	

Gary	I'm much closer with my Mum than my dad. I can talk to my dad about, um, everything except like emotional stuff and family stuff. Like we just don't talk about that at all with my dad. Uh, I don't know why. It's just, I guess because my Mum is better at it. Maybe my dad's better at it but he doesn't, but he has actually spoken to me a lot more about it recently. [R: Yeah.] Like we'd go and walk, like dog walks together and we have just a proper conversation about it. Like you'd never, I've never spoken with my Dad about anything personal before. And for the first time after this he's speaking to me about everything, like really deep stuff about like just about 'A' and life and things and he just, it makes me feel like I can actually talk to him. I'll probably still go to my Mum to talk about things, but he's there if I need to.
Gary	Yeah, I think we all have. I think we've all changed in how we feel about it and we've all sort of become just a lot more open with each other. So that, it's a good thing, I guess
Gary	Speak to my Mum about it. [R: Yeah.] I think my Mum's very good at speaking to give me advice and that's normally how I speak to if I need advice I guess.
Gary	Well, well, we've always had a very good, we talk about everything, but we're just talking a lot more about things. I think it's been very stressful for these few weeks and having to still go to work and come back.
Gary	Yeah. It's about half an hour. So we've got every uh, every night doing that. I'm just sitting there for a few hours and really talk about a lot of things you've never spoken about before. Quite honest with each other
Gary	we're a lot more open with each other and we've spoken about a lot of different things we'd never normally speak to each other now over these few weeks and we, and we've, every night we've sat down together and talked about the situation and we never would have normally done that
Gary	I guess because I guess we realised that it's important to talk about things because 'A', that's what 'A' said. That we just weren't talking about our problems and I guess we were just talking about everything now and thinking we all know now that we can talk to each other about whatever ever we want. It doesn't matter what we say. And that's what we do now.
Gary	I don't know. I think, I hope now that we are all a lot open, honest, honest with each other what we want, we'll actually plan things and we've, like, learnt, learned lessons from this but I hope it doesn't go back eventually fall back into older habits.
Gary	we're a lot more open with each other and we've spoken about a lot of different things we'd never normally speak to each other now over these few weeks and we, and we've, every night we've sat down together and talked about the situation and we never would have normally done that
Gary	I guess because I guess we realised that it's important to talk about things because 'A', that's what 'A' said. That we just weren't talking about our problems and I guess we were just talking about everything now and thinking we all know now that we can talk to each other about whatever ever we want. It doesn't matter what we say. And that's what we do now

	John	My Mum's started telling me like what's happening and all that
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2b. "we kind of get along a lot better now"	Barry	well me an 'E' are really close now
	Barry	Like the whole time from when she was, pretty much, admitted the first time and then until she was like, admitted like, still, like, to this day we've been like really close. Err, like all of a sudden when she was discharged and like part way through when she was in here first we just got really close all of a sudden
	Barry	it was more that I knew what she was going through, so I was being like, a lot like gentle around her. And we just like found stuff that we both liked and... did it and stuff.
	Barry	I think it's like sort of awkward because when she's like going to all these appointments I have to like ask 'ooh where you going?' even though I know and stuff just to keep my cover
	Barry	It's upsetting because like when she's been upset or something and like, been like thinking suicidal thoughts she like wouldn't be open once I was there. She's just like erm act all normal
	Barry	I don't really know because it's just like... erm... it's just an appointment, that's just all she wants me to know. Like at first when she'd go to the doctors she'd just say that it was a regular check-up when I didn't like know why she was going. But now I know where she's going so.. but like I can't say that I do so it's like pretty tough to keep your cover and stuff
	John	Uhm, well, I kind of became more worried and care about her more because we never got on before all this, now this has happened I care a lot more.
	John	Erm, yeah because we like we kind of get along a lot better now . And she says it's about that because I'm more mature now.
	John	I've stopped worrying about her a lot more [because I know she's in hospital]
	Peter	So after that I sort of realise how... it sounds really sappy, but how much I cared. It was quite, it was quite overwhelming at points.
Peter	Erm. Yeah, I'd say so. But I think, I think my relationship with P has always been sort of like I'm here if you need me, but otherwise bugger off because who wants to spend time with a sibling all day, you just don't do you? You live together. You're just like, you don't want to be there 24/7 because then you'd end up killing each other. But no erm i think we get on. Hmm. I think in some respects we are closer, especially in the past couple of weeks she started to talk to me more about things. Which although is hard to hear, is good to hear. [R:	

	Yeah.] If you know what I mean? So Yeah, she's spoke to me about more, which I think has sort of showed me we have grown quite close
Peter	it's not changing the way we act towards one another, but there's a greater understanding, I think on my part to her more so, cause obviously it's her who's been affected. So I feel like I've sort of grown to know her emotionally more
Peter	Whereas now I can see, so for instance, when we were in the car the other day I could see she was upset and she was more, she wasn't as nervous as being upset around me, so I think in that sense it's changed, but otherwise the relationship hasn't changed.
Tristan	They were better. It was like, after she came into hospital she started acting nicer. Yeah. And she was like more compassionate to me. Wasn't telling me to shut up all the time and letting me talk and stuff like that.
Tristan	They're nice. It's not like we can just talk openly like, and not just, because if I just walked up to her now and went 'hey L' she'd go 'ugh' or something like that but it's not like whenever I step in to the room she screams bloody murder
Tristan	It was good. Sometimes we'd bicker again but that was like normal sibling stuff.
Tristan	That was relieving. Because I thought that was for the rest of my life or whilst I was at home with her I wouldn't be able to do anything. So, it was relieving once she started letting me do more things.
Tristan	Yeah, because on Friday's we'd go and see my grandma and we'd come here and pick her up and stay here for like 20 minutes and then other times in the week I'd come over and see her. So I saw her more.
Tristan	She was letting me talk more. She wasn't telling me off for every little thing that I did. And every time I went past her, because at like the peak of it she was giving me dirty looks, she wasn't doing that anymore. Her face was more bright, I guess you could call it
Tristan	They're nice. It's not like we can just talk openly like, and not just, because if I just walked up to her now and went 'hey L' she'd go 'ugh' or something like that but it's not like whenever I step in to the room she screams bloody murder
Tristan	she didn't like me being around her and she thought I was embarrassing and stuff like that. So that was difficult because I couldn't be around my family because she'd always be downstairs with mum and dad.

	Gary	Um, I think it all does us good spending time, but um, but just not motivated enough to plan something to do every, every weekend. But I don't think we realised we didn't need to go on a big trip. We could have just had a big meal together or done something together in the house, but we just didn't do that. We just did our own things on the weekend and never talk to each other that much
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2c. "I was worried about her most of the time"	Barry	Because under her bed she's got a big drawer thing and under her bed she'd have like tissues of blood. From when she was like self-harmed
	Barry	I just like get really upset when I find out that she's like she doesn't want to live and stuff.
	Barry	Like when she was first in here she tried to run in to cars and stuff so my mum had to call the police to escort her back here and that was upsetting. But, uhm, at the moment like, she's been getting suicidal thoughts and that's quite upsetting
	Barry	I just like get really upset when I find out that she's like she doesn't want to live and stuff.
	Barry	Because sometimes when she's done something like to like harm herself and stuff they don't like to tell me about it because they don't want me to get upset.
	John	well anything to be honest – if she's upset or anything like that I'll go straight to my mum and tell her 'cos she's good with my mum, she talks to her... better than she used to.
	John	Well I was worried about her most of the time
	John	well last time she did it, the other day, erm, when my mum was like away for a few hours she was looking for like the medicine and I was in the house as well, and I didn't know... I kind of feel like that was my fault and I should have like been with her
	John	Most of the time, yeah... Sometimes it's like bad news and I just, I worry about her more now
	Tristan	I'm thinking about what she was like right before she did it. Because I remember before, about two hours before, I was sitting down with her and she seemed fine and then all of a sudden, she was being rushed off to hospital in my mum's car
	Tristan	Yeah. And I feel like the one who was scared most of all was L. Because she didn't know if she was going to die. If she was going to sleep one night and just never wake up.
	Tristan	Like my mum's fine but around L I'm just not, I don't really want to bring it up, if you know what I mean

Tristan	I was scared. I was, because I've heard about people overdosing and how it's like a dead quick death. I was scared that she was going to die. I remember sitting in bed, because we hadn't been able to see her the first night she was there, quivering, like shaking, is she going to die? Is she going to pull through? I remember just being really scared
Tristan	That was... odd. Because I felt like we should have been talking but at the same time I felt that we shouldn't at the same time My dad acted nonchalant, but I could tell he was very worried, but he was just trying to put on a brave face in front of me. And then like that night we didn't really talk about it, we were just trying to act normal. We eat tea. It was just me and him eating. We were talking
Tristan	about other stuff, like: how's your day been, how's work, stuff like that.
Peter	But, I think, I honestly think if I hadn't told her I was going to come downstairs. That I could have gone downstairs in the morning and found her lying there. Which I don't know. I might be overthinking it. Which is always a possibility. I'm the king of that! But I think, for me though, because of what happened, I think that was a genuine possibility. I could've gone downstairs and I could have found her lying there
Peter	To know that someone who's always been there, well for the most part, doesn't want to be.
Peter	I think as soon as I came here I knew she was in a better place here so she can get the help there. She's safe here because obviously you monitor her like every 20 minutes or so I think, it's horrific to think that, like my sister this person I've known since, since literally she was born, wants to take her own life. It's a horrific and it's a fear because you don't know if you're going to wake up one day and she's taken her life. That's, that is terrifying. When she was there the other night, after that thing I didn't want to go sleep, I didn't really go to sleep to be honest. But yeah. It is quite. I think fear is probably the best way to put it. [R: Yeah.] It's just a constant fear. It's not the so much fear, like obviously she's afraid of her own condition. And of course she is, cause it's terrifying to have something put into your head by your own head, that's horrendous. But, it's this fear cause obviously, my sister is, she's funny as hell. But it's this fear that you could wake up one day and she's not there. And I think because obviously suicide in teenagers is a massive thing. There's all, there's always stories on the news about it happening. There's obviously more cases than are reported, which is scary. I think when you look at things like the self-harm and because I know of her self-harm, I've never seen the self-harm that she's done. I don't think I could look at the self-harm she's done.
Peter	I wanted to go after her but I was at the other end so couldn't do that without drawing a load of attention in front of 1200 people. Yeah. Just nipping out, see you in a min. But it don't work like that does it? But she went with someone so it was fine. But it's like little things like that where I see her get up and leave and I think please for the love of God, don't say she's going to hurt herself with something out of fear and it's just constant worry. It's awful, it's horrible, it's there, you got to deal with it.

Peter	<p>Because at school, she can get hold of all sorts, all sharpeners and knives as well in school, forks and all sorts of things you could do damage to yourself with. And it's just this constant fear.</p>
Gary	<p>But after she did it, she said no one supported her on that Friday and no one made her feel any better. I didn't know what to do, like I always go in, and I know, I know I should do all the time, but that Friday I'd helped her as much as I can all day and offered food and drinks and tried to talk to her about things. But I wasn't really sure what else to do.</p>
Gary	<p>I don't know how it's affected me really, but it just makes me feel like I've done something wrong because she blamed a lot of it on us. She was saying that it was all our fault, that it was, our, that she did what she did. And it's hard to like sleep when you, when you've got that in your mind because it's not nice being blamed for such a serious thing. Mum says that that's just because she's in her head and that's how she's feeling. But it's hard to not let it get to you. That being blamed for all the negative things in her head.</p>
Gary	<p>And it was just sad that she had to do that and that things got so bad and getting blamed for things getting that bad on us was pretty bad. Like 'A' said it was our fault. Yeah, so getting blamed for that, it wasn't very nice, really. Hopefully things will get better.</p>
Gary	<p>It was difficult to, um, know what to do. Like I didn't know how to make her feel better and it was hard to I just sort of, it's quite hard to keep going in every time even though she doesn't want me to go in and I didn't know what to do really. I just wasn't sure. I was just hoping one of these therapists or something would help and make her feel better. Didn't happen really.</p>
Gary	<p>Uh, well on the Friday, this was like the night when she actually drank the paracetamol. She, she took the day off school cause she was just feeling so low. So, I was like I need to be trying even though she's doesn't want to I need to come and speak, so I woke up, because I was at home too because I still haven't been in school for a while. So I said, do you want me to make you breakfast cause I was like I've never made anyone breakfast but I thought she's really not feeling it today, I'll make her breakfast. And she says no, I don't want anything. And then I come in later again, she said, try and I say can I sit down? And I brought some work into do just like OK I'm just going to sit here and she's like get out, don't stay in here. But after she did it, she said no one supported her on that Friday and no one made her feel any better. I didn't know what to do, like I always go in, and I know, I know I should do all the time, but that Friday I'd helped her as much as I can all day and offered food and drinks and tried to talk to her about things. But I wasn't really sure what else to do.</p>

3. The future		
Subordinate theme	Ppt	Quotes
3a. "like this forever"	Peter	because again that highlighted sort of what was going through her head. And sort of the extent it has on people. So obviously P won't talk to me about that cause she won't talk to anyone about the level of intrusion in her thoughts. Obviously it's horrific for her. I think it horrifies her that her brain can come up with that. Yeah. Like it does with everyone, don't they? I'm just quoting the video now. Everyone has them but they just go get out of my head type thing.
	Peter	So it was just, highlighted how much it was but that's the only sort of information source I have really had on it and I think I'm on the fence of whether I want to know or whether I don't. So if I do know I find out more about it I realise how unwell she is. Whereas If I don't then I'm sat wondering about things and yeah, you can't find a medium cause no matter where you sit you're not happy.
	Barry	I think that like when she's older she'll probably like struggle to like live on her own and stuff. So like mum thinks that she'll always be living with them and I think she will too because it's just somewhere familiar.
	Barry	I think like it's something that she'll always have and she just needs to like channel it and like get the help that she needs and take her meds and stuff.
	Barry	Erm, if she stays at home I'll be like upset that she never got to go out and pursue her dream. But then I'd be happy because I know she's safe.
	Barry	No, she can't multi task all of a sudden. Like when she's doing something and you're trying to get her attention she just like blanks you out and she never used to do that. But I don't know.
	Tristan	I was feeling like she's going to be like this forever . She was gonna stay like this, be antisocial. Be that forever. She'd stay completely like that. But when she started opening up, being more social, it relieved me a lot because I knew she was getting better. And by the time, I don't know, she's 20 she'll have tonnes of friends and a job and stuff like that.
	Tristan	Because I didn't want her to live like that. I wanted her to have a nice life, with nice friends, and a nice cat
	Tristan	It was like I knew she was getting better and her life was turning around and look everything she had done to build it back up was actually working.

	Tristan	It was like, after she came into hospital she started acting nicer. Yeah. And she was like more compassionate to me. Wasn't telling me to shut up all the time and letting me talk and stuff like that.
	Tristan	Her face was more bright, I guess you could call it.
	Tristan	It was good. Sometimes we'd bicker again but that was like normal sibling stuff.
	Tristan	It made me feel much more relieved. So I knew she was getting better.
	Tristan	She was socialising more. Because when she was like not taking meds and at home she was, like she wouldn't talk to people much, and she was kind of like all drawn in an only talk to us but when she came here she made friends, she was doing stuff, she was going outside for walks. Stuff like that.
	Tristan	That was relieving. Because I thought that was for the rest of my life or whilst I was at home with her I wouldn't be able to do anything. So, it was relieving once she started letting me do more things.
	Tristan	They were better. It was like, after she came into hospital she started acting nicer. Yeah. And she was like more compassionate to me. Wasn't telling me to shut up all the time and letting me talk and stuff like that.
	Gary	We, we try and, like here she doesn't like speaking to us. She just wants to go home and because she hasn't had very good experience with talking to therapists in the past, she just thinks this is not going to work and it's not going to help her. And she's got very negative attitude towards it all at the moment. Not really sure how to do, how to change that.
	Gary	Yeah, it's still early days. I don't know if she, she realises that cause she's like, when she first came here she said like I've been here three days and it hasn't made a difference yet. She didn't understand that it takes a while.
	Gary	I don't think it's going to be a long-term effect for me. I think as soon as I'm better and be 'A's better and I know in my head that she is going to be okay and there's something for her - I think I can just move along. But, yeah, it's, it wasn't, it's not nice to know that things might never get better, but hopefully I can know in my head that things will never get worse and it won't go back to how she was.
	Gary	I don't know. I think, I hope now that we are all a lot open, honest, honest with each other what we want, we'll actually plan things and we've, like, learnt, learned lessons from this but I hope it doesn't go back eventually fall back into older habits.

3b. setbacks	Gary	Well, it's sad seeing her dip up and down and it's hard to, because we thought those the first two weeks she was just getting better every day. She was speaking to us and she was allowed on leave and we were going out and just really enjoying the time as a family. But now it's back down to, she's just not talking anymore. Don't know what to do.
	Gary	Yeah well, I thought it was going to be short. I thought she was going to be in here for a week or so. But we slowly started to understand that this is not a temporary thing, and this is going to take a while till she's better. [R: Yeah] and here she has her ups and downs. She

	hasn't spoken to us in like three or four days now she just doesn't speak but when she first came here she was speaking to us and she was all right again. It seemed like she was all right. She just has phases of being very negative and very positive.
Gary	Yeah. She just hardly speaking at all now and doesn't want to, just goes on her phone, sits in her room here. Same old habits that she was like before.
Barry	Erm, I think it will be better but sometimes she'll be in a low mood and it'll put her off doing stuff because she gets like bored quite easily
John	I feel like she's getting better... but it kind of happened again didn't it? I don't know what's the cause of that... I don't know... different things leading to one another and then she did it

4. Contact with professionals		
Subordinate theme	Ppt	Quotes
4a. "who was taking care of her?"	Peter	obviously I wasn't that, isn't that, but obviously it's just sort of in your head because you don't know what to expect because you know what's in a normal hospital because nearly everyone's been to hospital at some point. But when it's sort of a place like this, you don't know what's there. It wasn't that bad. But I dealt with it.
	Peter	I mean, I didn't want to come near this place to be honest with you, because I sort of avoided the whole concept, sort of like almost as if it was a taboo to me. I didn't want to come there. Because obviously it's a hospital first and foremost that she's having to stay in. I'm not bothered about hospitals at all, I've been in them quite a bit. But then I didn't want come to this place. Sort of meant seeing how bad things were.
	Peter	Partly my Mum, partly [girlfriend]. And then was just thinking about it myself in general. Because obviously my mum wanted me go see her. Admittedly I did miss her, didn't say that. But yeah, it was quite an odd one. I just sort of decided that, you know what, I'm going to go, sort of like a 'sod it', that situation where I just thought you know what I'm just going to, so I did. So I came and thought it's not that bad, I felt uncomfortable like for that. I was there. It was all right. It wasn't what I expected. I didn't know what I expected. I think in my head, I had it like, some people are going to be walking around in like these white coats and you know, so like you're in American horror movie type thing where it's all going on.
	Barry	it was weird because it was like an unfamiliar place but like almost every night we'd be in this room. And that table would be like over there and we'd play like board games and stuff.
	Barry	Yeah because I was too young to be able to go in like the bedrooms and stuff. But now I'm old enough.
	Tristan	I wanted to know who was taking care of her and who they were and how nice they were and stuff like that.
	Tristan	I found that, again, I hate to be repetitive, but I found that relieving knowing that she was getting better, and people were helping her.
	Tristan	it was kind of like I knew the people who were treating her, or at least FT
	Tristan	I knew the people who were looking after her were nice and supportive.
	Tristan	Yeah, I was thinking they'd all be like – have you ever read 'Grandpa's Great Escape'? I was thinking they'd all be like that.
Tristan	Mum dad did CAMHS really. I'd come around for visits and I'd come just before she got discharged for kind of party thing but that's all I really do. Like I wouldn't meet the nurses, or whatever you call them – matrons – I wouldn't see the doctor	

4b. "someone to talk to"	Barry	Uhm, because it likes brings us all together to like talk honestly. And it also just helps us like, we do fun stuff and talk and stuff
	Barry	But like the appointments they were a bit like weird at first. Because I didn't really know what was going on but like now its fine
	John	I've been to that family therapy with Mum and N. And, I think I'm going next time as well. And then that's it. I don't really talk much about it
	Tristan	At first I was apprehensive because I was like are they going to be nice, mean, supportive or cruel but after the first meeting, it was much better because it was like a weight had been lifted from my shoulder and I knew the people who were looking after her were nice and supportive
	Peter	And I think, and I think there needs to be something for parents especially but because obviously for a parent it's difficult, but I think the needs to be something there. Even if it's just a case of any person. It needs to be someone who's not trained to deal with it or anything
	Peter	So, I think just having something there, someone to talk to , whether it's a mentor or do you know what I mean? That sort of thing, because there is nothing in place to help the family
Gary	So, and we've done various things and talked to various people to help her with that, but it just didn't really get better and like we don't know what to do really	
Gary	It wasn't nice at all. Yeah. Having someone criticise everything you do in your life. It wasn't nice, but we tried to change. But eventually the old habits came back, and it, and it didn't really help and I don't know, school's not, her school wasn't doing very much to help her either. They didn't really, they never offered her much support.	

5. Opening up		
Subordinate theme	Ppt	Quotes
5a "emotionally shut myself off"	Barry	I just have to like occupy myself to, to try and not think about it. And that's why I don't want to go back to school because I'll be so bored that's all I could think about.
	Barry	Err, when it comes to something going wrong or like my PlayStation, I like bang the controller and stuff. And I broke like two controllers before but like I don't properly smash them and stuff, just hit them and stuff. And, like, recently I was like, with my heel I was banging on the back of stairs and it like broke.
	Barry	I'd just get angry like sometimes when I'm like miserable I just get angry over anything.
	Barry	I've like broken my drawers and like broken a bit of the stairs and stuff.
	John	I don't think its really changed me, or my mood or whatever... but like, they're trying to get me to like open up a bit more
	Gary	Yeah. it's hard to sleep at the moment. I haven't been getting as much sleep
	Gary	yes, it was, it was nice to talk to her about it and I'm not that much of an emotional person, so I don't think it will really affect me in the long run
	Peter	Cause otherwise I just sort of, I think I had emotionally shut myself off from it. Sort of detached from it a bit and just accepted factually what it was. Not on impact.
	Peter	But like I say it's a lot better now. I'm not that bothered now. Yeah. Especially now she's on the mend type thing. Yeah.
	Peter	I had just turned 18 - I went out. Got absolutely leathered for about five out of seven nights of the week I think at one point. I'd say I didn't get that bad every night. But I'd say I had a drink about five of seven nights and the week after. Well, it was quite weird actually because I always sort of, I started to understand why some people drank. Yeah. If you know what I mean. Which is awful because I'm 18 I know that is really bad. But it was sort of, it was a way to cope. It was a way to just switch off from it, which made it quite sort of easy to do. But I don't know. I felt, I felt like I needed to help her
Peter	I mean at one point, I was at a party actually, to tell you the truth, I actually downed like a bottle of vodka. That's not making myself like great... I don't have an alcohol problem!	
Peter	There's points where I've said prayers about stuff because I am a catholic, so like a default thing, you know, say a prayer. Makes things better. But... quite nice coping mechanism actually.	
Tristan	Like I'd play a game for like 4 hours straight and only come down if my mum called me or something. And then I'd like watch a TV show for a couple of hours. So, I was like doing less, just trying to... not like get away but focus more on that than the other things.	

Tristan	It was a bit like, I felt like I was alone. Isolated. But when I sort of immersed myself in stuff it was like, better
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5b. "I'm not the one who needs the attention"	Peter	So when she comes home for a weekend or something, they'll go shopping, they'll do this, or they'll do this. And I think it's sparked jealousy from the older sister. I don't see why personally, I can understand why, because obviously she's getting my mum's attention and I see it as well, course I do but I'm not bothered. My attitude is she's not home half the time. [R: Yeah.] She needs the attention when she can have it. She doesn't live with my and Mum at the minute
	Peter	because you don't want to be an inconvenience almost. Like I say, it's 'P' who needs the care
	Peter	obviously you're always told like you can come and speak to us anytime you want. But I won't do that. I never would. I'd never go out of my way to discuss my emotions with someone. For me that I just be like a broken, I'd be like, what's wrong with you? What's going on? I'd never do that. But I think if you have someone ask you, for me, if someone asks me if I'm okay and I'm not okay, generally if I'm really not okay, I will tell them that I'm like, okay.
	Peter	That someone's around me because they pity me or whatever, But, I don't want to be pitied because of that. And in that sense as well, it's not my problem. I'm not the one who needs the attention. It's obviously P that needs the attention. [R: Yeah.] So it's not, it's almost not my place to have sort of the care, because I don't need it. I'm not in a bad state myself. So in that sense that's just not talk about it. Keep it to myself.
	Peter	I won't speak to my mum about how I feel.
	Gary	Um, I think the reason I wasn't involved was because I wasn't the main problem - if that sounds right. Like I think 'A' was the most involved and my mum, cause they're the ones that needed the help from the family sessions. And me and my dad kind of just said, okay, we'll do what they want us to do and that's what we'll do. We'll carry on with it.
	John	Yeah, pretty much. When she comes home and all that I sit with her on the sofa

5c. stigma	Barry	don't really want any of my friends knowing because I don't want it spreading around school that Barry's sister is in hospital and stuff
	Barry	I just don't want it spreading around school. Because I don't want like people knowing. Because 'E' doesn't even know that I know [R: Ok] much about it
	Barry	I'd just rather just like not. Because like I don't really want my teachers knowing because it's just a bit awkward
	Barry	I just don't want it spreading around school. Because I don't want like people knowing. Because 'E' doesn't even know that I know
	Peter	But I think, it was a case of, like for instance the first person to speak to me about it was PJ, Mr. Johnson sorry, uhm he basically said to me it's okay not to be okay about it. At that point I started to get upset

<p>Peter</p> <p>Peter</p> <p>Peter</p> <p>Peter</p>	<p>I think with people when you talk about things, they feel like they have to, in a sense, because obviously if a person who opens up, you feel like responsible to help them through. So I work with little ones, if a kid comes to me with a little cut, I feel like all of a sudden I'm the one who's responsible for dealing with this cut. I need to put a plaster on it and make sure it's clean and whatever. Like you do feel automatically responsible to help a person, it's just your empathy kicking in. And, yeah, so I don't want to, uh, I don't, I don't want to be pitied.</p> <p>That someone's around me because they pity me or whatever, But, I don't want to be pitied because of that. And in that sense as well, it's not my problem. I'm not the one who needs the attention. It's obviously P that needs the attention. [R: Yeah.] So it's not, it's almost not my place to have sort of the care, because I don't need it. I'm not in a bad state myself. So in that sense that's just not talk about it. Keep it to myself.</p> <p>That people are around me cause they pity me. Don't me wrong, It's completely irrational. But hey-ho. But it's why I don't like to talk about it. I don't want to be talked to by person because they feel like they have to me, it's not what I want. So in that sense, I'd rather deal with it myself then talk to someone about it because it's just, I don't want to.</p> <p>obviously you're always told like you can come and speak to us anytime you want. But I won't do that. I never would. I'd never go out of my way to discuss my emotions with someone. For me that I just be like a broken, I'd be like, what's wrong with you? What's going on? I'd never do that</p>
<p>Gary</p> <p>Gary</p> <p>Gary</p> <p>Gary</p>	<p>I haven't let any of my friends know because, um, 'A', doesn't want, wants as little people to know as possible</p> <p>If I needed help, I can get help and uh, college has supported me, and they say spend as long as time off as you want. It's not the end of the world if you don't take your exams this year you can do it again. That made me feel, because I was very worried about college and work being ill and 'A'. So, we had a meeting, we had a meeting with them and it's fine. I can just do work from home until I get better and 'A' gets better.</p> <p>Yeah. That really did make, because I thought they were going to just kick me out when not if, when then they knew I wasn't going to be in for a while but, so, they're supporting me way better than I could ever imagine.</p> <p>But, um, a friend from school - I've known her since like primary and high school. And has a sister who's like gone through the similar thing. So she knows about it and I've talked to her and we just talk for ages about everything. And the same sort of thing with the family, we just opened up about everything and that makes me feel a lot better just having someone to be able to talk to about, because I don't think my friends would be very sympathetic with it. They wouldn't really understand. And so someone who understands and has been through it, a similar thing, it's a lot more relatable</p>
<p>John</p>	<p>It's only just started like a couple of weeks ago and he's pulled me out once or twice, yesterday I think. But he says he's going to try and find a time once or twice a week where I'll spend like half an hour with him</p>

	John	Schools tried to get involved and like try and get, like I've got someone from ESR who has to talk to me and he pulls me out of lessons and asks about things and all that
	John	Uhm, yeah they've emailed my teachers to say if I act differently to send me up and all that so I can talk to someone. So... yeah...

Appendix K: Author guidelines for intended journal of publication

1. Manuscripts should allow for 'blind/anonymised' refereeing and **must not** contain author names or any identifiable data.
2. Manuscripts **must** be typed in double spacing throughout, including quotation, notes and references in the following order:

Title Page: to contain the title of the paper, word count, suggested running head (short title for your paper), key words, author names, affiliations and contact details for the corresponding author.

Abstract: on a separate sheet, the title to be repeated followed by a summary of not more than 150 words. The suggested running head should also be present. *For tips on optimizing your abstract for search engines please click here.*

Practitioner Points: two to six bullet points of no more than 180 characters each (including spaces), up to a total of 480 characters.

Organisation of the text: see copy of Journal for the format currently in use.

Figures, tables, etc.: All figures and tables should be numbered with consecutive arabic numerals, have descriptive captions and be mentioned in the text. They should be kept separate from the text but an approximate position for them should be indicated. These will need to be uploaded separately. Please supply figures in the format in which they were created, if possible.

References (in text): These should be indicated by the name and date e.g. 'Carr (2009)'. If more than two authors are listed, cite the reference as 'McHugh et al. (2010)'. Quotations should include page numbers. Websites should also be cited in this way, with a full reference appearing in the References section (see below). Please check all websites are live and the links are correct at time of submission.

References: Should be listed at the end of the paper in alphabetical order according to the first author and be complete in all details following the APA style of referencing.

Articles: Altschuler, J. (2015). Whose illness is it anyway? On facing illness as a couple. *Journal of Family Therapy*, 37(1), 119-133.

Chapters: Burnham, J. (2012). Developments in the Social GRRRAAACCEESSS: visible-invisible and voiced-unvoiced. In I.B. Krause (Ed.), *Culture and Reflexivity in Systemic Psychotherapy. Mutual Perspectives* (pp 139-163). London: Karnac.

Books: Burck, C., & Daneil, G. (2010). *Mirrors and Reflections. Process of Systemic Supervision*. London: Karnac.

Web pages (no author or date identified): Counting the cost: caring for people with dementia on hospital wards. (n.d.) Retrieved from

http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1199.
[Cite in text as (“Counting the costs”, n.d.)]

For further details, please see the APA Style website:

<http://www.apastyle.org/learn/tutorials/basics-tutorial.aspx>

3. The word limit, excluding abstract and practitioner points will vary depending on the type of paper you are submitting. Please refer to the ‘Advice to Authors’ section below.

4. Style: Whilst Journal style is generally formal, originality in presentation does not necessarily preclude publication if clarity and readability is thereby enhanced. Sexist language forms are unacceptable.

Your manuscript will be returned to you if you fail to conform to these requirements.

ADVICE TO AUTHORS

Writing is a very enjoyable and satisfying way of being involved in the world of family therapy. The exchange of ideas and experience is important both for the development of our chosen field and for the development of the individual practitioner. We intellectually sustain ourselves by creating a healthy and vibrant literature. Family therapy needs to develop authors and *The Journal of Family Therapy* wants to hear from you.

These are the types of papers that are regularly submitted to the *Journal of Family Therapy*:

(The word count for all these papers does not include tables and figures.)

Research Presentation (3,000-6,000 words)

A research paper should include:

- An introduction to the principal concepts and theoretical issues relevant to the study
- Previous work
- Description of methodology including participants
- Results/Findings
- Discussion of results, including implications for future research and practice

<https://onlinelibrary.wiley.com/page/journal/14676427/homepage/forauthors.html>

Paper 3: Executive Summary

Background

Clinicians working in Child and Adolescent Mental Health Services (CAMHS) are aware of the impact a young person's mental health difficulties can have not just on the service user, but also on their wider system. With increasing numbers of young people being referred to CAMHS (Newlan, 2018), one can assume therefore that more families are affected. Research suggests that positive family engagement can reduce the likelihood of readmission to hospital after discharge (Green, et al., 2001).

Often, parents are negatively affected when their child is admitted to hospital (Clarke & Winsor, 2010) and this may impact on any children still living at home. However, little research has explored the effect an admission to an inpatient mental health unit can have on siblings and the support that they may need. For the siblings of the service user this may be their first encounter with mental health difficulties and this significant life event may also have an impact on their own wellbeing (Griffiths & Sin, 2013).

Aims

- To explore young people's experiences of having a sibling admitted to an inpatient mental health unit;
- To understand how professionals can support and include siblings in routine clinical practice.

Method

Siblings of young people who were admitted to a CAMHS inpatient unit in the West Midlands were interviewed between July 2018 and March 2019. Five brothers from White-British backgrounds who were aged between 12 and 18 were interviewed. 3 had older sisters (Barry, Tristan and John), and 2 had younger sisters (Peter and Gary) who were all currently an inpatient at time of recruitment.

The qualitative approach, Interpretative Phenomenological Analysis (Smith, Flowers, & Larkin, 2009) was used to analyse interview transcripts, from which key themes were identified. This method allows for an in-depth analysis to explore the significance of the hospital admission on participant's lives.

Key Findings

5 superordinate themes were identified with 13 subordinate themes. The 5 themes are summarised below.

"A shock to the system"

Participants described their sister's admission to hospital as a "*shock to the system*" (Peter), having an impact on them and their parents' lives. They felt the admission was more of a surprise as they had not been aware of how difficult their sister was finding things leading up to the admission.

Some shared that their parents were struggling with the situation also but trying to "*put on a brave face*" (Tristan).

"My dad acted nonchalant, but I could tell he was very worried, but he was just trying to put on a brave face in

front of me. And then like that night we didn't really talk about it, we were just trying to act normal." (Tristan)

The participants spoke about feeling helpless in being able to support their sister, especially if their sister experienced suicidal thoughts.

Relationship Changes

All the participants reported being more open with their parents. They noticed a greater closeness with their sister however worried more about them since learning that they experienced suicidal thoughts.

"we're a lot more open with each other and we've spoken about a lot of different things we'd never normally speak." (Gary)

*"it's not changing the way we act towards one another, but there's a greater understanding [...] I feel like I've sort of grown to know her emotionally more."
(Peter)*

"Sometimes it's like bad news and I just, I worry about her more now." (John)

"She's going to be like this forever"

Participants also worried about their sister's future and that they may never get better. They struggled if their sister had a setback whilst in hospital and described feeling worried a lot of the time about them.

"I was feeling like she's going to be like this forever. She was gonna stay like this, be antisocial. Be that forever. She'd stay completely like that." (Tristan)

"it's sad seeing her dip up and down" (Gary)

Contact with professionals

Some participants described being apprehensive about visiting the hospital for the first time as they did not know what to expect. They imagined that it would be like the negative images described in the media.

"I didn't know what I expected. I think in my head, I had it like, some people are going to be walking around in like these white coats and you know, so like you're in American horror movie type thing..." (Peter)

Those who had attended family therapy sessions described them as helpful but also shared that they did not know what to expect initially but appreciated being able to meet some of the professionals treating their sister.

Opening up

Participants spoke about how they felt they were managing the situation and their own feelings about their sister being in hospital. There was a sense that participants were disconnected from their emotions and using avoidance strategies, such as alcohol or distraction.

"I think I had emotionally shut myself off from it. Sort of detached from it a bit and just accepted factually what it was. Not on impact." (Peter)

"I just have to like occupy myself to, to try and not think about it." (Barry)

They also worried about detracting from the support their sister required by sharing how they were feeling. Some also worried that their friends would not understand mental health difficulties.

"it's not my problem. I'm not the one who needs the attention [...] So, in that sense that's just not talk about it. Keep it to myself." (Peter)

"I don't think my friends would be very sympathetic with it. They wouldn't really understand." (Gary)

Limitations

- The participants were all White-British males with sisters who had been admitted to hospital. The experiences of families from different cultural backgrounds or different family set-ups, such as step-siblings, may be different.
- The long-term implications of having a sibling in hospital was not explored, we can only make hypotheses based on what the participants shared as to how they may be affected.

Summary

This study aimed to explore the experiences of young people who have a sibling receiving treatment in a CAMHS inpatient unit, and to better understand how siblings can be supported by professionals. Our findings suggest that for young males whose sisters are admitted to hospital, they experience positive changes in their relationships with their parents and sibling due to a greater understanding and becoming more open with each other. However, they also described avoiding their own emotions through distraction or alcohol and report not wanting to share their own worries with their parents for fear of adding to their stress. Participants also worried a lot about their sister's safety especially if their sister had expressed suicidal thoughts. The young people interviewed also worried about stigma from their peers or felt unable to speak to their friends due to their sister not wanting others to know that they were in hospital. This had an impact on the social support available to the participants.

Future Research

- Further research into the experience of siblings would be beneficial to gain more information on their views especially for families from different cultural backgrounds and family set ups.
- Researching the potential effect on young people whose sibling has made an attempt to take their own life would be valuable as this could be a potentially traumatic event for siblings, yet little is known on how it impacts other family members.

Recommendations

- Ensure the wellbeing of any siblings is also explored at assessment with siblings being given the opportunity to ask any questions and share any worries they may have.
- An information resource for siblings of young people in hospital would be beneficial in helping siblings know what to expect once their brother or sister has been admitted to hospital, as well as psychoeducation on their brother or sister's mental health difficulties. This would need to be age-appropriate and delivered at their pace, in a person-centred way.
- Family therapy should continue to be routinely offered to families as this provides the family with a space to discuss how they are managing with their family member in hospital. However, other hospital staff can liaise with family members to listen to any questions or concerns they may have.

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