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Siblings of children with ADHD, chronic illness and developmental disorder:

Psychological impact and interventions

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Overview

This portfolio thesis comprises three parts: a systematic literature review, an empirical study and a set of appendixes.

Part one is a systematic literature review, in which the empirical literature relating to interventions for siblings of children with chronic illness and developmental disorder is reviewed. Siblings of children with such conditions have not been extensively studied within research and the review aimed to identify what interventions exist to support siblings in this area, to provide an overview of how rigorously these have been evaluated and to synthesise what findings have been documented with regards to the effectiveness of such interventions. An introduction to family and sibling research in this area is presented, followed by a rationale for why a review of intervention based literature in this area is considered to be a useful addition to the field. The paper goes on to specify the methods and search strategies used to identify suitable articles to meet the research aims and which satisfied set criteria for inclusion. Main findings are presented, conclusions made, and areas for further research identified.

Part two is an empirical study of siblings of children with ADHD. Part one highlighted the paucity of research in the domain of siblings and developmental disorder. The cross-sectional study examines the level of empathy, self-esteem, and the sibling relationship quality factors of warmth/closeness and conflict reported by a sample of siblings of children with ADHD, and compares these variables to a sample of children who have siblings with no diagnosed disorders. The paper reports the between groups outcomes for these variables, along with an examination of whether children's individual

characteristics such as empathy and self-esteem predict reports of warmth/closeness and conflict, based on Furman and Buhrmester's (1985) model of the determinants of sibling relationship quality. This is followed by an explanation of the clinical implications, the limitations of the study and consideration of further areas of research.

Finally, part three is a set of appendixes to support the work in the previous parts of the portfolio thesis. It contains a reflective account of the research process and documents the experiences and lessons learned in planning, implementing and writing this document.

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SIBLINGS OF CHILDREN WITH ADHD, CHRONIC ILLNESS AND
DEVELOPMENTAL DISORDER: PSYCHOLOGICAL IMPACT AND
INTERVENTIONS

Part 1

Systematic Literature Review

Interventions for Supporting Siblings of Children with Chronic Illness and Developmental
Disorder: A Systematic Review

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This paper is written in the format ready for submission to Clinical Psychology Review.

Please see Appendix A for the Guidelines for Authors.

Abstract

Siblings of children with chronic illness and developmental disorder have received little research attention historically, with most family studies focusing on either the child with the illness/disorder or the parents. More recently, research has identified that these children may need support in their own right, yet little intervention based research is reported to inform this support. The aim of this systematic review was to identify the extent to which psychological interventions for well siblings of children with chronic illness or developmental disorder have been researched in a systematic and empirical manner, to provide an overview of empirical evidence in this area, to synthesise the findings from this research and to identify any further research needs. The eighteen studies identified as suitable for inclusion represented thirteen different interventions. Numerous outcome variables were assessed and both the methodological quality of the research included and the findings they documented were variable. It was found overall that the studies identified offered tentative evidence that interventions for siblings of children with chronic illness and developmental disorder can be effective and promote psychological wellbeing. A need was identified for more rigorous empirical research in this area, which incorporates larger samples and uses randomised control design studies to test intervention efficacy appropriately.

Interventions for Supporting Siblings of Children with Chronic Illness and Developmental Disorder: A Systematic Review

Research suggests that in families facing the illness of one of its members, parents and children may face incredible stress, uncertainty and anxiety (for a review see Cohen, 1999). As a result there has been an increasing awareness of the need for the holistic care of families in such circumstances (Spath, 2007). Although adults have traditionally been the primary research focus, a growing number of studies have evaluated children's response to parental illness (e.g. Welch, Wadsworth & Compas, 1996). There is substantially less evidence available on the extent to which children within a family are affected when a sibling is diagnosed with a chronic illness or developmental disorder.

It is documented that around 80 per cent of children in the UK and US grow up with at least one brother or sister (Pike, Kretschmer & Dunn, 2009). Authors have highlighted the influential nature of these relationships (Larson & Richards, 1994) which have been conceptualised by researchers as intense socialisation environments (e.g. Brody, 2004). A steadily increasing number of studies have focused on outcomes for healthy siblings of children with illness or disability in more recent years. This is particularly the case in the area of chronic illness and, to a lesser extent, within the field of developmental disorders such as autism or attention-deficit hyperactivity disorder (ADHD). Whilst sibling research in this area is growing the findings are still variable with a wide range of both positive and negative outcomes documented for such siblings, making the literature highly contradictory and confusing for the reader (Rossiter & Sharpe, 2001). It has been suggested that siblings of children with chronic illness or developmental disorder are more likely to suffer from

depression or anxiety (Loos & Kelly, 2006), or display higher levels of anger (Jones, Welsh, Glassmire & Tavegia, 2006). Positive outcomes such as increased compassion, prosocial behaviour (Sargent et al., 1995) and empathy (Kramer, 1984) have also been shown. Additionally, some reviews of empirical literature in this area have concluded that there are often no differences in outcomes when compared to control groups (Johnston & Mash, 2001). This disparity in research findings means that it can be difficult to derive any clinical utility or coherent sense of what may be useful for siblings in terms of helping them adjust to having a sibling with a chronic illness or developmental disorder. It has been suggested that clinical planning for developmentally challenged children tends to marginalise the experience of other children within the family and often neglects to consider whether they may also be in need of services (Schuntermann, 2007). Although attempts to understand the needs and issues for siblings of children with disabilities are improving, there is still a paucity of support provision to address these needs, and a lack of evaluation of programmes offered (Dyson, 1998). In particular there is a distinct underreporting of research which documents intervention strategies for siblings of children with chronic illness and developmental disorders, and effectively and systematically evaluates such interventions (Smith & Perry, 2004; Pittman & Matthey, 2004). In addition to this underreporting of interventions, those which are reported often lack empirical methodology and a statistical analysis of effectiveness. Often the interventions are evaluated anecdotally with a lack of standardised or psychometrically validated outcome measures and it is often unclear what treatment model or underlying rationale has been utilised and tested within the intervention (Spath, 2007). This can make it difficult for those

working with these groups of children to extrapolate from the literature what may be useful for them. The aim of this review was to identify and examine empirical studies that investigate the impact of specific interventions for siblings of children with chronic illness and disability to address this identified need.

As previously stated, most psychological research in the domain of chronic illness or developmental disability remains focused on patients and parents, with a particular lack of attention paid to siblings. This lack of focus has been conceptualised as reflecting the siblings' potentially sidelined position in the family during the illness process (Houtzager, Grootenhuis & Last, 1999). Not only is it important to increase understanding of how such issues affect well siblings, but it could be considered of equal importance to find out how this understanding translates into practical and therapeutic support for these children. Intervention research with siblings is rare (Kazak, 2002) and it is hoped that a review to examine and synthesise the findings of what little research exists could be a useful addition to this field of research. Specifically the aims of the systematic review were to:

- i) Identify the extent to which psychological interventions for well siblings of children with chronic illness or developmental disability have been researched in a systematic and empirical manner.
- ii) Provide an overview of empirical evidence in this area to date, including information about: objectives; settings; methodological characteristics; outcome variables selected and the measures used to assess them; and the quality of studies conducted.

- iii) Synthesise the findings from this research and comment on reported effectiveness in terms of impact on outcome variables for siblings.
- iv) Identify any further research needs in this area.

Method

Data Sources and Search Strategy

Relevant electronic databases were searched for published empirical studies evaluating psychological interventions with siblings of children with chronic illness or developmental disorder. The databases searched were: The Cochrane Library, Medline, Cumulative Index to Nursing and Allied Health literature (CINAHL), PsycARTICLES, PsychINFO, and Applied Social Sciences Index and Abstracts (ASSIA). Searches were conducted regularly between January and April 2009. The choice of databases reflected the areas of psychology, medicine and social sciences which were of interest in this review.

Search terms used were designed to isolate appropriate sample population identifiers and identifiers for intervention studies. A number of searches were conducted using various combinations of the following search terms (* indicates truncation): sibling*, child*, chronic* AND ill*, developmental dis*, attention deficit disorder (and synonyms of adhd/ad?d/hyperkin*), cancer, diabet*, autis*, : interv*, eval*, support*, psycho*, family, therap*, group. The specific chronic illnesses and developmental disorders targeted were included in the search due to the focus of these conditions within published sibling literature, adding sensitivity to the search. Searches were performed using the title and abstract indexed for articles in each database, with limiters set to 1980 onwards. No other

restrictions were placed on the search. Further studies were obtained through bibliographic review of acquired publications. Key authors in the area of sibling research (Lobato, Kao, Stoneman and Brody) were also contacted to ascertain if any other relevant publications were known by them which had not been identified in the search, such as very recently published literature or articles in press. No further studies were identified this way.

Study selection (inclusion and exclusion criteria)

All references generated through the search were screened against specified inclusion and exclusion criterion. Sample size was not included as inclusion or exclusion criterion as the paucity of research in this area meant that this would rule out significant numbers of potentially useful studies for inclusion. Initial decisions regarding the suitability of papers for inclusion were made after reading the titles and abstracts of the articles identified using the search strategy described. If it could not be ascertained whether articles met all the inclusion criterion and none of the exclusion criterion at this stage, full text articles were obtained. These articles were further scrutinised against the criterion and a final decision regarding inclusion was made. Reference lists of included papers were hand searched for relevant articles and assessed in the same way. Due to the identification of many studies looking at chronic illness and few in the domain of developmental disorder, online hand searches of the Journal of Autism and Developmental Disorders and Journal of Attention Disorders were conducted for the period of 2005 -2009. This was to ensure that recent key pieces of research in the field of developmental disorders had not been omitted from the review. No relevant studies were identified this way.

Studies were included in the review if they satisfied the following inclusion criteria:

(1) published in the English language, (2) published in a peer-reviewed journal, (3) included participants aged 0-18 years who had sibling with a diagnosed chronic illness or developmental disorder, (4) had empirical design and were primary sources of quantitative or mixed design (though only quantitative outcomes would be reported in the review), (5) included an intervention element with sibling-specific content, directly aimed at improving psychosocial outcomes for siblings, (6) used at least one standardised outcome measure to enable meaningful comparison across studies and (7) evaluated the intervention and made attempts to analyse the intervention outcomes empirically. Studies were not included if they met any of the following exclusion criteria: (1) published before 1980, due to increased focus on siblings in research since this time (Brody, 2004), (2) unpublished dissertations, theses, case studies, literature reviews, discussion papers, secondary sources or papers aimed only at developing a measure, (3) interventions designed generically for families with no-sibling specific content, (4) intervention evaluations not reporting sibling outcomes and (5) interventions with only descriptive data and no empirical analysis.

Study quality assessment

All included studies were assessed on quality of the reported article. Studies were assessed against a checklist devised by Downs and Black (1998). This checklist was chosen as it has published validity and reliability data and is identified as appropriate for both randomised and non-randomised intervention studies (Downs & Black, 1998). 24 of the checklist's original 27 items were selected by the reviewer as appropriate for studies under consideration. Two items were added by the reviewer as they were considered

important to the quality of intervention studies in this area, namely whether the study used a control group and if so, whether the study attempted to match this control group with the clinical group on important demographic variables. Thus, the maximum quality score for an included study was 26. Each criterion on the list was scored as 'yes', 'no' or 'not applicable'. Positively scored items were summed to give total scores for each study, which were then expressed as a percentage of the maximum possible score (see Appendix C for a copy of the checklist). An independent researcher also rated the quality of eight of the studies using the same checklist (Downs & Black, 1998). A correlation of the overall scores was conducted to give an indication of inter-rater reliability. This indicated a strong positive correlation ($r = .810$). At this point any remaining discrepancies between criteria ratings were discussed and a shared decision was reached for each item. Due to the limited amount of published research in this area, ratings of methodological quality were not used as exclusion criteria, but the information was used to critique included studies. It was considered that this may be of interest in itself in terms of a potential lack of methodologically rigorous studies in this area.

Data extraction

Data extraction was performed systematically using an extraction form specifically designed to record relevant details from included studies, allowing the research aims for this review to be addressed (See Appendix D for a copy of the data collection form). Information on areas such as research aims, target population, participants (gender, age, sample size), research design/method, theoretical model, intervention aims, method and components and outcome measures used were collected.

Data synthesis

Due to the heterogeneity of included studies in terms of research aims, design, interventions and outcome measures used, a meta-analysis was not appropriate. Data was therefore synthesised from a qualitative perspective.

Details of included and excluded studies

Electronic searches using this strategy produced 2434 results, of which 301 were duplicates. Within the remaining 2133 articles, 1016 were excluded due to a focus on genetics or medical aspects of the various conditions. From the remaining 1117 articles, a further 1086 studies were excluded from title and abstract as obviously not focusing on siblings or being intervention based. The remaining 31 full papers were accessed and of these, 5 were excluded as they did not include a sibling-specific intervention. One article was excluded as it did not include outcome data for siblings and 10 were excluded due to utilising a non-standardised outcome measure. Three studies sourced from the reference lists of other papers were identified as meeting the inclusion criteria. In total eighteen studies met all inclusion criteria.

Results

As a result of the search strategy and review process employed, 18 studies published between 1989 and 2008 met the inclusion criteria. Within these 18 studies, 13 different sibling interventions were included. Two studies (Barrera, Chung, Greenberg & Fleming, 2002; Barrera, Chung & Fleming, 2004) explore the same interventions but with different samples at different time points. Packman et al. (2004; 2005) use the same intervention and data set but present different outcome variables in each article. Lobato and Kao (2002;

2005) describe the same intervention, with the 2005 study being a downward extension of the 2002 study, adapted for younger siblings. Williams et al. (1997) describe a pilot study for the intervention reported in Williams et al. (2003) but use a different sample in each study, and Kazak et al. (1999) also describes a pilot study which is developed further and uses a different sample in the subsequent publication (Kazak et al., 2004). Main characteristics of the included studies are shown in Table 1. See Appendix E (Table A) for information on excluded studies.

Table 1*Main characteristics of included studies*

Study	Design	Sample	Setting/ format of intervention	Intervention description	Main intervention objectives (areas covered)	Main variables, outcomes measures and reported changes
Barrera, Chung, Greenberg & Fleming (2002)	Pre and post intervention assessment	12 siblings of children with cancer (age 6-17)	Group	Treatment group: Manualised program 'Siblings Coping Together'. 8 weekly, 2 hour sessions. Based on Cognitive Behaviour Therapy and family systems theory. Content: Medical information giving, psychosocial, generating hope for siblings future, coping and problem solving. No control	•Coping •Medical knowledge	Depression (CDI) (s +) Anxiety (STAIC) (s +, p =) Behaviour (YSR, CBCL) (s =, p =) Sibling Perception (SPQ) (s +, p =)
Barrera, Chung & Fleming (2004)	Pre and post intervention assessment	47 siblings of children with cancer (age 6-14)	Group	Same intervention as described by Barrera et al. (2002), 'Siblings Coping Together'. Different data set for each study.	•Coping •Medical knowledge	Depression (CDI) (s +) Anxiety (STAIC) (s +, p +) Behaviour (CBCL) (s =, p =)
Dolgin, Somer, Zaidel & Zaizov (1997)	Pre and post intervention assessment	23 siblings of children with cancer (age 7-11 and 12-17 years)	Group	Treatment group: 6 sessions on consecutive weeks. No information on theoretical framework. Content based on literature review and parent/sibling feedback from previous study. Content: Group discussion of experience and impact of illness, creative activities to promote interaction and non- verbal expression of relevant feelings and themes. No control group.	• Medical knowledge • Feelings and attitudes towards cancer • Mood • Family communication	Feelings and Attitudes (s +) interpersonal problems (s +) intrapsychic preoccupation (s +), disease-related communication (s +) fear (s +) Cancer-Related Knowledge (s +) Mood Questionnaire mood state (s +, p +)

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Giallo & Gavidia-Payne (2008)	Randomised Controlled Trial	21 siblings of children with disability or chronic illness (age 8-16 years) and their parents	Family-based psycho-education	Treatment group: Manualised intervention 'Sibstars' - 6 weeks duration. Based on cognitive-behavioural research and family systems. Randomised into intervention group (n = 12) and waitlist control (n = 9). Content: One face to face family session with therapist, weekly activities for siblings 20-30 minutes each (parental assistance allowed if needed), weekly telephone support as work through booklet. Topics such as 'coping with things that stress you out', 'getting along with others' and 'dealing with problems'.	<ul style="list-style-type: none"> • Coping, • Parenting behaviour • Family communication problem-solving, and hardiness. 	<p>(p): Sibling Adjustment (SDQ) + emotional</p> <p>(s): Sibling Stress (DLSS) + perceived intensity of daily hassles relating to child with disability/illness</p> <p>Sibling Coping (SCS) + distancing coping</p>
Gursky (2007)	Pre and post intervention assessment (control group no intervention)	50 siblings of hospitalized children (20 male, 30 female, aged 6-17).	Individual	Treatment group (n = 25): Educational intervention for children immediately following pretest. One session of 25 – 35 minutes. Teaching protocol adapted according to grouping based on Piaget's stages of cognitive development. Content: Description of illness/injury, treatment, medical equipment, daily routine and period of hospitalization. Control group (n = 25): pretest and posttest only. Matched on age range (Piaget stage) and sex.	<ul style="list-style-type: none"> • Medical information / educational 	<p>Anxiety (RCMAS) + experimental - control, both (s)</p>

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Heiney, Goon-Johnson, Ettinger & Ettinger (1990)	Pre and post intervention assessment	14 siblings of children with cancer (age 9 – 15)	Group	Treatment group (n = 7): Seven one hour sessions. Based on Yalom's therapeutic group processes, facilitated by therapists. Content: Sessions centred around topics selected by researchers from existing research including: diagnosis, treatment, school, coping, family relationships and the future. Control group (n = 7): no structured contact with treatment staff.	<ul style="list-style-type: none"> •Medical knowledge •Coping 	Social Adjustment (Social Adjustment Scale – Self Report) Peer Relations subscale (s =) and Family subscales (s =)
Houtzager, Grootenhuis & Last (2001)	Pre and post intervention assessment	24 siblings of children with cancer (age 7-18)	Group	Treatment group: 5 week intervention, weekly sessions. Based on coping theories. Content: Information giving, group discussion on prearranged topics designed to enhance perceptions of control, illness-related emotions discussed. No control group.	Medical knowledge, coping	Anxiety (STAI-C) (s +)
Kazak et al. (1999)	Pre and post intervention assessment (pilot study)	4 siblings of children with cancer (age not stated for siblings) Includes 19 families, 19 childhood cancer survivors, 19 mothers and 13 fathers.	Group	Treatment group: 'Surviving Cancer Competently Intervention Program' (SSCIP). Manualised 4 session / one-day family group intervention for cancer survivors, parents and siblings. 5 hours therapy and 2 hours informal. Based on Cognitive-Behavioural and family therapy approaches. Content: initial separate group sessions for siblings, mothers, fathers, cancer survivors. Discussion of impact of cancer on family, applying ABC Adversity-Belief-Consequence models to the upsetting memories identified. Use of multiple family discussion groups enabling families to share strategies. No control group. Pilot for 2004 study (see below).	<ul style="list-style-type: none"> • Posttraumatic stress reduction • Anxiety • Cancer beliefs/ treatment • Social support • Family communication 	Post-traumatic stress (PTSD-RI, IES) (s +, c +, p +) Anxiety (STAI, RCMAS) (s +, c +, p +)

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Kazak et al. (2004)	Randomised Controlled Trial	43 siblings (19 treatment, 24 control; age 10-20)	Group	Treatment group (n = 19): SCCIP as described above (Kazak et al., 1999) building on pilot. Therapists trained for 12 hours and evaluated before administering intervention. Control group (n = 24): waitlist control no intervention. Randomised to group.	<ul style="list-style-type: none"> • Coping • Family communication • PTS reduction 	Post-traumatic stress (IES-R, PTSD-RI) (s) = Anxiety (RCMAS) (s) =
Lobato and Kao (2002)	Pre and post intervention assessment (with 3 month follow up)	54 well siblings of children with CI/DD (24 male, 30 female, aged 8-13) and 47 parents	Group	Treatment group: ‘SibLink’ intervention, 6 sessions of 90 minute duration over 6 – 8 week period. Manualised. No theoretical framework specified. Based on review of literature. Content: Group sessions targeted at improving sibling knowledge and family information exchange, managing emotions and problem-solving around challenging situations. One session focused on siblings’ individual needs. Parent groups paralleled content. Integrated sibling and parent groups also conducted to enhance mutual understanding and perspective taking. Siblings created videotapes about experience of being a brother/sister that parents reviewed. Interactive exercises, read books about siblings and illness or disability together. No control group.	<ul style="list-style-type: none"> • Sibling knowledge • Sibling adjustment to CI/DD • Sibling connectedness 	Sibling Knowledge of CI/DD (Researcher devised interview) + posttest, - follow up (sibling report) Sibling Adjustment (SPQ) + posttest, + follow up (sibling report), = posttest (parent report) Sibling Global Behavioural Functioning (CBCL) Internalizing: + posttest, + follow up; Externalizing: + posttest, = follow up (parent report) Sibling Connectedness (s +)

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Lobato and Kao (2005)	Pre and post intervention assessment (with 3 month follow up)	43 healthy siblings (17 male, 26 female; aged 4 to 7 years) of children with CI/DD and 40 parents	Group	Same as above (Lobato & Kao, 2002) but a downward extension for younger siblings. Paralleled original intervention model for older siblings. Separate parent and sibling group treatment manuals devised. No control group.	<ul style="list-style-type: none"> • Sibling knowledge • Sense of connectedness • Global functioning 	Sibling Knowledge of CI/DD (Researcher devised interview) + posttest, = follow up (s) Sibling Connectedness (Researcher devised 2 item questionnaire) + posttest (s p), + follow up (s p) Sibling Global Functioning (PS and CBCL) PS (s): Competence (cognitive; physical) both +posttest, =follow up; Acceptance (peer; maternal) both =posttest CBCL (p) = posttest
Packman, Chesterman, vanZutphen, Golan & Amylon (2004)	Pre and post intervention assessment	77 siblings of children with cancer (aged 6-17)	Camp	Treatment group: Intervention Camp Okizu Special and Important Brothers and Sisters (SIBS) camp. One week. No theoretical framework specified. Content: peer interaction to validate feelings and bolster self-confidence and self-esteem, group discussion (family situation/coping), activities such as archery, swimming, boats and arts and crafts, trust activities e.g. team events, high rope course for older siblings. Posttest: 3 months after camp. No control group.	<ul style="list-style-type: none"> • Coping • Recreation 	Post-traumatic stress (UCLA PTSD Index for DSM-IV) (s +) Anxiety (RCMAS) (s +) Quality of Life (PedsQL) (s +) Self-esteem (RSE) (s +)

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Packman, Chesterman, vanZutphen, Golan & Amylon (2005)	Pre and post intervention assessment	77 siblings of children with cancer – same data set as 2004 study (aged 6-17)	Camp	Same intervention as 2004 study. Same data set. No control group.	<ul style="list-style-type: none"> • Coping • Recreation 	Quality of Life (PedsQL) (s +, p =)
Sahler & Carpenter (1989)	Pre and post intervention assessment	90 siblings of children with cancer (aged 6-17)	Camp	Treatment group: 5 day residential camping program. No theoretical framework specified. Content: recreational activities, medical information session, psychosocial support sessions, vignettes presented by theatre group depicting common themes if families with childhood cancer, subsequent discussion with psychologist/other professional. Posttest: 3 months after camp. No control group.	<ul style="list-style-type: none"> • Medical knowledge • Coping • Recreation 	Anxiety(SRP) (s+) Social Adjustment (SPPC) (s+) Self-esteem (SPPC) (s+) Medical Knowledge (SPQ) (s +) Perception (SPQ) – interpersonal (s =), intrapersonal (s +), communication (s =), fear of disease (s +) Mood (SPQ) (s +, p +)
Sidhu, Passmore & Baker (2006)	Pre and post intervention assessment (with 8 week follow up)	26 siblings of children with cancer (aged 8-13)	Camp	Treatment group: Residential camp program ‘Camp Onwards’. 4 day camp. Manualised approach (not yet published in 2006). No theoretical framework specified. Based on review of literature, clinical experience and triangulation with parent focus groups. Content: psycho-education, activity participation for health promotion, self-expressive and cognitive behaviour principles, activities such as outdoor adventure challenges, didactic education, therapeutic and social activities. Posttest: Immediately after intervention. 8 week follow up. No control group.	<ul style="list-style-type: none"> • Medical knowledge • Coping • Recreation 	Emotions and self-perceptions (SRP: BASC) Overall SRP (s +), Subscales: Emotional symptoms (s +), Anxiety (s +), Clinical Maladjustment (s =), School Maladjustment (s =), Personal Adjustment (s =) Self Perception (SPPC) Total SPPC (s +), Social Acceptance (s +) Sibling Perceptions (SPQ) Overall (s +), Interpersonal (s +), Fear of disease (s +) <i>Continues on next page</i>

Siblings of children with ADHD, chronic illness and developmental disorder

Smith & Perry (2004)	Pre and post intervention assessment	26 siblings of children with autism and related disorders (12 males, 14 females; age 6-16 years)	Group	Treatment group: Sibling support group. 8 sessions over consecutive weeks. No theoretical framework specified. Content: exercises, games, activities designed to be fun and promote group cohesion, information sessions on autism and related disorders, facilitated discussion related to feelings and attitudes associating with living with a sibling with a developmental disability. No control group.	<ul style="list-style-type: none"> • Knowledge and understanding of autism • Feelings • Coping • Enhancing self-concept • Recreation 	(s): Self-concept (SCS) (s +) Knowledge (AKM) (s +) Anger/Resentment (subscale CAS) (s =)
Williams, Hanson, Karlin, Ridder et al (1997)	Pre and post intervention assessment	22 siblings of children with chronic illness, 9 males, 13 females) aged 8-15 years) and their parents	Group	Treatment group: Structured educational and support group sessions with siblings. Theoretical framework: Family systems and learning theory. Content: diagnostic information giving (teaching sessions, psycho-social and social-recreation components, group discussions). Parents had one 3 hour session covering sibling needs and ways to meet them, to enhance awareness. No control group. Pilot for Williams et al. (2003).	<ul style="list-style-type: none"> • Medical knowledge for siblings • Parental awareness of sibling needs • Parent satisfaction with programme 	Medical Knowledge (Knowledge of Illness Tests) + knowledge (s) Sibling Perception of Family Experiences (SPQ) no pre and post data, descriptive data

Continues on next page

Siblings of children with ADHD, chronic illness and developmental disorder

Williams, Williams, Graff, Hanson et al (2003)	Randomised three-group repeated measures design	252 siblings of children with chronic illness or disability (age 7-15 years)	Camp	Same intervention as that described for Williams et al. (1997). States intervention design based on review of literature and consultation with professionals in the field, in addition to previous theories stipulated. Experience of a 5 day residential summer camp added to the structured teaching, and psychosocial sessions to form the full treatment group (n = 79). Partial treatment group (n = 71) involved attending the usual camp without the specialist sessions and a waitlist control group (n = 102) attended camp after the last data collection. Randomised into groups. 4 postintervention periods: 5 days, 4 months, 9 months and 12 months after baseline.	<ul style="list-style-type: none"> • To examine effects of ISEE intervention (relating to full, partial and control conditions), • Objectives relating to variables not explicitly stated 	Knowledge (Knowledge Test) (s) + full, = partial, = control Social Support (SSCS) (s) + full, partial and control Self-Esteem (SPPC) (s) + full, + partial, = control Mood (SPQ – Mood Scale) (s) + full, = partial, = control Behaviour (Eyberg Child Behaviour Inventory) (p) + full, = partial, = control Attitude (SPQ – Attitude Scale) (s) + full, = partial, + control
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Note: For clarity and to meet aims of the study, only outcomes directly related to siblings are included, or measures where other family members reported on same variable in addition to sibling report; (s) indicates sibling self-report; (p) indicates parental report; (c) sibling with chronic illness/developmental disorder report; + indicates statistically significant improvement in the desired direction compared with control/pre-assessment; - indicates statistically significant impairment compared with control/pre-assessment; = indicates no significant difference between intervention and control group or no significant change from pre- to post-assessment. Abbreviation for Measures used: AKM = Autism Knowledge Questionnaire; CAS = Coping and Adjustment Scale; CBCL = Child Behaviour Checklist; CDI = Children's Depression Inventory; DLSS = Daily Life Stressors Scale; IES = Impact of Events Scale; PedsQL = Pediatric Quality of Life Inventory; PS = Pictorial Scale of Perceived Competence and Social Acceptance for Young People; PTSD-RI = Post-Traumatic Stress Disorder Reaction Index; RCMAS = Revised Children's Manifest Anxiety Scale; RSES = Rosenberg Self Esteem Scale; SCS = Self-Report Coping Scale; SDQ = Strengths and Difficulties Questionnaire; SPPC = Self-Perception Profile for Children; SPQ = Sibling Perception Questionnaire; SRP = Self-Report of Personality, Subtest of Behaviour Assessment System for Children (BASC); SSCS = Social Support for Children Scale; STAI = State Trait Anxiety Inventory; STAIC = State Trait Anxiety Inventory for Children; YSR = Youth Self-Report.

Characteristics of Sibling Intervention Research

The following section aims to provide an overview of the characteristics of the sibling intervention research included in this review in terms of participant samples, methodological quality and the aims and research questions highlighted in the studies themselves.

Participant samples

The eighteen studies comprised data from 828 participants ranging from 6 to 20 years of age. Fifteen studies had sample sizes of over 20 siblings but there was a wide range of participant numbers (4 to 252 siblings). Most appeared to use convenience sampling, though few studies made this explicit. All included studies involved siblings of children with diagnoses of either chronic illness or developmental disorder but a range of diagnoses were included. The majority of interventions focused on cancer (Barrera, Chung, Greenberg & Fleming, 2002; Barrera, Chung & Fleming, 2004; Dolgin, Somer, Zaidel & Zaizov, 1997; Heiney, Goon-Johnson, Ettinger & Ettinger, 1990; Houtzager, Grootenhuis & Last, 2001; Kazak et al., 1999; Kazak et al., 2004; Packman et al., 2004; Packman et al., 2005; Sahler & Carpenter, 1989; Sidhu, Passmore & Baker, 2006). Two focused on chronic illness and developmental disorder including physical disabilities, autism spectrum disorders and medical disorders (Lobato & Kao, 2002; 2005). One study included cancer, cystic fibrosis and spina bifida (Williams et al., 1997). A further two studies included diagnoses such as Down's syndrome, autism, ADHD and congenital heart disorder (Giallo & Gavidia-Payne, 2008; Williams et al., 2003). Other groups included

hematology/oncology and infectious disease (Gursky, 2005) and autism and other related disorders (Smith & Perry, 2004).

Overview of methodological quality of the research

Overall range in rated quality of the papers was 35 % (Lobato & Kao, 2002) to 73 % (Kazak et al., 2004), using the adapted Downs and Black (1998) checklist. Approximately half of the studies clearly described outcomes to be used in the introduction or method sections. Most studies described the aims and hypotheses clearly but in the majority of studies no differentiation between aims of intervention and aims of research study was made. All studies described sample size and main findings. Only three studies made it clear if their samples were representative from the population from which they were drawn (Giallo & Gavidia-Payne, 2008; Kazak et al., 2004; Williams et al., 2003). No studies reported power estimates in terms of sample size selection and only 19% of studies used a control group, limiting the validity of the data provided. Approximately 44% of studies described attrition data or participants lost to follow up.

Methodology of Sibling Intervention Research

Included studies were examined with regards to design methodology, description and characteristics of samples utilised, and the overall methodological quality of the research presented. Most studies were found to use non-experimental single-group designs without control groups, with few randomised controlled designs. Overall only 5 of the studies included a control group, and only 3 of those randomly assigned participants to the intervention or control condition.

Study design

Eleven of the studies reviewed used a pre/post-intervention design with no control group (Barrera et al., 2002; Barrera et al., 2004; Dolgin et al., 1997; Houtzager et al., 2001; Kazak et al., 1999; Packman et al., 2004; Packman et al., 2005; Sahler & Carpenter, 1989; Sidhu et al., 2006; Smith & Perry, 2004; Williams et al., 1997). Two implemented a pre/post-intervention design with an additional three month follow-up period (Lobato & Kao, 2002; Lobato & Kao, 2005). Non-randomised control groups were used in addition to the pre/post-evaluation by two studies (Gursky, 2007; Heiney et al., 1990). Houtzager et al. (2001) used the State-Trait Anxiety Inventory for Children (STAIC; Spielberger, 1983) norms as a control, but this could be considered as insufficient for use in intervention research. Only three studies were based on randomised controlled trials (RCTs) (Giallo & Gavidia-Payne, 2008; Kazak et al., 2004; Williams et al., 2003). Williams et al. (2003) used a randomised three-group repeated measures design, consisting of full, partial and control conditions. None of the included studies were longitudinal in design, with the longest period of follow up being the 3 month period in Lobato and Kao's studies (Lobato & Kao, 2002; 2005).

Sample characteristics

The sample sizes used in the included studies varied considerably from 4 (Kazak et al., 1999) to 252 siblings (Williams et al., 2003) with an age range from 6 (Barrera et al., 2002; Barrera et al., 2004) to 20 years (Kazak et al., 2004). All eighteen studies used a mixed gender sample. With the exception of four studies (Giallo & Gavidia-Payne, 2008; Kazak et al., 1999; Kazak et al., 2004; Williams et al., 1997), all included articles assessed

the effect of the intervention on siblings only. Kazak et al. (1999; 2004) also evaluated the impact of intervention on parents and childhood cancer survivors, but used sibling-specific material when working with the siblings. Giallo and Gavidia-Payne (2008) studied the intervention impact on parenting behaviours and family functioning in addition to sibling outcomes. Lobato and Kao (2002; 2005) evaluated an intervention which involved integrated parent-sibling groups, although outcomes were focused on siblings. Williams et al. (1997) targeted parental awareness of sibling needs in addition to sibling outcomes.

Time since onset of chronic illness or diagnosis of developmental disorders varied between 2 months (Houtzager et al., 2001) and 13 years (Lobato & Kao, 2005). Only four of the studies reported time since diagnosis (Dolgin et al., 1997; Houtzager et al., 2001; Lobato & Kao, 2005; Sahler & Carpenter, 1989) leaving a substantial majority which did not acknowledge this potentially important variable. One study stated siblings had been hospitalised for an average length of 6 days (Gursky, 2007); one that cancer treatment was completed an average of 4.80 years prior to intervention (Kazak et al., 2004) and one reported that 48 % of siblings had been diagnosed with cancer in the last year (Sidhu et al., 2006).

To summarise, the majority of studies used no control group which severely limits the validity of any findings relating to intervention effects. A wide range of diagnoses were included, but most interventions were aimed at siblings of children with cancer. Both sample sizes and attempts to describe the sample were variable.

Overview of Interventions Evaluated

This section aims to give an overview of the interventions evaluated within the studies including the following information: settings; delivery format; professionals delivering interventions; aims and objectives of interventions; and brief information about described content and theoretical basis of interventions.

Types of intervention

Eleven of the thirteen interventions included were delivered in a structured group format (Barrera et al., 2002; Barrera et al., 2004; Dolgin et al., 1997; Heiney et al., 1990; Houtzager et al., 2001; Kazak et al., 1999; Kazak et al., 2004; Lobatao & Kao, 2002; Lobato & Kao, 2005; Smith & Perry, 2004; Williams et al., 1997). Group sizes showed large variation with a range from 4 siblings (Barrera et al., 2002; Barrera et al., 2004) to 22 siblings (for parts of the intervention by Williams et al., 1997). Number of sessions and duration of group interventions ranged from four sessions in one day (Kazak et al., 1999; Kazak et al., 2004) to 8 sessions on a weekly basis (Barrera et al., 2002; Barrera et al., 2004; utilising the same intervention content). Four of the interventions reviewed were provided in a camp setting (Packman et al., 2004; 2005; Sahler & Carpenter, 1989; Sidhu et al., 2006; Williams et al., 2003). The duration of camp interventions ranged from 4 days (Sidhu et al., 2006) to 7 days (Packman et al., 2004; Packman et al., 2005). Giallo and Gavidia-Payne (2008), reported a family-based psycho-educational intervention with weekly telephone contact with those delivering the intervention for a 6 week period. None of the studies gave a rationale for length of intervention duration. Only one study provided an individual intervention and this was for siblings of hospitalised children (Gursky, 2007).

This consisted of one educational session lasting 25 to 35 minutes. Of the six group studies not solely focusing on siblings of children with cancer, five of the interventions were not specific to the diagnosis of the participating child's sibling (Giallo & Gavidia-Payne, 2008; Lobato & Kao, 2002; Lobato & Kao, 2005; Smith & Perry, 2004; Williams et al., 2003). These studies appeared to adopt a non-categorical approach to intervention by assuming children would face similar difficulties in adjusting to sibling illness regardless of diagnosis. However, only one study clearly documented and gave a rationale for this assumption (Giallo & Gavidia-Payne, 2008). Only Williams et al. (1997) separated the children into diagnosis-specific groups for parts of the intervention, though this was primarily for the educational component relating to the siblings' illness. For psychosocial and social-recreational components of this intervention the groups were combined and the researchers stated that generally the intervention assumed a view that common needs existed across the diagnostic groups. Gursky (2007) reported an individualised educational intervention, which therefore necessarily focused on the specific condition the siblings' brother or sister was diagnosed with.

Intervention delivery

The interventions were administered by a variety of professionals. Seven were provided by a single profession, namely by trained psychologists or graduate psychology students (Barrera et al., 2002; Barrera et al., 2004; Giallo & Gavidia-Payne, 2008; Houtzager et al., 2001; Lobato & Kao, 2002; Lobato & Kao, 2005), and clinical child life specialists (Gursky, 2007). Most interventions were provided by interdisciplinary teams consisting of professionals such as psychologists, psychiatrists, specialist nurses and social

workers (Dolgin et al., 1997; Heiney et al., 1990; Kazak et al., 1999; Kazak et al., 2004; Packman et al., 2004; Packman et al., 2005; Sahler & Carpenter, 1989; Williams et al., 1997; Williams et al., 2003). This information was not available for two of the studies (Sidhu et al. 2006; Smith & Perry, 2004). Only three studies stated training professionals to deliver the intervention (Kazak et al., 1999; Kazak et al., 2004; Sidhu et al., 2006), although a manualised approach was used in five interventions accounting for nine studies (Barrera et al., 2002; Barrera et al., 2004; Kazak et al., 1999; Kazak et al., 2004; Lobato & Kao, 2002; Lobato & Kao, 2005; Sidhu et al., 2006; Williams et al., 1997; Williams et al., 2003). One study used a researcher-devised protocol adapted for developmental stages within the sample (Gursky, 2007), while the rest were carried out with no standardised intervention protocol (Dolgin et al., 1997; Giallo & Gavidia-Payne, 2008; Heiney et al., 1990; Houtzager et al., 2001; Packman et al., 2002; Packman et al., 2005; Sahler & Carpenter, 1989; Smith & Perry, 2004).

Aims and objectives of interventions

The aims and objectives of the interventions varied considerably, both in terms of content and in how explicitly they were stated. Nonetheless eight broad areas were identified across the included studies. Enhancement of coping with sibling-specific stressors, such as illness-related fear or management of emotions like anxiety and depression, were important objectives stated in twelve studies (Barrera et al., 2002; Barrera et al., 2003; Dolgin et al., 1997; Giallo & Gavidia-Payne, 2008; Heiney et al., 1990; Houtzager et al., 2001; Kazak et al., 2004; Packman et al., 2004; Packman et al., 2005; Sahler & Carpenter, 1989; Sidhu et al., 2006; Smith & Perry, 2004). Thirteen of the studies

had a primary aim of enhancement of medical knowledge/understanding for the siblings (Barrera et al., 2002; Barrera et al., 2004; Dolgin et al., 1997; Gursky, 2007; Heiney et al., 1990; Houtzager et al., 2001; Lobato & Kao, 2002; Lobato & Kao, 2005; Sahler & Carpenter, 1989; Sidhu et al., 2006; Smith & Perry, 2004; Williams et al., 1997; Williams et al., 2003). A further two of these interventions were also aimed at improving feelings and attitudes towards the illness (Dolgin et al., 1997; Williams et al., 2003). Two studies in the domain of childhood cancer focused on a reduction in post-traumatic stress which they hypothesised could be a possible reaction for family members coping with cancer (Kazak et al., 1999; Kazak et al., 2004). Several of the studies aimed to improve the siblings' well-being in a wider context, focusing on areas such as enhancing family communication (Dolgin et al., 1997; Giallo & Gavidia-Payne, 2008; Kazak et al., 1999; Kazak et al., 2004) and increasing social support (Kazak et al., 1999; Williams et al., 2003). Two studies focused on an aim of facilitating sibling 'connectedness' (Lobato & Kao, 2002; 2005). This was defined as giving children the opportunity to connect with, and learn from, other children in similar family circumstances. Other studies focused on improving behavioural or global functioning of siblings (Barrera et al., 2002; Barrera et al., 2004; Lobato & Kao, 2002; 2005; Williams et al., 2003) and two studies on the development of greater self-concept (Packman et al., 2004; Smith & Perry, 2004). Providing siblings with opportunities for recreation and peer support was the apparent aim in four camp-based studies, though there was variability in the explicitness of the rationale for this aim and in how clearly it was stated as an aim (Packman et al., 2004; 2005; Sahler & Carpenter, 1989; Sidhu et al., 2006).

Content of interventions

The content of interventions covered a multitude of areas. The rationale for specific components was not always clear and researchers rarely linked choice of components with a theoretical framework. Generally studies did not provide enough information for replication and few stated a manual being available from the researchers. The most commonly utilised components were medical information giving/psycho-education, group discussions, coping/emotion-focused work and recreational activities. Full discussion of intervention content is beyond the scope of this paper due to the heterogeneity of the interventions and lack of detail across the included studies. Table 1 gives more information on intervention content.

Theoretical basis of interventions

Nine studies explicitly identified a theoretical framework which formed the basis of their intervention. Five of these were based on combinations of cognitive-behavioural therapy and family therapy (Barrera et al., 2002; Barrera et al., 2004; Giallo & Gavidia-Payne, 2008; Lobato & Kao, 2002; Lobato & Kao, 2005). Heiney et al. (1990) used Yalom's theoretical framework for the therapeutic value of groups (Yalom, 1983) as the basis for their intervention. Williams and colleagues' (Williams et al., 1997; 2003) based their intervention on family systems approaches in combination with learning theory. Houtzager et al. (2001) clearly stated using three theories of coping as the basis for intervention: Lazarus and Folkman's (1984) theory of appraisal and coping; cognitive models of perceived control (Rothbaum, Weisz & Synder, 1982); and a model of psychosocial support (Last & Grootenhuis, 1998). These theories were clearly and

efficiently integrated into the intervention framework, with authors stating how this led to choice of intervention components and desired outcomes. This was the only study managing to integrate the theory and intervention rationale so coherently and explicitly.

Three of the studies developed group content from pre-intervention surveys or research into the needs of siblings rather than using a theoretical framework (Dolgin et al., 1997; Packman et al., 2004; Packman et al., 2005) and a further seven studies chose their content as a result of reviewing clinical/research literature in the area (Gursky, 2007; Lobato & Kao, 2002; Lobato & Kao, 2005; Packman et al., 2004; Packman et al., 2005; Sahler & Carpenter, 1989; Smith & Perry, 2004).

In summary, interventions were predominantly provided in a group or camp format, though few studies justified this choice or stated why they had chosen these formats over other alternatives such as individual or family-based interventions. Other than those focused solely on cancer, most studies involving siblings of children with several different conditions chose not to deliver diagnosis-specific interventions and most did not state their assumptions with regards to this decision. Those delivering the interventions seemed rarely to be trained in doing so and only half the interventions were manualised, thus limiting the reliability and replicability of interventions. The stated aims and objectives of interventions covered many areas making cross-study comparison difficult. Few studies had an explicit theoretical basis for their intervention which threatened their internal validity.

Effectiveness of the Interventions

This review aimed to synthesise the findings from included research and comment on the reported effectiveness in terms of impact on outcome variables for siblings. To

answer this question, the psychological factors and main outcome measures relating specifically to siblings were extracted from the studies and synthesised within the following section. The reported effectiveness for each variable was considered, along with information regarding characteristics of effective interventions.

Psychological factors and main outcome measures

Although a variety of psychological factors were explored within the literature reviewed, there was some overlap between which variables studies aimed to explore and what measures were utilised in doing so. Some studies considered many different variables or did not investigate particular variables both pre and post intervention. In light of this only the main findings in relation to siblings and those represented by standardised pre-post outcome measures, are considered in this section.

- ***Depression***

Barrera and colleagues (Barrera et al., 2002; Barrera et al., 2004) explored the impact of a group intervention on sibling levels of depression pre- to post-intervention. They utilised the psychometrically validated self-report Children's Depression Inventory (CDI; Kovacs, 1992) to measure this and found in both studies that siblings' levels of depression were significantly lower post-intervention (reported only for 2004 study, effect size = .20).

- ***Anxiety***

Eight of the included studies investigated the impact of the intervention on sibling levels of anxiety (Barrera et al., 2002; Barrera et al., 2004; Gursky, 2007; Houtzager et al., 2001; Kazak et al., 1999; Kazak et al., 2004; Packman et al., 2004; Sidhu et al., 2006).

Most studies used the State-Trait Anxiety Inventory for Children (STAIC; Spielberger, 1983) or the Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1985) as psychometrically validated measures of anxiety. Seven studies evidenced a decrease in self-reported anxiety levels post-intervention on the STAIC and the RCMAS, with the exception of Kazak et al. (2004) who found no such significant reduction in their RCT. Only Barrera et al. (2004) and Packman et al. (2004) reported effect sizes, which ranged from .19 to .43 indicating small/moderate and moderate/large effects respectively (Field, 2009). Sidhu et al. (2006) found significant reductions in anxiety, using the Self-Report of Personality (SRP) a subtest of the Behaviour Assessment System for Children (BASC; Reynolds & Kamphaus, 1992). Significant differences in anxiety reduction were found in individual (Gursky, 2007), group (Kazak et al., 1999) and camp interventions (Packman et al., 2004; Sidhu et al., 2006). No conclusive differences between studies with or without anxiety reduction could be found concerning sample size. Kazak et al.'s (2004) RCT with non-significant results for anxiety had 43 siblings (19 treatment, 24 control), whereas those studies with significant results had a range of sample sizes from 4 siblings (Kazak et al., 1999) to 77 sibling participants (Packman et al, 2004).

- ***Mood***

Three studies explored a more general variable of mood. Sahler and Carpenter devised the Mood Questionnaire and used it in their study (Sahler & Carpenter, 1989). This questionnaire was also used by Dolgin et al. (1997). Sahler and Carpenter (1989) found significant changes in the desired direction in both positive and negative mood categories for older campers' self-report and parental report, and for parent reports of negative mood

in younger campers. Dolgin et al. (1997) found significantly positive intervention effects for mood rated by parents and by self-report. Williams et al. (2003) used the Mood Scale of the Sibling Perception Questionnaire (SPQ; Sahler & Carpenter, 1989) in their RCT and found that only the full treatment group exhibited any statistically significant results in the desired direction. This occurred 9 and 12 months after baseline but was not evident at 4 months. This was compared to a partial intervention condition and a control condition which showed no such significant findings. None of the studies exploring mood as a variable reported effect sizes. It should be noted that the SPQ is a widely used measure for siblings' responses to childhood cancer but has no normative data available yet (Sidhu et al., 2006).

- *Self-esteem and self-concept*

Four studies evaluated self-esteem or self-concept before and after the intervention and all reported significant improvements in this domain (Packman et al., 2004; Sidhu et al., 2006; Smith & Perry, 2004; Williams et al., 2003). Packman et al. (2004) used the widely used and validated Rosenberg Self-Esteem Scale (RSES; Rosenberg, 1965) and found significant improvement in reported levels of self-esteem post-intervention, with results indicating a large effect size of .47 (Field, 2009). Two studies used the Self-Perception Profile for Children (SPP-C; Harter, 1985). Williams et al. (2003) in their RCT study found that both full and partial treatment groups showed significantly improved self-esteem from baseline scores on this measure. Sidhu et al. (2006) in their pre/post-intervention design found that although self-esteem did not improve at post-intervention, it was significantly higher at an 8 week follow up. This study also used the Self-Report of

Personality (SRP), a subtest of the Behavioural Assessment System for Children (BASC; Reynolds & Kamphaus, 1992) to explore self-esteem and self-reliance. Significant change was reported at follow up but again, not at post-test. The fourth self-esteem measure utilised in the studies was the Piers-Harris Children's Self-Concept Scale (Piers & Harris, 1969; Piers, 1984) and using this measure Smith and Perry (2004) documented significantly higher self-concept post-test compared to pre-test. The interventions reported by Packman et al. (2004), Sidhu et al. (2006) and Williams et al. (2003) were all set in a camp format, whereas Smith and Perry (2004) used a support group format. Sample sizes ranged from 26 (Smith & Perry, 2004) to 252 siblings (Williams et al., 2003).

- ***Social and emotional adjustment***

The 18 studies reviewed comprised five studies focusing on outcome variables of 'sibling adjustment' (Giallo & Gavidia-Payne, 2008; Heiney et al., 1990; Lobato & Kao, 2002; Sidhu & el., 2006; Smith & Perry, 2004). It is hard to make substantial conclusions regarding 'adjustment' as assessment, definition and findings varied so much between these studies. Giallo and Gavidia-Payne (2008) focused on behavioural and emotional adjustment as defined by scores on the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) and showed significant improvements in emotional symptoms only on this measure. The authors also explored sibling coping under the umbrella term of 'adjustment' with use of the Self-Report Coping Scale (SCS; Causey & Dubow, 1992) and found that the intervention group reported significantly less use of distancing coping than the waitlist group at post intervention, as per the study's aims. Heiney et al. (1990) found no significant improvement for Social Adjustment, using the Social Adjustment Scale – Self Report

(Weissman & Bothwell, 1976). Lobato and Kao (2002) utilised the Sibling Perception Questionnaire (SPQ; Sahler & Carpenter, 1989) to explore Negative Adjustment by forming a composite scale of the interpersonal, intrapersonal and fear subscales. They also created a parent version of the SPQ to assess parental perception of adjustment. The intervention improved self-reported adjustment in siblings, but showed no significant change for parental report on the same variable. Sidhu et al. (2006) used the Self-Report of Personality (SRP) and the overall score of the Emotional Symptoms Index (ESI) which has subscales relating to adjustment in terms of clinical maladjustment, school maladjustment and personal adjustment. Researchers found that the ESI score revealed clinically and statistically significant improvements at both pre/post-intervention and at follow up. The Clinical Maladjustment composite demonstrated significant changes at post test, but this was not statistically significant at follow up. No statistically significant changes were demonstrated in the two other composites of the SRP (school maladjustment and personal adjustment). Smith & Perry (2004) utilised a non-validated researcher-devised questionnaire entitled 'What It's Like To Have a Brother or Sister with a Developmental Disorder' (Coping/Adjustment Scale; Perry, 1989) which focused on psychosocial adjustment in relation to anger/resentment. No significant difference was found pre- to post-intervention.

- *Post-traumatic stress*

Three of the studies reviewed used self-reported post-traumatic stress as an outcome variable, and all involved siblings of children with cancer. Findings on this variable were inconsistent. Packman et al. (2004) used the UCLA Posttraumatic Stress Disorder (PTSD)

Index (Rodriguez, Steinberg & Pynoos, 1998) and found significant reduction in PTSD pre- to post- camp intervention. However Kazak and colleagues (Kazak et al., 1999; Kazak et al., 2004) found no significant reduction in symptoms for siblings using the Post-Traumatic Stress Disorder Reaction Index (PTSD-RI; Pynoos, Frederick, Nader & Arroyo, 1987) and the Impact of Events Scale (IES; Horowitz, Wilner & Alvarez, 1979), both validated and reliable scales. There was considerable variability in sample sizes for these three studies, with two pre/post-intervention design studies involving 4 and 77 siblings respectively (Kazak et al., 1999; Packman et al., 2004) and an RCT which had 43 siblings (Kazak et al., 2004).

- ***Global functioning and behavioural problems***

Five publications assessed parent-rated and self-rated behavioural problems (Barrera et al., 2002; Barrera et al., 2004; Lobato & Kao, 2002; 2005; Williams et al., 2003) and again presented very mixed findings. The most commonly used measure was the Child Behaviour Checklist (CBCL; Achenbach, 1991) and on this measure decreases in externalising and internalising problems post-intervention were documented (Barrera et al., 2004; Lobato and Kao, 2002) with externalising behaviour improvements maintained at 3 months (Lobato & Kao, 2002). Other studies found no significant differences pre- to post-intervention (Lobato & Kao, 2005; Barrera et al., 2002). On self-report measures, Barrera et al. (2002) found no significant differences using the Youth Self-Report (YSR; Achenbach, 1991); whilst Williams et al. (2003) displayed significant decline in behaviour problems at 9 and 12 months post-intervention for the full treatment condition using the Eyberg Child Behaviour Inventory (Eyberg & Robinson, 1983). Lobato and Kao (2005) used the Pictorial

Scale of Perceived Competence and Social Acceptance for Young Children (Harter & Pike, 1983) and found that siblings' cognitive and physical competence scores increased pre- to post-intervention. Results for peer acceptance and maternal acceptance on this measure were not significantly different at post-intervention. Again the influence of the sibling interventions on sibling behaviour is hard to ascertain due to the mixed findings represented here.

- ***Sibling connectedness***

Lobato and Kao (2002; 2005) conducted the only studies to explore the variable of sibling connectedness. Sibling connectedness appeared to be a researcher-defined concept developed for evaluating the intervention and was described as being the siblings' sense of connectedness to other children in similar family circumstances. Researchers used a questionnaire of their own design to assess how well siblings had connected with each other. In both studies sibling and parent report of sibling connectedness increased significantly from pre- to post-treatment and this was maintained at 3 month follow up. However no other studies looked at this variable and the measure used has no reliability or validity data.

- ***Medical knowledge and health related variables***

Studies included in this review explored various factors relating to medical knowledge of the siblings' condition, health-related quality of life outcome measures, siblings' feelings and attitudes towards the illness and sibling stress related to the illness.

Medical knowledge of the ill siblings' condition was measured using various methods across the reviewed studies. Dolgin et al. (1997) utilised the Cancer Related

Knowledge Questionnaire (Carpenter, Sahler & Davis, 1990); Lobato and Kao (2002; 2005) used the Sibling Knowledge of Chronic Illness/Developmental Disability Interview (Lobato & Kao, 2002); Sahler and Carpenter (1989) included the Sibling Perception Questionnaire (SPQ) - Medical knowledge; SPQ –Medical Knowledge and Fear of disease subscales was used by Sidhu et al. (2006); the Autism Knowledge Measure for Young Children (Perry, 1980) was used in Smith and Perry's (2004) study; and the Knowledge of Illness Tests (Williams et al., 1997) was used by Williams and colleagues (Williams et al., 1997; Williams et al., 2003). All studies focusing on increase in medical knowledge displayed significant results in the desired direction. Five were provided in a group setting and three in a camp setting (Sahler & Carpenter, 1989; Sidhu et al., 2006; Williams et al., 2003). Health-related quality of life was examined in two studies (Packman et al., 2004; 2005), using the Pediatric Quality of Life Inventory (PedsQL; Varni, Seid & Kurtin, 1999). Both studies showed significant improvements in self-reported health-related quality of life for siblings from pre- to post-camp. Barrera et al. (2004) found significant changes reported by non-bereaved parents on this variable also. However where the child with cancer had died, parent report yielded no significant changes.

Feelings and attitudes towards the illness were the focus of four studies. Dolgin et al. (1997) used the Feelings and Attitudes Questionnaire (Sahler & Carpenter, 1989). The other three studies used subscales of the Sibling Perception Questionnaire (SPQ; Sahler & Carpenter, 1989). Sahler and Carpenter (1989) used the Perceptions and Affective Responses about Disease Influence subscale; Sidhu et al. (2006) the Fear of Disease subscale and Williams et al. (2003) the Attitude scale. All studies reported siblings'

feelings and attitudes towards their brother or sisters' illness significantly improved after intervention regardless of setting. Two studies were camp based (Sahler & Carpenter, 1989; Williams et al., 2003) and one was of group design (Dolgin et al., 2003).

Sibling stress relating to the disease was investigated by Giallo and Gavidia-Payne (2008) utilising the Sibling Daily Hassles and Uplifts Scale, based on items from the Daily Life Stressors Scale (Kearney, Drabman & Beasley, 1993). The intervention group reported significantly lower perceived intensity of daily hassles/stress related to child with disability or illness at post-test, and compared to a waitlist control group. In this case the intervention was family-based psycho-education.

Predictors of Intervention Effects

Six studies examined predictors of intervention effects (Barrera et al., 2004; Houtzager et al., 2001; Lobato & Kao, 2002; Packman et al., 2004; Packman et al., 2005; Sahler & Carpenter, 1989). Type of diagnosis was found to have a predictive effect on outcomes in two studies (Houtzager et al., 2001; Lobato & Kao, 2002). Only slight and non-significant trends were noted in other studies: younger age in two (Barrera et al., 2004; Sahler & Carpenter, 1989); for children with pre-existing behavioural problems and returning campers (Sahler & Carpenter, 1989); and for first-time campers (Packman et al., 2004). It is hard to make conclusive statements about potential predictors of treatment success as these were not explored systemically across studies and results were variable.

Overall sibling interventions included covered a range of outcome variables and utilised a large number of measures to assess the effectiveness of these interventions. Positive intervention effects were noted for depression, anxiety, mood overall, and self-

esteem, with more variable findings for adjustment, behaviour and post-traumatic stress. Sibling connectedness and medical knowledge consistently displayed significant changes in the desired direction, but these were two areas particularly limited by the lack of reliable/valid measurement tools. There were significant threats to validity for three of the studies (Lobato & Kao, 2002; 2005; Smith & Perry, 2004) due to the use of psychometrically untested tools. These included the Sibling Knowledge of Chronic Illness and Developmental Disability Interview and the 4 item measure of Sibling Connectedness, each devised and used by Lobato and Kao (2002; 2005). Two of the four measures used by Smith and Perry (2004) had no psychometric properties tested or reported and were investigator devised instruments from a previous study (Perry, 1989). The Sibling Perception Questionnaire (SPQ; Sahler & Carpenter, 1989) was widely used and despite having no currently available normative data is accumulating evidence of reliability and validity which is reported in all relevant studies. Threats to construct validity also included the fact that many interventions comprised novel elements such as camp experiences, tours of hospitals, refreshments and recreational activities which may induce reports of more positive outcomes related to satisfaction rather than the intended psychosocial outcomes for example. Due to the variation in lengths of interventions, it is hard to rule out exposure to confounding variables during the intervention and studies which delayed in obtaining post-test evaluation (e.g. Packman et al., 2004; Sahler & Carpenter, 1989) may also have been subject to confounding influences which has implications for the validity of the results.

Discussion

The aims of the current review were to identify the extent to which interventions aimed at improving psychological outcomes for well siblings of children with chronic illness or developmental disability have been researched in a systematic and empirical manner; to provide an overview of empirical evidence in this area; to synthesise the findings and comment on reported effectiveness for siblings and to identify any further research needs in this area. A systematic procedure was used in order to identify as fully as possible the research literature in this field and meet these aims. Eighteen studies representing thirteen different interventions met the criteria for inclusion which included mostly pre/post-interventions, two non-randomised control group designs and only three RCTs. In terms of intervention settings, seven were group-based; four camp-based; and one used family-based psycho-education. Only one individual intervention was identified.

The results demonstrate that interventions for siblings of children with chronic illness or developmental disorder are not extensively researched or empirically validated. The review found that the content of interventions, the variables studied and the measures used to document outcomes were inconsistent across studies, as was the methodological quality of the literature included. It was therefore hard to provide conclusive evidence about the overall effectiveness of sibling interventions for such children.

Overview of research findings in this area

Although searches were broad in relation to diagnostic category and any condition under the umbrella term of ‘chronic illness’ or ‘developmental disorder’ would have been included within this review, eleven of the eighteen studies identified focused on siblings of

children with cancer. This may represent a perception within the sibling literature that cancer is a unique stressor and more likely to cause distress for well siblings due to its life-threatening nature (Houtzager et al., 1999). Not only were chronic illnesses other than cancer neglected within the intervention research, there was a significantly low representation of developmental disorders. This is despite a growing body of literature suggesting that siblings of children affected by developmental disorder need further research and support (Jones et al., 2006; Mikami & Pfiffner, 2007). Where intervention research was included for siblings of children with developmental disorders, it was often in a transdiagnostic manner with siblings of children with chronic illness being included also.

Although all studies examined the effects of an intervention aimed at improving psychological outcomes for siblings, their aims, methods and outcomes were fairly wide ranging. This meant that findings were diverse with great variation in what could be considered useful in terms of intervention efficacy and outcome data. It was also difficult to establish any coherent sense of what predictor variables could be considered to have an important impact on how siblings respond to interventions as so few studies examined these. Those that did attempt exploration of predictors produced a range of findings.

When looking at the settings in which interventions were provided, it was striking how many of these were provided in either a group or a camp environment and that only two studies were provided in a different setting – one working within individual family groups and one as an individual educational intervention. There was not always a clearly stated rationale for choice of delivery format and there seemed to be an ongoing assumption, rather than a theoretically based conclusion, that meeting others in a similar

position would be therapeutic. Unfortunately none of the existing studies allowed for a comparison of the efficacy of group intervention with an individual format for example, and few made a clear justification for why they chose one format over the other.

Outcome evaluations again covered a range of variables making cross-study comparisons difficult. It appears that overall the interventions described generally provided beneficial outcomes for participating siblings. The most evidence was provided for the effectiveness of interventions on variables such as anxiety, depression, self-esteem and those relating to medical knowledge and other health-related variables. Indeed studies aiming to improve medical knowledge or health-related outcomes were the most prevalent. Studies looking at these areas consistently reported significant results in the desired direction and all were provided in either a group or camp format. However it has been acknowledged that measuring an increase in knowledge does not necessarily translate into improving psychosocial outcomes for siblings such as enhanced coping (Spath, 2007), and studies neglected to make this link. Less conclusive evidence was displayed for intervention effectiveness with regards to global or behavioural functioning and social and emotional adjustment. Adjustment was the least clearly defined variable within the research and within the five different studies exploring variables in this area, seven different outcome measures were used. Sibling connectedness was found to be improved in the two studies looking at this. However these same authors had both defined the concept of connectedness and developed their own research tool to measure it. This limits the reliability of their findings as this variable is not represented elsewhere in the literature. In terms of post-traumatic stress (PTS), this was only covered in relation to cancer and in the

three studies exploring this (representing two different interventions), only one found a significant reduction in post-traumatic stress for siblings. The sample size for studies exploring this variable was however very varied, with one study which found no PTS reduction only incorporating a sample size of four siblings. Only one intervention showed no quantitative change in outcome variables for siblings post-intervention (Kazak et al., 2004). This intervention was an RCT, included a sample of 43 siblings and was primarily designed for parents and children with cancer despite some sibling specific elements. Although not consistently reported within the studies, there appeared to be a slight trend for participants of a younger age and who were male, to gain the most benefit from interventions. Again it must be highlighted that the diversity of the included studies inhibits conclusive interpretations of patterns noted across the studies. Predictor variables were not assessed systematically in any of the studies and this coupled with the great variety of outcome measures makes comparisons difficult.

Cross-study comparison is problematic due to the range of variables, measurement tools and the variety of intervention components/settings. Perhaps even more importantly, the lack of consistency in how thoroughly the content of these interventions is described makes it hard to begin to draw out what components of the interventions are effective for siblings. In particular modular interventions with several different components mean that it is hard to isolate or determine the effective components within each intervention in addition to the difficulties in looking at this across several studies. It also means that there is little possibility of replication of studies and of comparability between interventions delivered. Despite the difficulties inherent in including such a diverse range of studies in the review,

the paucity of intervention-based research in this area meant that this enabled all available evidence to be considered.

Sample sizes showed considerable variation across the studies and it has been documented that both small and large sample sizes can affect reliability of findings (Tabachnick & Fidell, 2007). Studies rarely justified sample size so it is difficult to ascertain which sample sizes within the included studies are able to give reliable data. A wide range of diagnoses, even within the cancer focused interventions, were included and therefore may reflect differing experiences of individual siblings to unique factors associated with each condition. Very few of the studies analysed whether this was a confounding variable and therefore impacted results. Those that did find that diagnosis did make a difference to intervention effects (Houtzager et al., 2001), suggesting a potential methodological flaw in those studies which ignored this factor. Finally, the diversity of findings can possibly be attributed to the range of methodological designs used between the reviewed studies which may inhibit a fair cross-study comparison. In addition to limitations between the studies, there were also limitations within the studies included.

Limitations of included studies

The reliability of findings could be compromised by the quality of the studies reviewed. Due to the lack of intervention research in this area, studies were not excluded on the basis of lower methodological quality scores on the checklist. The use of an inclusion criterion of at least one standardised outcome measure and an empirical analysis however potentially excluded lower quality studies from the review such as those attempting no

analysis of data, either qualitative or quantitative. Included studies ranged from 35 % to 73% in terms of quality ratings indicating the variability of research standards in this field.

There were some common limitations in terms of the quality of studies. Generally sample sizes were fairly small, with only six studies reporting a sample size of fifty or above. Several of the researchers commented on their small sample size and lack of ability to recruit further due to the small numbers of potential participants within the population. This meant that low statistical power was a limitation in most of the studies due to these primarily small sample sizes and the lack of reported power estimations justifying sample size selection. It could also be considered a threat to internal validity that selection of participants involved volunteer participants which may not represent the general population of children being studied and may bias towards more positive outcomes (Barker, Pistrang & Elliott, 2001). External validity was also compromised in most studies in terms of the lack of diversity within the samples as they often represented only white, middle-class families. This is documented as a problem for sibling research generally (Stoneman, 2005) and there is a need to expand such studies to make results more generalisable and samples more representative. Researchers rarely described how representative the sample was compared to the general population of children being studied. Houtzager et al. (2001) used samples from two settings in different countries with mixed ethnicity but there was no comparison of these groups so this provides limited information on the intervention's generalisability.

Only three studies used an RCT design, even though this is considered the gold standard for intervention evaluations (Chambless & Hollon, 1998). The majority of studies

used a pre/post design which limits validity of any findings as changes seen in outcome measures may simply be due to the effects of time or maturation rather than intervention effects (Spath, 2007). Very few of the interventions used a control group which severely limits the conclusions that can be made from the findings and greatly decreases the reliability of any intervention effects documented. With the exception of two studies, none of the included interventions allowed for follow up assessments within the design to assess the long term efficacy of intervention effects. Those that did only had a 3 month follow up period which limits the extent to which it can be claimed the intervention has lasting effects. As highlighted earlier, instrumentation reliability was also a significant threat to validity in many of the studies due to the use of psychometrically untested tools.

Limitations of the review

The current review has allowed for greater insight into the current status of empirical research relating to interventions for siblings of children with chronic illness and developmental disorder. However limitations of the review methodology exist. Firstly despite the detailed and systematic searching of literature, it is possible that relevant studies were not included due to not having the specified key terms used within the search. Despite inter-rater reliability data for assessing the quality of included studies, overall data was collected by only one researcher meaning it could be subjective. It is also possible that the review was subject to publication bias as it excluded studies which were not published in a peer-reviewed journal. This may mean that less significant, less interesting results or inconclusive interventions were not incorporated (Sharpe & Rossiter, 2002). Also the search was limited to papers published from 1980 onwards and in the English language,

meaning that older papers or those published in other languages may have held important data which is not included.

Clinical implications and directions for future research

It has been documented by many researchers and reviewers in this area that siblings of children with chronic illness, disabilities and developmental disorders are neglected within empirical research (e.g. Houtzager et al., 1999; Spath, 2007; Mikami & Pfiffner, 2007). The current review clearly shows that there is a need for an increased research focus on siblings of children with chronic illness and developmental disorder. Specifically there is a need for more systematic intervention-based research which is of greater methodological quality and uses randomised controlled designs. Use of theoretical models is essential for future intervention development and testing. The lack of explicit theoretical frameworks in the included studies mean potentially significant mediating variables are often neglected and not incorporated into study designs. This lack of a solid theoretical basis is an issue that has been highlighted for sibling research in chronic illness generally (Sharpe & Rossiter 2002). It is important that sibling interventions are manualised, as currently the small amount of research that exists does not provide much information about the effective components of each intervention and not enough detail is given to enable replication. This also limits its usefulness in terms of clinical application. Future interventions should be designed in such a way that the various components can be evaluated separately; therefore providing more evidence around what produces the most beneficial effects for siblings. The results also indicate a need for more evidence to be built up around the best way to deliver these interventions to siblings. Studies which compare

group, camp and individual interventions would be necessary for direct comparison regarding psychological outcomes and relative effectiveness of each format.

Conclusions

The current review provides an overview of intervention-based research for siblings of children with chronic illness and developmental disorder. Regardless of the great variation and diversity in terms of design, objectives, intervention components and delivery, sibling interventions seemed to produce overall positive effects on psychological variables regardless of delivery format. The overall results of this review support the utility and efficacy of such interventions. However, conclusions are tentative because due to the wide-ranging methodologies, quality of studies and variable findings, cross-study comparison is difficult. This review highlights the need for continuing and expanding research into the experiences of siblings of children with chronic illness and developmental disability and how this may translate into providing support and strengthening individual resources. This research needs to be conducted more systematically, with routine use of control groups and with more robust use of theoretical frameworks, in order to establish effective components and ensure outcomes obtained are valid and reliable.

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Siblings of children with ADHD, chronic illness and developmental disorder

SIBLINGS OF CHILDREN WITH ADHD, CHRONIC ILLNESS AND
DEVELOPMENTAL DISORDER: PSYCHOLOGICAL IMPACT AND
INTERVENTIONS

Part 2

Empirical Paper

Siblings of Children with Attention-Deficit Hyperactivity Disorder (ADHD): Empathy,
Self-Esteem and the Quality of the Sibling Relationship

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This paper is written in the format ready for submission to Child Development.

Please see Appendix B for the Guidelines for Authors.

Abstract

This study investigated empathy, self-esteem and sibling relationship quality for siblings of children with ADHD (n = 30) relative to a control group of siblings of children with no diagnosed disorders (n = 30). Siblings of children with ADHD reported significantly higher levels of empathy, and significantly higher conflict within their sibling relationships than the control group. No significant differences in self-esteem or warmth/closeness of the sibling relationship were found. Empathy was a significant predictor of warmth/closeness and conflict overall, but the nature of the predictive effect was not influenced by having a sibling with or without ADHD. The findings suggested although such sibling relationships may be characterised by conflict, this does not necessarily indicate that only negative outcomes exist for undiagnosed siblings.

Key words: Siblings, Attention-Deficit Hyperactivity Disorder, ADHD, Empathy, Self-esteem, Sibling Relationship Quality.

**Siblings of Children with Attention Deficit Hyperactivity Disorder (ADHD):
Empathy, Self-Esteem and the Quality of the Sibling Relationship**

Attention Deficit Hyperactivity Disorder (ADHD) is a syndrome characterised by pervasive and impairing symptoms of inattention, hyperactivity and impulsivity as defined by DSM-IV criteria (Diagnostic and Statistical Manual of Mental Diseases: DSM-IV, 1995). Whilst other common terms of reference include Attention Deficit Disorder (ADD), Hyperkinetic Disorder (HKD) and Hyperkinesis, ADHD is the term most commonly used when discussing this disorder (Carr, 2006) and as such will be adopted throughout the current study. A growing body of research has shown that children diagnosed with ADHD may often experience difficulties in forming social relationships (Zager, 1999) and may show higher rates of behaviours considered domineering or aggressive such as teasing or hitting peers (Mrug, Hoza & Gerdes, 2001). These particular difficulties indicate the potential for ADHD to have a substantial impact on how children diagnosed with the condition relate to others and maintain relationships.

Family systems and ADHD

Systemic theory suggests that when a family system has a member with an illness or any kind of condition which presents adaptive challenges, this will have an impact on all other parts of the system (Cox & Paley, 1997). Research on familial adjustment to chronic illness or disability has indicated it can be a stressful and difficult experience (e.g. Wochna, 1997; Houtzager, Grootenhuis & Last, 1999) but little research has looked at how families are affected by having a child with a developmental disorder such as ADHD. Jones and

Passey (2004) indicated sources of parental stress such as lack of support and societal attitudes for families of children with developmental disorder, but only 5 children in their sample had ADHD. In childhood disability research there is a growing body of evidence to suggest that some families are not just coping with having a child with difficulties, but may be thriving and positively benefiting despite these difficulties. It has been suggested that there is a need to move such research forwards by looking at positive outcomes and move beyond negative and 'stress and coping' models (Dykens, 2005). Scorgie and Sobsey (2000) suggested there can be evidence of "transformational outcomes" in the lives of many families of children with developmental disorders including parents' perceptions of personal growth, better relationships with other people, and a change in life view or spirituality.

Sibling relationships

Johnston and Mash (2001) in a review of literature on families and ADHD highlighted the need to expand such research beyond mother-child dyads to include other family subsystems including sibling relationships. Siblings are considered to play an important role in many areas of a child's psychological development (Brody, 2004) and such relationships are considered to be an important antecedent to peer and later adult relationships (Lobato, Faust & Spirito, 1988). The findings of longitudinal studies such as that of Gass, Jenkins and Dunn (2007) have suggested that positive elements of the sibling relationship may even moderate the impact of stressful life events on a child's individual adjustment.

Siblings of children with ADHD

Despite increasing acknowledgement of the important and influential nature of sibling relationships, this has yet to be documented extensively in terms of the impact on typically developing children of having a brother or sister with ADHD. There is now a greater recognition that siblings of children with illness or disorders may be affected in some qualitatively different way by their experiences as a sibling, than siblings of children without such conditions. However much of the literature thus far has tended to focus on clearly visible difficulties such as severe learning disabilities, physical or sensory impairments (Fisman, Wolf & Ellison, 2000) and chronic illness (Labay & Walco, 2004) for example (for a meta-analysis of the literature in this area see Rossiter & Sharpe, 2001). It has been suggested that a developmental disorder such as ADHD has its own unique variables with regards to familial adjustment, as its existence and effects may only be realised gradually over the course of a child's development (Carr, 2006).

Research exploring sibling relationships of children with ADHD

Research exploring sibling relationships where one child has ADHD is limited. One of the first significant pieces of research to explore the impact of ADHD on siblings was a qualitative study conducted by Kendall (1999) who documented high levels of anger and resentment reported by siblings. However Kendall also described two of the 11 children talking positively about having a caretaking role for the child with ADHD due to resulting feelings of competence. Kendall's study was limited by the small sample size and lack of a control group, but nonetheless was an important start to an otherwise neglected area of research. Relatively few studies in this domain have been conducted since this time. Such

studies have demonstrated significantly poorer quality sibling relationships (Greene et al., 2001) and more negative behaviours in observations of play (Mash & Johnston, 1983) between such siblings and control groups. Mikami and Pfiffner (2007) found that sibling relationships where one child had ADHD comprised greater levels of conflict but no significant differences in warmth, when compared to a control group. This study focused primarily on the child with ADHD and had a relatively small control group of 14 children compared to the 77 children with ADHD. Jones, Welsh, Glassmire and Tavegia (2006) explored psychological functioning in 45 siblings of children with ADHD and found significantly higher levels of anger, but no differences in depression or anxiety when compared to a control group. Studies in the area of developmental disorder have generally been dominated by a focus on autism with some sibling studies here documenting higher levels of depression and behaviour problems (Hastings, 2003; Verte, Roeyers & Busse, 2003) and others finding increased levels of prosocial behaviours and positive adjustment (Kaminsky & Dewey, 2002). There is little doubt that having a sibling with ADHD has the potential to cause conflict and difficulties for the children involved (e.g. Kendall, 1999; Jones et al., 2006; Mikami & Pfiffner, 2007; Greene et al., 2001) but research such as this in the field of autism and to a lesser extent ADHD (e.g. Kendall, 1999), begins to suggest potentially positive outcomes in addition to the difficulties.

Empathy, self-esteem and sibling relationship quality

Empathy

To date, much of the literature that aims to incorporate the potentially more positive aspects of having a sibling diagnosed with a specific condition comes from the chronic

illness literature and, to a lesser extent, the research on intellectual disability (e.g. Orsmond & Seltzer, 2000). One such positive variable highlighted most frequently in the sibling chronic illness literature is that of empathy. Empathy has been defined as “*a quality in which one person understands the perspective of another, accepts this perspective as belonging to the other person and conveys this understanding and acceptance back to the person*” (Golding, 2008, pp. 102). Within the developmental psychology literature, empathy has been described as having an inhibitory effect on aggression and a facilitating effect on social relationships and prosocial behaviours (Owen-Anderson, Jenkins, Bradley & Zucker, 2008). Siblings of children with chronic illness have been shown to display higher levels of empathy than siblings of children without such difficulties (e.g. Harder & Bowditch, 1982; Faux, 1991; Walker, 1990). Research by Labay and Walco (2004) found empathy to be a significant predictor of behavioural problems displayed by the healthy sibling in cases of childhood cancer. To the best of the authors’ knowledge, no research to date has focused on increased empathy as a possible outcome, or moderator of difficulties, for siblings of children with ADHD.

Self-esteem

Self-esteem has been shown to be both an important protective factor in sibling adjustment, and also a positive aspect of emotional and psychological development for siblings of children with chronic illness (e.g. Faux, 1991; Stoneman & Brody, 1993; Walker, 1990). Self-esteem has been defined as ‘*the positive or negative attitude about the self, the degree of liking or satisfaction with the self and one’s feelings or perceived worth as compared with others*’ (Davis-Kean & Sandler, 2001, p. 888). High self-esteem has been

associated with good personal adjustment across the lifespan whilst low self-esteem has been associated with poor psychological adjustment (Carr, 2006). Research involving siblings of children with autism has documented increased levels of self-concept and self-esteem in comparison to control groups (Macks & Reeve, 2007; Kaminsky & Dewey, 2002). Research regarding self-esteem in siblings of children with ADHD is lacking. It is possible that the unique challenges faced by siblings of children with ADHD may increase their self-esteem. Kendall's (1999) research highlighted that care taking tasks relating to a sibling with ADHD gave children a sense of competence and of being helpful to parents. It is also possible that high self-esteem could protect a child from the potentially more negative and disruptive influences that other studies report in sibling relationships where one child has a diagnosed condition such as ADHD.

Sibling Relationship Quality – Warmth/Closeness and Conflict

Sibling relationship quality where one child has ADHD has not been substantially researched. The author is only aware of one such study by Mikami and Pfiffner (2007), yet their focus was primarily on the child with the condition despite including sibling reports. Researchers have found that most relationships between children with disabilities and their siblings are nurturing and satisfying (e.g. Bäckholm & Gillberg, 1991; McHale & Gamble, 1989; Kaminsky & Dewey, 2001) and potentially even more positive than those of control siblings (Stoneman, 2005). Generally speaking, sibling relationships can be emotionally intense environments for a child with both positive and negative exchanges observed frequently between siblings (Ross, Filyer, Lollis, Perlman & Martin, 1994). Conflict may also provide children with important experiences of reciprocal social

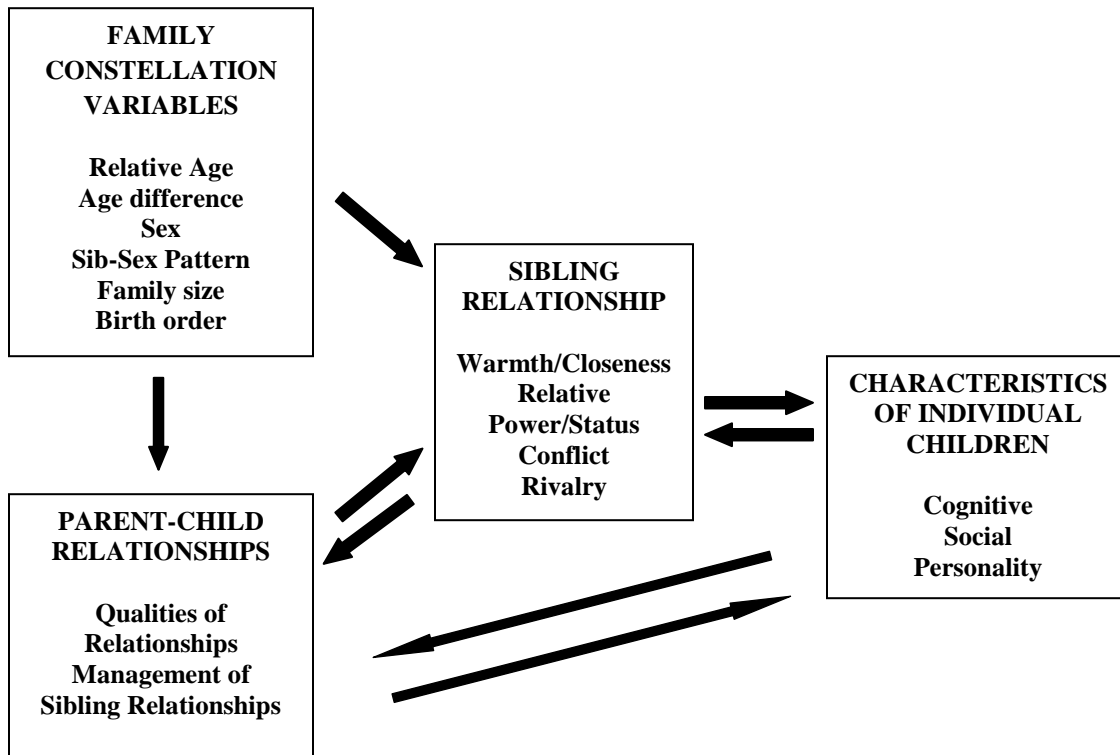
relationships, and of cause and effect with regard to their behaviour (Dunn & Munn, 1985). Conflict and warmth have been shown to be relatively independent constructs in terms of sibling relationship quality (Furman & Buhrmester, 1985) making it theoretically possible for sibling relationships to be high in conflict without excluding the existence of warmth and closeness.

Sibling Relationship Quality as an Outcome

Life-span developmental psychologists have suggested that social relationships can be considered outcomes in themselves, and that to consider them only as predictors of wellbeing misses their importance (Antonucci, Langfahl & Akiyama, 2004). The scarce research that exists in the domain of siblings and ADHD often focuses on the absence of negative symptoms as evidence of ‘adjustment’. Stoneman (2005) highlights this ‘empty’ conceptual framework as having generated a large body of research that has actually yielded very little in the way of useful or valid information and stresses the importance of re-evaluating what is considered to be a ‘good’ relationship. Furman and Buhrmester (1985) state the importance of examining the qualities of sibling relationships in order to understand the variable influence siblings have. They conclude that differences in sibling relationships warrant study in themselves beyond purely researching familial structural or constellation variables such as ordinal position, sex of sibling and age spacing. They conducted an extensive study using interviews and self-report measures with children to identify the general dimensions of sibling relationships. Using factor analysis four main dimensions of warmth/closeness, relative power/status, conflict and rivalry were identified.

Figure 1 demonstrates Furman and Buhrmester's model of the primary determinants of sibling relationship quality.

Figure 1 Furman and Buhrmester's (1985) Model of Determinants of Sibling Relationship Quality



This model has not yet been applied to the study of sibling relationships where one child has a developmental disorder or chronic illness. The current study proposed incorporating research findings from the field of developmental disorder and chronic illness and to examine how identified individual characteristics/variables potentially impact upon the sibling relationship quality for siblings of children with ADHD, using elements of Furman and Buhrmester's model as a framework. Specifically, the interaction between sibling relationship quality and the characteristics of the sibling without the disorder was

the selected focus. This would incorporate not only findings regarding specific individual characteristics (empathy and self-esteem in this case) of siblings of children with and without ADHD, but also to consider how these variables impact on the reported quality of the sibling relationship. This means that empathy and self-esteem might not only be outcomes, but may also predict the quality of the sibling relationship. This may go some way to explain the variability in the literature highlighted thus far, as previous studies have not explored what influences reports of sibling relationship quality and have mainly focused on individual outcomes for children where one child has a disorder or illness. Authors have highlighted the need to begin to explore the variability in findings within sibling research, and to consider what factors may contribute to whether a sibling adjusts well to such a relationship or experiences difficulties (e.g. Stoneman, 2005; Hastings, 2003). Within this model then, greater empathy for example may make a child more understanding of a sibling's differing needs or the differential allocation of parental resources, resulting in higher reports of warmth and perhaps lower reports of conflict due to an increased tolerance. High self-esteem is thought to buffer children from negative life events and stresses, therefore children with higher levels of self-esteem may equally perceive their sibling relationship more positively as a result of this protective quality. The sibling relationship in itself also potentially influences the individual child's characteristics, meaning that a sibling of a child with ADHD may become more empathic and develop greater self-esteem as highlighted earlier, due to the socialisation context of that relationship.

Aims and Hypotheses

The primary aim of this study was to examine perceptions of the quality of sibling relationships where one child has ADHD, from the perspective of the sibling without the disorder. To enable both positive and negative elements of this relationship to be incorporated, reported warmth/closeness and conflict were the selected focus in terms of sibling relationship quality. Research investigating the influence of having a sibling with ADHD on the warmth/closeness of the relationship is sparse, but based on the limited available literature in this area (e.g. Mikami & Pfiffner, 2007) it was predicted that siblings of children with ADHD would report no significant differences in warmth/closeness when compared to children in the control condition. As research has suggested such relationships can be characterised by anger (Jones et al., 2006) and increased conflict (Mikami & Pfiffner, 2007), it was hypothesised that siblings of children with ADHD would report more conflict in this relationship than that reported by a control group of siblings.

The second aim of this study was to examine whether siblings of children with ADHD display any differences in reported empathy and self-esteem when compared to a control group of siblings of children with no diagnosed disorders. Existing literature reports that siblings of children with chronic illness may develop increased empathy due to their experiences within the socialisation context of the sibling relationship (Faux, 1991; Stoneman & Brody, 1993) and studies including siblings of children with autism have documented increased self-concept and self-esteem (Macks & Reeve, 2007; Kaminsky & Dewey, 2002). It was hypothesised that this increase in empathy and self-esteem may

extend to the experience of having a sibling with ADHD, and therefore that these siblings would report higher levels of both these variables than a control group.

Finally, the study aimed to identify whether empathy and self-esteem are predictor variables for reported quality of the sibling relationship, and to investigate whether the nature of the prediction was the same for the two groups by exploring interaction effects. This was with the aim of investigating whether the potentially predictive nature of individual children's characteristics (namely empathy and self-esteem) operate in the same way for ADHD as has been suggested from reviewing the literature on chronic illness and autism (e.g. Labay & Walco, 2004; Faux, 1991; Stoneman & Brody, 1993; Walker, 1990; Kaminsky & Dewey, 2001). Based on literature in these areas, it was hypothesised that levels of empathy and self-esteem would significantly predict reported levels of warmth/closeness and conflict in the sample overall, and that the predictive effect of both empathy and self-esteem would be stronger in the clinical group. This is based on previous research by Labay and Walco (2004), which found empathy to be a significant predictor of problems displayed by the healthy sibling in cases of childhood cancer. It was hypothesised that self-esteem may have the same impact and both variables may have predictive value in terms of the reported quality of sibling relationships where one child has ADHD due to the protective and 'buffering' qualities of empathy and self-esteem highlighted earlier.

This would also enable exploration of Furman and Buhrmester's (1985) model of sibling relationship quality and its applicability in terms of examining whether these individual characteristics predict reports of sibling relationship quality for siblings of children with and without ADHD.

Method

Participants

Participants were 60 children (29 boys, 31 girls) recruited from local charitable organizations supporting families of children with ADHD and local NHS services for children with ADHD (clinical group); and local primary and secondary schools (control group). Inclusion criteria for participation were: aged between 8 to 13 years; living at home with at least one biological parent; an ability to read/understand English language; and having at least one biological sibling aged 5 to 16 years (no more than 3 years older or younger than the participating sibling). Where more than one suitable sibling was available to take part in the study, the sibling closest in age to the participating child was selected. Included age range was selected to minimise potential confounding effects of age/developmental stage. Sample sizes were calculated according to a 'rule of thumb' for multiple regression models, which required 10 cases per predictor variable to achieve sufficient statistical power (Tabachnick & Fidell, 2007). Sample size targets were met.

For inclusion in the clinical group the participating child had to have a sibling with a diagnosis of ADHD (any subtype) who met the above inclusion criteria for age. Parental reports of ADHD symptoms had to surpass clinical thresholds for the child with a diagnosis of ADHD, using the ADHD Index from the Conners' Parent Rating Scale Revised – Short Form (CPRS-R:S; Conners, 1997). Inclusion in the control group required the child to have a sibling meeting all of the above inclusion criteria and to have no diagnosis of ADHD or other disorder/disability. Again this was confirmed for research purposes with the use of the

CPRS-R:S, whereby scores had to be below clinical thresholds, as defined by the scale (Conners, 1997). In order to meet screening criteria for inclusion in the study participating children in both the clinical and control group had to score below the 'abnormal' band of the Hyperactivity-Inattention Index as determined by parental report on the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997).

74 families were identified as potentially eligible for the clinical group, from families attending charity groups and from the families having given generic research consent on the NHS waiting list. Letters of invitation were sent out to these 74 families and 39 parents responded to request information sheets (response rate = 52.7%). 33 families went on to contact the researcher after receiving information sheets. Three of these potential clinical group participants were excluded from the study. Parental report on the CPRS-R:S indicated the sibling of one potential participant did not reach the required score indicative of ADHD (for research purposes) and hence their data was excluded. Two siblings were excluded prior to participation as they did not meet the age criteria; one young person being 15 years old and the other being 6 years older than the sibling with ADHD. The final clinical group sample consisted of 30 siblings of children with ADHD ranging in age from 8 to 13 years ($M = 10.46$, $SD = 1.41$); 14 were female and 16 male. 12 of the participating siblings were younger than the child with ADHD and 18 were older. In terms of comorbid diagnoses of non-participating siblings with ADHD, three parents reported comorbidities of conduct disorder, one of oppositional defiance disorder (ODD) and one of Asperger's syndrome.

A convenience sample of siblings of children with no diagnosis of ADHD or other disability/disorder was recruited through local primary and secondary schools in the same geographic area as the clinical sample by contacting head teachers (see Appendix F for letter). Control group recruitment progressed in a stepwise fashion with schools being approached one after another until thirty appropriate participants were recruited. A total of three hundred and twenty-two letters of invitation were sent out to parents in participating year groups at four schools (see Appendix G). A total of 41 responses to request full information leaflets were obtained (response rate = 12.7 %). 35 of these respondents contacted the researcher wishing to participate. Five control group children were excluded from participating at this point due to: sibling having a diagnosis of autistic spectrum disorder ($n = 1$), sibling having a learning disability ($n = 1$) and the remaining three due to having a larger than 3 year age gap between potential participating and non-participating siblings. The final control group sample of 30 participants ranged in age from 8 to 13 years ($M = 10.53$, $SD = 1.51$); 17 were female and 13 male. 14 participating siblings were younger than the child with ADHD and 16 were older.

Procedure

Ethical approval was obtained from the local Research Ethics Committee and subsequent Trust approval was granted (see Appendixes H and I). For the clinical group officers of the local ADHD charities involved allowed the researcher to attend support groups and speak briefly to attending parents about the research being conducted. Interested parents took home letters about the research and contacted the researcher if they and their child wished to take part. For clinical group participants recruited through the NHS, those

Siblings of children with ADHD, chronic illness and developmental disorder

on a waiting list for family effectiveness training in relation to their child with ADHD were sent out letters (see Appendix J for letter). Only those families who had previously given generic consent to be contacted for research purposes were sent letters. For control group participants head teachers of local primary and secondary schools allowed the researcher to briefly describe the research to children in participating years who had siblings, and give out letters to interested children (sealed and addressed to parents) to take home.

All letters had return slips on the bottom for the parent to request further information about the study if they and their child were interested in participating. When a slip was received, further letters (Appendixes K and L) and information sheets for both parent and child were posted out (Appendix M), along with consent/assent forms (Appendix N). Families were invited to contact the researcher after reading the provided information if they wished to take part. Appointments were arranged for the family to meet with the researcher and complete questionnaires, either at their home or at the research base. In the case of the control group, appointments at school were also offered. One parent and the participating sibling only attended this appointment.. Before completing the measures, parents and children were asked to re-read the appropriate information sheets and sign consent forms in the case of parents, and assent forms in the case of children if they still wanted to participate. Opportunity was provided for any questions at this point and it was made clear there was no still no obligation to take part. All measures were completed in the presence of the researcher and attending parent. Parents first completed demographic data sheets and screening measures for both the participating and non-participating siblings. Children then filled in questionnaires with the researcher available to answer any questions

or clarify concepts or language used within the measures, whilst maintaining a standardised protocol. Both parent and child were then given debriefing information (Appendix O).

Measures

Demographic variables

The participating parent completed a demographic questionnaire to ascertain various demographic variables regarding the family, the participating child and the non-participating sibling (see Appendix P). This included information such as the family's eligibility for free school meals (as a brief, non-formal representation of socio-economic status), whether parents had completed higher education, number of children in the family, ethnic origin, ages of participating and non-participating children, and time since diagnosis of ADHD and existing comorbidities if in clinical group.

Screening measures

Conners' Parent Rating Scale Revised: Short Form (Conners, 1997)

Non-participating siblings of children taking part were screened to confirm ADHD diagnosis for research purposes (clinical group), or confirm no diagnosable ADHD (control group) using the Conners' Parent Rating Scale Revised: Short Form (CPRS-R:S; Conners, 1997) which is validated for 3-17 year olds. The CPRS-R:S is a widely used and well validated scale designed to characterise patterns of a child's behaviour that indicate ADHD. Only the ADHD Index with 10 items was used for this study. Each item consisted of a 5 point likert scale (1 = never, 5 = very often), with higher scores representing more severe ADHD. An average T score of 50 represents the exact equivalent to the mean score of that age and gender group. For the purposes of the current study, participating children's

siblings with ADHD for the clinical group had to have a T score of 60 or above which indicates high average/elevated levels of ADHD symptoms. Non-participating children whose siblings were in the control group had to have a T score of 59 or less, indicating characteristics within the average range or below. High reliability and excellent internal consistency ($\alpha = .91$) have been reported for the ADHD Scale (Kumar & Steer, 2003) and Conners (1997) has reported total reliability coefficients ranging from .857 to .938 (see Appendix Q for measure).

Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997)

Parents completed the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) as a screening measure to confirm lack of ADHD symptomatology in participating children. The SDQ is a brief questionnaire designed for parental report for children/young people aged 4 – 16, with a self-report version for 11 – 16 year olds. The parental report was used for all children in the current study. It covers common areas of emotional and behavioural difficulty displayed by a child and incorporates 25 items covering 5 subscales. For the purposes of the current study, only the 5 items comprising the Hyperactivity-Inattention Scale were used. Parents are asked to rate statements regarding their child's behaviour/difficulties over the last 6 months as 'Not True', 'Somewhat True', and 'Certainly True'. These are scored as 0 = not true to 2 = certainly true, with some items being reverse scored where indicated. The Hyperactivity-Inattention Scale includes items such as 'Restless, overactive, cannot stay still for long'. Children in the study had to score below 6 on this scale to be included (0 – 5 = normal, 6 = borderline and 7 – 10 = abnormal; Goodman, 1997). The Hyperactivity-Inattention Scale has been shown in large scale studies

to have the sensitivity/screening efficiency to identify over 70 % of individuals with hyperactivity, ADHD or hyperkinetic disorder in community samples (Goodman, Ford, Simmons, Gatward & Meltzer, 2000) with extensive validity and reliability data reported including internal consistency (mean $\alpha = .73$) and test-retest stability ($\alpha = .62$) (Goodman, 2001; see Appendix R for a copy of this measure).

Research measures

Index of Empathy for Children (IEC; Bryant, 1982)

Participating children completed the Index of Empathy for Children and Adolescents, a 22-item self-report questionnaire for children 6 years and older with high test-retest reliability ($\alpha = .81$) and convergent validity ($r = .54$) reported (IEC; Bryant, 1982). The IEC provides a measure of the child's empathy as they rate 22 statements according to whether they feel it describes them or not. Each item is scored dichotomously with 1 = yes and 0 = no. Half the items are worded negatively and are therefore reverse scored 0 = yes or 1 = no. Examples of positively worded items include 'It makes me sad to see a boy who can't find anyone to play with' and 'I get upset when I see a boy being hurt'. Negatively worded items include statements such as 'It's hard for me to see why someone else gets upset' and 'Kids who have no friends probably don't want any'. The total of all items gives an overall empathy score with higher numbers indicating higher levels of empathy. This total over all items was used for the analysis (see Appendix S for a copy of the measure).

Rosenberg Self-Esteem Scale (RSES; Rosenberg, 1965)

Participating children completed the Rosenberg Self-Esteem Scale (RSES; Rosenberg, 1965) as a unidimensional measure of self-esteem. This widely used self-report questionnaire is validated for ages 8 and upwards. It comprises 10 items with individual items scored from 0 to 3 whereby 3 = strongly agree, 2 = agree, 1 = disagree and 0 = strongly disagree (for the first 5 items) and the reverse for the last 5 items whereby 3 = strongly disagree and so on. Scores range from 0 to 30 and normal range is 15-25 with scores below 15 considered to be indicative of low self-esteem (Rosenberg, 1965). As this scale has been cited as the most widely used self-esteem measure in research (Mruk, 1999) there is extensive reliability and validity data available (e.g. Bagley & Mallick, 2001). Rosenberg demonstrated high internal reliability estimates ($\alpha = .77$ to $.88$) and high test-retest reliability correlations ($r = .82$ to $.88$) on a population of older primary and secondary school children. Example items include ‘I am able to do things as well as most other people’ and reverse score items such as ‘At times I think I am no good at all’ (See Appendix T for a copy of the measure).

Sibling Relationship Quality

This variable was measured using the brief version of the child-report Sibling Relationship Questionnaire – Revised which is validated for use with children aged 7 years and older (SRQ-R Brief; Furman & Buhrmester, 1985). The SRQ-R Brief consists of 39 items and is used to measure four factor scores. The current study utilised items related only to factors of warmth/closeness (15 items) and conflict (6 items) as in Mikami and Piffner’s (2007) study. This was in order to capture both positive and negative aspects of

the sibling relationship quality as related to the study's aims. Each item is rated on a 5 point Likert scale for how much the child believes the statement describes their relationship with their sibling (0 = hardly at all, 4 = extremely much). Both factor scores are derived by averaging the scores for the 15 items for warmth/closeness and the 6 items for conflict. Example items include 'How much do you look up to and feel proud of this sibling?' (warmth/closeness) and 'How much do you and this sibling disagree and quarrel with each other?' (conflict). Psychometric properties for the original version of this scale have been widely reported in terms of validity and reliability data, with internal consistency coefficients (mean $\alpha = .80$ for all scales) and test-re-test reliability (mean $r = .71$) data reported (Furman & Buhrmester, 1985). This research uses the revised version which has minimal revisions compared to the SRQ (as checked by correspondence with the first author of the scale, Professor Furman), but has yet to report norms or reliability/validity data. Cronbach's alpha for the current study indicated high reliability for the warmth/closeness factor ($\alpha = .95$) and for the conflict factor ($\alpha = .88$), according to general guidelines (Field, 2009). This is also comparable to other research in this area by Mikami & Pfiffner (2007) who cited reliability for warmth/closeness ($\alpha = .83$) and conflict ($\alpha = .85$) in their sample. For further information on psychometric properties and development of SRQ factors see Furman and Buhrmester (1985). (see Appendix U for a copy of this measure).

Statistical Analyses

The Statistical Package for the Social Sciences version 16.0 (SPSS Inc., 2007) was used for analyses. Statistical significance was set at 5 % ($p = .05$) for all analyses. Significant differences between the clinical and the control group on measures of empathy,

self-esteem, SRQ factors ‘warmth/closeness’ and ‘conflict’ were tested for initially with the use of independent t-tests. Bivariate correlations were conducted using Pearson’s r . A univariate general linear model (GLM) was used for regression calculations to incorporate both interval data (empathy, self-esteem, warmth/closeness, conflict) and categorical variables relating to group (clinical or control). Interaction effects were tested for using this model to identify the predictive effects of empathy and self-esteem on reported sibling relationship quality between groups.

No cases were excluded from the data set as there were no missing data.

Results

Demographic data

Relevant demographic information pertaining to children and parents was compared between the groups. Table 2 represents the proportion of clinical and control group participants and their parents in demographic sets categorised by parental gender, marital status, ethnic origin, higher education and family eligibility for free school meals (as an informal indication of socio-economic status) and child participant gender and birth order in sibling dyad. χ^2 tests were performed to compare the two groups on each category. There were no significant differences in any of these demographic sets ($p > .05$).

Table 2

Demographic characteristics according to group and χ^2 test results

	Clinical group (Siblings of child with ADHD, n = 30)					Control group (Siblings of child without ADHD, n = 30)					χ^2	p value
	Male		Female			Male		Female				
<i>Parent</i>	Male		Female			Male		Female				
Gender (%)	53.3		46.7			43.3		56.7			.438	ns
Marital status (%)	S	D	M	Co		S	D	M	Co			
	16.7	10.0	53.3	20.0		6.7	13.3	66.7	13.3		.276	ns
Ethnic origin (%)	W	A	M	B	O	W	A	M	B	O		
	90.0	0.0	3.3	0.0	3.3	90.0	3.3	3.3	3.3	0.0	.501	ns
Higher education (%)	Yes		No			Yes		No				
	33.2		66.8			49.8		50.2			.191	ns
Eligibility for free school meals (%)	Yes		No			Yes		No				
	30.0		66.7			10.0		86.7			.151	ns
<i>Child participant</i>	Male		Female			Male		Female				
Gender (%)	53.3		46.7			43.3		56.7			.438	ns
Birth order in sibling dyad (%)	Older		Younger			Older		Younger				
	60.0		40.0			53.3		46.7			.607	ns

Note: Marital Status: S=Single, D=Divorced, M=Married, Co=Cohabiting; Ethnic origin: W=White, A=Asian/British Asian, M=Mixed race, B=Black/Black British, O=Other race not specified above. One participant response of 'decline to answer' in control group.

Table 3 presents the mean scores and standard deviations for clinical and control groups for number of children in participating families, age of participating child, age of non-participating sibling and time since diagnosis of sibling with ADHD for the clinical group. With the exception of time since diagnosis, the clinical and control group were

compared on each of these demographic variables to establish if there were any significant differences between groups. There were no significant differences between groups on any of these demographic variables ($p > .05$). Mean time since diagnosis ranged from 3 to 48 months for the children with ADHD ($M = 17.20$, $SD = 10.70$).

Table 3

Means and standard deviations (SD) for demographic variables according to group and independent t-test results

	Clinical group (Siblings of child with ADHD, n = 30)		Control group (Siblings of child without ADHD, n = 30)		t-test	p value
	M	SD	M	SD		
Age of child participant	10.46	1.41	10.53	1.51	- .608	ns
Age of child non-participant	10.04	2.52	10.41	2.21	- .162	ns
Number of children in family	2.50	.683	2.67	.758	- .895	ns
Time since diagnosis (months)	17.20	10.70				ns

This illustrates that the samples for the clinical and control group displayed no significant between group differences on several variables highlighted as potential confounders within research focused on families and sibling relationships.

Sibling Relationship Quality – Warmth/Closeness and Conflict

To test the hypotheses related to the primary aim of the research study and enable differences between the clinical and control group reports of sibling relationship quality to

be determined, independent samples *t*-tests were used to test for differences between the groups of siblings on the variables of SRQ factors warmth/closeness and conflict (See Table 4 for means and standard deviations). For the comparison of warmth/closeness scores, there was no significant difference between the mean scores for the clinical group ($M = 1.85$, $SD = 0.60$) and the control group ($M = 1.89$, $SD = 0.58$; $t(58) = -.26$, $p = .80$). There was no significant difference in conflict scores between the clinical group ($M = 2.03$, $SD = 0.58$) and the control group ($M = 1.788$, $SD = 0.59$; $t(58) = 1.583$, $p = .119$). These results supported the hypothesis that there would be no significant difference in warmth/closeness between the groups, but did not support the hypothesis that siblings of children with ADHD would report significantly higher conflict than the control group.

Table 4***Group Means and Standard Deviations for IEC, RSES, SRQ Warmth/Closeness and SRQ Conflict***

Measure	Clinical group (siblings of children with ADHD)		Control group (siblings of children without ADHD)		<i>P</i> value
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Index of Empathy (IEC)	11.80	4.60	9.20	3.64	.019*
Self-Esteem Scale (RSES)	20.07	4.77	19.33	5.27	.574
SRQ Warmth/Closeness factor (SRQ-R)	1.85	0.60	1.89	0.58	.799
SRQ Conflict factor (SRQ-R)	2.03	0.58	1.79	0.59	.119

*= $p < .05$

Note: Possible score ranges of measures: Totals: IEC (0 – 22); RSES (0 – 30); Averages: SRQ Warmth/Closeness (0 – 60 raw, 15 items for factor so highest average possible = 4); SRQ Conflict (0 – 24 raw, 6 items for factor so highest average possible = 4).

Empathy and self-esteem between groups

To test the hypotheses related to the secondary aim of the study, independent samples *t*-tests were conducted to compare empathy and self-esteem scores across the clinical and the control group (See Table 4 for means and standard deviations). *T*-tests displayed a significant difference for empathy scores between the clinical group ($M = 11.80$, $SD = 4.60$) and the control group ($M = 9.20$, $SD = 3.64$; $t(58) = 2.43$, $p = .019$), with the clinical group scoring significantly higher on the empathy measure ($d = .63$). *T*-tests comparing self-esteem scores for the clinical group ($M = 20.07$, $SD = 4.77$) and the control group ($M = 19.33$, $SD = 5.27$) showed no significant difference ($t(58) = .57$, $p = .574$) between the groups. These results supported the hypothesis that empathy would be significantly higher in the clinical group compared to the control group. However the hypothesis that the same difference would be found in terms of self-esteem, was not supported.

Empathy and self-esteem as predictors of warmth/closeness and conflict

In the first stage of analysis, bivariate correlations between empathy, self-esteem, warmth/closeness and conflict were conducted to examine the relationship between these variables. These correlations are shown in Table 5. Group was not included in the correlation due to it being a categorical variable. Analysis using Pearson's *r* indicated that empathy was significantly positively correlated with warmth/closeness ($r = .46$, $p < .01$) and with self-esteem ($r = .67$, $p < .01$). Additionally, self-esteem was significantly positively correlated with warmth/closeness ($r = .27$, $p < .05$). Warmth/closeness was

significantly negatively correlated with conflict ($r = -.51, p < .05$). Subsequent univariate general linear model regression calculations (GLM) were conducted using empathy and self-esteem as predictor variables and warmth/closeness and conflict as separate dependent variables (as supported by the bivariate correlation results for warmth/closeness and conflict presented previously). This was in order to explore the hypotheses relating to the final aim of this study, namely whether empathy and self-esteem predict reports of warmth/closeness and conflict and whether interaction effects exist for these predictor variables with group (clinical or control).

Table 5

Correlation matrix for empathy, self-esteem, warmth/closeness and conflict

	Empathy	Self Esteem	Warmth/ Closeness
Empathy			
Self Esteem	.670**		
Warmth/Closeness	.455**	.266*	
Conflict	-.242	-.100	.509**

Note: $N = 60$; * $p < .05$; ** $p < .01$

A univariate general linear model (GLM) regression calculation was conducted using warmth/closeness as the dependent variable, with empathy and self-esteem incorporated as predictors. Interactions between group (clinical or control) and both empathy and self-esteem were included within this initial regression model. Interactions between group and empathy and group and self-esteem, were explored to see if being in

either group resulted in a stronger predictive effect of levels of empathy or self-esteem on levels of warmth/closeness. Group did not significantly influence the effect of empathy on warmth/closeness ($F[1,54] = .79, p = .379$) or the effect of self-esteem on warmth/closeness ($F[1,54] = 2.87, p = .096$). In order to simplify the main model, the GLM regression calculation was repeated, removing the non-significant interactions. In this simplified model, group was found to have no significant effect on levels of reported warmth/closeness ($F[1,56] = 2.77, p = .102$). Empathy was a significant predictor of warmth/closeness with a significant main effect displayed ($F[1,56] = 12.91, p = .001, \eta_p^2 = .19$). Self-esteem was shown to have no significant main effect on warmth/closeness ($F[1,56] = 0.56, p = .456$).

A univariate general linear model regression calculation was then conducted with conflict as the dependent variable, empathy and self-esteem as predictor variables, and interactions between group and empathy and group and self-esteem incorporated to explore the influence of group condition on predictive strength of empathy and self-esteem. Interactions between group and empathy and group and self-esteem, were explored to see if being in either group resulted in a stronger predictive effect of empathy or self-esteem on levels of conflict. Group did not significantly influence the effect of empathy on conflict ($F[1,54] = 0.87, p = .356$) or that of self-esteem on conflict ($F[1,54] = 3.05, p = .086$). The model was therefore simplified by removing these non-significant interactions. The simplified model showed that without these interactions, group had a significant main effect on conflict ($F[1,56] = 6.47, p = .014, \eta_p^2 = .10$). Empathy was also shown to have a main effect on reported conflict ($F[1,56] = 7.17, p = .010, \eta_p^2 = .11$). Self-esteem was not

shown to have a significant main effect on conflict ($F[1,56] = 1.29, p = .262$). Table 6 depicts the results of the simplified GLM regressions (See Appendix V for selected SPSS output).

Table 6

Univariate General Linear Model Regression for simplified models without interactions

Predictor Variable	<i>df</i>	<i>F</i>	η_p^2	<i>p</i>	<i>B</i>	<i>SE B</i>
Dependent variable: Warmth/Closeness						
Group	1	2.77	.05	.102	-.24	.14
Empathy	1	12.91	.19	.001**	.08	.02
Self-esteem	1	.56	.01	.456	-.01	.02
Dependent variable: Conflict						
Group	1	6.47	.10	.014*	.38	.15
Empathy	1	7.17	.11	.010*	-.06	.02
Self-esteem	1	1.29	.02	.262	.02	.02

Note: * $p < .05$; ** $p < .01$

So despite previous *t*-tests displaying no significant difference between the groups on warmth/closeness and conflict, these GLM calculations showed that when controlling for empathy and self-esteem, group did significantly predict conflict. The clinical group reported significantly higher levels of conflict in their sibling relationships than the control group did within this analysis. There remained no significant difference between the groups on the warmth/closeness variable when empathy and self-esteem were controlled for. These findings support the hypotheses of this study that predicted siblings of children with ADHD would report no significant differences in warmth/closeness but would report significantly higher conflict levels. The results indicate empathy does significantly predict warmth/closeness in terms of the overall sample, and indeed higher empathy predicted higher warmth. This predictive ability remained when the GLM calculation was simplified and self-esteem and group were controlled for. No difference in the nature of this predictive ability was displayed between the clinical and the control group. Empathy was also shown to predict conflict across the whole sample (higher empathy being associated with lower conflict), although this was a statistically significant predictor only when self-esteem and group were controlled for within the analysis. Empathy was therefore shown to predict reports of conflict, though again no difference in the nature of this predictive ability was displayed between the clinical and the control group. Self-esteem was not found to predict either warmth/closeness or conflict.

Overall as the interactions between group and self-esteem and group and empathy (for both dependent variables of warmth/closeness and conflict) were not statistically significant, this suggested the effects of empathy and self-esteem as predictors/moderators

of sibling relationship quality were no different between the clinical and the control group. This indicates empathy and self-esteem do not operate in the same way as moderators of perceived sibling relationship quality for siblings of children with ADHD as they appear to do in chronic illness literature.

Discussion

The aim of this study was to quantitatively examine potentially positive outcomes for siblings of children with ADHD and the quality of their sibling relationships. Siblings of children with ADHD reported significantly higher levels of empathy than the control group, but no significant differences in reports of self-esteem were found between the groups. Overall, sibling reports of warmth/closeness were not significantly different between the groups. Whether children had a sibling with or without ADHD was shown to have no significant influence on reported warmth/closeness, however the level of empathy reported was shown to have a predictive main effect on reported warmth/closeness over the whole sample (higher empathy scores meant higher reported warmth/closeness). This predictive effect was not however shown to be significantly different between the groups. Being a sibling of a child with or without ADHD did not affect the predictive nature of empathy on warmth. Self-esteem was not found to predict warmth/closeness, regardless of group. In terms of the amount of reported conflict within the sibling relationships, whether the sibling had a brother or sister with ADHD did significantly predict the amount of conflict a child reported in the sibling relationship. Siblings of children with ADHD reported higher mean levels of conflict, which was not shown to be significant in initial *t*-

tests but group was found to be a statistically significant predictor when empathy and self-esteem were controlled for within the univariate model of analysis. Being the sibling of a child with or without ADHD did not influence the predictive nature of either empathy or self-esteem on conflict. Empathy predicted the amount of conflict reported for the sample overall (higher empathy scores meant lower levels of conflict reported), but was only a statistically significant predictor when self-esteem and group were controlled for.

The findings of the current study supported the hypothesis regarding warmth/closeness which suggested siblings of children with ADHD would report no significant differences in this factor in comparison to a control group. This replicates the findings of Mikami and Pfiffner (2007) who also found that siblings of children with ADHD displayed no significant differences in the warmth/closeness reported. The hypothesis that siblings of children with ADHD would report higher levels of conflict was also supported by the univariate analysis, when empathy and self-esteem were controlled for. This could be explained in one of two ways. Firstly it is possible that a genuine difference between groups on conflict does exist, but that it is hidden by the confounding effects of empathy and self-esteem if they are not adjusted for within the analysis. Secondly, it could indicate that the statistical significance between the groups on conflict is relatively small and only detected in some analyses. This would require replication with a larger sample in order to test this or to make any firm conclusions regarding the implications of such a finding. However the results of this study are generally in line with the findings of Mikami and Pfiffner (2007) who found higher levels of conflict reported by siblings of children with ADHD. It also supports the findings of other studies in the area of

ADHD research that suggests relationships between siblings where one child has ADHD are conflictual (e.g. Kendall, 1999; Greene et al., 2001; Mash & Johnston, 1983 and is also in line with findings in the area of childhood autism (Hastings, 2003). Importantly the current study found evidence of this increased conflict in comparison to a control group, rather than assuming any reports of conflict indicated problems or difficulties in itself. This is especially important considering observations that sibling relationships generally are often a source of conflict for children and that this is not always harmful in terms of psychosocial development (e.g. Dunn & Munn, 1985). What is interesting to observe in the current study is that the existence of conflict seems not necessarily to denote the absence of warmth/closeness within the relationship, as demonstrated by the fact siblings of children with ADHD displayed no significant differences in warmth/closeness compared to a control sample despite this relative elevation in conflict. This is line with researchers and authors in the field who suggest that sibling relationships may equally display both negative and positive facets (e.g. Ross et al., 1994) and that relationship-based constructs such as warmth and conflict can be relatively independent (Furman & Buhrmester, 1985) and not mutually exclusive. So few studies have been conducted regarding the quality of sibling relationships where one child has ADHD, that it is necessary to consider the findings of this study in the wider research context of sibling disability. Several studies have documented that most relationships between siblings of children with disabilities and their siblings are positive (e.g. Bagenholm & Gillberg, 1991; Kaminsky & Dewey, 2001; Rivers & Stoneman, 2003) and such findings have been replicated across a range of research modalities such as sibling report (Cuskelly & Gunn, 2003; McHale & Gamble, 1989; Roeyers & Mycke, 1995),

observations of siblings (Lobato, Miller, Barbour, Hall & Pezzullo, 1991) and parental report (McHale & Gamble, 1989). Whilst this study has not identified that this relationship is necessarily more positive when one child has ADHD, it does indicate the possibility that there are at least no differences in the warmth/closeness of the relationship experienced by these children and comparison siblings. Most importantly perhaps, the findings of the current study suggest even though these relationships can be more conflictual, they can still be equally as warm and close as those of children of siblings without ADHD. In the domain of childhood disability more generally, researchers have found either less conflict than that experienced by comparison siblings (Kaminskey & Dewey, 2001; McHale & Gamble, 1989) or no differences in conflict (Brody, Stoneman, Davis & Crapps, 1991; Stoneman, Brody, Davis & Crapps, 1987; 1989). The results of the current study, whilst contradicting the findings highlighted here for siblings of children with intellectual disabilities or physical disabilities, support the findings of researchers such as Mikami and Pfiffner (2007) suggesting that sibling relationships where one child has ADHD are indeed characterised by more conflict. It could be that the specific characteristics of children with ADHD make conflict within this relationship more likely, than those displayed by children with other difficulties. Examples of this were highlighted earlier in terms of the difficulties in making relationships (Zager, 1999), increased evidence of aggressive behaviours (Mrug et al., 2001) and perhaps the inattentive or externalising behaviours associated with the disorder.

As predicted, it was found that siblings of children with ADHD reported higher levels of empathy than children in the control group. This finding however did not extend to self-esteem as hypothesised, as there were no significant differences between the groups

in this domain. Empathy has not been researched in the area of sibling ADHD to the best of the researchers' knowledge, so again it is necessary to draw comparisons with other sibling literature. Empathy has been most extensively researched in the domain of chronic illness and several studies in this area have documented that siblings of children with cancer (Faux, 1991) or cystic fibrosis (Harder & Bowditch, 1982) for example, display higher levels of empathy than comparison siblings. The findings of the current study are therefore consistent with several studies in the area of sibling chronic illness and suggest that positive outcomes such as empathy can be extended from the field of chronic illness to ADHD. The lack of a significant between-group finding in the domain of self-esteem does not support the hypothesis that siblings of children with ADHD may display higher levels of self-esteem than a control group. This hypothesis was based primarily on findings of studies involving siblings of children with autism (Macks & Reeve, 2007; Kaminsky & Dewey, 2002). Studies in the domain of childhood disability have shown no differences in self-esteem, self-concept or perceived competence between such siblings and comparison siblings (e.g. Bäckholm & Gillberg, 1991). This suggests that the impact upon a siblings' self-esteem when their sibling has ADHD may potentially be more comparable to the experience of a sibling of a child with disability as opposed to autism. It may be possible that the experience of having a sibling with autism promotes different outcomes in comparison to having a sibling with a developmental disorder such as ADHD. Macks and Reeve (2007) suggest that autism is different to other disorders in terms of its level of complexity, unpredictability and perceived inexplicability. Indeed ADHD in turn could also be different to autism and other disorders in terms of the potentially unique impact of the

condition on a sibling's development. Further research involving comparison groups of such siblings would need to be conducted before this could be ascertained. It could be that the positive impact on traits such as self-esteem develop longitudinally over time when in relation to growing up with a sibling with ADHD. However it is important to note that although siblings of children with ADHD did not report higher levels of self-esteem than a control group, they displayed no significant differences in relation to this variable. Indeed children in both the clinical and the control group obtained self-esteem scores within the 'normal' range cited for this measure (Rosenberg, 1965). This suggests that having a sibling with ADHD does not appear to have a detrimental effect on a child's self-esteem and this in itself could be considered a positive outcome considering the higher conflict levels reported.

It was found that empathy predicted reports of warmth/closeness and conflict for the sample overall but that self-esteem did not influence warmth/closeness or conflict in this way. In terms of interactions, it was found that whether a child had a sibling with or without ADHD did not predict levels of warmth/closeness reported, but did predict the conflict reported when empathy and self-esteem were controlled for (siblings of children with ADHD reporting higher conflict). The same points highlighted earlier for the predictive effect of group on conflict need to be considered and replication with a larger sample would be recommended to explore why this occurred. Overall the current study's finding for empathy fits with the findings of Labay and Walco (2004) who found empathy to significantly predict adjustment difficulties in well siblings of children with cancer, if sibling relationship quality is conceptualised as a relevant contextual adjustment. Self-

esteem has not been explored in this way in terms of its predictive effect and the current study would suggest that self-esteem does not influence how a child perceives and experiences their sibling relationship in the domains studied.

Overall the current findings lend support to Furman and Buhrmester's (1985) model generally, and also to the potential applicability of this model to sibling relationships where one child has ADHD. The current study suggests that empathy as an individual characteristic of a child does have a relationship to how the quality of the sibling relationship is perceived by that sibling. Not only does it appear to positively influence reports of warmth/closeness and conflict overall (i.e. for the whole sample), it can be seen as a potential outcome of sibling relationships where one child has ADHD due to the significantly higher reports of empathy for these siblings. Interestingly, the influence of empathy on reports of sibling relationship quality were found to work in the same way for siblings of children with ADHD as for the control sample, suggesting this model can also be applied to siblings of children with disorders such as ADHD as well as 'typical' sibling dyads. Self-esteem however does not appear to be an individual characteristic with such a strong influence on the perception of sibling relationships. It is possible that self-esteem, as considered earlier, has more of a 'buffering' or protective function rather than being an outcome of such relationships, and further studies could investigate this further in terms of whether children with higher levels of self-esteem go on to experience less conflict/difficulties in their relationships with their sibling with ADHD over time. The cross-sectional nature of this study may have prevented this long-term protective function being evidenced here.

Clinical Implications

The findings of this study suggest that the general picture for siblings of children with ADHD does not need to be a negative one. Siblings who had a brother or sister with ADHD not only rated areas of warmth/closeness and self-esteem no differently (in terms of significance) to siblings of children without ADHD; they also displayed a positive outcome of higher empathy levels than that reported in the control group. This was despite the higher levels of conflict reported. Previous research in the domain of ADHD has the potential to suggest a negative impact for siblings in terms of psychopathology and conflictual sibling relationships, but this research suggests this may not necessarily always be the case and even then, that the existence of conflict does not necessarily exclude positive outcomes for that child. These results suggest data should be collected on positive as well as negative outcomes in terms of both the sibling and wider family experience and to raise awareness of the potential for psychosocial growth even in the face of difficulty. A greater focus on these transformational outcomes for siblings and the wider family will allow children and families who may be struggling in these circumstances, to learn from those who are thriving and doing well. The clinician can most usefully be the conduit for this process.

Considering the sibling relationship itself as the context of adjustment and the quality of this as an outcome in its own right, allows for better systemic understanding of how such conditions impact on siblings. Traditionally siblings have either been largely ignored in the research (Ferrari, 1984) or only their negative symptoms have been explored and related to having a sibling with a condition such as ADHD. This research attempted to

begin to understand what contributes to a sibling experiencing this relationship positively and thriving within that context, and what contributes to siblings finding this a difficult experience. Researchers have identified this as the single most important next step in terms of the clinical application of such research (Hastings, 2003; Stoneman, 2005). Most importantly of all is how such research translates into informing the support given to siblings. Interventions to help support siblings of children with chronic illness and developmental disorder have not been rigorously evaluated and are often provided based on facilitators' assumptions of what the issues are for these children (Wilson & Bowyer-Crane, in preparation). Strengthening the evidence base around what contributes to children doing well may feed into more empirically validated intervention strategies and thus give siblings who are struggling more effective support. This may enable a focus on strengthening siblings' existing resources rather than assuming a deficit-based approach. One such resource may be the sibling relationship itself, given its influence on psychosocial development, and interventions in this arena may also be a useful focus for future research and clinical application.

Limitations

Research findings and conclusions need to be considered in the context of study limitations. These focus around three areas of design, sampling and measurement techniques. The cross-sectional methodology utilised disallows firm conclusions regarding cause and effect. It is possible factors other than whether the child had a sibling with or without ADHD influenced the results found. Use of a longitudinal design would allow examination of empathy, self-esteem and sibling relationship quality over time as children

enter different developmental stages and more adequately pick up on the dynamic nature of sibling relationships, illness, and adaptation processes in families over time (Bradford, 1997). Sampling relied on participants contacting the researcher meaning the sample was open to volunteer bias thus limiting generalisability (Barker, Pistrang & Elliott, 2002). This was compounded by the fairly low response rates obtained in this study, which were most noticeable in the control group. In this case, parents in the clinical group who responded may have been more interested in the issues and needs for their children without ADHD and thus have supported them accordingly over time. A random, stratified sample would have been more representative of the population of interest, but was beyond the scope of the current study to achieve in terms of time scales and access to large enough representative populations. The external validity of the findings may be compromised by other confounding variables within the sample. Although the clinical and control groups did not differ on sibling age, gender, birth order and other demographic variables identified earlier in this paper, there may have been other potentially confounding variables. A full assessment of socio-economic status was not conducted and this has been shown within research to have a significant impact on how families cope with having a child with a disability or disorder such as ADHD (Johnston & Mash, 2001), which is in turn likely to impact on how siblings cope. Maternal mental health, parental stress and coping have all been shown to have an impact on sibling adjustment for chronic illness (for a review see Houtzager et al., 1999) and, in the case of ADHD, the externalising behaviours of the child with ADHD have been shown to be influential (Mikami & Pfiffner, 2007). Time since diagnosis has also been considered as an important factor in how siblings of children with

chronic illness adjust and to have an impact on family relationships (e.g. Schuler et al, 1985). In this study, time since diagnosis varied considerably throughout the sample which may have introduced a confounding variable, potentially influencing the results. Although comorbidity was reported where applicable for five siblings of children in the clinical group, this was not included as a variable within the analysis which leaves the possibility for a confounding effect. However it is reported that most studies do not often document comorbidities (Barkley, Fischer, Edelbrock & Smallish, 1991) despite the high prevalence in ADHD, so acknowledgement of comorbidities could be considered a strength in the current study. Finally, ethnicity may be an issue with regards to the samples included in the current research. Most sibling research tends to comprise convenience samples of predominantly white middle class families and the majority of participants in this study classed themselves as 'white' when asked to choose the category they felt represented their ethnicity. It is important to move such research forwards to consider and begin to understand how cultural factors interact with personal and situational factors.

The final area of limitation concerns measurement methods utilised in this study. Self-report measures were used to gain insight and understanding into the undiagnosed siblings' experiences. It has been suggested that in terms of rating sibling relationship quality, siblings actually report this more representatively than parents who may often produce more negative conceptualisations of the impact on their undiagnosed child. Conversely, parents who are less focused on the impact upon siblings may minimise the potential effects. However triangulation of data would lead to more reliable and valid results (Barker et al., 2002) such as getting reports of siblings' relationship quality and

ability to empathise with others for example corroborated by others or by using observational techniques, would increase the reliability and minimise risk of socially desirable responses influencing results. It would be important to find a balance between ways to minimise this limitation by gathering data from multiple sources, whilst still fully capturing the experiences of children who have a brother or sister with ADHD.

Areas for further research

As highlighted in this paper, sibling relationships in the field of ADHD research have to date only produced limited research. This study was one of the first to systematically study both positive and negative experiences and outcomes for siblings of children with ADHD and to begin to identify what variables may predict these outcomes. This has provided a baseline for further research which needs to continue to expand to increase knowledge and understanding of the experiences of siblings of children with ADHD to a level comparative with chronic illness or even autism. Specific advances for this area of research would be the inclusion of longitudinal design studies to look at sibling relationships over time, perhaps even into adulthood, to understand the long term implications on psychosocial development. Larger samples to obtain enough statistical power to incorporate variables involving wider family context, socio-economic status, ethnicity and also variables relating to the sibling such as level of externalising behaviours and comorbidities would be useful expansions to the current study. This would also enable issues identified earlier around why empathy and group predicted conflict only when the other variables were controlled for, to be addressed. Future studies should also focus on the experience of the sibling with ADHD and the reciprocal nature of this relationship as the

social, personality and cognitive characteristics of both children are likely to define and shape the sibling relationship. Going back to Furman and Buhrmester's (1985) model of sibling relationship quality, it would be useful to consider specifically how the characteristics of the child with ADHD impact upon the quality of the sibling relationship, on parent-child relationships and the management of sibling relationships by parents. The focus of future research needs to be on developing and testing coherent and robust models for understanding sibling adjustment, which will integrate research findings and provide a framework within which research can move forwards.

Conclusions

This study indicated that siblings of children with ADHD showed higher levels of both empathy and conflict in sibling relationships than a control group, but did not show any significant differences in the areas of warmth/closeness or self-esteem. Whether a child had a sibling with or without ADHD predicted the level of conflict the sibling reported within the sibling relationship when empathy and self-esteem were controlled for, but did not predict the level of warmth/closeness that the child experienced. Empathy predicted warmth/closeness overall and it was found that higher levels of empathy were associated with higher self-esteem, greater warmth and lower conflict in sibling relationships. Self-esteem had no such predictive quality. Clinical implications include the importance of not neglecting to assess or acknowledge sibling issues when supporting families of children with ADHD, whilst also acknowledging that siblings may still benefit positively from this relationship. This does not however mean that these strengths protect them from negative feelings. Experiences of conflict may be commonplace but do not appear to negate the

positives gleaned from such experiences. More comparable research on a larger scale and with a longitudinal design is needed to clarify the nature of the experiences for siblings of children with ADHD and ensure that such findings are related to the disorder itself and not other confounding variables.

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Part 3

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Appendix A: Guidelines for the Authors for the Systematic Literature Review



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Clinical Psychology Review

Guide for Authors

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Siblings of children with ADHD, chronic illness and developmental disorder

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For Books: Hersen, M. (Ed.). (2005). Comprehensive handbook of behavioral assessment (2 Volumes). New York: Academic Press (Elsevier Scientific).

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Appendix B: Guidelines for Authors for the Empirical Paper

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Child Development considers manuscripts in formats described below. Inquiries concerning alternative formats should be addressed to the Editor prior to submission. All submissions are expected to be no more than 40 manuscript pages, including tables, references, and figures (but excluding appendices). Authors should provide a justification if the submission is substantially longer. Unless the Editor finds that justification compelling, the submission will be returned to the author for shortening prior to editorial review.

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Empirical reports are reserved for short cutting-edge empirical papers that are no longer than 4000 words in length (including text, tables, footnotes, appendices), which advance research and knowledge in an area through noteworthy findings and/or new methods. For manuscripts that require longer descriptions of methods and results, authors should use the Empirical article format.

Reviews focus on past empirical and/or on conceptual and theoretical work. They are expected to synthesize or evaluate a topic or issue relevant to child development, should appeal to a broad audience, and may be followed by a small number of solicited commentaries.

Essays describe original concepts, methods, trends, applications, and theories; these may also be accompanied by solicited commentaries.

Child Development and ... are articles that provide readers with tutorials about some new concept or academic specialty pertinent to research in child development. These papers should review the major definitions, methods, and findings of the concept or specialty and discuss past or potential links to child development.

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Appendix C: Downs & Black (1998) Quality Checklist
 (Items added by reviewer highlighted in bold)

Study Title _____ Rater _____

	Question	Yes	No	N/A	Rater Comments
1	Is the hypothesis / aim / objective of the study clearly described?				
2	Are the main outcomes to be measured clearly described in the Introduction or Methods section?				
3	Are the characteristics of the patients included in the study clearly described?				
4	Are the interventions of interest clearly described?				
5	Are the distributions of principal confounders in each group of subjects to be compared clearly described?				
6	Are the main findings clearly described?				
7	Does the study provide estimates of the random variability in the data for the main outcomes?				
8	Have the characteristics of patients lost to follow-up been described, if applicable?				
9	Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?				
10	Were subjects asked to participate in the study representative of the entire population from which they were recruited?				
11	Were those subjects prepared to participate in the study representative of the entire population from which they were recruited?				
12	Was an attempt made to blind study subjects to the intervention they received?				
13	Was an attempt made to blind those measuring the main outcomes of the intervention?				
14	If any of the results of the study were based on 'data dredging' was this made clear? (i.e. retrospective unplanned analyses)				
15	In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls? (if differences in follow-up are ignored, state 'no').				
16	Were the statistical tests used to assess the main outcomes appropriate?				
17	Was compliance with the interventions reliable?				
18	Were the main outcome measures used accurate? (valid and reliable)				

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19	Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies), recruited from the same population?				
20	Were study subjects randomised to intervention groups?				
21	Was the randomised intervention assignment concealed from both patients and staff until recruitment was complete and irrevocable?				
22	Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?				
23	Were losses of patients to follow-up taken into account?				
24	Did the study report a power calculation?				
25	Did the study use a control group?				
26	Was there an attempt to match the control group with the clinical group on important clinical / demographic variables?				

Appendix D: Review Data Collection Form

Author(s)	
Title of study and year of publication	
Research aims	
Target population	
Participants – gender	
Participants – age	
Sample size	
Research design/methodology	
Methodological quality (as assessed by checklist)	
Theoretical model specified	
Intervention used (aims/focus, name of programme if relevant, number of conditions, content of intervention package, theoretical model if specified, duration of intervention, delivery mode of intervention, any mediating variables specified)	
Outcome measures (method of measurement, direct/indirect, who completed, what measured, when measured – baseline/post intervention, reliability and validity of measures reported?)	
Statistical analysis (techniques, any follow up data included)	
Main findings	
Conclusions (both authors and reviewers e.g. limitations of method, sample etc)	

Appendix E: Table A – Information on Excluded Studies

Study	Reason for exclusion
Adams-Greenly et al. (1986)	No standardised outcome measure
Bendor et al. (1990)	No standardised outcome measure
Carpenter et al. (1990)	Same intervention, data set and outcome variables as Sahler & Carpenter (1989).
Chinitz (1981)	No standardised outcome measure No empirical analysis of data, only description
Cunningham et al. (1981)	No standardised outcome measure
Dyson (1998)	No standardised outcome measure
Gaudet & Powers (1989)	No outcomes for siblings considered No sibling specific component to intervention Family focus involved parents only
Hastings (2003)	No sibling specific component to intervention
Howlin & Yates (1990)	No standardised outcome measure
Kazak et al. (2005)	No standardised outcome measure No sibling specific component to intervention
Kiernan et al. (2004)	No sibling specific component to intervention
Kinrade (1985)	No standardised outcome measure
Kramer & Moore (1983)	No standardised outcome measure
Lopez et al. (2005)	No sibling specific component to intervention Family focus involved parents and children with ADHD only
Packman et al. (2008)	No standardised outcome measure
Schriebman et al. (1983)	No sibling-specific component to intervention No outcomes for siblings considered, just for their autistic brothers and sisters
Wellisch et al. (2006)	No sibling-specific intervention documented

Note: For clarity only the main reasons for exclusion are documented

Appendix F: Letter to head teachers (control group) [On University Headed Paper]

Claire Wilson
Trainee Clinical Psychologist and Researcher
Department of Clinical Psychology
Hertford Building
University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: 01482 464101
Email:

Dear Headteacher,

I am currently studying for a Doctorate in Clinical Psychology at the Department of Clinical Psychology at the University of Hull. As part of my qualification to become a Clinical Psychologist, I am conducting a piece of research looking at sibling relationships. I am writing to Head teachers of primary and secondary schools to request help with accessing participants between the ages of 8 and 13. I have a current valid full CRB check as part of my employment with the Humber Mental Health Teaching NHS Trust and would be happy to send out further confirmation of this if you require.

This research aims to examine the experiences of siblings of children with a diagnosis of Attention-Deficit Hyperactivity Disorder (ADHD). It is widely accepted that sibling relationships play a significant role in the psychological and emotional development of children but there is little research into how siblings of children with ADHD are affected by this relationship. However, there is often a focus within research on the child with a diagnosis of ADHD and far less attention is paid to the impact this relationship can have on siblings. We would like to find out more about these siblings' experiences and how this might differ from those where neither child has such a diagnosis. By conducting research in this area we hope to be able to develop clinical services and enable greater understanding of the effects that having a child with ADHD can have on the wider family. In order to do this effectively we need to look at sibling relationships where neither child has ADHD, as a comparison group. It is hoped that information gained from such research will allow services to support families and siblings more effectively in the future. It will also contribute to the wider literature on sibling relationships in general.

I am writing to request your permission to ask families from your school to take part. This would help us greatly in obtaining participants who have siblings where neither child has a diagnosis of ADHD.

If you agree to the research taking part at your school, I would like the opportunity to visit the classes that include children between the ages of 8 and 13 and briefly explain the research to them and what would be involved should they choose to participate. I would expect to take up no more than 10 minutes of class time in each instance. This would also allow me to distribute letters for the children to take home to their parents with attached slips to return if parents or children would like more information about the study.

Should interested parents return the slips to myself, they will be sent out information sheets (for both parent and child) to their home address detailing the study, its rationale and what involvement would entail.

Parents/carers/guardians would be invited to send back the slips to myself if they wished their child to take part. They would be given my contact details as the main researcher for this project so they could ask any questions either they or their child had, prior to consenting to take part. All correspondence from potential participants and their families will be sent directly to myself as the researcher, and not to the school. The school's role in the research would primarily be to allow letters to be handed out to children by the researcher and to allow the researcher to attend appointments at the school with families where this is agreed. If both parent/carer/guardian and child gave agreement to take part, I would offer to see the child in school (if you gave agreement for this), at the research base (The University of Hull) or at their home if they prefer. If appointments were allowed to take place at school a private room would be needed so that interviews could take place in confidentiality.

In the case of a school appointment, I would offer a one hour appointment for each child participating and the parent would also be invited to attend. Their participation would involve both parent and child filling in some questionnaires with me for around thirty minutes, with the remaining time being available for answering any questions they may have. Both parent and child taking part will have questionnaires to fill in. Should the parent prefer that I see the child at school but are unable to attend themselves, the questionnaires for the parent will be sent home to them with a request they return them to myself. I shall enclose a stamped addressed envelope in parental questionnaire packs for this purpose.

Thank you for taking the time to read this letter. If you have any questions or would like to discuss this further, please do not hesitate to contact me on the above number.

We will telephone you within 2 weeks of sending this letter to give you the opportunity to discuss any queries you may have.

Yours sincerely,

Claire Wilson
Trainee Clinical Psychologist and Researcher

An ethics committee reviews all proposals for research involving human participants before they can proceed. The Local Research Ethics Committee reviewed and approved this research.

Appendix G: Initial letter to parents (control condition) [On University Headed Paper]

Claire Wilson (Trainee Clinical Psychologist and Researcher)
Department of Clinical Psychology
Hertford Building
University of Hull
Hull
HU6 7RX

Tel: 01482 464101

Email:

An investigation into the experiences of brothers and sisters of children with and without Attention-Deficit Hyperactivity Disorder (ADHD)

Dear Parent/Carer/Guardian,

As part of my qualification to become a clinical psychologist, I am currently carrying out some research with families in the local area. This research aims to look at the experiences of brothers and sisters of children with a diagnosis of ADHD (Attention-Deficit Hyperactivity Disorder) and to find out more about how children feel about these relationships. ADHD is a developmental disorder characterised by core difficulties of inattention, over-activity and impulsivity. The impact on families of having a child with ADHD can be immense. To understand this experience a bit better we also need to talk to children who have a brother or sister who does not have ADHD so we can compare the results. We are particularly interested in talking to children aged between 8 and 13 who have at least one brother or sister. Ideally the age gap between the child taking part and their sibling should be no more than 3 years.

I would be very grateful if you and your child could help me with my study by completing some questionnaires. These questionnaires cover areas such as feelings about themselves and others, brother/sister relationships, and behaviour and should take no more than 30 minutes of your time, with an additional 30 minutes allocated for any questions you may have. I can offer appointments at your home, at your child's school, or at the University of Hull where the research is based, depending on your preference. If the appointment is at school, you have the option to attend with your child or to complete the forms at home and return them by post.

If you are interested in taking part please fill in the slip at the bottom of this letter and send it back to me in the envelope provided. I will then send you out information sheets for both you and your child, detailing the study further. If you and your child agree to participate in the study, you will be given a consent form to sign for yourself and your child's participation. If you would like to take part but are unable to attend an appointment in person, please contact me to confirm your understanding of the study and ask any questions. I will then send a consent form to you which you will need to complete and return before your child can participate. There will also be time during appointments for you or your child to ask me any questions you may have prior to starting the questionnaires with me.

Siblings of children with ADHD, chronic illness and developmental disorder

Please feel free to contact me on the above number/email to discuss any queries you or your child may have about the project, or to make an appointment to see me.

Yours sincerely,

Claire Wilson
Trainee Clinical Psychologist and Researcher

An ethics committee reviews all proposals for research involving human participants before they can proceed. The Local Research Ethics Committee reviewed and approved this research.

Please return the slip below in the envelope provided if you wish to be sent more information about this study. This will not oblige you to take part in any way. The researchers will not contact you using these details as if you are interested in participating you will be invited to contact us on the letter sent out with the information sheets.

Yes - I would like to find out more information about this study. Please send information sheets for myself and my child to the following address:

Name:

Address:

.....

.....

.....

Postcode:

School child attends

Appendix H: Ethics Committee Approval

Removed for hard binding

Appendix I: Trust Research Governance Approval

Removed for hard binding

Appendix J: Initial Contact Letter (clinical group) [On University Headed Paper]

Claire Wilson (Trainee Clinical Psychologist and Principal Investigator)
Department of Clinical Psychology
Hertford Building
University of Hull
Hull
HU6 7RX

Tel: 01482 464101
Email:

An investigation into the experiences of children who have brothers or sisters with and without ADHD (Attention-Deficit Hyperactivity Disorder)

Dear Parent/Carer/Guardian,

As part of my qualification to become a clinical psychologist, I am currently carrying out a research study with families using local charity and NHS services in the local area. I am contacting you as you have given permission to be contacted for research purposes. This does not however mean you are obliged to take part. Please read the following letter before you make any decisions. Your decision will not affect any current or future care within the NHS, support from the charity, or affect your place on the waiting list for any services. You only need to contact me if you do wish to take part.

This research aims to look at the experiences of children who have a brother or sister diagnosed with ADHD (Attention-Deficit Hyperactivity Disorder). The aim is to find out more about how individual children perceive that relationship and what factors may help them view this relationship more or less positively. We are also speaking to children who have siblings without the condition to compare the results. I would be very grateful if you and your child could help me with my study by completing some questionnaires. These questionnaires cover areas such as your child's feelings about themselves and other people, brother/sister relationships and should take no more than one hour of your time. I can offer appointments at your home or at the University of Hull where the research is based, depending on your preference. If you are interested in taking part please fill in the slip at the bottom of this letter and send it back to me in the envelope provided. I will then send you out information sheets for both you and your child, detailing the study further. If you and your child agree to participate in the study, you will be given a consent form to sign for yourself and your child's participation. There will be time during the appointment to ask me any questions you may have prior to starting the questionnaires.

Siblings of children with ADHD, chronic illness and developmental disorder

Please contact me on the above number/email to discuss any queries you or your child may have about the project, or to make an appointment to see me.

Yours sincerely,

Claire Wilson
Trainee Clinical Psychologist and Researcher

An ethics committee reviews all proposals for research involving human participants before they can proceed. The Local Research Ethics Committee reviewed and approved this research.

Please return the slip below in the envelope provided if you wish to be sent more information about this study. This will not oblige you to take part in any way. The researchers will not contact you using these details as if you are interested in participating you will be invited to contact us on the letter sent out with the information sheets.

Yes - I would like to find out more information about this study. Please send information sheets for myself and my child to the following address:

Name:

Address:

.....

.....

.....

Postcode:

Appendix K: Parent letter [On University Headed Paper]

(both groups, to be enclosed with information sheet)

Claire Wilson (Trainee Clinical Psychologist and Researcher)
Department of Clinical Psychology
Hertford Building
University of Hull
Hull
HU6 7RX

Tel: 01482 464101

Email:

An investigation into the experiences of brothers and sisters of children with and without Attention-Deficit Hyperactivity Disorder (ADHD)

Dear Parent/Carer/Guardian,

Thank you for requesting further information about the above study. Enclosed with this letter is an information sheet for parents, explaining more about the study. There is also a letter for your child and an information leaflet for them which you may wish to go through with them. This will give you information about why we are doing the study and what would be involved should you choose to participate. Please ensure both you and your child have read these sheets to help you make your decision.

Please contact the researcher on the above telephone number or email address if you wish to discuss any aspect of the research further, or if you would like to take part.

Yours sincerely

Claire Wilson (Researcher)

Trainee Clinical Psychologist
Department of Clinical Psychology
The University of Hull.

Appendix L: Child Letters [On University Headed Paper]

Letter for control group

Would you like to take part in our study?

Title of study: **An investigation into the experiences of brothers and sisters of children with and without Attention-Deficit Hyperactivity Disorder (ADHD)**

By receiving this letter, you and your parent are being asked to consider taking part in a research study.

This study is looking at the relationships between brothers and sisters. We are contacting brothers and sisters of children with ADHD (Attention-Deficit Hyperactivity Disorder) to find out more about their relationships. We also need to speak to children like you who have a brother or sister who **doesn't** have ADHD.

Before you decide if you want to take part or not, it is important for you to understand why the study is being done and what it will involve if you agree to take part. Attached to this letter is an information sheet which explains the study a bit more. If you think you might like to take part, please read the information sheet to help you decide. You can talk to other people, like your parents, to help you decide too. Your parents have got a separate letter and information sheet to help them decide about taking part.

If there is anything else you would like to know please ask your parent to contact me. My details are on the bottom of the information sheet for parents.

Thank you for reading this letter.

Yours sincerely,

Claire Wilson
Trainee Clinical Psychologist and Principal Researcher
Department of Clinical Psychology
University of Hull.

Appendix L: Child Letter
Letter for clinical group

Would you like to take part in our study?

Title of study: An investigation into the experiences of brothers and sisters of children with and without Attention-Deficit Hyperactivity Disorder (ADHD)

By receiving this letter, you and your parent are being asked to consider taking part in a research study.

This study is looking at the relationships between brothers and sisters. We are contacting brothers and sisters of children with ADHD (Attention-Deficit Hyperactivity Disorder) to find out more about their relationships. We would like to speak to you because you have a brother or sister with ADHD.

Before you decide if you want to take part or not, it is important for you to understand why the study is being done and what it will involve if you agree to take part. Attached to this letter is an information sheet which explains the study a bit more. If you think you might like to take part, please read the information sheet to help you decide. You can talk to other people, like your parents, to help you decide too. Your parents have got a separate letter and information sheet to help them decide about taking part.

If there is anything else you would like to know please ask your parent to contact me. My details are on the bottom of the information sheet for parents.

Thank you for reading this letter.

Yours sincerely,

Claire Wilson
Trainee Clinical Psychologist and Principal Researcher
Department of Clinical Psychology, University of Hull.

Appendix M: Information sheets
Parent Information Sheet Control Group

An investigation into the experiences of brothers and sisters of children with and without Attention-Deficit Hyperactivity Disorder (ADHD)

Information Sheet

This research study is being done as part of an educational qualification jointly with the University of Hull Doctorate in Clinical Psychology course and the Humber Mental Health Teaching NHS Trust.

What is the study about?

This study is aiming to examine the experiences of brothers and sisters of children with Attention-Deficit Hyperactivity Disorder (ADHD). It has been found that relationships between brothers and sisters play an important part in children's development, but there is little research looking at how brothers and sisters of children with ADHD are affected by this experience. To help us to research this area, we also need to look at the experiences of children who have a sibling with no diagnosed disorder or problems such as ADHD. This will help us to make comparisons and look at the wider experience for children who have a sibling.

What is ADHD?

ADHD is short for a condition called "Attention-Deficit Hyperactivity Disorder". This is a condition characterised by core difficulties of inattention, over-activity, and impulsivity. There are many different theories as to the causes of ADHD but it is considered most probable that a variety of biological and psychosocial factors interact in complex ways to give rise to the condition. The impact on families of having a child with ADHD can be immense.

Why is this study being done?

By conducting research in this area we hope to be able to develop clinical services and enable greater understanding of the effects that having a child with ADHD can have on the wider family. It is hoped that this information will allow services to support families and children more effectively in the future. To do so it is important we gain information from as many families as possible. It may also further understanding of the influence of sibling relationships in general if we include children who have siblings who do not have diagnosed problems such as ADHD.

What would it involve?

It is up to you and your child to decide whether you wish to take part in this study. Your child has been given a separate information sheet which you can read with them if you wish. If you decide to take part, we will give you a consent form to sign. You and your participating child will be asked to complete some questionnaires on one occasion, which

will cover a variety of issues such as feelings about themselves and others, behaviour, and positive or more challenging parts of the relationships between your children. The appointments will be one hour in duration and will allow time for any further questions you may have, both before and after completing the questionnaires. You and your child can attend this appointment together either at school, the University of Hull (the research base) or at your home if you prefer. If you wish, your child can attend the appointment at school and we can send your questionnaires home to you.

How will this study help my family?

We cannot promise any immediate benefits for your family from this study. However we hope to improve our ability to help different families in the future. We aim to gain a better understanding of what it is like for a child without ADHD to have a brother or sister with the condition and it is hoped that furthering this understanding will help services supporting the wider family of children with ADHD. We can only do this properly if we can talk to children who have a sibling without the condition so we can see how the experience is different.

Is there anything I should be concerned about if we take part?

The questionnaires used are not designed to raise uncomfortable issues or painful feelings for either you or your child. However every individual will experience different feelings about their family and relationships. If either you or your child were to experience distress as a result of completing the questionnaires, you would be welcome to discuss this with me and if I had any significant concerns about your welfare as a result, I would raise relevant matters with key people involved in your family's care.

Our study needs to make sure that the participating child and their sibling do not have ADHD to ensure this group is different to the ADHD group. This will be done with questionnaires for yourself as the parent to complete and will involve thinking about some of the behaviours your children display in everyday life. If we found your child to have some of the symptoms indicating they may have ADHD we would discuss this with you and give you appropriate information to decide what you wanted to do about this. We would not inform any people involved in your child's care unless you expressly wished us to do so and we would not include your data in the research. However the questionnaire involved will not be used to provide a diagnosis of ADHD and is used only as a screening measure to give general indication of levels of behavioural difficulties.

What will happen to the information we give you?

If you decide to take part in the study any information gathered or anything you told us about will be kept strictly confidential and will not be traceable back to yourself or your family. The only exception to this would be if areas of concern about harm to yourself or your children arose from your participation in the research when we would have to inform an appropriate person. If you do decide to take part you are still free to withdraw at any time without having to give a reason. Additionally, your child is also free to withdraw at any time. None of the information either you or your child have given will be included in the

Siblings of children with ADHD, chronic illness and developmental disorder

research should this happen. Your decision to take part or not will not affect the care you or your child receive currently, nor impact on any future care.

If you or your child would like more information about this study please contact Claire Wilson (Researcher) on 01482 464101, Department of Clinical Psychology, University of Hull, Hull, HU6 7RX. or email on

Thank you for taking the time to read this information sheet

Appendix M: Information sheets
Parents (Clinical Group)

An investigation into the experiences of brothers and sisters of children with and without Attention-Deficit Hyperactivity Disorder (ADHD)

Information Sheet

This research study is being done as part of an educational qualification jointly with the University of Hull Doctorate in Clinical Psychology course and the Humber Mental Health Teaching NHS Trust.

What is the study about?

This study is aiming to examine the experiences of brothers and sisters of children with Attention-Deficit Hyperactivity Disorder (ADHD). It has been found that relationships between brothers and sisters play an important part in children's development, but there is little research looking at how brothers and sisters of children with ADHD are affected by this experience. We would like to find out more about the experiences of children *without* ADHD with regards to their experience of having a brother or sister with ADHD. We will also be contacting schools in your area to speak to children who have siblings who don't have the condition in order to compare the experiences of children. If you receive any information pack through the school in addition to this one, then you do not need to respond.

Why is this study being done?

By conducting research in this area we hope to be able to develop clinical services and enable greater understanding of the effects that having a child with ADHD can have on the wider family. It is hoped that this information will allow services to support families and children more effectively in the future. We feel to do so it is important we gain information from as many families as possible.

What would it involve?

It is up to you and your child to decide whether you wish to take part in this study. Your child has been given a separate information sheet which you can read with them if you wish. If you decide to take part, we will give you a consent form to sign. You and your child will be asked to complete some questionnaires on one occasion, which will cover a variety of issues such as feelings about themselves and other people, behaviour, and positive/more challenging parts of the relationships between your children. The appointments will be an hour in duration and will allow time for any further questions you may have, both before and after completing the questionnaires. You and your child can attend this appointment together.

How will this study help my family?

We cannot promise any immediate benefits for your family from this study. However we hope to improve our ability to help families who share similar experiences to yours. We aim to gain a better understanding of what it is like for a child without ADHD to have a brother or sister with the condition and it is hoped that furthering this understanding will help services supporting the wider family of children with ADHD.

Is there anything I should be concerned about if we take part?

The questionnaires used are not designed to raise uncomfortable issues or painful feelings for either you or your child. However every individual will experience different feelings about their family and relationships. If either you or your child were to experience distress as a result of completing the questionnaires, you would be welcome to discuss this with me and if I had any significant concerns about your welfare as a result, I would raise relevant matters with key people involved in your family's care.

Our study needs to make sure the participating child without ADHD does not appear to have the condition themselves. This will be clarified with a questionnaire for yourself as the parent to complete and will involve thinking about some of the behaviours your child displays in everyday life. If we found your child to have some of the symptoms indicating they may have symptoms often indicative of ADHD we would discuss this with you and give you appropriate information to decide what you wanted to do about this. We would not inform any people involved in your child's care unless you expressly wished us to do so. However the questionnaires will not be used to provide a diagnosis of ADHD and are used as a screening measure only to provide a general level of behavioural difficulties.

What will happen to the information we give you?

If you decide to take part in the study any information gathered or anything you told us about will be kept strictly confidential and will not be traceable back to yourself or your family. No information will be given to clinic staff or to those involved in your care. The only exception to this would be if areas of concern about harm to yourself or your children arose from your participation in the research. If you do decide to take part you are still free to withdraw at any time without having to give a reason. Your child is also free to withdraw at any time. None of the information either you or your child have given will be included in the research should this happen. Your decision to take part or not will not affect the care you or your child receive currently, nor impact on any future care.

If you or your child would like more information about this study please contact Claire Wilson (Researcher) on 01482 464101, Department of Clinical Psychology, Hertford Building, University of Hull, Cottingham Road, Hull, HU6 7RX or email on

Appendix M: Information Sheets [With University Headed Paper Logo on leaflet]
Information sheet for Children in Control Group (provided in leaflet form and replicated here as text only for clarity).

An investigation into the experiences of children who have brothers or sisters with and without ADHD

(Attention-Deficit Hyperactivity Disorder)

You and your parent have been asked to take part in a research study. This study is being done as part of an educational qualification. Before you decide if you would like to take part or not, please read this sheet. If you have any questions please ask your parent to contact us.

Information about our research study

What is “Research”?

- People who carry out research have a question they want answered or a problem they want to understand more about.
- Research is about collecting information to help answer that question or understand more about the problem itself.
- People who carry out research are called “researchers”. Researchers who have questions to do with people or families need to speak to people who can help them answer those questions.

Why are you doing this research?

- We want to look at how children feel about their relationships with their brothers or sisters
- We are very interested in children who have brothers or sisters with ADHD but we also want to know about the experiences of children with brothers and sisters who do not have the condition.
- We want to talk to lots of different children in different families to get a better picture of what it’s like to have a brother or sister.
- We hope to help people understand a bit more about how these relationships affect children

What is ADHD?

- ADHD stands for “Attention-Deficit Hyperactivity Disorder”.
- ADHD is a problem that some people have where their brain may work a little differently from other people’s.
- People with ADHD might find it hard to concentrate on one thing at a time, find hard to sit still and hard to keep from acting quickly without thinking first.

Why have you asked me to take part?

- You have a brother or sister and they do not have ADHD.

- If you have other brothers and sisters but they have not been asked to take part this is because we are only asking one child in each family to help us.
- To get useful information we need to speak to as many children and their parents as we can.

What will I be asked to do if I say yes?

- If you decide you would like to take part in our study your parent will have to agree too. Your parent has an information sheet as well and details of how to contact me (the researcher) to say you would both like to take part.
- Even after you have said yes, you can change your mind at ANY time and we won't use any information about you in the study. Saying no would not affect the care you receive from anybody like a doctor or others in the NHS.
- Taking part will mean you and your parent meet once with me for around 30 minutes. We will give you some questionnaires to answer about your feelings and about your relationship with your brother or sister who has ADHD.
- This meeting can be at your home or at the University of Hull where the research is based.
- We cannot promise that you will get any benefit from this study yourself, but we hope that the information you give us can help improve services for different types of families. We would like to understand more about children like you who have a brother or sister.
- We hope thinking about your feelings and relationships won't upset you, but if it did we would help you get any support you needed.
- None of the information you or your parent gives us will be able to be traced back to you or your parent—it stays PRIVATE or “confidential”. The only time this changes is if we heard something that worried us about you or somebody else's safety in which case we would have to tell somebody.
- Your name will not be put on the questionnaires.

Thank you for taking the time to read this sheet. Ask your parent to contact me (Claire Wilson) if there is anything else you want to know

Appendix M: Information sheets [With University Headed Paper Logo on leaflet]
Information sheet for Children in Clinical Group (provided in leaflet form and replicated here as text only for clarity).

An investigation into the experiences of children who have brothers or sisters with and without ADHD

(Attention-Deficit Hyperactivity Disorder)

You and your parent have been asked to take part in a research study. This study is being done as part of an educational qualification. Before you decide if you would like to take part or not, please read this sheet. If you have any questions please ask your parent to contact us.

Information about our research study

What is “Research”?

- People who carry out research have a question they want answered or a problem they want to understand more about.
- Research is about collecting information to help answer that question or understand more about the problem itself.
- People who carry out research are called “researchers”. Researchers who have questions to do with people or families need to speak to people who can help them answer those questions.

Why are you doing this research?

- We want to look at how children feel about their relationships with their brothers or sisters who have ADHD
- We think this is important information because if we know more about your experiences of having a brother or sister with ADHD, we might know more about how to help families like yours in the future.
- We want to talk to lots of different children in different families to get a better picture of what it’s like to have a brother or sister so we are talking to children with brothers and sisters who don’t have ADHD too.
- We hope to help people understand a bit more about how these relationships affect children.

What is ADHD?

- ADHD stands for “Attention-Deficit Hyperactivity Disorder”.
- ADHD is a problem that some people have where their brain may work a little differently from other people’s.
- People with ADHD might find it hard to concentrate on one thing at a time, find hard to sit still and hard to keep from acting quickly without thinking first.

Why have you asked me to take part?

- You have a brother or sister and they have ADHD.

- If you have other brothers and sisters but they have not been asked to take part this is because we are only asking one child in each family to help us.
- To get useful information we need to speak to as many children and their parents as we can

What will I be asked to do if I say yes?

- If you decide you would like to take part in our study your parent will have to agree too. Your parent has an information sheet as well and details of how to contact me (the researcher) to say you would both like to take part.
- Even after you have said yes, you can change your mind at ANY time and we won't use any information about you in the study. Saying no would not affect the care you receive from anybody like a doctor or others in the NHS.
- Taking part will mean you and your parent meet once with me for around 30 minutes. We will give you some questionnaires to answer about your feelings and about your relationship with your brother or sister who has ADHD.
- This meeting can be at your home or at the University of Hull where the research is based.
- We will be speaking to school children who have a brother or sister without ADHD so we can compare the experiences. If you get a letter at school, you don't have to tell anyone you are already taking part or reply to the letter at all.
- We cannot promise that you will get any benefit from this study yourself, but we hope that the information you give us can help improve services that families like yours are given. We would like to understand more about children like you who have a brother or sister with ADHD.
- We hope thinking about your feelings and relationships won't upset you, but if it did we would help you get any support you needed.
- None of the information you or your parent gives us will be able to be traced back to you or your parent—it stays PRIVATE or “confidential”. The only time this changes is if we heard something that worried us about you or somebody else's safety in which case we would have to tell somebody.
- Your name will not be put on the questionnaires.

Thank you for taking the time to read this sheet. Ask your parent to contact me (Claire Wilson) if there is anything else you want to know

Appendix N: Consent and Assent Forms

Assent Form for Children in Control Group [On University Headed Paper]

ASSENT FORM – For children taking part

An investigation into the experiences of brothers and sisters of children with and without Attention-Deficit Hyperactivity Disorder (ADHD)

Please circle

- | | | | |
|---|---|-----|----|
| 1 | I have read the information sheet for children taking part in this study and I have had the chance to ask questions | YES | NO |
| 2 | I understand that I have been asked to take part in this study because I have a brother or sister without ADHD | YES | NO |
| 3 | I understand that I have the choice to take part in this study and that I can say no or change my mind at any time | YES | NO |
| 4 | I understand that if I change my mind about taking part my care from people like doctors or others, will not be affected. | YES | NO |
| 5 | The researcher explained “confidentiality” to me and how the information I and my parent give will be treated as private unless they are worried about my safety or the safety of other people. | YES | NO |
| 6 | I agree to take part in the study | YES | NO |

Name.....(child)..

Signed.....

Date.....

Name..... (researcher)

Signed.....

Date.....

Appendix N: Consent and Assent Forms

Assent Form for Children in Clinical Group [On University Headed Paper]

ASSENT FORM – For children taking part

An investigation into the experiences of brothers and sisters of children with and without Attention-Deficit Hyperactivity Disorder (ADHD)

Please circle

- | | | | |
|----------|--|------------|-----------|
| 1 | I have read the information sheet for children taking part in this study and I have had the chance to ask questions | YES | NO |
| 2 | I understand that I have been asked to take part in this study because I have a brother or sister with ADHD | YES | NO |
| 3 | I understand that I have the choice to take part in this study and that I can say no or change my mind at any time | YES | NO |
| 4 | I understand that if I change my mind about taking part my care from people like doctors or others, will not be affected. | YES | NO |
| 5 | The researcher explained “confidentiality” to me and how the information I and my parent give will be treated as private unless they are worried about my safety or the safety of other people. | YES | NO |
| 6 | I agree to take part in the study | YES | NO |
| 7 | I understand that the researcher might contact my school so that other children there can take part in this research | YES | NO |
| 8 | I understand that the researcher will not inform the school I am already taking part or pass on any details | YES | NO |

Name.....(child)
Signed.....
Date.....
Name.....(researcher)
Signed.....
Date.....

Appendix N: Consent and Assent Forms

Consent form for parents (both groups)

CONSENT FORM – for parents taking part in the study

An investigation into the experiences of brothers and sisters of children with and without Attention-Deficit Hyperactivity Disorder (ADHD)

- | | | |
|--|-----|----|
| 1. I confirm I have read the participant information sheet for the above study and I had the opportunity to ask questions | YES | NO |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time | YES | NO |
| 3. I understand that my child is free to withdraw from the study at any time. | YES | NO |
| 4. I understand that medical or other forms of care for myself or my child will not be affected if either I or my child wish to withdraw | YES | NO |
| 5. The researcher has explained that the information I and my child give will be treated as confidential and the circumstances under which confidentiality would be broken if necessary. | YES | NO |
| 6. I agree for both myself and my child to take part in this study | YES | NO |

Signed.....

Relationship to child.....

Date.....

PRINT NAME.....

Appendix O: Debriefing Forms [On University Headed Paper]
Parent (both groups)

An investigation into the experiences of brothers and sisters of children with and without Attention-Deficit Hyperactivity Disorder (ADHD)

Debriefing Form for Parents

This research study was undertaken with the aim of investigating the experiences of siblings of children with Attention-Deficit Hyperactivity Disorder (ADHD). To do this we needed to talk to a group of children who have a sibling with ADHD, and to a group of children who have a sibling without any diagnosed disorders of any kind. In the research to date there has been very little focus on how siblings experience their relationships with children with ADHD. Some research has found that this experience can be difficult for the non-diagnosed child and some has found it can actually be a relationship they learn a lot from or have positive experiences with.

This research aimed to look at these more positive experiences as well as the potentially negative effects. We used a questionnaire with your child which asks them questions about their sibling relationship – questions designed to look at both the warmth and closeness of this relationship, but also any conflict they might experience within it. We were also interested in knowing a bit more about your child's feelings for others generally (their "empathy" for others) and their feelings about themselves (their "self-esteem") so two of the questionnaires covered these areas. We are investigating whether the "empathy" and "self-esteem" of a child may protect them from the potentially more negative aspects of sibling relationships such as conflict, or whether it influences the level of warmth and closeness they feel within that relationship. We asked all children the same questions, regardless of whether their sibling had ADHD or not, to try to find out if there are any differences in these areas between children whose sibling has ADHD and those whose sibling does not.

We wanted parents to participate as it was important to know some background information about your family such as the number of children in your family overall, the time since diagnosis if one child has ADHD, and some information about both the sibling who is taking part, and the sibling who is not participating in the study. The questionnaires you were given were designed to cover these areas. This way we can start to look at if any of these pieces of information have an impact on how children feel about their sibling relationship.

Feedback Request

Once the information has been collected from all those taking part, the results will be studied and written up. If you would like to gain some feedback about these results, please return the slip below to the Principal investigator. You can fill it in straight after reading this, or you can wait and send it at a later date. This is up to

you. You have a choice of a written summary of the feedback and results or a meeting with me to discuss them. Your child could attend this too if they would like to know the findings. No personal information about you will be kept so if you want this feedback when we have it available, please complete your preferred method of contact below. This information will be kept securely in a locked cabinet at the research base and no one but the Principal Investigator (Claire Wilson) will have access to this information. It will not be used for any other purpose than to contact you regarding feedback.

1. I have read the above debriefing sheet about the study YES NO
myself and my child participated in.

2. I would like to receive feedback about the study YES NO

3. I would like the feedback about the study in the following way
(please select the preferred option)

Option 1 - I would like a written summary of the results YES NO

Send to this address (postal or email)
.....
.....
.....

Option 2 - I would like a meeting with the researcher YES NO

Claire Wilson, to receive feedback on an individual basis.

Please give preferred contact method and information below in

order that we can contact you to arrange this when feedback is available

Telephone

Email

Postal address
.....
.....
.....
.....

Appendix O: Debriefing Forms [On University Headed Paper]

Child (both groups)

An investigation into the experiences of brothers and sisters of children with and without Attention-Deficit Hyperactivity Disorder (ADHD)

Debriefing Form for Children

This research study was done to look at the experiences of brothers and sisters of children with Attention-Deficit Hyperactivity Disorder (ADHD). To do this we needed to talk to a group of children who have a sibling with ADHD, and to a group of children who have a brother or sister without ADHD or any other similar problems. Some other research in this area has found that being a brother or sister of a child with ADHD can be quite difficult at times. Other research has found it can actually be a relationship they learn a lot from or have good experiences with.

This research aimed to look at these good experiences as well as the difficult ones. You filled in a questionnaire which asked you questions about your sibling relationship – questions to look at both the warmth and closeness of this relationship, and also questions about any “conflict” or difficulties you might have with your brother or sister. We were also interested in knowing a bit more about your feelings for others generally (your “empathy” for others) and your feelings about yourself (your “self-esteem”) so two of the questionnaires covered these areas. We are investigating whether the “empathy ” and “self-esteem” of a child may protect them from any “conflict” in their relationship with their brother or sister, or whether it makes children feel closer to them. We asked all children the same questions, regardless of whether their brother or sister had ADHD or not, to try to find out if there are any differences between their experiences/feelings.

We wanted parents to participate as it was important to know some background information about your family such as the number of children in your family overall, and some information about you and your brother or sister who was not taking part in the study. The questionnaires your parents were given were designed to cover these areas. This way we can start to look at if any of these pieces of information seem to make difference about how children feel about their relationship with their brother or sister.

Feedback Request

Once the information has been collected from all those taking part, the results will be studied and written up. If you would like to gain some feedback about these results, please return the slip below to the researcher (Claire Wilson). Show this form to your parent or whoever gave permission for you to take part and ask them if it is okay for you to have feedback and what information you can fill in. You have a choice of a written summary of the feedback and results or a meeting with me which your parent should attend too. No personal information about you will be kept so if you want this feedback when we have it available, please complete your preferred method of contact below and send it back to us using the addressed envelope enclosed. This information will be kept securely in a locked cabinet at the research base (University of Hull Clinical Psychology Department) and no one but the researcher (Claire Wilson) will have access to this information. It will not be used for any other purpose than to contact you regarding feedback.

1. I have read the above debriefing sheet about the study YES NO
myself and my parent/carer participated in.

2. I would like to receive feedback about the study YES NO

3. I would like the feedback about the study in the following way
(please select the preferred option)

Option 1 - I would like a written summary of the results YES NO

Send to this address (postal or email)
.....
.....
.....

Option 2 - I would like a meeting with the researcher YES NO

Claire Wilson, to receive feedback on an individual basis.

Please give preferred contact method and information below in

order that we can contact you to arrange this when feedback is available

TelephoneEmail.....

Postal address

.....
.....
.....

Appendix P: Demographic Data Sheet

Demographic Data Collection Form – for Parent Completion

The following information will be kept confidential and anonymous and is collected only for research purposes. Please tick the appropriate response and fill in information where necessary.

1. Relationship to child – mother (), father (),
other (please state)
2. Marital status – single (), divorced (), cohabiting (), married ()
3. Which best describes your ethnic origin: White (), Asian/Asian British (),
Mixed (), Black/Black British (), Other ethnic group (),
I do not wish to disclose ()
4. Higher education (beyond school leaving age): Yes (), No ()
5. Number of children in the family overall:
6. Age of child taking part in the study:years andmonths
7. Age of sibling with ADHD (or non-participating sibling if neither has ADHD):
.....years andmonths
8. Time since child was diagnosed with ADHD:years ormonths
9. Does child with ADHD have any other diagnoses or conditions? Yes (), No ().
If yes, please state them
here.....
10. Does the participating child have any diagnoses or conditions? Yes (), No (). If
yes, please state them here
.....
11. Are any of the children in your family in receipt of free school meals?
Yes (), No (), Decline to answer ()

Thank you for taking the time to complete this questionnaire.

Appendix Q: Conners' Parent Rating Scale – Revised: Short Form (Conners', 1997)

Removed for hard binding

Appendix R: Strengths and Difficulties Questionnaire (SDQ: Goodman, 1997).

Removed for hard binding

Appendix S: Index of Empathy (IEC; Bryant, 1982)

Items in italics score negatively. Dichotomous scale yes=1, no=0, reverse scoring for italicised items.

1. It makes me sad to see a girl who can't find anyone to play with
2. *People who kiss and hug in public are silly*
3. *Boys who cry because they are happy are silly*
4. I really like to watch people open presents, even when I don't get a present myself
5. Seeing a boy who is crying makes me feel like crying
6. I get upset when I see a girl being hurt
7. Even when I don't know why someone is laughing, I laugh too
8. Sometimes I cry when I watch TV
9. *Girls who cry because they are happy are silly*
10. *It's hard for me to see why someone else gets upset*
11. I get upset when I see a boy being hurt
12. It makes me sad to see a boy who can't find anyone to play with
13. Some songs make me so sad I feel like crying
14. I get upset when I see a boy being hurt
15. *Grown-ups sometimes cry even when they have nothing to be sad about*
16. *It's silly to treat cats and dogs as though they have feelings like people*
17. *I get mad when I see a classmate pretending to need help from the teacher all the time*
18. *Kids who have no friends probably don't want any*
19. Seeing a girl who is crying makes me feel like crying
20. *I think it's funny that some people cry during a sad movie or while reading a sad book*
21. *I am able to eat all my cookies even when I see someone looking at me wanting one*
22. *I don't feel upset when I see a classmate being punished by a teacher for not obeying school rules*

Appendix T: Rosenberg Self-Esteem Scale (RSES; Rosenberg, 1965)

ROSENBERG SELF-ESTEEM SCALE

ID NO.....DATE.....

Please place a tick in the appropriate box to say whether you strongly agree, agree, disagree, or strongly disagree with the statements below.

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. On the whole I am satisfied with myself				
2. At times I think I am no good at all				
3. I feel I have a number of good qualities				
4. I am able to do things as well as most other people				
5. I feel I do not have much to be proud of				
6. I certainly feel useless at times				
7. I feel that I am a person of worth at least on an equal plane with others				
8. I wish I could have more respect for myself				
9. All in all I am inclined to feel that I am a failure				
10. I take a positive attitude towards myself				

Appendix U: Sibling Relationship Questionnaire – Revised (SRQ-R; Furman & Buhrmester, 1985)

Removed for hard binding

Appendix V: SPSS Results Selected Output

Figure A. Box Plot for Total Empathy Between Groups

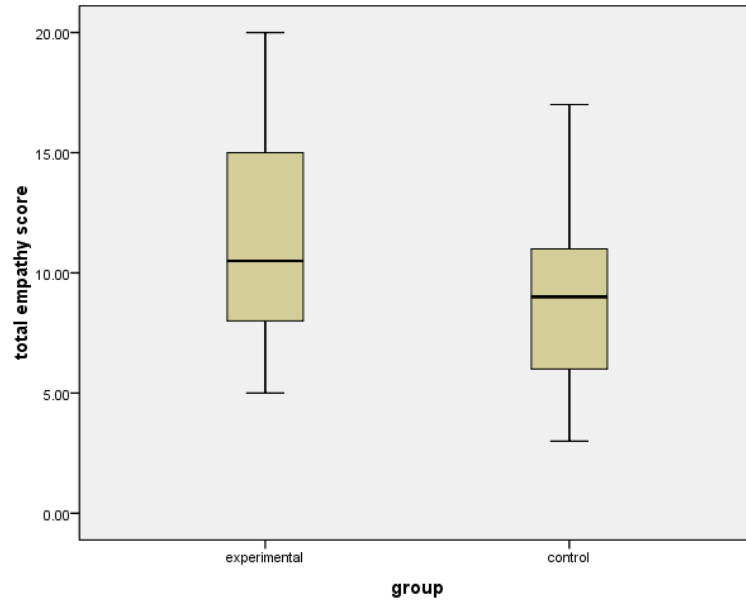


Figure B. Box Plot for Total Conflict Between Groups

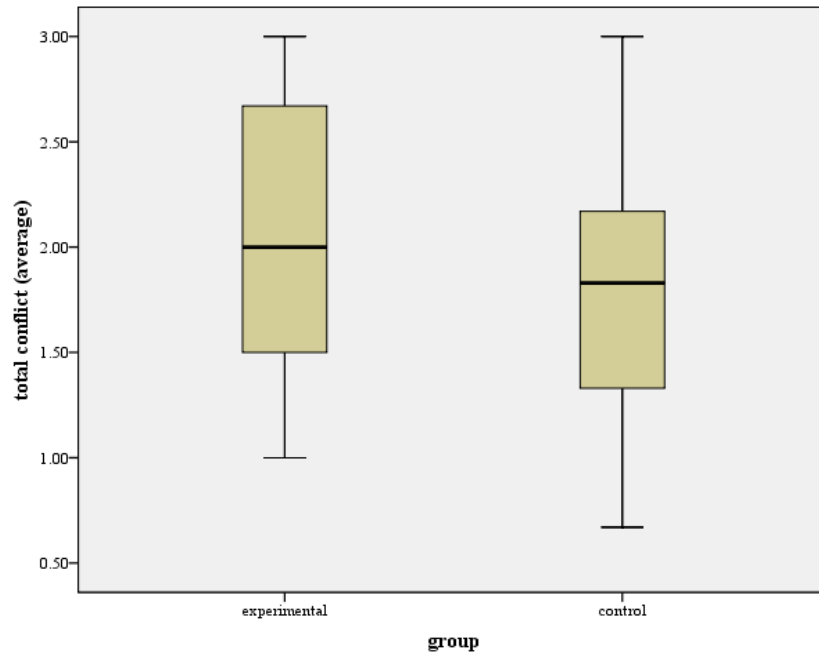


Figure B. Matrix Scatterplot of empathy, self-esteem, warmth/closeness and conflict

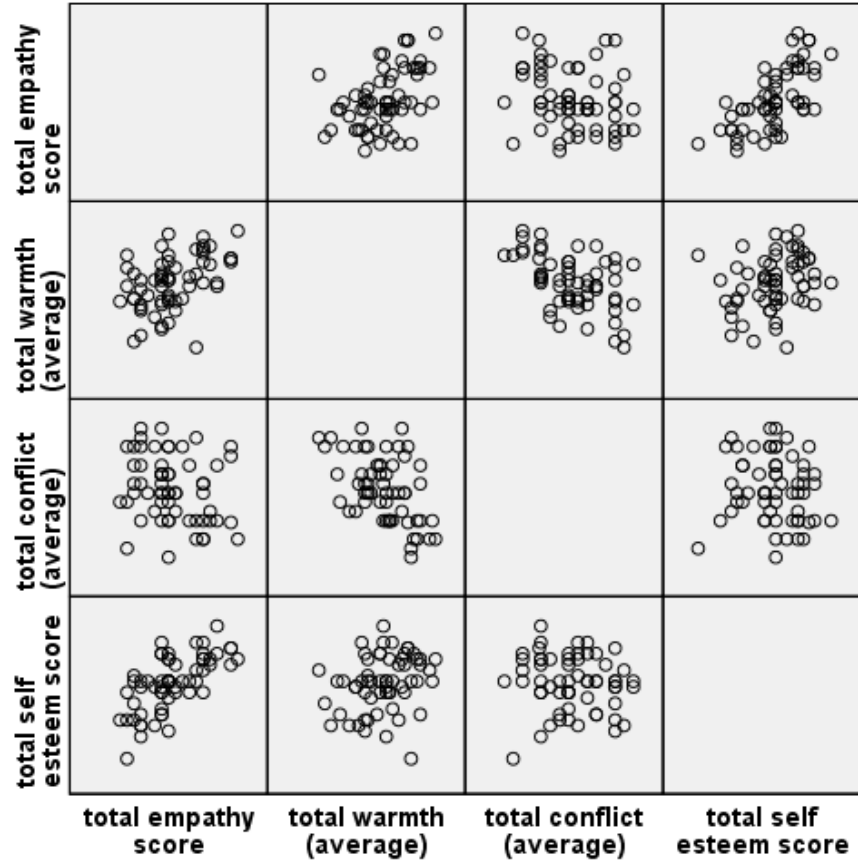


Table B. Univariate GLM Regression Table for warmth as dependent variable

Tests of Between-Subjects Effects

Dependent Variable:total warmth (average)

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	5.005 ^a	3	1.668	6.124	.001	.247
Intercept	5.958	1	5.958	21.868	.000	.281
group	.755	1	.755	2.770	.102	.047
empathtot	3.518	1	3.518	12.911	.001	.187
tslfest	.154	1	.154	.564	.456	.010
Error	15.257	56	.272			
Total	230.563	60				
Corrected Total	20.262	59				

a. R Squared = .247 (Adjusted R Squared = .207)

Table C. Univariate GLM Regression Table for conflict as dependent variable

Tests of Between-Subjects Effects

Dependent Variable:total conflict (average)

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	3.323 ^a	3	1.108	3.610	.019	.162
Intercept	16.200	1	16.200	52.794	.000	.485
group	1.984	1	1.984	6.465	.014	.103
empathtot	2.200	1	2.200	7.170	.010	.114
tslfest	.395	1	.395	1.286	.262	.022
Error	17.184	56	.307			
Total	238.782	60				
Corrected Total	20.506	59				

a. R Squared = .162 (Adjusted R Squared = .117)

Appendix W: Reflective Statement

When this portfolio thesis was in its early stages of development, in the planning and conceptualisation phase, the end goal of producing this document seemed the primary if somewhat daunting aim. Whilst putting together this document has in itself been a valuable exercise in strategic planning, time management and scientific writing, I have come to realise that the lessons learned along the way to adding in this final piece of the jigsaw, are perhaps the most valuable of all.

The creation of this portfolio thesis has been a long and often challenging journey. Even at the most difficult times however, I have also often felt that I was in a privileged position to be learning so much, both from those supporting me academically to do this research but also in terms of the opportunity to plan, develop and carry out a project of this scale from start to finish. At the most challenging of times, I found this was a useful aspect to reflect upon and to conceptualise these challenges as the lessons I would be likely to end up learning the most from.

The process of reflection throughout has helped me to clearly consider my assumptions in doing this piece of research and has facilitated and enhanced the learning process along the way. It was important not only to reflect on my own research, but on the research in the field I was beginning to familiarise myself with. It seemed that there was a lot to learn from reading other literature in the area and considering how to improve and build on it. I remember noting at the start of this research journey, that reflection would be an important part of the learning process but it seemed that at the very times when stepping

back and reflecting would have been the most useful, it was the most difficult to achieve. With such a big task in hand, it is tempting to keep “doing” and stop thinking to the same degree. However, I did keep a reflective journal as was suggested to us by more knowledgeable members of the research team and I found this helped immensely, probably more so towards the end of the process when I needed to think clearly about what I had been trying to do from the beginning. Nearing the end of the process, it is easy to lose sight of why we are researching what we are researching, but having a document which tracked my thought processes as I discovered new key pieces of literature to look back on was invaluable. This made me think of how much I have learnt about research over the course of this process. When we first began our research sessions on the doctorate, I clearly recall wondering at this suggestion of keeping a reflective journal about our research. How could one reflect about research – a scientific and rational endeavour? Only through doing the research itself and approaching the end of this journey, have I come to fully understand the contribution that keeping such an account of the research process made. Such a long term and large scale project is the result of a multitude of small yet vital decisions and if these are not documented along the way and made thoughtfully, the end destination of the journey can end up being the sole focus with no consideration of the best and most fruitful way of arriving there. Looking back on the journal I kept I can recall the confusion I felt initially as I tried to navigate my way through the sibling literature, trying to work out other researcher’s definitions of ‘adjustment’. However, having learnt more about research myself along the way, I have now come to realise that I was confused because of the lack of the clarity and clear theoretical frameworks within the research in this area and I hope that

the way my thesis evolved and developed over time helped my own clarity of thought as I tried to learn from what had gone before.

In a similar vein, in future research projects I feel it would be useful to conduct the systematic literature review before embarking on the empirical study, primarily because I feel I learnt so much about research by immersing myself in the literature and evaluating the studies within that area. However, the most thrilling part for me was finding evidence along the way that supported the way I was approaching my empirical study and the rationale I had based it on, and this gave me further ideas of how I wanted to develop and write up my empirical paper, so a symbiotic process was still possible from the two elements of the thesis.

Planning and time management were the two most crucial elements to this process, and again I feel this is something I have learnt about along the way. I found I work best when I have a clear schedule of what I want to achieve and using the research journal to help me with this was of great benefit. Recruitment was challenging but I found having a back-up plan in place was essential and this in the end meant that original targets were met.

Conclusions

Incorporating the study of positive elements of sibling experience whilst they grow up in potentially challenging circumstances has helped me a great deal in coping with the process of conducting this research myself. As I highlighted earlier, it was at the most challenging points that I reminded myself that this was an opportunity above all else, to develop skills and grow in terms of my research ability. It has been hard at times, primarily as this thesis feels like the culmination of six years of hard work to attain my goal of

becoming a clinical psychologist and at the times I found the process most challenging this was at the forefront of my mind. I feel I have learnt more than just how to conduct research, as it also feels like I have experienced a personal learning curve and a lesson in how to approach challenges and grow from them rather than be overwhelmed by them. Balancing the demands of research with the clinical and academic components of the course has been perhaps the biggest challenge of all, but I feel I can take the lessons learned and use them to help me professionally and to help my clients. That is after all what clinical research is all about.

The decision to write my Systematic Literature Review for Clinical Psychology Review and the empirical paper for Child Development was made in part due to their large readership as indicated by consistently high impact ratings. It also felt that with a focus on siblings without disorders or illnesses that this research needed to reach the widest audience possible, whilst still maintaining a psychological focus and both of these journals enabled this. It was felt in particular that submitting the empirical paper to Child Development would allow my research to be disseminated to a wide range of professionals whilst keeping a focus on issues of children's psychosocial wellbeing and adjustment. Writing papers specifically for these journals has been a useful learning process and a transferable skill that I hope to use in further clinical research to ensure that my writing and dissemination skills keep developing and that even service-related research is conducted systematically and with quality in mind. This is something I will definitely take into any research I embark upon in the future, and indeed putting together this thesis has primed me well and given me immense enthusiasm for taking on more research in the future.

