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THE IMPACT OF CHILDHOOD HEALTH CONDITIONS: EXAMINING
EXPERIENCES OF THE FAMILY AROUND THE CHILD

Section A: Understanding family functioning in the context of childhood
chronic conditions: a meta-synthesis of the qualitative literature

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Section B: When a sibling has a mental health condition: a grounded theory
analysis of children's experiences and views on the sibling relationship

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This work is dedicated to my mother, without whom none of this would have been possible. It is also in memory of my father, whom I wish was here to witness this journey.

Summary of the Major Research Project

Section A is a review and meta-ethnographic synthesis of qualitative literature related to family functioning within the context of childhood chronic health conditions. This review sought to examine how families are impacted by such conditions and to examine factors influencing functioning. The synthesis demonstrates that it is the appraisal of potential stressors and resources that influences how families function, and not simply the presence of stress or availability of support. Findings are discussed in relation to the research and clinical implications.

Section B is an empirical paper using constructivist grounded theory methodology to explore the experiences of children who have a sibling with a mental health condition. This study examined children's view of the sibling relationship and how this was impacted by the presence of a mental health condition. There was a link between the process of establishing connections to others (sibling, parents) and gathering information about mental health conditions and this fed into their understanding of their sibling and subsequently their view of this sibling dynamic. The clinical and practical implications of these findings were considered alongside direction for future research.

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Section A: Literature Review Paper

Understanding family functioning in the context of childhood chronic conditions: a meta-synthesis of the qualitative literature.

Word count: 8526

Abstract

Background: Research has examined family functioning in relation to childhood chronic conditions; some findings suggest a detrimental impact of illness on functioning, others suggest no impact or instances of improved functioning. This review collated qualitative data, to understand the factors facilitating healthy functioning.

Method: Four electronic databases were searched: Web of Science, Medline, CINAHL and Psych INFO and ten papers were identified.

Results: A meta-ethnographic synthesis showed that families encounter a variety of potential stressors, such as distress following diagnosis. They manage these through various resources including contact with health services. The synthesis highlighted an appraisal process mediating the perception of stressors and resources. This process occurs on interconnected levels (individual, family and wider system) and it is this, rather than the specific stressors or resources encountered, that impacts functioning.

Discussion: The challenges commonly encountered by families managing childhood chronic conditions can be experienced very differently depending on their systems of appraisal. This has clinical implications as health services should not only offer holistic support to families but regularly review how this support is perceived. Research could be extended to investigate which factors promote a more positive appraisal of challenging situations.

Keywords: childhood, chronic conditions, family functioning, stressors, resources

Introduction

Childhood chronic conditions

Chronic diseases, chronic illnesses or chronic conditions are terms commonly used to define a health issue in relation to its duration, level of impact on an individual's functioning and its interference with their daily activities (Westbom & Kornfält, 1987; Van Cleave, Gortmaker & Perrin, 2010). Whilst the terms chronic disease and chronic illness are often used interchangeably within clinical, health and policy related literature, the two can convey different meanings; chronic disease is typically defined based on biomedical disease classifications whilst chronic illness commonly refers to a person's lived experience of managing a chronic disease (Martin, 2007). The term chronic condition, which the World Health Organisation defines as those requiring "ongoing management over a period of years or decades" (Pruitt & Epping-Jordan, 2002 p.11), may therefore be an appropriate umbrella term to use that encompasses definitions of both chronic disease and chronic illness. Chronic conditions may include non-communicable conditions, persistent communicable conditions, long-term mental disorders, ongoing physical/structural impairments (Pruitt & Epping-Jordan, 2002). Whilst the specific aetiologies and presentations of conditions will impact on factors such as adjustment and management (Van Den Bos, 1995; Wolfe, Song, Greenberg & Mailik, 2014) the common theme across conditions is the need for a complex response (including input from various healthcare professionals) over an extended period of time (Nolte & McKee, 2008). Chronic conditions contribute to the major health burden in developed countries with similar trends also appearing for developing countries; they are affected by factors such as socioeconomic status, education, environment and employment (Pruitt & Epping-Jordan, 2002).

Whilst chronic health conditions can affect individuals at any stage of life, there have been increased rates of chronic conditions in children (Van Cleave et al., 2010; Perrin, Bloom & Gortmaker, 2007). There are many different chronic conditions that affect children, including: asthma, cystic fibrosis, diabetes, obesity, cancer, chronic pain, neurodevelopmental disorders, autoimmune conditions, depression, cerebral palsy or sensory impairments (Jin, An & Wang, 2017; Ni Mhurchadha & O'Sullivan, 2017). Prevalence rates of childhood chronic conditions are estimated to be between 10 to 30%, dependant on the definitions or criteria used (Jin et al., 2017; Akinbami, Moorman, Garbe & Sondik, 2009; Robison, Sclar, Skaer & Galin, 1999; Van Der Lee, Mokkink, Grootenhuis, Heymans & Offringa, 2007).

Impact of childhood chronic conditions

Chronic conditions can have a serious impact on many areas of a child's life. Evidence highlights that children experiencing chronic conditions may face difficulties within their social interactions for instance more exposure to bullying and reduced contacts with peers (Svetaz, Ireland & Blum, 2000; Lucas, Jernbro, Tindberg & Janson, 2016; Westbom, 1992). Research suggests that chronic conditions have a detrimental impact on factors associated with quality of life such as physical and psychological wellbeing and social functioning (Bai, Houben-van Hertem, Landgraf, Korfage & Raat, 2017). Conditions may result in frequent pain, feelings of discomfort, delays in growth and development and may require frequent and ongoing contact with medical services, including admissions to hospital. These factors can impact on involvement in activities and result in time away from school (Shiu, 2001). The literature highlights that isolation and social stigma are ongoing concerns for children living with chronic conditions; this can be a source of distress even amongst those who have close links to family

and other support networks (Ni Mhurchadha & O'Sullivan, 2017; Suris, Michaud & Viner, 2004; Taylor, Gibson & Franck, 2008; McCarroll, Lindsey, MacKinnon-Lewis, Chambers & Frabutt, 2009). It is important to recognise that children with chronic health conditions continue to experience the same developmental issues and challenges (biological, social, cognitive) as children without; however, this development can be disrupted by factors related to their condition (Taylor et al., 2008; Ni Mhurchadha & O'Sullivan, 2017).

The impact of a childhood chronic condition is also felt in other areas such as family and social networks (Ni Mhurchadha & O'Sullivan, 2017). There can be a range of emotional experiences felt by various family members within the child's network; there may be feelings of grief or sadness relating to the loss of the life or future that was imagined for the child.

Following diagnosis or confirmation of a condition it is common for parents to react in a variety of ways, including experiences of shock, denial, anger or guilt (Kepreotes, Keatinge & Stone, 2010). Researchers have also noted increased rates of psychological distress amongst parents of children with chronic conditions, with many meeting clinical criteria for depression and anxiety (Quittner, Blackwell & Schechter, 2010).

Furthermore, there can be implications for the dynamics and relationships within a family. Chronic conditions can affect the bond between a child and their caregivers and have long-lasting implications on roles and relationships in the family (Quittner et al., 1998). Parents may struggle to find the balance between allowing autonomy and independence in their child whilst continuing to provide support for the management of their condition; equally the child can find this reliance on their parents as overwhelming (Leis-Newman, 2011). In the case of conditions where there is a genetic aetiology, there may be feelings of guilt or resentment felt between parents and children (Vermaes, van Susante & van Bakel, 2012).

The experience of a chronic condition can impact the relationship between both parents, for instance due to differences in perspectives about the condition and treatment or when the burden of care weighs more heavily on one parent (Quittner et al., 2010). In families of multiple children, the siblings of the ill child may feel neglected or resentful of the additional support and attention given to their brother or sister (Lewandowski, 1992). The experience of living with a chronic condition may eventually lead to a breakdown in family relationships, particularly where there are pre-existing difficulties within the family environment (Tew, Payne, & Laurence, 1974; Quittner, DiGirolamo, Michel & Eigen, 1992). The family experience can also be impacted by other factors such as the economic and practical consequences of a condition, isolation from others and the ongoing challenges of understanding and navigating healthcare systems (Newacheck & Halfon, 1998; Quittner et al., 2010).

Whilst the literature notes several potentially negative or detrimental implications for the families of children with chronic conditions, there is also research which highlights the areas of family strength and resilience. Families can often become highly resourceful when seeking out information and support (Ni Mhurchadha & O'Sullivan, 2017); where children and families have been able to engage well with early intervention strategies this has had a positive impact on their ability to cope with their condition and in turn reduced the ongoing burden on healthcare systems (Ni Mhurchadha & O'Sullivan, 2017). Evidence also suggests that experiences of ill health can make individuals and families change their perspectives on life and feel better equipped to manage other challenges (Barakat, Alderfer & Kazak, 2005; Leis-Newman, 2011). This evidence aligns with the notion of post-traumatic growth, the phenomenon of positive psychological change occurring as a result of adversity (Tedeshi & Calhoun, 2004).

Family functioning within the context of childhood chronic conditions

Family functioning is a commonly used term to describe the social and structural properties of the family environment and includes concepts such as parenting role, parent-child interactions, family communication, decision making, problem solving, adaptability and cohesion (Rolland, 1993; Lewandowski, Palermo, Stinson, Handley & Chambers, 2010). It is proposed that healthy family functioning occurs in environments where there are well-defined roles, clear communication, cohesion and good affect regulation whereas poor family functioning occurs in disorganized families with high levels of conflict and poor affective and behavioural control (Lewandowski et al., 2010). Much of the existing literature on family functioning encompasses principles of family systems theory (Dai & Wang, 2015). This theory defines the family as an emotional unit where each member plays specific roles and individuals can only be understood in relation to one another. Patterns develop and lead to either function or dysfunction, or both, within the system (Bowen, 1966).

There have been a variety of theories relating to family functioning, which tend to fall into two main categories: results-oriented models or process-oriented models (Dai & Wang, 2015). Results-oriented models tend to define family functioning by specific features of the family (Dai & Wang, 2015). One example is the Olson Circumplex Model which notes flexibility, cohesion and communication skills as defining variables in family interactions (Dai & Wang, 2015; Olson, 2000). It suggests that an imbalance of cohesion and flexibility leads to problematic family functioning (Dai & Wang, 2015; Olson, 2000). Another example is the Beavers systems theory, which incorporates two key dimensions: family competence (structure, flexibility, available information) and family style (stylistic qualities of interactions). When these

two dimensions are combined, they define distinct family typologies ranging from functional to problematic (Dai & Wang, 2015; Beavers & Hampson, 2000).

Process-oriented models describe family functioning by the tasks a family needs to complete (Dai & Wang, 2015). The McMaster model (Epstein, Ryan, Bishop, Miller, & Keitner, 2003) proposes that the core function of the family is to provide adequate conditions to enable its members to accomplish tasks such as providing food and shelter, promoting growth and development and responding to emergencies. The ability to complete these tasks is related to six dimensions of family life: problem-solving, communication, roles, affective responsiveness, affective involvement and behaviour control. The process model of family functioning (Skinner, Steinhauer & Sitarenios, 2000) builds upon the McMaster model, with emphasis on the interaction between the individual family members and the family unit. This model proposes that family functioning relates to seven domains: completion of tasks, role, communication, emotional expression, involvement, behaviour and values and rules. Many standardised measures of family functioning have been developed based on these models and are frequently cited within the literature. The Family Assessment Device [FAD] (Epstein, Baldwin & Bishop, 1983) is based on the McMaster model and assesses seven dimensions of family functioning: problem solving, communication, roles, affective responsiveness, affective involvement, behavioural control, and general functioning. The Family Assessment Measure [FAM] (Skinner, Steinhauer & Santa-Barbara, 1983) is based on the process model of family functioning and examines strengths and weaknesses in task accomplishment, role performance, communication, affective expression, involvement, control, values and norms. Another commonly used measure is The Family Environment Scale [FES] (Moos & Moos, 1981), which assesses the social and environmental characteristics of family functioning, including interpersonal relationships,

personal growth, and family structure. The reliability and validity of these standardised measures are well documented (Lewandowski et al., 2010).

Research suggests that family functioning is associated with various elements of childhood chronic conditions such as functional disability, experiences of pain, relationship with medical professionals and medication adherence (Patterson, McCubbin & Warwick, 1990; Gavin, Wamboldt, Sorokin, Levy & Wamboldt, 1999; Jastrowski Mano, Khan, Ladwig & Weisman, 2009). Family functioning also plays a critical role in adjustment to chronic conditions with some authors noting that good family functioning is a more important predictor of psychosocial outcomes than disease severity (Aasland, Flatø & Vandvik, 1997; Pless, Roughmann & Haggerty, 1972; Sawyer, Spurrier, Kennedy & Martin, 2001; Wallander & Thompson, 1995; Thompson et al., 1999; Hamlett, Pellegrini & Katz, 1992).

Some studies have found deficits in some components of functioning within families managing childhood chronic conditions (Brandt, 1998; Satterwhite, 1978; Sawyer, 1992; Lewandowski et al., 2010). Families of young children with phenylketonuria (a rare genetic disorder) showed lower levels of adaptability and cohesion than matched comparison families (Kazak, Reber & Snitzer, 1988). In addition, adolescents with juvenile primary fibromyalgia syndrome reported poorer overall family functioning and more conflicted family relationships than peers without a chronic condition (Kashikar-Zuck et al., 2008). One study, that performed secondary analysis on existing studies, found no significant differences in scores on a measure of family functioning for families of children with chronic conditions and those without (Herzer et al., 2010). Rodrigues and Patterson (2006) reported that families of children with chronic conditions functioned just as well or better when compared to families of healthy children.

Drotar (1997) examined multiple studies which explored the role of parent and family functioning on the psychological adjustment of children with chronic health conditions. It was noted that measures which reflected supportive family variables, such as cohesion, predicted fewer behavioural symptoms and more competent psychological functioning in children whilst those that assessed more problematic qualities, such as conflict, predicted higher levels of behavioural symptoms and worse psychological adjustment.

Lewandowski et al. (2010) conducted a review of studies relating to chronic pain in children and adolescents in which validated measures, such as the FAD or the FES, were used to examine associations between family functioning, pain and disability. This review noted variability in findings with some studies reporting an association between family factors and disability and others finding no association. Similarly, when examining the relationship to pain symptoms, the reviewed studies reported that better family functioning was associated with more pain, less pain or both.

Another article aimed to review and critique studies on the functioning of families of children with a range of chronic conditions in order to find parallels across the literature and provide direction for future research (McClellan & Cohen, 2007). Similar, to the review conducted by Lewandowski et al (2010) there was variability in findings. One study featured in the McClellan and Cohen (2007) review found that in comparison to healthy controls, families with a child with cystic fibrosis displayed poorer communication, interpersonal involvement, affect management, behaviour control, and role allocation (Spieth et al., 2001) whilst another found that families of adolescents with cystic fibrosis were more likely to be categorized as good problem solvers than families of physically healthy adolescents (Blair, Freeman & Cull, 1995). When comparing families of children with diabetes to healthy controls, few or no significant

differences on domains of family functioning were noted (Hamlett et al., 1992; Standen, Hinde & Lee, 1985; Frank et al., 1998). Similarly, no differences were found when comparing families with children with juvenile rheumatoid arthritis to healthy control families (Harris, Newcomb & Gewanter, 1991; Huygen, Kuis & Sinnema, 2000; Gerhart et al., 2003). One study found no differences in the functioning of families of children with Sickle Cell Disease compared to families with physically healthy children whilst another found that parents of children with Sickle Cell Disease reported greater cohesiveness and reduced family conflict (Noll et al., 1994; Midence, McManus, Fuggle & Davies, 1996). Overall McClellan and Cohen (2007) found that childhood chronic conditions did not have a consistently negative impact on family functioning. The findings suggest that whilst some families may encounter some barriers to optimal functioning, most function similarly to families who are not managing a chronic condition and, in some cases, show improvement in areas such as family cohesion and problem solving.

Rationale for review

There is a variety of research on family functioning and childhood chronic conditions however, findings in these areas have been mixed, with no clear consensus on whether family functioning is negatively impacted by chronic conditions.

The 2007 review by McClellan and Cohen analysed data related to six specific childhood chronic conditions (cystic fibrosis, juvenile rheumatoid arthritis, diabetes, asthma, haemophilia and sickle cell disease). The authors chose to review papers that included a matched healthy control group for comparison with the chronic condition group. The reviewed papers included data from self-report measures of family functioning or utilised observational measures of family functioning such as coding of family interactions. McClellan and Cohen (2007) suggest that

other factors such as medication adherence and parental depression can influence reporting on measures of family functioning and other variables. They also note that, as family functioning is a multifaceted concept, it is difficult for any single measure to capture all the important dimensions. They advocate the use of multiple assessment methods and informants when investigating family functioning.

The methodological limitations noted by McClellan and Cohen (2007) suggest that other research methods may be useful when conducting research in this area. Whilst quantitative and observational research methods provide valuable insights, qualitative methods of enquiry may also broaden understanding of this area. Qualitative research is useful for capturing individual perspectives about an experience or phenomenon, understanding processes and generating hypotheses for further research (Fiese & Bickham, 1998; Atieno, 2009).

This current review draws together papers featuring the personal accounts and views of families of children with a chronic condition and aims to explore three broad research questions:

- What are the views of family members about how they function whilst managing a childhood chronic condition?
- What are the shared experiences across families and across chronic conditions?
- What factors are important for healthy functioning in families managing a childhood chronic condition?

Method

Eligibility Criteria

The review sought to explore the lived experience and views of families, therefore only studies including qualitative findings were included. The aim was to establish key concepts, commonalities and differences within the realm of family functioning and chronic conditions. To allow for a thorough examination of all relevant literature, no time frame was placed on searches, however care was taken to ensure that the search terms reflected changes in terminology or language over time. In order to retain the focus on family experiences of managing conditions, papers that described an evaluation of a specific programme or resource and research that assessed the utility of a measure (questionnaire or coding system) were excluded. Review articles, book chapters, letters and commentaries were not included within this review. The inclusion criteria are outlined in Table 1.

Table 1- Inclusion Criteria for Review

Criteria	Description
Qualitative data	Studies including qualitative data or mixed-methods studies which include a qualitative component.
Childhood chronic condition	Studies focussing on a chronic condition, as defined by the World Health Organisation (Pruitt & Epping-Jordan, 2002), affecting a child aged under 18 years.
Study Focus	<ul style="list-style-type: none"> • Studies with research questions or objectives that explicitly aimed to explore family functioning in relation to a childhood chronic condition. • Studies which situated their study aims in relation to existing literature in the area of family functioning. • Studies that included qualitative analysis as an adjunct to data from a quantitative measure of family functioning.
Participants	Includes data from one or more family member affected by a childhood chronic condition including the child with chronic condition, parent/caregiver, sibling or other relative).

Publication Type Studies published in peer-reviewed journals

Language Studies published in English

Literature search

A search of the literature was undertaken in January 2019, using 4 electronic databases: Web of Science, Medline, CINAHL and Psych INFO (Table 2), using the search terms outlined in Table 3. Following the search (process outlined in Figure 1), a total of 10 papers were selected for review.

Table 2- Database Search Results

<u>Database</u>	<u>Number of articles retrieved</u>
Web of Science & Medline	70
CINAHL	34
PsychINFO	12

Table 3- Literature Search Terms

<u>Terms</u>
Family AND function* AND qualitative AND Child* AND “chronic illness” OR pediatric OR OR paediatric “chronic disease” OR “chronic condition”

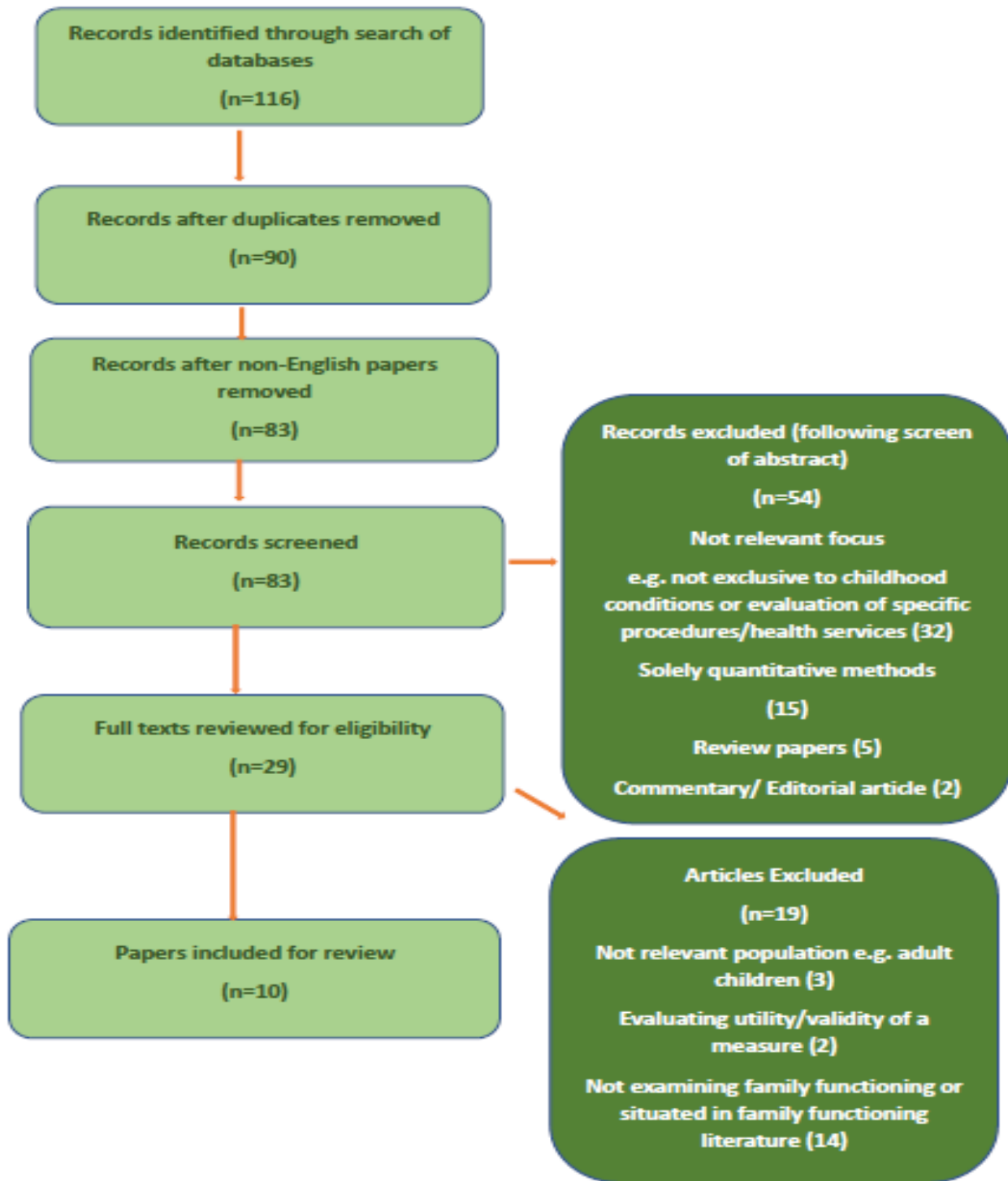


Figure 1- PRISMA diagram of literature search process

Synthesis of Study Findings

A meta-ethnographic approach was used to synthesise the findings of all reviewed studies in line with the methods proposed by Noblit and Hare (1988). This method enables a deeper and more comprehensive understanding of a topic; it moves beyond aggregating or summarising findings and involves the reanalysis and reinterpretation of existing data. Noblit and Hare (1988) first used this approach to allow for the interpretation of different study findings whilst considering the various study contexts and cultures, they described this process as “making a whole out of something more than the parts imply” (p.22). Whilst this approach was initially proposed for drawing together the results of ethnographic studies, it has also been widely used for the synthesis of other types of qualitative studies. Given the variability in the existing literature regarding family functioning within childhood chronic conditions, a meta-ethnographic approach may provide a deeper evaluation of the data, which accounts for various settings and nuances. The method involves an iterative, seven-phased process of noting concepts and themes within data, determining similarities and differences amongst studies and translating concepts into one another. This method and its application to this review are summarised in Table 4.

Table 4- Overview of Meta-ethnographic synthesis process

<u>Phases of meta-ethnographic synthesis (Noblit and Hare, 1988)</u>	<u>Description of process and application within current review</u>
Phase 1 Getting started	Identifying an area of interest that may be informed by qualitative research. <i>The scope of this review is stated within Methods section</i>
Phase 2 Deciding what is relevant to the initial interest	Determining which accounts are of interest, with consideration to the availability and credibility of studies and the intended audience of the synthesis. <i>The scope of this review is stated within Methods section</i>

Phase 3	Reading the studies	Thorough and repeated reading of papers, noting down metaphors/ concepts (explanatory idea) or themes (patterns across data sets).
Phase 4	Determining how the studies are related	Analysing the relationship between studies; assessing similarities or differences across concepts. <i>Examples of common themes across studies are shown in Table 7</i>
Phase 5	Translating the studies into one another	Systematically comparing the meaning of concepts, considering different contexts (e.g. when, where and with whom). 3 mechanisms of translation: <ul style="list-style-type: none"> - Reciprocal: Overlap or similarity between study concepts. The concepts of one study can be encompassed into the concepts of another study. - Refutational: Concepts across studies contradict or refute one another. - Line of argument: Various aspects of a concept that can be drawn together. <p><i>Within this review, translations were made in relation to reciprocal concepts and those that formed a line of argument. Examples of translations are shown in Appendices C and D.</i></p>
Phase 6	Synthesising translations	Further comparing of translated concepts to reach new understandings. Utilising three layers of interpretation: <ul style="list-style-type: none"> - The view of the research participant (1st order) - The interpretation of the participant's view by the study researcher (2nd order) - The interpretation of the researcher's report by the meta-ethnographer (3rd order) <p><i>Examples of interpretations are shown in Appendices C and D. Figure 2 shows the three overarching concepts discovered through this synthesis.</i></p>
Phase 7	Expressing the synthesis	Tailoring communication and presentation of synthesis findings to intended audience.

Review

Overview of studies

Ten articles were identified for review (Cipolletta, Marchesin & Benini, 2015; Hodgkinson & Lester, 2002; Jackson, Higgins, Frydenberg, Liang & Murphy, 2018; Knafl & Zoeller, 2000; Kountz-Edwards et al., 2017; Lee et al., 2004; Mitchell et al., 2007; Nabors et al., 2013; Soliday, Kool & Lande, 2000; Whyte, Baggaley, & Rutter, 1995).^{*} An overview of the studies is presented in Tables 5.

The papers were all featured in peer-reviewed journals from a variety of disciplines including nursing, physiotherapy and psychology. All studies were published between 1995 and 2018 across multiple countries including the UK, Italy, Korea, the United States and Canada. Five of the reviewed papers utilised purely qualitative research methods whilst the remaining employed qualitative analysis in conjunction with other research methods.

The studies were related to a range of conditions such as cancer, juvenile rheumatoid arthritis, sickle cell disease, heart disease, cystic fibrosis, and juvenile dermatomyositis.

Focus of studies

Many of the reviewed studies were interested in family experiences of coping with a childhood chronic condition^{2, 3, 7, 8}. One study⁴ explored how chronic conditions were experienced from different perspectives in the family. Another study¹⁰ examined the needs of families managing chronic conditions and the gaps in service provisions. The authors of one paper⁶ were interested in developing a clear frame for conceptualising family resilience,

^{*} The studies will be numerically cited for the rest of the review: Cipolletta et al. (2015)¹; Hodgkinson and Lester (2002)²; Jackson et al. (2018)³; Knafl and Zoeller (2000)⁴; Kountz-Edwards et al. (2017)⁵; Lee et al. (2004)⁶; Mitchell et al. (2007)⁷; Nabors et al. (2013)⁸; Soliday et al. (2000)⁹; Whyte, et al.(1995)¹⁰

commonly seen as a family's ability to withstand and recover from points of crisis and adversity (Walsh, 1996; Patterson, 2002). One study¹ looked at the relationship between family functioning and the course of the condition whilst another⁹ examined parental stress, child behavioural problems and the family environment. The authors of one paper⁵ explored general family functioning as well as the impact of chronic conditions on parental distress and mood. All studies included the views of parents and caregivers^{1, 3, 5, 6, 7, 8, 9, 10}. One study specifically looked at the experiences of mothers² whilst another compared the perspectives of mothers and fathers within the same family⁴.

Conceptualisations of Family Functioning

The authors of one paper⁶ offered a clear conceptualisation of family functioning based on their own previous study (Lee et al., 2002); defining it as a “dynamic process of changing and restructuring the family when confronted with stressful situations” (p.637). The authors of another study⁸ based their aims and objectives on a model by Walsh (2006) which proposes that positive family functioning and family hardiness (the internal strengths and durability of the family unit) minimises the impact of stressors, leading to less anxiety in caregivers. Some studies^{1, 9} discussed literature related to family systems theory whilst others^{1, 2, 5} referred to existing research regarding family functioning concepts such as family roles, expressiveness, conflict and cohesion. Whilst some studies did not provide an explicit conceptualisation of family functioning, many cited research on the family impact of chronic conditions^{3, 4, 7, 10}.

Quality assessment

The quality of studies was assessed using a tool for appraising qualitative research proposed by the Critical Appraisal Skills Programme [CASP] (Public Health Research Unit, 2006). This tool (Appendix A) features sections about the validity, results and value of the research including questions to consider in relation to each study. An overview of ratings assigned to each study is presented in Appendix B.

The CASP tool was used as a framework for considering the value and quality of the papers and although some key limitations were noted, no study was excluded for review based on poor quality. Key strengths and limitations of all the studies are summarised below:

Design

Many authors presented clear and succinct research objectives or situated their aims in relation to past studies, for example one study⁸ expanded on the work of Greeff and Wentworth (2009) who found that family hardiness was a predictor of positive family functioning in those experiencing heart problems. Some authors explained how their research aimed to fill the gaps in literature; one study⁴ noted that previous research has suggested parental differences in views but as this had not been explicitly explored, they opted to examine the mutuality of views between mothers and fathers. Some authors^{7, 10} provided less details about related research and instead focussed on the clinical impact of the study aims, reflecting their own roles in clinical research settings.

Very few authors provided detailed rationale about the choice of methodology. The authors of one study³ provided some justification for their methods by noting the lack of existing qualitative data about the specific challenges faced by parents of a child with heart disease whilst

another paper⁷, which utilised mixed-methodology, noted that previous qualitative studies could have been strengthened by combining analysis from quantitative measures. The authors of one paper⁴ reported findings from a secondary analysis of their own earlier study and noted how this work had been extended. In another paper⁶ the authors utilised the hybrid model of concept development (Schwartz-Barcott & Kim, 2000) as a framework for their research which involved identifying existing knowledge, conducting fieldwork then amalgamating these findings. There were a variety of research methods used including interviews (individual or more than one family member), focus groups, questionnaire and literature reviews. In most studies, there were no justifications or references provided in support of the selected methods nor a reflection on alternative options.

Sampling

All authors can be credited for providing clear details about their sampling methods (mainly convenience and purposive methods); many provided details about recruitment settings and inclusionary criteria. Many of the papers noted the key role clinicians played in supporting recruitment^{1, 3, 6, 7}. Furthermore, many authors can be credited for commenting on patterns in recruitment, for instance a tendency for mothers to volunteer their participation more often than fathers⁵, struggles in recruiting diverse family groups¹⁰ or reasons for declining participation^{1, 5, 9, 10}. There was variability in the reporting of demographic variables about participants; some papers provided details such as gender, age, ethnicity, family configuration, level of education and household income^{2, 4, 5, 6, 7, 8, 10} whilst others gave very little information about these variables^{1, 3, 9}.

Ethical issues

With the exception of two papers^{4,7}, most authors noted ethical review of their research by an appropriate body. There was variability in the details given by authors regarding informed consent and confidentiality within data collection. The authors of one study³ can be praised for detailing the consent process, including the use of a plain language summary, and offering participants the opportunity to meet with a psychologist if they experienced distress. Other studies failed to state how they considered the potential emotional or psychological impact of research participation.

Data collection and analysis

Most studies focussed on qualitative data from interviews, however one featured analysis of focus group discussions⁷ and another⁹ analysed responses to two open ended questions within a measure of child behavioural problems and competencies. There were differences across the papers in the level of detail included about data collection processes however many noted the use of interview guides and gave an overview of topics^{1,4,5,6,8}. One paper² stated that their interview guide was based on previous literature and had been piloted before the study, however the authors did not provide specific examples of questions. Other studies can be credited for including sample interview questions within the paper^{3,7}. Some authors provided details about interview recording and transcription, however the authors of one study¹⁰ indicated that in their initial interviews (which featured mothers alone), notes were taken whilst follow up interviews (which often featured both parents), were tape recorded; no justification is provided for this difference in approach. Other authors provided additional details about data collection with some stating the time period^{2,10} and the setting in which interviews were conducted^{1,2,3,7}. One

paper⁷ offered the reader a deeper understanding of the focus group sessions, with reference to practical elements (meals, group rules) and attempts to build rapport before discussions. Many authors neglected to include details about data saturation (the point when no new information is discovered in data analysis), however some included a clear account of how this was achieved^{1, 2, 6}.

All studies gave some details about the process of qualitative analysis, however in some cases^{9, 10} descriptions were left vague; one paper simply stated that “28 major categories were classified” (p.516) without a clear indication of how this was established¹⁰. Several studies described using specific forms of analysis and provided references for these^{1, 4, 6, 8}, examples included thematic analysis, grounded theory and framework analysis. Many authors discussed how consensus in themes was reached and how disagreements in coding were resolved^{1, 2, 3, 5, 6, 8}. Interestingly one paper⁶ utilised the themes found across interviews to identify a single model case family (displaying attributes of family resilience), however the exact process of establishing this model case is unclear.

Validity of Study Findings

Most authors provided a clear and coherent narrative about their findings with illustrative quotes. The authors of one paper¹⁰ chose to “extract 3 sections” (p.516) for discussion, however it is unclear how these map onto the categories identified during analysis. Similarly, the authors of another paper presented “highlights” of data within the main text and then displayed key themes within a table⁷. Some of the mixed methods papers can be praised for drawing together quantitative and qualitative findings, which enhanced the validity and credibility of findings^{4, 5, 6}.

^{7,8}. One paper¹ mentioned an aim of “achieving credibility” (p.6) in line with specific quality criteria for qualitative research (Lincoln & Guba, 1985).

All studies contribute to the literature on family functioning in the context of chronic conditions. Many of the studies linked their findings to past research, noting the commonalities and differences^{3,4,5,8,9}, with some providing clear directions for future research^{1,4,8}.

Importantly many authors highlighted the clinical implications of their research^{1,3,4,5,8,9,10}, with specific points for clinicians to acknowledge and suggestions for family support. In some cases, there was limited comment on the clinical relevance of the study^{5,7}, which is perhaps a missed opportunity given the aims of the studies. In the case of one study⁶, their methods and findings were utilised to form a comprehensive concept model of family resilience which may be useful in other research and clinical contexts.

Cultural and geographical context of research

The reviewed papers featured research from various countries, therefore findings and implications should be considered in relation to contextual factors such as cultural practices and access to healthcare. Most authors did not comment on these factors or the potential limitations in generalising findings out of the research context. One paper⁵ noted the geographical diversity of families, as they recruited across different American states, however the authors acknowledged that the sample may not fully represent the ethnic and socioeconomic diversity across those areas. Authors of one study³ noted the high percentage of participants who had private health insurance and contrasted this to the percentage of the Australian population with private insurance. One study⁶ can be credited for noting how cultural practices in South Korea

influence families' responses to illness and how these may differ to similar studies conducted in Western societies.

Role of the researcher

Across all papers there was limited discussion about the role of the researcher throughout each stage (formulation of research question through to analysis). Nevertheless, some authors appear to have given some thought to the impact of their role or potential bias by noting the use of clinical staff to support recruitment^{1, 6, 7}, the value of multiple coders and collaboration between researchers and participants when establishing themes^{2, 3, 5, 6, 7, 8, 9}.

Table 5- Overview of Study Information

<u>Study</u>	<u>Study Aims</u>	<u>Type of Chronic Condition</u>	<u>Participants</u>	<u>Data collection</u>	<u>Qualitative analysis</u>	<u>Overview of qualitative findings</u>
1 Cipolletta, Marchesin and Benini (2015)	<ul style="list-style-type: none"> ●To examine how family functioning influences the course of the illness over time. 	Variety of chronic illnesses including central hypoventilation syndrome, CHARGE syndrome, Menkes syndrome, Duchenne muscular dystrophy, central core disease, spinal muscular atrophy, brain tumour, spinal dysraphism, transverse myelitis, Down Syndrome	<ul style="list-style-type: none"> ●20 mothers ●13 fathers ●Recruited from a paediatric hospice in Italy 	<ul style="list-style-type: none"> ●Semi-structured Interview with parents ●Review of medical records ●Interview with physician caring for child 	Grounded Theory (Strauss & Corbin, 1998)	<ul style="list-style-type: none"> ●Identified four illness trajectories (possibility, focus on illness, denial and anger) and proposed that these are more influenced by structure of the family than specific aspects of the illness. ●Acceptance of the illness and the promotion of the child's autonomy allows for recovery and progression.

<u>Study</u>	<u>Study Aims</u>	<u>Type of Chronic Condition</u>	<u>Participants</u>	<u>Data collection</u>	<u>Qualitative analysis</u>	<u>Overview of qualitative findings</u>
2 Hodgkinson and Lester (2002)	<ul style="list-style-type: none"> To explore the stresses experienced by mothers and their methods of coping. 	Cystic Fibrosis	<ul style="list-style-type: none"> 17 mothers Recruited from cystic fibrosis clinic at children’s hospital in the UK 	<ul style="list-style-type: none"> Semi-structured interviews with mothers 	Themes identified and refined using Framework Analytic approach (Bryman & Burgess, 1994)	<ul style="list-style-type: none"> Stress was experienced in relation to factors such as decision making, burden of care and changes in identity. Support was commonly sought from others including medical professionals. More positive relationships noted in secondary care contexts than primary care settings.

<u>Study</u>	<u>Study Aims</u>	<u>Type of Chronic Condition</u>	<u>Participants</u>	<u>Data collection</u>	<u>Qualitative analysis</u>	<u>Overview of qualitative findings</u>
3 Jackson, Higgins, Frydenberg, Liang and Murphy (2018)	<ul style="list-style-type: none"> ●To understand from the parents' perspective, the stress points and the challenges faced and ways of coping at different phases of their child's illness. ●To use this information to direct resources. 	Heart conditions	<ul style="list-style-type: none"> ●15 mothers ●2 fathers ●Recruited from a family support program at a children's hospital in Australia 	<ul style="list-style-type: none"> ●Semi-structured Interview with parents 	Content analysis	<ul style="list-style-type: none"> ●Identified commonalities in stressors experienced by families and a range of coping strategies employed to manage these. ●Parents coping capacity adapted in response to the challenges encountered.

<u>Study</u>	<u>Study Aims</u>	<u>Type of Chronic Condition</u>	<u>Participants</u>	<u>Data collection</u>	<u>Qualitative analysis</u>	<u>Overview of qualitative findings</u>
4 Knafl and Zoeller (2000)	<ul style="list-style-type: none"> To explore whether mothers and fathers have a shared view of their child's illness and its impact on their lives. 	Variety of chronic illnesses including diabetes, asthma, juvenile rheumatoid arthritis	<ul style="list-style-type: none"> 43 couples 7 women whose husbands did not participate in the research Secondary analysis of data from larger study conducted in the USA 	<ul style="list-style-type: none"> Questionnaire measures completed by parents Semi-structured interview with parents Narrative family case summaries were completed 	Constant comparison and matrix display techniques (Lincoln & Guba, 1985; Miles & Huberman, 1994)	<ul style="list-style-type: none"> Parents within the same family typically shared the same views about the experience and impact of their child's chronic condition. In the minority of the cases where perspectives of mothers and fathers differed, it was usually the mother who emphasised negative elements of the illness.

<u>Study</u>	<u>Study Aims</u>	<u>Type of Chronic Condition</u>	<u>Participants</u>	<u>Data collection</u>	<u>Qualitative analysis</u>	<u>Overview of qualitative findings</u>
5 Kountz-Edwards, Aoki, Gannon, Gomez, Cordova and Packman (2017)	<ul style="list-style-type: none"> ●To explore whether there are differences in family functioning between those with juvenile dermatomyositis and those with other chronic illnesses. ●To assess the impact of juvenile dermatomyositis on parents' psychological health. 	Juvenile dermatomyositis	<ul style="list-style-type: none"> ●36 mothers ●3 fathers ●Recruited participants in the USA via newsletters, websites, emails, support groups and a conference 	<ul style="list-style-type: none"> ●Questionnaire measures completed by parents. ●Semi-structured interview with parents 	Responses coded and themes identified	<ul style="list-style-type: none"> ●Parents reported feelings of anxiety around child's diagnosis and prognosis. ●Parents may experience some degree of posttraumatic growth.

<u>Study</u>	<u>Study Aims</u>	<u>Type of Chronic Condition</u>	<u>Participants</u>	<u>Data collection</u>	<u>Qualitative analysis</u>	<u>Overview of qualitative findings</u>
6 Lee, Lee, Kim, Park, Song and Park (2004)	<ul style="list-style-type: none"> ●To create a clear conceptualisation of family resilience. 	Cancer	<ul style="list-style-type: none"> ●11 parents ●Recruited from paediatric oncology unit in Korea 	Hybrid model of concept (Schwartz-Barcott & Kim, 2000): <ul style="list-style-type: none"> ●Theoretical-literature review ●Empirical (fieldwork) -in depth interviews with parents. ●Analytical - comparison and interpretation of theoretical and fieldwork 	Thematic analysis (Lofland & Lofland, 1984; Mariano, 1995)	<ul style="list-style-type: none"> ●Resilience occurs when families adapt their modes of functioning in order to problem solve any challenges they encounter. ●Noted the importance of factors such as tranquillity, hope and mutual understanding.

<u>Study</u>	<u>Study Aims</u>	<u>Type of Chronic Condition</u>	<u>Participants</u>	<u>Data collection</u>	<u>Qualitative analysis</u>	<u>Overview of qualitative findings</u>
7 Mitchell, Lemanek, Palermo, Crosby, Nichols and Powers (2007)	<ul style="list-style-type: none"> To explore the relationship between coping, family functioning and use of health care services. 	Sickle Cell Disease	<ul style="list-style-type: none"> 53 parents (4-8 in each focus group). Recruited from 3 large urban children's hospitals in the USA 	<ul style="list-style-type: none"> Questionnaire measures completed by parents Eight focus groups with parents 	Responses coded and categories identified	<ul style="list-style-type: none"> Parents and children play complementary roles in managing sickle cell disease and associated pain. Families benefit from decreasing negative thinking and utilising a variety of coping strategies. Identified a need for clinical staff to promote positive coping in patients and parents.
8 Nabors, Kichler, Brassell, Thakkar, Bartz, Pangallo, Van Wassenhove and Lundy (2013)	<ul style="list-style-type: none"> To understand ways that caregivers cope with their child's illness. To identify facilitators and barriers to coping. 	Variety of chronic illnesses including heart issues, cancer, blood disorders and birth defects	<ul style="list-style-type: none"> 63 mothers 20 fathers 12 guardians Recruited from residential accommodation for families of hospitalized children in the USA 	<ul style="list-style-type: none"> Questionnaire measures completed by caregivers Semi-structured interview with caregivers 	Grounded Theory (Strauss & Corbin, 1990)	<ul style="list-style-type: none"> Support from others was noted as an important factor in caregivers' abilities to cope with the illness. Increased levels of caregiver stress felt as a result of difficult interactions with medical staff or from feeling poorly equipped to attend to their child's needs.

<u>Study</u>	<u>Study Aims</u>	<u>Type of Chronic Condition</u>	<u>Participants</u>	<u>Data collection</u>	<u>Qualitative analysis</u>	<u>Overview of qualitative findings</u>
9 Soliday, Kool and Lande (2000)	<ul style="list-style-type: none"> ●To examine how the family environment impacts upon child behaviour problems and parenting stress. ●To compare prevalence and severity of issues across three diagnoses and children without chronic illness. 	Kidney disease (3 subtypes: steroid sensitive nephrotic syndrome, chronic renal insufficiency, end-stage renal disease)	<ul style="list-style-type: none"> ●41 families of children with kidney disease ●34 families of healthy children ●Recruited from paediatric clinics in a teaching hospital and a regional teaching centre in the USA & Canada 	●Questionnaire measures completed by parents	Coding of responses to two open-ended items of the Child Behaviour Checklist (Achenbach, 1991)	●Parents reported concerns regarding things such as their child’s development, adjustment and behaviour, however many noted positive traits and qualities of their children.

<u>Study</u>	<u>Study Aims</u>	<u>Type of Chronic Condition</u>	<u>Participants</u>	<u>Data collection</u>	<u>Qualitative analysis</u>	<u>Overview of qualitative findings</u>
10 Whyte, Baggaley and Rutter (1995)	<ul style="list-style-type: none"> ●To explore the needs of families caring for children with a chronic illness. ●To examine similarities and differences in family responses across four diagnoses. ●To use this information to design a questionnaire for a larger scale study. 	Congenital heart disease, asthma, diabetes mellitus, cystic fibrosis	<ul style="list-style-type: none"> ● 4 families from each illness group ●Recruited from outpatient clinics at local hospital 	<ul style="list-style-type: none"> ● 2 Semi-structured Interview: first usually with the mother only and the second usually with both parents 	Data grouped into categories.	<ul style="list-style-type: none"> ●Confronting a diagnosis of a chronic condition seen as a 'crisis' point. ●Commonalities in stressors experienced by parents across conditions and confidence was noted as a crucial factor for coping

Study Findings

There were common themes across study findings, as illustrated in Table 6. Many families commented on the challenges they encountered as a result of the condition including the initial emotional response to receiving a diagnosis, the difficulties of the ongoing management of the condition and concerns about the child's development and adjustment^{2, 3, 5, 8, 9, 10}. Whilst there were commonalities in the types of issues faced, participants across the studies noted ways that their family had adapted to and coped with chronic conditions. Reference was made to specific coping strategies, flexibility in family roles and tasks and how families adjusted their style and functioning to cope with various issues^{1, 3, 4, 5, 6, 7, 8, 10}. There were consistent reports about the role of support both within and outside the family^{2, 4, 8} with factors such as confidence, open communication and shared understanding impacting how this support was received and used^{4, 6, 8, 10}. Furthermore, there were accounts of the more positive aspects of family life for instance reflections on the strengths of the family, a renewed appreciation of relationships and a greater sense of connectedness^{1, 5, 6, 9}. Many papers included family views on health services with many participants noting both positive and negative elements of their interactions with professionals^{2, 4, 7, 8, 10}.

Table 6- Themes across study findings

<u>Experience and impact of chronic condition</u>	<u>Dealing with challenges</u>	<u>Relationships and dynamics within family</u>	<u>Relationships with and to others</u>
<ul style="list-style-type: none"> ● Response to diagnosis (emotional reaction e.g. shock, relief) ● Views on condition (understanding of condition, perspectives on cause of condition, denial/acceptance) ● Impact on child (hospital visits, pain, distress, decreased school attendance) ● Impact on other family members (emotional/psychological impact, financial impact, changes in employment) ● Course of illness (prognosis, possibility of death, key milestones) 	<ul style="list-style-type: none"> ● Points of stress (medical emergencies, hospitalisations, conflicts, disagreements) ● Ways of coping (connecting with others, facing each problem as it arises, reframing of problems) ● Personal and family resources (optimism, resilience, confidence, experience) ● Access to support and information (friends/family, support groups, information about condition) 	<ul style="list-style-type: none"> ● Roles and tasks in the family (division of tasks, level of burden) ● Shared or different perspectives (agreement/conflict) ● Ways of communicating (openness, freedom of emotional expression) 	<ul style="list-style-type: none"> ● Connections to extended family/ friends (close relationships, social isolation) ● Role of family, friends, community (emotional support, practical support e.g. childcare) ● Experience of healthcare professions (relationships with staff, responsiveness of clinicians) ● Comparison to others (families with healthy children, families also facing chronic conditions, adults with same condition)

Synthesis Findings

The synthesis involved comparing study findings then developing another layer of understanding based on participant accounts and researcher interpretations across studies. Some studies were translated into one another by considering how concepts overlapped or encompassed one another (reciprocal mechanisms). In some instances, concepts across studies were drawn together to build a 'line of argument'. Through the process of synthesis (Appendices C & D), three overarching translations emerged (Figure 2): potential stressors faced by families, potential resources utilised by families and the process of appraising these stressors and resources.

Potential stressors

The findings from the reviewed papers are useful for highlighting the potential stressors facing families managing chronic health conditions. All authors noted stressors directly related to the health condition such as the process and experience of diagnosis, daily management of the condition, medical procedures or complications. Stress can occur as a result of factors such as emotional distress, economic or financial strain and difficulties within environments such as work or school^{1, 2, 3, 7, 8, 9, 10}; the continuous management of a chronic condition can be a contributing and exacerbating factor in all these areas.

Relationships with others such as partners, siblings, parents or healthcare professionals can also be a source of stress, ^{1, 2, 3, 4, 7, 8, 10}. There may be existing tensions within certain relationships or specific scenarios which lead to difficult interactions such as making critical decisions about medical care.

The reviewed papers explored the elements that may cause stress or distress to individuals and families and through synthesis of these findings the commonalities in experiences across diagnostic groups and other demographic variables are highlighted.

Potential resources

Many papers noted the ways that families managed chronic conditions and the factors that supported wellbeing and resilience. Accounts highlighted various coping or management strategies. There were a wide range of examples including individual or familial disposition (optimism, resilience, maturity, responsibility) and specific methods of coping including typically 'adaptive' forms such as problem-solving and typically 'maladaptive' forms such as denial or emotional numbing^{2, 3, 4, 5, 6, 7, 9}. One recurrent theme amongst study findings was the utility of connecting with others (immediate and extended family, friends, support groups and professionals such as healthcare staff and childminders) as this allowed for increased emotional and practical support^{1, 2, 3, 5, 6, 7, 8, 10}. It was noted that access to information about the experience and management of the health condition was beneficial for family coping^{3, 5, 6, 7, 10} alongside experiences of faith and religion^{1, 6, 8}.

Process of appraisal

Whilst the reviewed papers note commonalities in potential stressors, findings within and across the studies suggest that there is variability in the reported experience of these. There appears to be a process of registering and evaluating certain variables, which may involve an internalising, externalising, reframing, overestimating or minimising of potential stressors and resources.

Many authors referred to caregivers accounts of receiving a diagnosis for their child or managing aspects of their child's condition. The quotes featured below demonstrate how similar experiences can be appraised in different ways:

“we were relieved at the time to have a definite cause for her symptoms”

(Whyte et al., 1995, p.516)

“we were told that she might die when she was in her teens”

(Whyte et al., 1995, p.516)

“she had meningitis as well and she came through that. We can get her through anything”

(Whyte et al., 1995, p. 517)

“my main thing was, will this baby have a quality of life, that's all I needed to hear”

(Jackson et al., 2018, p.e13)

“other mums change the diaper, feed their child with a bottle. I attach a pump and allow her to inhale; in short this is our normalcy”

(Cipolletta et al., 2015, p. 9)

“cystic fibrosis isn’t something you fit in when you can, cystic fibrosis dominates your life”

(Hodgkinson and Lester, 2002, p.380)

Many participants within the featured studies note how things such as medical support from healthcare professionals, contact with friends and family and other personal resources have been beneficial for their sense of wellbeing and ability to cope. However, the quotes below illustrate how these potential resources have been evaluated by family members:

“the hospital has been very good. If anything happens to Kate you can phone up ward 9 and take her back just like that”

(Whyte et al., 1995, p.518)

“in intensive care I felt like I was always consulted, like they never made a decision unless they had me part of that decision”

(Jackson et al., 2018, p.e13)

“God knew that we could look at her, give her the love that someone else could not give her.”

(Cipolletta et al., 2015, p. 11)

“Margaret’s brother is very responsible; he knows what he must do and say. If we are not in, he is even more responsible”

(Cipolletta et al., 2015, p. 12)

“communication between the hospital and the GP seems to have gone out of the window- John had his drugs changed and no-one told us”

(Whyte et al., 1995, p.519)

“questioning can I let him cry for a couple of minutes, if he vomits do I just give him more formula”

(Jackson et al., 2018, p.e14)

The synthesis suggests that there are various factors that contribute to this process of appraisal, such as family history and past experiences, the specific context in which potential stressors arise such as a home environment or healthcare setting and other key elements such as relationship to others and ways of communicating (feeling included, involvement in decision making). Families need to believe that any potential resource will be useful and that it will be appropriate for their concern or difficulty. Many authors noted the utility and value of increased support for families managing chronic health condition. However, the findings suggest that it is not enough simply to increase resources, there also needs to be consideration of how relevant and worthwhile these resources are perceived to be.

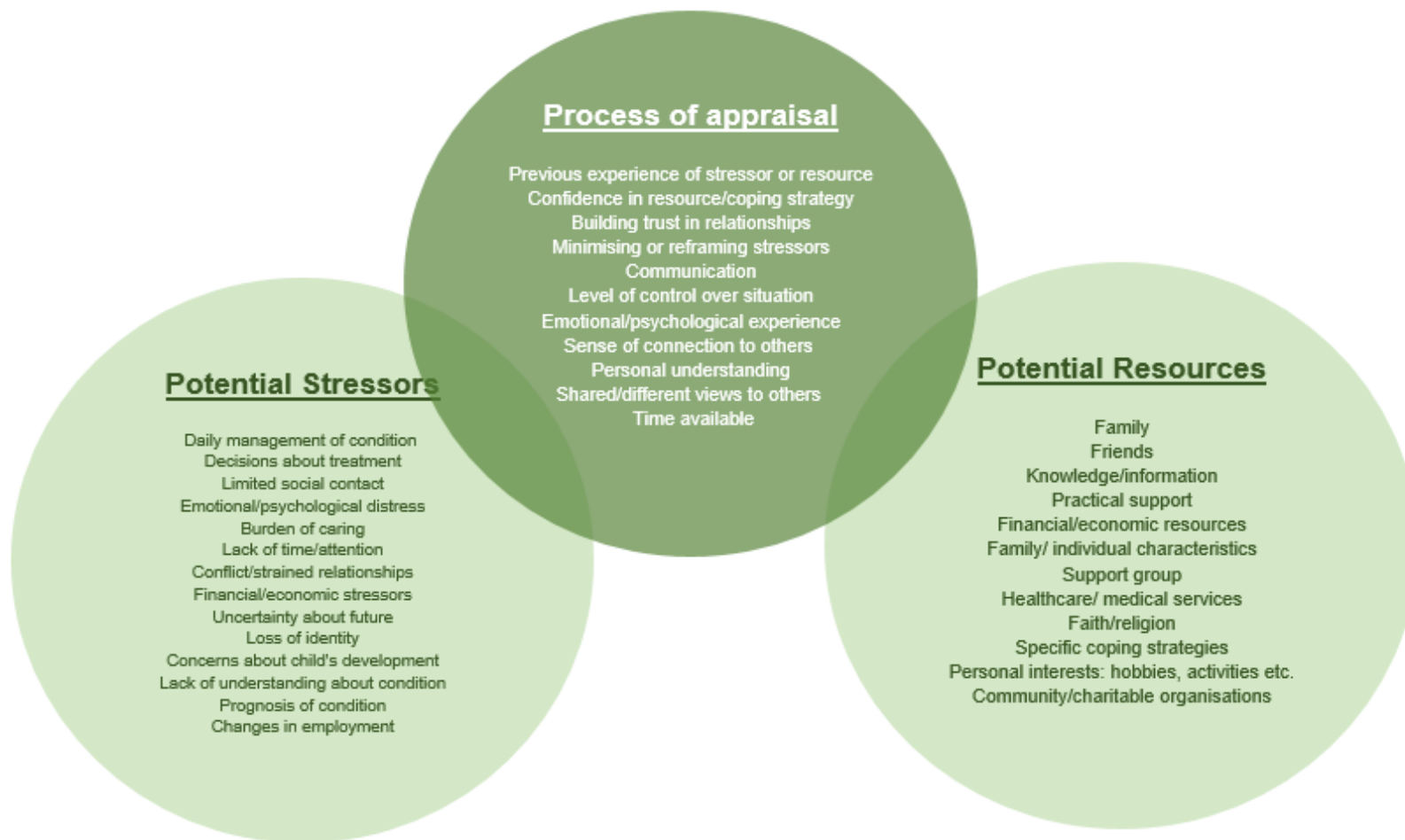


Figure 2- Key Concepts discovered through the synthesis

Impact on functioning

The reviewed literature suggests that there is a dynamic system in which the processes for identifying stressors and resources and the processes for appraising them are in constant communication. Where there are perceived stressors, these are evaluated in relation to the available resource and vice versa (Figure 3).

One summation would be that optimal family functioning is achieved by having fewer stressors and increased resources, however, there are various levels of depth and context that also need to be considered. These processes are occurring within interconnected systems (Figure 4) including the individual family member, the family unit and their wider context (including family, friends, communities and health care services).

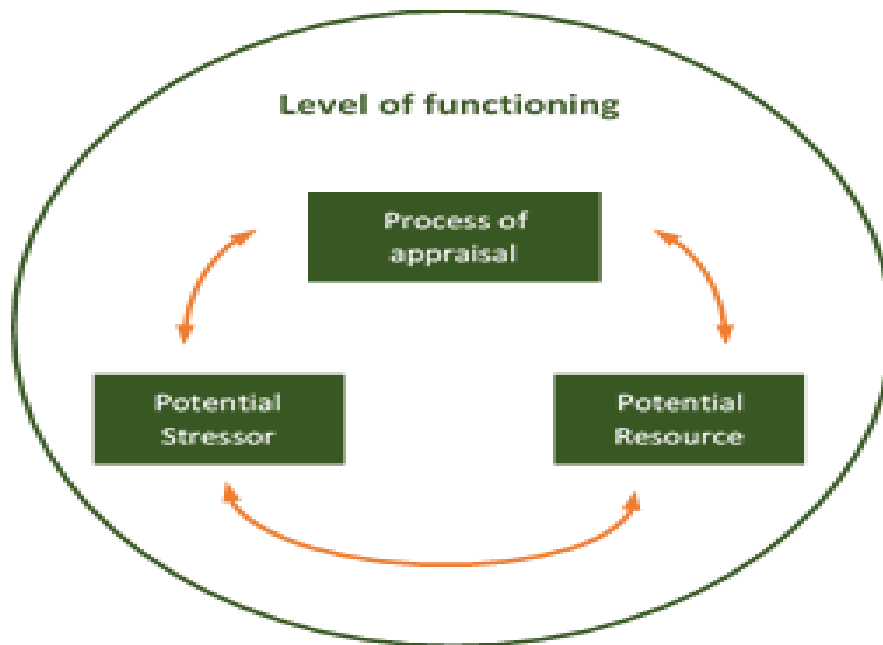


Figure 3- Interaction between stressors, resources and appraisal

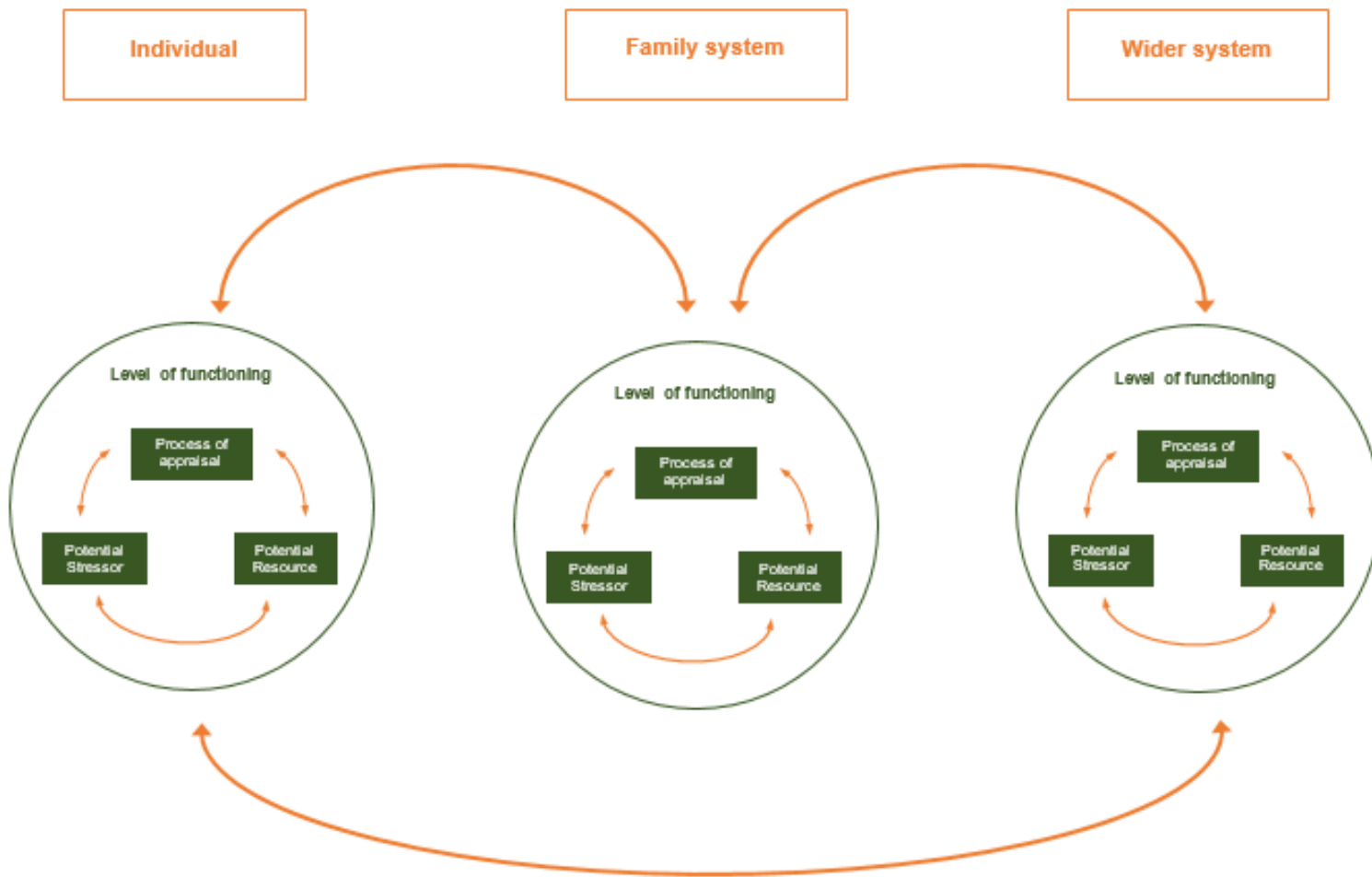


Figure 4- Interaction between stressors, resources and appraisal at various levels

Discussion

There is a wealth of literature exploring family functioning within the context of chronic health conditions, with many researchers focussing specifically on those conditions affecting children. Many authors in this field have utilised validated questionnaires or observational methods to examine this area but there are limitations to these methodologies. This current review collated and evaluated qualitative findings related to family functioning and childhood chronic conditions with the aim of eliciting the personal accounts and perspectives of family members about the ways their family functions, finding the commonalities and differences in experiences and discovering which factors influence healthy functioning.

The review findings give an insight into the experiences of families managing childhood chronic conditions and note common challenges and points of distress such as receiving diagnosis, dealing with fluctuations of illness and medical procedures, dynamics within and outside of the family unit, changes to roles, social isolation and financial pressures. These add to and expand upon the findings presented within previous studies (Svetaz et al., 2000; Lucas et al., 2016; Westbom, 1992; Bai et al., 2017; Leis-Newman, 2011; Vermaes et al., 2012; Quittner et al., 2010). These findings echo those of existing literature (Ni Mhurchadha & O'Sullivan, 2017) about the necessity and value of appropriate coping mechanisms and support such as contact with others, positive reframing of difficulties and access to advice and information. Many researchers have considered the clinical implications of family functioning noting the potential impact on health outcomes and engagement with services (Quittner et al., 2010; Ni Mhurchadha & O'Sullivan, 2017; Patterson et al., 1990; Gavin et al., 1999; Jastrowski Mano et al., 2009). Authors of the reviewed papers have also commented on the role that medical professionals play

in supporting families to manage chronic conditions and provide suggestions on how clinicians can better serve the needs of all family members.

Many of the accounts included in these studies, map on to the concepts and factors noted within models of family functioning. Several authors (Dai & Wang, 2015; Olson, 2000) refer to the concept of family cohesion and within the reviewed data, participants speak of their experiences bringing the family closer together, the value of spending quality time with one another and also threats to cohesion such as differing perspectives. It is suggested that functioning is impacted by the roles in the family (Epstein et al., 2003; Skinner et al., 2000, Dai & Wang, 2015); this is also demonstrated within the review findings with participants reflecting on the distinct positions that each family members fulfils, the division of tasks and parenting styles. The data also emphasise the importance of clear communication, emotional expression and a level of flexibility within the family- which are factors referenced in various models (Olson, 2000; Beavers & Hampson, 2000; Epstein et al., 2003; Skinner et al., 2000).

This review supports the results of other review papers which could not draw firm conclusions on whether family functioning is significantly impacted or impaired as a result of childhood chronic conditions (McClellan & Cohen, 2007; Lewandowski et al., 2010). Whilst the synthesis concludes that many families are utilising various methods to navigate adversity, it suggests that there are more complex and nuanced processes governing their experiences of stress and ways of coping.

Following this synthesis of qualitative data, the author encountered the work of Patterson and Garwick (Patterson, 1988; Patterson & Garwick, 1994); their findings reinforce the conclusions drawn within this review. Patterson (1988) outlined the family adjustment and adaptation response model which notes that family systems maintain balanced functioning by

using their capabilities (resources and coping behaviours) to meet its demands. This model notes the importance of the meanings that families ascribe to challenges and the interactions between the individual, the family and the community. This theory was also linked to family functioning and chronic conditions with Patterson and Garwick (1994) suggesting a reciprocal relationship between the condition, the development of individuals in the family and family functioning which continues in a circular pattern over time. The consistency in observations from Patterson's original work in 1988 to the recent publications included in this review, indicates that these concepts may have universal applicability as they do not appear to be impacted by space or time. Whilst the specific nature or quality of stressors and resources may be more changeable (as they will be influenced by factors such as culture, geography or resources), this process of appraisal remains consistent.

This also maps onto ideas related to family adaptability, which notes how family systems change their structure, roles and relationships in response to stress (Olson et al., 1983) and family hardiness which notes how families employ an active approach to adjust to stressful situations (Failla & Jones, 1991). These processes are also noted within the literature on family resilience which asserts that resilience is fostered through adversity, not despite it (Walsh, 1996). There is an overlap between the basic elements of resilience and concepts which are commonly cited within the family functioning literature such as cohesion, flexibility, open communication and problem solving. A resiliency-based view of family functioning situates families in relation to their challenges, constraints and resources; many authors propose that this offers a valuable framework for identifying and strengthening processes that allow families to overcome stresses (Walsh, 1996). Rutter (1987) also notes that in order to encourage protective mechanisms and

resilience, it is necessary to examine the interaction between what occurs within families and what occurs within the wider political, economic and social systems.

Parallels can also be drawn to theories outside of the family functioning and family systems literature. Rogers' (1975) protection motivation theory proposes that there are two systems for human protection: the threat appraisal which assesses the severity and seriousness of a situation and the coping appraisal which governs response to the situation. This theory is often aligned with terror management theory which suggests that an individual's drive for self-preservation conflicts with their knowledge of the inevitability and unpredictability of death; this leads to feelings of terror which are managed through embracing beliefs that provide long-lasting personal meaning and negate the realities of life (Greenberg, Pyszczynski & Solomon, 1986). The patterns across the literature suggest that many researchers have been investigating similar processes but from different perspectives (individual or system levels).

Limitations

Whilst this review offers further insight into the perspectives of families managing childhood chronic conditions, some limitations are noted. Firstly, there is variability in the conceptualisations of key terms used within the review. The review aimed to explore literature related to chronic conditions and used the World Health Organisation definition (Pruitt & Epping-Jordan, 2002) as a framework for this. However, as various terms are used within the literature such as chronic illness or chronic disease, there may have been differences in how researchers defined and selected cases for inclusion. The aetiology of a condition impacts how individuals and families respond and adapt to conditions (Van Den Bos, 1995; Wolfe, Song, Greenberg & Mailik, 2014), therefore as some studies focussed on specific conditions such as

cancer or cystic fibrosis and others focussed on a variety of conditions, it is unclear whether some trends noted within this synthesis relate to specific conditions or the general experience of managing any chronic condition. Furthermore, as all studies focussed on physical health conditions, caution should be taken when considering how the findings apply to other types of chronic conditions. It may be that there may be nuances or differences in the processes described within this review for those managing intellectual disabilities and mental health conditions, particularly as existing literature highlights the specific challenges raised by these conditions, such as increased stigma and discrimination (Goffman, 1963; Corrigan & Miller, 2004).

There may also be key differences in how family functioning is defined across the literature. Some authors gave clear descriptions of their interpretations of this area, with reference to commonly used theories and models, whilst others did not clearly state how they construed family functioning. The findings of this review are linked to evidence in other areas such as family resilience and family adaptability; it may be difficult to ascertain whether these concepts are distinct from or related to family functioning. Therefore, the conceptualisation of family function used within this review may have excluded other relevant studies within this area; it is possible that other related research papers may have added to or deviated from the patterns drawn within this synthesis.

Furthermore, whilst the focus of the review was on family functioning, this was often only reported from the perspective of one or two family members. As all studies reported the views of parents or caregivers, the conclusions drawn within this review may be more reflective of the impact on parental functioning or parent perspectives of family function. As perspectives of children within the family (including the child with the chronic condition or siblings) were

lacking within the featured studies, we cannot be sure how the review findings correlate to their lived experiences and there is a need for these views to be explored further.

When assessing the quality of studies, it was noted that many authors neglected to give thorough details about analysis, data saturation and reflexivity within the research process. Whilst it was valuable to draw together these findings, these methodological issues may limit the conclusions or hypotheses that can be drawn. Whilst a meta-ethnographic approach can be valuable for providing a rich analysis of research papers, the process of synthesising and aggregating findings from a diverse range of studies may have meant that certain complexities within the literature were missed. Given the interpretative nature of this approach it is possible that alternative interpretations or conclusions could also be drawn from the data.

Direction for future research

It may be valuable for researchers to continue to collate qualitative findings about this area, perhaps expanding search criteria to capture research related to family resilience, family adaptability and family hardiness. Future studies could also explicitly explore how families describe or define concepts such as resilience and hardiness using their own words. Researchers may want to focus on how these processes occur in more prevalent childhood conditions such as asthma, diabetes and epilepsy and then note similarities or differences between conditions. It has been suggested that one singular research methodology may not fully capture the complexities and nuances of the family experience, therefore future research may be improved using multiple, mixed methods such as validated quantitative measures combined with qualitative interviews and observations. Efforts should be made to elicit the views of multiple family members, particularly those whose perspectives are typically missed in existing research and to consider the impact of

wider social, economic and political factors on family functioning. In addition, attention should be given to further exploring the potential mechanisms involved in the appraisal of stressors and resources.

Clinical Implications

It is important for services that support families to regularly review how this support is perceived. In addition, clinicians may benefit from ongoing training on recognising and addressing the medical, social, emotional and psychological needs of all family members. Clinical psychologists may have valuable skills to offer within this domain and could provide indirect support (multi-disciplinary working, consultation to medical teams, involvement in service development initiatives) or direct psychological assessment and intervention to children and their families. Clinical services may want to play a facilitative role in empowering families by supporting family centred initiatives such as support groups. There is also a need for the systems around the family to be cohesive and flexible, so families are reassured that all parties, including community and specialist health services, are working together.

Conclusions

This review explored family functioning from the perspectives of family members managing childhood chronic conditions. Families can experience many challenges, however, findings show that there are many ways that families assess and respond to these. Whilst methodological limitations are acknowledged, this synthesis offers a deeper understanding of these issues and may explain the variability in previous findings. The review supports the notion that active efforts should be made to decrease the stressors and increase the resources of these

families, however it is beneficial to also identify and reinforce the factors that encourage a more positive evaluation of stressors and available resources.

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Section B: Empirical Paper

When a sibling has a mental health condition: a grounded theory analysis of children's experiences and views on the sibling relationship.

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For Submission to Journal of Child Psychology and Psychiatry

Abstract

Background: There is emerging research about the experiences of siblings of individuals experiencing a mental health condition, however this tends to be from an adult perspective with limited accounts from children. This study aimed to understand the views of children who have a sibling with a mental health condition and their perceptions of the sibling relationship.

Method: Seven children were interviewed about their experiences and a grounded theory methodology was used for data analysis.

Results: Three interrelated concepts of establishing connections, gathering information and developing an understanding of the sibling were noted to impact the view of the sibling relationship. Fluctuations within relationships, lack of clear information about the sibling's condition alongside dissatisfaction with the process of integrating and evaluating experiences may have a detrimental effect on the sibling relationship and individual wellbeing.

Discussion: This study suggests that whilst changes and fluctuations are a typical feature of sibling relationships, there may be increased uncertainty and fluctuations within the relationships of those encountering certain health conditions. Findings are discussed in relation to possible interventions and avenues for future research.

Keywords: child and adolescent mental health, brother, sister, sibling relationships

Introduction

The role of sibling relationships in child development

There is a wealth of literature noting the importance of social relationships for child development in terms of interpersonal competence, conflict-resolution, academic attainment and social success in later life (Parker & Asher, 1987; Jones, Greenberg & Crowley, 2015). Sibling relationships are often the longest-lasting relationship in an individual's life (Cicirelli, 2013; Hernandez, 1997) and provide an important context for a child's social, emotional, moral and cognitive development (White & Hughes, 2018; McAlister & Peterson, 2006).

Siblings can serve as play mates, role-models and rivals (White & Hughes, 2018; Tucker, McHale & Crouter, 2008). Many psychological theories have been used to understand sibling relationships. Attachment theory (Bowlby, 1951) enabled a greater understanding of the bond between a child and their primary caregiver, with important links made between these relationships and other areas of personal development. It is also known that children can form attachments to others in their social world therefore some children may use their sibling as a secure base from which to explore or as a source of comfort (Samuels, 1980; Ainsworth 1989). Social learning perspectives are also used to understand sibling dynamics as it is proposed that children learn a range of behaviours through observing others (Bandura, 1977; Tucker, Finkelhor, Shattuck & Turner, 2013). Siblings often serve as a reference point for one another (Bank & Kahn, 1982) therefore a child may acquire novel behaviours, attitudes and beliefs via reinforcement and observation of their sibling's behaviours (Whiteman, McHale & Soli, 2011).

The role of siblings within the wider family context has often been considered using Bronfenbrenner's (1979) ecological model of development or using family systems perspectives (Bowen, 1966). Bronfenbrenner's (1979) model includes four hierarchical system levels. The

first level of the micro-system may include specific relationships within an environment such as parent-child or sibling relationships within a household. The meso-system refers to collections of micro-systems and incorporates the interaction between relationships in different contexts. The exo-system captures elements of the physical environment such as home or school whilst the macro-system refers to the influence of more abstract factors such as class or culture. Family systems theory views individual family members and dyadic relationships as interdependent parts of a family unit (Bowen, 1966). This perspective notes how certain dyadic relationships impact on others, for instance differential parental treatment between children will impact sibling interactions and spousal relationship difficulties will impact parent-child and sibling relationships (Jenkins, Rasbash, Leckie, Gass & Dunn, 2012; Gerard, Krishnakumar & Buehler, 2006).

Within early childhood, sibling relationships are generally characterised as ambivalent with high rates of both positive and negative behaviours such as periods of extended play or displays of physical aggression (Kramer, 2010; Dunn, 2002). Later in childhood and adolescence, siblings may become less involved as they develop friendships outside of the family; despite this pattern of reduced time together siblings remain an important source of support for children (Furman & Buhrmester, 1992; Whiteman, McHale & Soli 2011). Sibling relationships tend to be ‘heterotypic’, whereby there is considerable stability in the quality of a sibling relationship across time despite the significant developmental changes that occur. Therefore, it is suggested, siblings who tend to get on well within early years will also get along well within later life. However the way sibling qualities are expressed may change as children grow up (White & Hughes, 2018).

Marotta (2015) found that sibling relationship quality (as measured by ratings of warmth, conflict, and rivalry) is significantly related to affectivity, self-esteem, and altruism. A meta-analytic study found that greater sibling warmth was linked to less internalizing and externalizing behaviours (social withdrawal, somatic complaints, bullying and vandalism) whilst increased sibling conflict was linked to more problematic outcomes (Buist, Deković & Prinzie, 2013). High levels of tension and conflict between siblings during childhood and adolescence may have harmful and longer lasting effects such as increased risk of antisocial behavior (Branje, Van Lieshout, Van Aken & Haselager, 2004; Bank, Burraston & Snyder, 2004). Whilst sibling conflict and rivalry is frequently noted and examined within the literature, this may simply reflect the involuntary and very familiar nature of these relationships (Dunn, 1983; Howe, Ross & Recchia, 2010).

Individual traits, family configuration, birth order, gender and the wider context can affect sibling relationships. Siblings who are closer in age often have more involvement, which includes both companionship and conflict, whilst those with greater age differences often spend less time together and display less conflict (Buhrmester & Furman, 1990; Furman & Buhrmester, 1985; Kramer & Kowal, 2005). Older siblings typically take the lead in initiating more positive interactions such as teaching or play but are also more likely to initiate conflict (Buhrmester & Furman, 1990; White & Hughes, 2018). Siblings of the same sex are often noted to have more positive relationships which may be due to an increased likelihood of shared interests (Edwards, Mauthner & Hadfield, 2005). Sisters may more commonly use talk to maintain closeness to their sibling whilst brothers typically use shared activities (Edwards, Mauthner & Hadfield, 2005). A child's temperament also affects their relationship with a sibling, with those displaying high levels of negative emotionality often having poorer sibling relationships than those with more

favourable temperaments. Some have suggested that the compatibility between siblings' temperaments is also important (Volling, 2003; Stoneman & Brody, 1993).

The impact of childhood health conditions on sibling relationships

Life stressors, including illness and disability, can play a significant role within family and sibling relationships bringing both positive and negative changes (White & Hughes, 2018). Research suggests that having a sibling with a learning disability or chronic illness can negatively impact psychological functioning and emotional regulation (Sharpe & Rossiter, 2002; Taylor, Charman & Fuggle, 2001). There may be increased instances of internalising behaviours such as anxiety and depression within these siblings as they may not feel able to express negative emotions due to the uncertainties of the sibling's health condition (Sharpe & Rossiter, 2002). Goffman (1963) proposed that family members may experience 'courtesy stigma' and negative consequences as a result of being associated with someone with health concerns; these themes have also been echoed in more recent empirical research (Angermeyer, Schulze & Dietrich, 2003).

More recent evidence suggests that in sibling pairings, where one has a health condition, the relationship can be equally or sometimes more positive than pairings when there is no health concern (Sharpe & Rossiter, 2002; D'Urso, Mastroyannopoulo & Kirby, 2016). It is widely acknowledged that the impact of a health condition on family members is heavily influenced by contextual factors such as family environment, geographic location, cultural practices and economic resources (White & Hughes, 2018).

The impact of a childhood mental health condition on sibling relationships

Within the UK there has been an increase in the reporting of symptoms of common mental health conditions, including depression, anxiety, panic disorder, phobias, and obsessive-compulsive disorder, over the last few decades (Baker, 2018). Prevalence of these conditions within the general population is frequently cited as between 16-25% (Baker, 2018; McManus, Meltzer, Brugha, Bebbington & Jenkins, 2009). It is estimated that half of all mental health difficulties begin to manifest before the age of 14, although many will not receive a formal diagnosis or treatment until later in life (Patel, Flisher, Hetrick & McGorry, 2007).

Much of the responsibility of caring for people with mental health conditions falls on family members and can lead to feelings of burden and distress (Veltman, Cameron & Stewart, 2002). Some families report feeling that others avoid them due to negative stereotypes about mental illness and in some cases the families' own feelings of shame lead them to avoid contact with others (Corrigan & Miller, 2004). Whilst there is evidence of the more detrimental effects of caring for a family member with a mental health condition, some research notes more positive outcomes such as personal growth, empathy and increased resilience (Kinsella, Anderson & Anderson, 1996; Marsh, Appleby, Dickens, Owens & Young, 1993; Veltman et al., 2002).

Despite this increased prevalence of mental health conditions within child populations, research tends to focus on the impact of terminal or chronic physical illness, intellectual disabilities, autism spectrum disorders and behavioural conditions on sibling dynamics in children (McKeever, 1983; Abrams, 2009). There is evidence that suggests the impact of health conditions on siblings varies depending on the aetiology of the condition as Wolfe, Song, Greenberg & Mailik, (2014) note that siblings of individuals with genetic conditions, that are

evident from birth such as Down syndrome, show better adjustment and more positive sibling relationships than siblings of those with neurodevelopmental or mental health conditions.

It is possible that mental health conditions have a greater impact on siblings than other conditions because of the typically acute nature of illness onset (White & Hughes, 2018). Judge (1994) proposed that normative sibling relationships may be disrupted by the emergence of a serious mental health condition as individuals may struggle to define their own identity when a key reference figure is experiencing distress.

One study interviewed adult participants about their childhood experiences of having a sibling with severe mental illness; these participants revealed an impact on their sense of personhood and disruption to roles and boundaries (Lukens, Thorning & Lohrer, 2004). Another retrospective study noted the coping mechanisms used by individuals who had grown up with either a parent or sibling with serious mental health difficulties such as occupying time with activities outside of the family, seeking support and information, isolating themselves or using drugs or alcohol (Kinsella et al. 1996). Evidence from the adult literature notes that people often felt poorly informed about their siblings' mental health diagnosis and treatment plan and would have benefitted from better access to support and resources (Landeem et al., 1992; Lukens, Thorning & Lohrer, 2002; Kinsella et al. 1996).

Having a sibling with a mental health condition also impacts other family dynamics and experiences. Parents of children with mental health difficulties may be less available to meet the practical and emotional needs of other children within the family leading to these children feeling disregarded or overlooked (Brodoff, 1988; Lukens, Thorning, & Lohrer, 2004). Marsh et al. (1993) noted that siblings of those with mental health difficulties may experience

‘replacement child syndrome’ in which they feel they have to compensate their parents for their unwell sibling.

This literature suggests that the experience of having a sibling with a mental health condition can affect many areas of an individual’s life including personal wellbeing and relationships with others.

Rationale for current study

Whilst there is a wealth of literature regarding the individual experience of mental health conditions, accounts of the perspectives of siblings are lacking. Where sibling perspectives are gathered these are typically from an adult’s current or retrospective accounts. This current study investigates the experiences and perspectives of children who have a sibling with a mental health condition.

Aims

The study aims to investigate the experiences of children, who have a sibling with a mental health condition, and examine their perspectives on the dynamics of their sibling relationship.

The study explores the following research questions:

- What are the core features of the relationship between these siblings?
- What elements of the sibling relationship present as being impacted by the mental health condition?
- What is the individual experience of the child?
- What other areas of the child’s life has this sibling relationship or experience influenced?

Methods

Design

A non-experimental qualitative design was used for this study; these methods are beneficial for exploring the perspectives of participants without attempting to determine or predict aspects of their experiences (Hatch, 1995). Several qualitative methods could have been employed to explore sibling relationships in relation to childhood mental health conditions, such as thematic analysis or interpretative phenomenological analysis (Willig, 2013). However, given the dearth in literature and theoretical understanding within this area, it was felt that grounded theory was a valuable methodology to use. This approach moves beyond descriptions of findings and allows for the formation of hypotheses about factors that impact upon processes and the generation of a theoretical model (Willig, 2013).

This study employed Charmaz's (2006) social constructionist stance to grounded theory which views the derived theory as a socially construed reality as opposed to an objective 'truth'. This perspective proposes that meanings are co-constructed by researcher and participant (Charmaz, 2008). This approach is valuable when conducting research in the constantly changing world of children as it examines both individual and relational processes and enables consideration of how these may have changed over time (Charmaz, 2006; Greig, Taylor & MacKay, 2007).

Participants

The study sought to interview children, aged 18 and under, who had a sibling (also aged 18 and under) with a mental health condition. Consideration was given to various factors

including the participant age, conceptualisations of mental health conditions, recruitment methods and risk management.

Age

The accuracy of children's responses during research tasks is dependent on their language and developmental capacities; it is suggested that a child's ability to answer questions which require memory retrieval will not be comparable to an adult until the end of their primary school education (Greig, Taylor & MacKay, 2007). Accounting for these specific issues and acknowledging the educational pressures on children within the final years of secondary school education, recruitment was limited to children aged between 11 and 15 years old.

Conceptualisations of Mental Health Conditions

There is variability in personal, familial and organisational definitions of mental health conditions with conceptualisations commonly including symptoms of emotional or psychological distress, formal psychiatric diagnoses, neurodevelopmental and behavioural difficulties. The Office for National Statistics (2015) note that mental ill-health in children can lead to behavioural and conduct issues, such as Attention Deficit Hyperactivity Disorder (ADHD), and other issues such as depression or anxiety. They also highlight that these conditions can be symptomatic of other environmental or developmental factors (family conflict, neurodevelopmental conditions).

This study utilises the term mental health condition and conceptualises this (based on knowledge, clinical experience and discussions with the research supervisor) as an issue "*which affects every day functioning, where its impact can be seen or felt such as anxiety, low mood,*

unusual experiences or experiences that are not easily understood, eating disorders or other difficulties". However, given the paucity of existing knowledge about this research area, rigid or stringent definitions of mental health conditions were not enforced during study recruitment.

Recruitment and Sampling

Research with children often involves liaison with authority figures, such as parents, and 'gatekeeping' organisations (Greig, Taylor & MacKay, 2007). In order to gain access to the desired population, whilst also considering the specific ethical issues that arise within these populations, various organisations were approached to assist with recruitment to this study. Participants were recruited via charitable organisations that provide support to children and families across London and Kent, between March 2018 and April 2019. Efforts were made to develop good relationships with 'gatekeepers' and gain the full cooperation of both the children and parents interested in participating in the research.

Information about the study was circulated to families via representatives from the recruiting organisations (either in person, via post or email). At times, convenience sampling methods were used with information provided to any available families, at other times purposive sampling techniques were employed whereby information was provided specifically to those believed to fulfil the inclusion criteria. Any interested participants were encouraged or supported to contact the researcher directly to discuss involvement in the research. The inclusion and exclusion criteria for this study are included within Appendix E.

Seven participants were included within this study; demographic details and family information are provided within Table 8.

Ethical considerations

The study received ethical approval from the Salomons Research Ethics Panel at Canterbury Christ Church University (Appendix F). Parental consent was sought prior to any direct interactions between potential participants and the researcher.

Parents and children were given thorough verbal and written information about the study (Appendices H, I and J) including details about their rights to withdraw from the study and storage and use of their data. They were advised that details of the interview would not be shared with others (including family members or staff) except in cases where safeguarding concerns were raised. Informed consent was sought (Appendices K and L) from parents and children prior to the interviews and children were reassured that they could make the final decision about participation in the research, regardless of the views of others.

Given the lack of familiarity with the researcher and the sensitive nature of discussions, attention was given to building rapport and ensuring the comfort of the participant before the interviews commenced. The researcher remained sensitive to any verbal or non-verbal indicators of distress and tailored interview pace and style to suit each participant. Details of support services (Appendix N) were also provided to both the participants and their parents at the close of the interview session.

Data collection and analysis

This study adhered to specific guidance regarding conducting research with children such as using clear and unambiguous questions and making efforts to appear friendly and reassuring (Greig, Taylor & MacKay, 2007). Decisions about the interview setting were made in collaboration with participants, their parents and in some cases representatives from the

recruiting organisations; attention was given to participant comfort, privacy and accessibility. Four participants were seen at school, one within a community setting and the remaining were seen within the premises of recruiting organisations. Interviews were conducted using a semi-structured interview guide (Appendix M); appropriate prompts and clarifying questions were used throughout. As advised by Charmaz (2006) the closing questions of all interviews were broader and more conversational to allow the interview to end on a lighter note- this was felt to be particularly important given the young age of participants (Charmaz, 2006). All interviews were between 30 and 50 minutes in duration; all were audio-recorded and later transcribed for analysis.

Within grounded theory methodology, data collection and analysis occur concurrently; this allows for the refinement of later interview in line with the emerging codes and concepts (Bryant & Charmaz, 2007). Analysis using grounded theory consists of three main stages of coding: initial, focussed and theoretical. This process is outlined in Table 7 and examples included within Appendices O and P).

Table 7- Overview of grounded theory analysis process

Analysis Process

Open coding	To allow thorough understanding and immersion of the data, interview transcripts were initially coded line-by-line. As advocated by Charmaz (2006) initial open coding was performed using gerunds (noun forms of verbs) and emphasis was placed on coding quickly and keeping codes as close to the data as possible (examples of this can be found within the sample transcript in Appendix O). This process helped to define what was occurring within sections of text.
Focussed coding	Following review of the first few interview transcripts, many initial codes were developed. Constant comparison techniques were used to examine similarities and differences in the data and to ensure accurate coding of

participant accounts (Charmaz, 2006). Emerging patterns within and across the data were explored in subsequent interviews.

Initial codes were reviewed, and the most salient codes were developed into broader, more descriptive codes. Codes that appeared to be connected or overlapping were also grouped together. (Appendix P)

This allowed for synthesis and organisation of larger segments of transcripts and a more conceptual view of the data (Charmaz, 2006).

Theoretical coding

Codes were used to develop hypothetical concepts and theory. An important step within this stage of analysis was the naming of relationships between constructs to explain how one concept encompasses or impacts another (Urquhart, 2013).

A tentative model of processes within these sibling experiences and relationships was developed. This was expressed using diagrams and written memos (Appendix P) based on the focused codes and relationships between them.

Memo Writing

Memos were used to note any emerging ideas during the analysis process and were useful for concept and theory development (Strauss & Corbin, 1990).

Such memos were made after each interview, including reflections about the participant's experiences and the researcher's reaction.

As analysis continued, more conceptual memos were made in relation to the initial and focused codes. These were used to record thinking about how and when certain processes happened and to consider the meaning of emerging concepts.

Data sufficiency

Given the scale and constraints of this current study, analysis focussed on reaching theoretical sufficiency (Dey, 1999) as opposed to data saturation (when no new information is discovered during the process of data analysis; Glaser & Strauss, 2017). Sufficiency was deemed to have been met when there were consistent patterns observed across participant accounts. Data collection ended at the point when the emerging theoretical concepts made sense to the researcher and research supervisor (Morse, 2007) and were felt to have good explanatory power.

Quality assurance and reflexivity

A social constructionist epistemological stance within research challenges the notion that a researcher can or should be without any prior knowledge when developing a theory of a particular social phenomena (Charmaz & Mitchell, 1996). Cutcliffe (2000) notes the need for researchers using grounded theory methodology to acknowledge explicitly how their prior knowledge and experiences affect the development of theory. The influence of the researcher in the analysis process of this research was acknowledged and addressed using supervision and by documenting the research process within a research diary (Appendix Q, Lincoln & Guba, 1985). A 'Bracketing interview' (Appendix R) was conducted early on in the data collection process; this allowed the researcher to consider any prior views or assumptions about the area under investigation (Rolls & Relf, 2006). These methods allowed for consideration of coherence or divergence between researcher and participant positions. Although the researcher did not share the participants experiences of having a sibling with a mental health condition, there was resonance with some themes raised (family relationships, mental health presentations) due to personal and professional experiences. There was acknowledgment of how contextual factors (perceived authority or expertise of researcher/organisations) contributed to the collection and

interpretation of data. In line with constructionist grounded theory, the researcher aimed to develop an abstract understanding of the studied phenomena by attending to ‘what’ and ‘how’ questions throughout the research process (Charmaz, 2008).

Sections of interview transcript were jointly coded with a colleague of the researcher and subsequently discussed with the research supervisor. To increase the credibility and validity, illustrative participant feature throughout the results section (Williams & Morrow, 2009). This study aimed to adhere to Yardley’s (2000) criteria for good quality qualitative research including sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.

Table 8- Participant Information

<u>Participant</u>	<u>Sibling with mental health condition</u>	<u>Description of sibling’s condition (provided by parent/staff from recruiting site):</u>	<u>Family members within the household</u>
Richard* Age: 13 Gender: Male Ethnicity: White British	Lewis Age:16 Gender: Male Ethnicity: White British	<ul style="list-style-type: none"> • Attention Deficit Hyperactivity Disorder (ADHD) • Autism Spectrum Disorder (ASD) • Oppositional Defiance Disorder (ODD) 	<ul style="list-style-type: none"> • Mother • Father • 4 children (aged between 11 and 16)
Heather* Age: 11 Gender: Female Ethnicity: White British			
Tom Age: 11 Gender: Male Ethnicity: White British	Suzanne Age: 14 Gender: Female Ethnicity: White British	<ul style="list-style-type: none"> • Anxiety • Depression 	<ul style="list-style-type: none"> • Mother • Father • 2 children
Michaela Age: 14 Gender: Female Ethnicity: White British	Alfie Age: 11 Gender: Male Ethnicity: White British	<ul style="list-style-type: none"> • ADHD and ASD traits 	<ul style="list-style-type: none"> • Mother • Father • 2 children
Nicholas Age: 13 Gender: Male Ethnicity: White British	Maria Age: 15 Gender: Female Ethnicity: White British	<ul style="list-style-type: none"> • Low mood/ anxiety • ASD traits 	<ul style="list-style-type: none"> • Mother • Father • 2 children

RUNNING HEADER: SIBLING RELATIONSHIPS AND CHILDHOOD MENTAL HEALTH CONDITIONS

Bridgette Age: 15 Gender: Female Ethnicity: White British	Leonie Age: 18 Gender: Female Ethnicity: White British	<ul style="list-style-type: none">• Anxiety• Depression• Eating Disorders	<ul style="list-style-type: none">• Mother• Father• 2 children
Joanna Age: 13 Gender: Female Ethnicity: Black British	Andrew Age: 17 Gender: Male Ethnicity: Black British	<ul style="list-style-type: none">• ADHD• ASD	<ul style="list-style-type: none">• Mother• 7 children (aged between 1 and 18)

*Participants part of the same family

Results

Overview of model

Following analysis, a theoretical model was constructed based on three main categories: establishing connections, gathering information and developing an understanding. All categories were interrelated, and shaped participants views of their sibling relationship. These categories and connecting processes were influenced by the child's developmental capacity and environmental factors.

A detailed explanation of the theoretical model is presented below in Figure 5.

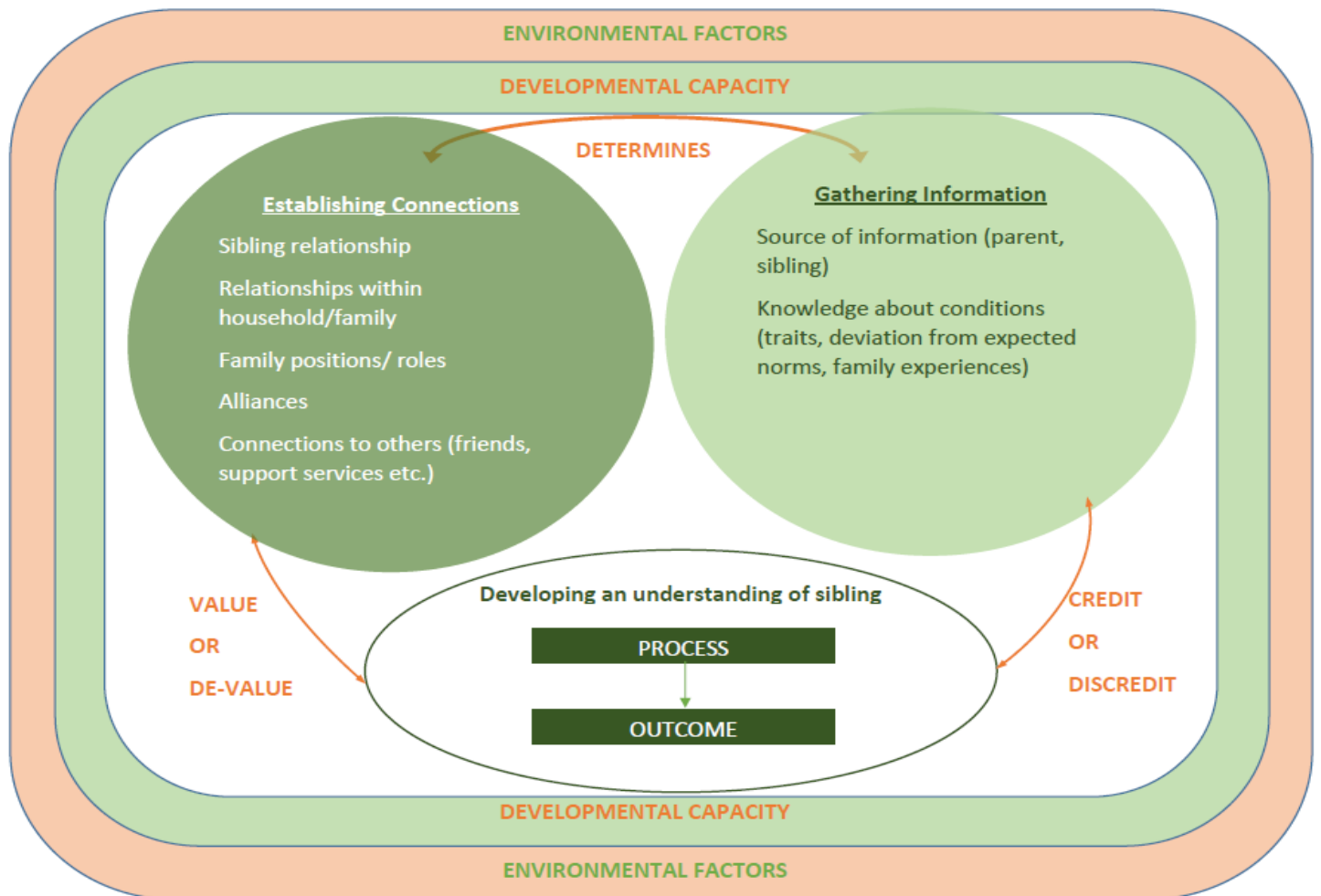


Figure 5- Overview of Theoretical Concepts

Establishing Connections

Sibling Relationship

All participants gave accounts of how they interacted with their sibling citing examples of kindness and companionship coupled with instances of arguments and conflict. One common theme was the frequent fluctuations within the sibling dynamic. Many reported that their sibling's mood or behaviour could be very changeable leading them to feel a sense of uncertainty about how interactions or discussions may unfold:

“he gets very angry sometimes, some days he can be like nice and go buy stuff for some people...but then some days like you could say a nice thing to him and then he would be so angry for the rest of the day”

Richard

Alongside observations of the consistencies and changes within the dynamic, there was an ongoing process of comparing and contrasting themselves with their siblings. Most participants noted how closeness to their sibling was often expressed or maintained through shared interests and activities. For some, there was contemplation of how their own traits and those of their sibling may work in a complementary fashion (confident or vulnerable, sociable/outgoing or quiet/introverted). Some accounts demonstrated a consideration of their sibling's individual perspectives and reflection about their sibling's strengths and needs. However, it was interesting to observe that whilst participants had made efforts to understand their sibling, some did not feel that their sibling would have the same level of understanding about them:

“Participant: there’s some occasions where she can be very confident but there’s others that when she’s vulnerable, she needs a bit of help getting back up

Researcher: sounds like you have a good understanding of Maria and how she feels, do you think she has a good understanding of you and how you feel?

Participant: No way”

Nicholas

Relationships within household/ family

All participant accounts were situated within their experience of their family as a whole. Participants commented on the quality of the relationship between their sibling and parents with most describing moments of closeness as well as episodes of conflict. Many participants commented on their parents’ perception of their relationship with their sibling; with most noting that this was in line with their own evaluation. Participants often commented on the differences in parental treatment between them and their sibling; many expressed feelings that this disparity in treatment may be due to their sibling having greater or differing needs to them:

“I think them [parents] giving more attention to Maria helps in some ways...I think she needs more attention than I do because I’m less of a drama person...”

Nicholas

Family Positions/ Roles

In many instances, participants noted that parents played the role of mediator or negotiator between them and their sibling. Participants noted that a parent may have the deciding vote when there were conflicting views between the participant and their sibling or they may facilitate increased contact, for instance by arranging activities or enforcing rules:

“we usually have to get one of the parents involved...one child ends up being really regretful for arguing and the other child is really happy because they're right”

Nicholas

“sometimes my mum like makes him get off the Xbox...so if she does that more often then we could like just hang out more...”

Michaela

For the participants who were in sibships of more than two, their accounts noted how this specific sibling dynamic linked to relationships with other siblings. They commented on how the sibling with the mental health condition was perceived by other siblings and spoke of the similarities and differences in interactions between all siblings. Other siblings were also used as a mode of comparison or way to gauge quality of this specific relationship:

“I think Lewis is worse [than Bradley] though because he's like comes round our side and starts shouting...Bradley comes and sits on my bed and just says, but doesn't shout”

Richard

Participants made observations about closeness between family members, with some noting which relative may have the best understanding of them or their siblings:

“I think I’m more worried about my sister than everyone else is... I think my parents are good with calming her down, but I don’t think they’re very good at noticing signs that she’s not ok”

Nicholas

More generally, participants described the level of family cohesiveness and communication styles amongst members; a few participants acknowledged a lack of closeness within the family unit or increased distance between all individuals over time. Participants described shared family experiences such as mealtimes and excursions and many described a change in dynamics over time, which was sometimes attributed to their sibling’s health condition and sometimes seen as a natural result of factors such as age.

Alliances

Participants commented on roles and dynamics within the families; many noted alliances and similarities between certain family members. Some participants noted a closeness or bond with one parent whilst acknowledging how this contrasted with their sibling’s bond with the other parent:

“it’s always been like my mum and Alfie and then me and my dad having things in common”

Michaela

“if dad wants to go do something that maybe mummy doesn't want to do, he'll suggest it and she'll [sibling] follow along...”

Nicholas

Connections to others

The relationship with a sibling was also described within the wider context of the young person's life including their experience of school, friendships, extended family and links to support service. Four participants attended the same school as their sibling and some made observations about how their sibling related to others, such as their own friends and teachers, and noted when this pattern had been changeable. Interestingly some participants noted how being affiliated with a sibling affected their friendships, with many speaking of negative experiences of being ridiculed or being put in difficult situations:

“they kept on going Lewis is your brother and all this and they were all sort of saying...oh yeah tell him this...tell him that...”

Richard

Participants noted how interactions with their sibling differed between home and school; one noted a positive experience of having the same friend as their sibling:

“she doesn't pay much attention to me... she will usually try and keep other people happy and I usually have to go on my own”

Nicholas

“he [brother] says that she's like his best mate as well...I think it's good because if we go out together and that...”

Michaela

In instances when families had contact with mental health or support services, participants noted the impact of this on their sibling or other family members but there was limited direct contact or support for the interviewees themselves:

“We had lots of people coming round our house from the CAMHS team... I wasn't asked how it was...it was very confusing”

Bridgette

Many participants described their relationships with other important people in their lives including friends from their neighbourhood and extended family such as grandparents, aunts, uncles and cousins. Closeness within these relationships was often attributed to proximity and level of contact.

More broadly, some participants made comparisons between their experiences and that of others, for instance noting occasions when they had observed behaviour similar to their siblings in others or noticing patterns of sibling relationships within other people's lives. These comparisons allowed them to see that some patterns of conflict or disagreement are typical amongst many families, not just their own.

Gathering Information

Source of information about sibling's condition

Participants reported gaining knowledge about these conditions from sources other than the sibling themselves. In most cases it was the participants' mothers who provided information, however some reported gaining knowledge from other sources.

“my sister was acting really weird at the time and I was talking to my mum... I asked her what was going on with my sister...and she just told me...”

Tom

“My mum said that he might have autistic traits or ADHD”

Michaela

Knowledge about conditions

Participants tended to describe their siblings' conditions in very behavioural or relational terms, with accounts lacking description of the perceived emotional or psychological experiences of the sibling themselves:

“she never went out the house... she never really had any friends at that moment...she went away from her friends”

Tom

“he always wants attention really...like from people on the Xbox and that...he'll just try and be in charge...”

Michaela

Furthermore, some accounts suggested that a sibling's conditions were noticed because they were different to normal or somehow deviated from expected norms:

“everyone saw he was just unusually angry”

Richard

“He would lose his temper and do things he wasn't meant to do”

Joanna

A few participants noted similar traits or conditions, such as ADHD traits or depression, within other family members. Often this knowledge about other people's conditions also came from a source other than the person themselves:

“My dad has depression, so I know a bit about that”

Tom

“she [mother] thinks, my dad has ADHD as well because like he's never like sitting down or resting”

Michaela

Many spoke of the lack of knowledge about their sibling's conditions and some accounts noted limits in how openly these issues could be discussed with them:

“We [sibling and participant] never talk about mental health at all, it's kind of like an unsaid thing”

Bridgette

Some spoke of ways for their sibling to manage or cope with their condition such as contact with mental health services or by taking medication. However, for many there was lack of clarity and uncertainty about the treatment or support available to their sibling.

Links between establishing connections and gathering information

The processes of establishing connections and gathering information appeared to be interconnected. Most participants noted how their relationships with siblings and others determined the knowledge they had and vice versa.

Some participants noted that their parents would typically have a better understanding of their sibling's condition than them or their sibling. One participant noted that his father's own experience of a mental health condition possibly increased his understanding of these issues and led to a more positive relationship between him and the sibling:

“my dad has depression... my sister has both like with the anxiety...they never got on but then since the past week or something they've got on really well...”

Tom

Another participant suggested that his mother was seeking guidance and support from a wellbeing service in order to become closer to his sibling:

“I think mummy wants to have a better understanding of Maria than I or other people do because she's worried...I think what's happening is that she's worried about getting distant with Maria”

Nicholas

Some participants noted that, on occasions having or wanting more knowledge can lead to negative consequences for themselves or others:

“they [friends] knew he [brother] had ADHD and then it ended up for me getting hurt in a way”

Richard

“they [parents] go up to her room and kind of push me out...which is a good idea because sometimes if you're a bit too curious that can be a bit harmful to others”

Nicholas

Developing an understanding of the sibling

There appears to be an internal processing system in which children evaluate and integrate information and views about relationships to form an understanding of themselves, their sibling and the world around them. This process involves a weighing up of concepts, for instance valuing or devaluing connections to others, with some relationships held in higher regard than others (family valued more than friends or vice versa). This process may also involve an assessment of the credibility or validity of the information held about the sibling's condition/behaviour and a decision to credit or discredit certain pieces of knowledge.

In some cases, children can come to a clear and coherent understanding about their sibling and consequently their relationship with their sibling. For one participant the changes in her relationship with her sibling were attributed to a specific cause and this perhaps made it

easier to manage, particularly as there was hope that a close relationship would resume at some point:

“think it's just the fact that he's like stuck on the Xbox, I don't think it's really anything to do with his mental health or anything”

Michaela

In other cases, it is not possible to come to a satisfactory understanding about their sibling, their relationship and the nature of their condition. The accounts provided by participants reflected strong themes of uncertainty and this was often observed in the emotional tone during interviews (frustration, anxiety, sadness):

“sometimes we get on really well and then like other times ...she gets annoyed at me...then I just don't speak to her...and she comes back...like she comes and speaks to me like nothing happened”

Tom

“I never really knew when she was going to come from the hospital...so for a while it felt like it was never going to end”

Bridgette

“I don't want to be the family member who's so laid back that if something goes wrong...that I only come to the rescue when something bad is happening”

Nicholas

Participants overall view of the relationship with their sibling is not only impacted by the outcome of this process but also by the process itself. The need to constantly weigh up information, make assessments and evaluate relationships may be experienced as very unsettling, particularly when this process is happening very frequently and when understanding of the mental health condition remains limited. Participants within this study spoke of regularly having to make sense of how to behave or communicate with their sibling and having to navigate interactions with others such as other family members and friends.

Some participants struggled to know the best thing to say or understand why they may have annoyed or upset their sibling:

“I think that sometimes if I want to say something I need to analyse if it’s the proper thing to say”

Nicholas

“I never really knew where we were...if I could make a joke or something...whether it would be funny or if I’d have to back off”

Bridgette

Impact of contextual factors

Children’s experiences and understandings are influenced by their developmental ability and capacity, for instance their ability to process information is impacted by their age and maturity and similarly other people’s perceptions (parents, siblings, teachers) of this may also influence how information is shared with them.

Furthermore, other contextual factors shape how experiences are evaluated, for instance the number of people within a household, geographical location, family resources and culture will impact upon a young person's world view.

Discussion

This study aimed to examine the individual experiences of such children, their view of the sibling relationship and the impact of the condition on this relationship and their lives more generally.

The data show that there is variety in sibling interactions; participants stated that fluctuations in their sibling's mood or behaviour impacted on communication and time spent together. Many participants expressed a good understanding of their sibling's needs and often contrasted these to their own, however there was often doubt about whether their sibling would have a similar level of insight about them. Although previous literature has noted stability in the quality of sibling relationships over time (White & Hughes, 2018), the data gathered in this study could suggest that sibships, which are impacted by a mental health condition, may deviate from this heterotypic trajectory or experience increased fluctuations within it.

Family systems theory (Bowen, 1966) notes the interdependent nature of relationships within a family; this was reflected in participants' accounts as sibling relationships were described in relation to other family relationships. In alignment with Bronfenbrenner's (1979) model, these relationships were also described across various levels, including meso-systems such as the wider family and exo-systems such as home or school. In families of more than two children, participants spoke of their connections to other siblings and often used this to gauge the quality of the relationship to their sibling with the mental health condition. There were

observations made about the relationship between their sibling and their parents, notably that their sibling may require more parental input or attention. This aligns with previous literature which notes that parents of children with mental health needs are less able to attend to the needs of other children within the family (Brodoff, 1988; Lukens, Thorning, & Lohrer, 2004). Parents were seen to mediate the relationship between siblings by resolving disputes, making decisions or facilitating shared activities. Interestingly, participants spoke of alliances and pairings within families (one parent allied with one child and the other parent allied with the sibling) with commonalities described as shared activities and interests.

Participants spoke of how their sibling relationship impacted upon their connections to others, outside home, including school friends, teachers, extended family and support services. In some cases, participants described negative interactions with peers whilst others reported a greater appreciation for friends or teacher. For participants who attended the same school as their sibling, observations were made about their sibling's relationships to others such as increased tensions or avoidance of others. Some spoke of how their sibling relationship impacted upon their own friendships, with some reporting instances of disagreements or being ridiculed. This mirrors findings from existing research which notes that family members of those with health issues may be avoided by others or be impacted by the negative views held by others (Angermeyer, Schulze & Dietrich, 2003).

Whilst many of the participants were able to name specific conditions that their sibling experienced, such as ADHD, autism, anxiety or depression, there appeared to be variation in the levels of understanding of these terms. Participants usually described these conditions by giving examples of their sibling's behaviour and relationship to others, inferring that these were in some way unusual or undesirable (attention-seeking, social withdrawal). Within these accounts, there

was a lack of understanding about their sibling's own experience of these conditions or how they may impact upon their sibling's internal state (perception, mood, energy). This dearth in knowledge possibly reflects the nature of communication about mental health within families, with participants disclosing that information about their sibling's condition was often shared via a parent and often in very little detail or depth. Developmental factors may also play a role in these experiences, as a child's ability to make sense of information (regardless of how much is shared with them) is affected by their biological maturation, environment and social interactions (Piaget, 1936; Vygotsky, 1978). In cases where families had received input from mental health or support services for the sibling's mental health condition, participants were rarely included or aware of what these interventions entailed.

Analysis of the data highlighted how participants utilised their connections to a sibling, and others, alongside existing knowledge to assess and evaluate their own experiences, including their view of the sibling relationship. This is a dynamic process of weighing up details and attempting to formulate coherent conclusions. The theory derived from the data, suggests that it is not only the specific conclusion or outcome drawn that impacts a child's view of their relationship to a sibling with a mental health condition, but also their experience of the process itself. Whilst all sibling relationships may involve processes of interpreting information and noticing relationships which will be governed by an individual's stage of emotional, cognitive and psychosocial development, the presence of a mental health condition within a sibship may add a layer of complexity to this. The unexpected and sometimes frequent fluctuations in their sibling's mood accompanied with the participant's lack of knowledge about mental health conditions may lead them to feel uncertain, frustrated or concerned about many aspects of their lives. Conversely when children can come to conclusions that feel satisfactory or adequate or

when fluctuations are anticipated this can have a more positive outcome on their own mood and perception of the sibling relationship.

It has been suggested that siblings of those with neurodevelopmental or mental health conditions may encounter more negative consequences or adjustment difficulties than siblings of those with physical or genetic conditions (Wolfe, Song, Greenberg & Mailik, 2014; White & Hughes, 2018; Judge, 1994); the potential for more frequent feelings of turbulence and uncertainty within these relationships may account for these differences in outcome.

Variables such as age, birth order, sex and temperament have been shown to play an important role in sibling relationships. Therefore, the processes and concepts proposed in this study must be viewed with due regard to these factors. As siblings who are closer in age tend to have more involvement with one another (Buhrmester & Furman, 1990; Furman & Buhrmester, 1985; Kramer & Kowal, 2005) some participant accounts of issues such as conflict may be reflective of this increased proximity, as well as the presence of a mental health condition. Similarities and differences in the sex and temperaments of each sibling impact upon contact and communication (Edwards, Mauthner & Hadfield, 2005; Stoneman & Brody, 1993); these are elements that could have strengthened or weakened the quality of the sibling relationships examined in this study.

Limitations

Whilst the study offered valuable insight into the impact of a mental health condition on sibling relationship, various limitations can be noted. The study aimed to explore a variety of views and as such a broad conceptualisation of mental health conditions was employed. There was variation in how recruiting organisations, families and individuals defined mental health

conditions which may have impacted upon the research process. Furthermore, there was a lack of diversity in the sample particularly in relation to factors such as ethnicity and family configuration. As participants were recruited from a specific age bracket, the proposed theory may not be generalisable to children of different ages or developmental stages. Although the data collected were deemed to reach theoretical sufficiency, validity and cogency of the theoretical model could be enhanced with a larger sample size.

Participant involvement within this study was mediated by various ‘gatekeepers’ including parents and staff at the recruiting organisations; whilst all participants provided their own informed consent, involvement may have been impacted by the views of others. Furthermore, the differences in age or perceived power and authority may have influenced participants’ discussions with the researcher.

This study examined sibling relationships; however, this was only from the perspective of one sibling; it is possible that the other sibling’s evaluation of the relationship may differ significantly. As participants were only interviewed on one occasion, the findings provide a snapshot of experiences as opposed to a thorough evaluation over time.

Future Research

The finding from this study, along with the limitations noted above, provide direction for future research. It would be valuable to replicate this study and include a more diverse sample of participants, in terms of demographic features such as ethnicity, religion and family configuration, to ascertain the generalisability of the proposed theory and to explore the specific impact of these variable on the proposed concepts. It would be useful to examine the impact of

specific mental health conditions on the theoretical model and include respondents who are the siblings of those with severe and enduring conditions.

Future research could examine this experience from various perspectives including the child with the mental health condition, their sibling, parents and other family members. It may be beneficial to include the views of other key parties such as teachers or clinicians, to highlight the similarities and differences in perspectives and to allow for greater validity and credibility of the model. Research in this area could be strengthened by using mixed methods approaches, for instance by combining interviews with validated measures of sibling relationship quality or observations of interactions. Quantitative measures could also be used as a way of testing the emerging theory, such as correlating a measure of relationship quality with a measure of mental health knowledge. Given the ever-changing nature of sibling relationships, it would also be valuable to conduct longitudinal research to assess how dynamics change over time.

Clinical and Practice Implications

The theory developed from the data offers some potential areas for clinical intervention and practical support. Efforts can be made, within families managing childhood mental health conditions, to strengthen sibling and wider family connections for instance by increasing opportunities for shared activities.

Participants noted limits in their knowledge of their sibling's condition, which aligns with the retrospective accounts of adult siblings of individuals with a mental health diagnosis (Landein et al., 1992; Lukens et al. 2002; Kinsella et al. 1996). It would therefore be beneficial for siblings to be provided with more information about the possible aetiologies, impact and lived experience of mental health conditions, in a manner that is appropriate to their age and

understanding. Care must be taken to ensure that children are adequately supported in processing and managing that information so that they are not unduly overwhelmed. Families should be encouraged and supported to have open and honest discussion about mental health conditions to allow for a better understanding of the personal meanings of such conditions.

Individuals experiencing mental illness and also their family members can experience stigma from others (Goffman, 1963; Corrigan & Miller, 2004); therefore there is a wider need for all children to have better knowledge of these issues, possibly through school or community based initiatives, to combat the taboo and misconceptions about mental illness.

Siblings of children with certain conditions may have difficulties expressing their own emotions and may utilise maladaptive ways of coping such as social withdrawal or substance abuse (Sharpe & Rossiter, 2002; Kinsella et al. 1996). Therefore, children who have a sibling with a mental health condition should be provided with forums to disclose their own needs, concerns and fears both within and outside of the family unit. It may also be beneficial to provide individual or family based therapeutic interventions to increase a child's ability to recognise their emotions and potential triggers for distress, to problem- solve and encourage tolerance and resilience. Compassion focussed or Acceptance and Commitment based therapies may be suitable for this population of children as these encourage individuals to feel an increased sense of safeness in themselves and in their relationships to others, to have increased acceptance and tolerance of difficult feelings and to have greater psychological flexibility (Gilbert, 2009; Hayes, Strosahl & Wilson, 2012).

The data highlight the systemic and contextual nature of these children's experiences, therefore any clinical or support initiatives needs to be mindful of these factors. Whilst many organisations, including health services, schools and community bodies, already operate with

these ideas in mind, it is essential that support is grounded in the specific needs of each family and that interventions are offered in a fluid and flexible manner rather than applying a fixed model to all families.

Conclusion

This study examined the views of children who have a sibling with a mental health condition. A grounded theory analysis of the data identified that this sibling dynamic was situated within wider family and community dynamics. For these children there were gaps in knowledge about mental health conditions and limits on how these were discussed within the family. A child's connection to their sibling, other family members and significant figures was impacted by their knowledge about mental health conditions and the level of information gathered also determined their relationship to others. There is an internal process of evaluating and integrating information and it is this process, alongside the resulting outcome, that shapes the view of the sibling dynamic. In instances when the outcome feels unsatisfactory or the process itself feels unsettling, there may be a negative impact on the child's own wellbeing and also their evaluation of their relationship to the sibling with a mental health condition. This theoretical model offers some possible avenues for future research and clinical intervention including a focus on systemic interventions and research featuring multiple informants, mixed methodologies and longitudinal observations.

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Section C: Appendices and Supporting Information

Appendix A- CASP Qualitative Assessment Tool



CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- ▶ Are the results of the study valid? (Section A)
- ▶ What are the results? (Section B)
- ▶ Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA ‘Users’ guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

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Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

4. Was the recruitment strategy appropriate to the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- If the researcher has explained how the participants were selected
 - If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
 - If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- If the setting for the data collection was justified
 - If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
 - If the researcher has justified the methods chosen
 - If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
 - If methods were modified during the study. If so, has the researcher explained how and why
 - If the form of data is clear (e.g. tape recordings, video material, notes etc.)
 - If the researcher has discussed saturation of data

Comments:

6. Has the relationship between researcher and participants been adequately considered?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

8. Was the data analysis sufficiently rigorous?

Yes

Can't Tell

No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
 - To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes

Can't Tell

No

HINT: Consider whether

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature)
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix B- Overview of study ratings according to CASP criteria

	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?
Cipolletta, Marchesin and Benini ¹	Yes	Yes	Can't Tell	Yes	Yes	Can't Tell	Yes	Yes	Yes
Hodgkinson and Lester ²	Yes	Yes	Yes	Yes	Yes	Can't Tell	Yes	Yes	Yes
Jackson, Higgins, Frydenberg, Liang and Murphy ³	Yes	Yes	Yes	Yes	Yes	Can't Tell	Yes	Yes	Yes
Knafl and Zoeller ⁴	Yes	Yes	Yes	Yes	Yes	Can't Tell	Can't Tell	Can't Tell	Yes
Kountz-Edwards, Aoki, Gannon, Gomez, Cordova and Packman ⁵	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't Tell	Yes
Lee, Lee, Kim, Park, Song and Park ⁶	Yes	Yes	Yes	Yes	Yes	Can't Tell	Yes	Yes	Yes
Mitchell, Lemaneck, Palermo, Crosby, Nichols and Powers ⁷	Yes	Yes	Yes	Yes	Yes	Can't Tell	Can't Tell	Yes	Yes
Nabors, Kichler, Brassell, Thakkar, Bartz, Pangallo, Van Wassenhove and Lundy ⁸	Yes	Yes	Yes	Yes	Yes	Can't Tell	Yes	Yes	Yes
Soliday, Kool and Lande ⁹	Yes	Yes	Yes	Yes	Yes	No	Can't Tell	Can't Tell	Yes
Whyte, Baggaley and Rutter ¹⁰	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't Tell	Can't Tell

Appendix C- Examples of Line of Argument Synthesis

'Line of argument' synthesis examples		
Participant Quote (1st order)	Researcher interpretation (2nd order)	Translation (3rd order)
<p>"I have been told to give her prednisolone when she is at her worst but I find it difficult to know exactly when she is at her worst. This worries me"</p> <p>Whyte et al., 1995, p. 517</p>	importance of confidence	<p>Claiming a sense of confidence and control over condition management</p>
<p>"I am very confused about whether or not we are ever going to have this under control"</p> <p>Knafl and Zoeller, 2000, p.294</p>	competence with treatment regimen	
<p>"you begin very slowly to become confident with the illness that very slowly is not 'rare' anymore, it becomes yours"</p> <p>Cipolletta et al., 2015, p. 9</p>	ownership of the situation	
<p>"the hospital has been very good. If anything happens to Kate you can phone up ward 9 and take her back just like that"</p> <p>Whyte et al., 1995, p. 518</p>	ready availability of hospital staff who know the child	<p>Feeling that support is accessible and able to meet</p>
<p>"we are lucky because he [Michael's brother] has been a stimulus. If there would have been only Michael, we would have not gone to the sea"</p> <p>Cipolletta et al., 2015, p. 10</p>	siblings as a resource	
<p>"they are good people and did even more than necessary"</p>	trust in health care system for care and comfort	

Cipolletta et al., 2015, p. 13		needs
“well, the fact we get to come to a place with such great doctors. We know everybody at (the hospital) is very helpful” Nabors et al., 2013, p. 176	medical staff as a source of comfort and support	
“communication between the hospital and the GP seems to have gone out of the window -John had his drugs changed and no-one told us, so the prescription was left lying” Whyte et al., 1995, p. 519	breakdown in communication between hospital and community team	Evaluating whether support systems are working effectively
“we have been navigating in the ocean on our own” Cipolletta et al., 2015, p. 14	carelessness on part of health care systems	
“before that she had frequent sore throats and ear infections and coughs and was frequently at the doctor. We have both found it difficult to accept the diagnosis, although we were relieved at the time to have a definite cause for her symptoms” Whyte et al., 1995, p. 516	diagnosis protracted and stressful	Emotional response to condition impacted by past and present experiences
“we were told he would have died, thus, when, two days later, we were told he had Ondine syndrome, thereby there was a possibility to manage it to live; it was a blessing for us” Cipolletta et al., 2015, p. 8	relief compared to previous uncertainty	

<p>“the short-term effects are a lot of hassle for the whole family. Having a child that’s going in and out of hospital is not the easiest thing to live with”</p> <p>Whyte et al., 1995, p. 516</p>	<p>struggle to restore equilibrium</p>	<p>Recognising a change in patterns of being with one another</p>
<p>“the domestic situation is completely distorted: I sleep with Alan and the father with his twin”</p> <p>Cipolletta et al., 2015, p. 16</p>	<p>destruction of the house order</p>	
<p>“before, we lived too much of a race; we met too little. On the contrary now... sometimes I say that it has been better like that”</p> <p>Cipolletta et al., 2015, p. 8</p>	<p>discovery of new ways of being in a relationship</p>	

Appendix D- Examples of Reciprocal Synthesis

Reciprocal synthesis examples		
Participant Quote (1st order)	Researcher interpretation (2nd order)	Translation (3rd order)
<p>“it was on day 2 that they found a heart abnormality - the doctor put the fear of death into us. It was very traumatic at first and we were both shocked”</p> <p>Whyte et al., 1995, p.516</p>	diagnosis was threatening	Experiencing emotional distress related to condition
<p>“at the back of your mind there’s the knowledge that children can die of asthma if it is not treated properly”</p> <p>Whyte et al., 1995, p. 517</p>	uncertainty for the future	
<p>“it is like if you are quietly walking and fall down in a ravine, it upsets you”</p> <p>Cipolletta et al., 2015, p.7</p>	Initial feeling of loss	
<p>“we have some battles here now. Robert doesn’t like the taste of Ventolin and wouldn’t take it for a long while”</p> <p>Whyte et al., 1995, p. 517</p>	conflict with child not uncommon	Navigating differences in perspectives
<p>“the boys don’t understand that it hurts her more when they start playing rough. My husband doesn’t understand either”</p> <p>Knafl and Zoeller, 2000, p. 295</p>	emphasis or minimisation of illness impact	

<p>“my Mum is fantastic ... she really wants to learn all about the diabetes and will always help”</p> <p>Whyte et al., 1995, p. 518</p>	giving of time and practical support	Sharing tasks and responsibility with others
<p>“my husband’s mom helps, too, by checking in on our other children”</p> <p>Nabors et al., 2013, p. 176</p>	Support from immediate family	
<p>“we joined the BDA and went on the family weekend. I think that was the watershed, as we realised others had gone through the same problems and emerged”</p> <p>Whyte et al., 1995, p. 518</p>	Role of support groups	Finding sources of strength and hope
<p>“I have a kind of faith that is all mine, but my faith helps me”</p> <p>Cipolletta et al., 2015, p.11</p>	faith as a way to cope	
<p>“we live and think in similar ways on important matters, especially in difficult moments”</p> <p>Cipolletta et al., 2015, p. 9</p>	relationships were already solid	Valuing relationships with others
<p>“it’s pulled us closer. We try to support and help one another. It’s been a big adjustment for our family, but we have adjusted just fine.”</p> <p>Knafl and Zoeller, 2000, p. 292</p>	Shared views	

Appendix E- Study Inclusion and Exclusion Criteria

Inclusion

- Young person aged 11- 14 years old with a sibling, who is aged under 18, who has a mental health condition (which affects every day functioning, where its impact can be seen or felt such as anxiety, low mood, unusual experiences or experiences that are not easily understood, eating disorders or other difficulties. This can be experienced without a mental health diagnosis or ongoing contact with health services)

Exclusion

- Young people who have received a formal mental health diagnosis themselves
- Young people with any significant intellectual or sensory difficulties which would impede their ability to consent to or partake in a research study.

Appendix F: Salomons Ethics Panel Outcome Letter

This has been removed from the electronic copy

Appendix G: Chronology of Study

December 2017	Salomon's Ethics Panel Approval		
February 2018	Amendment approved by Salomon's Ethics Panel	Changes made to protocol/information sheets to offer participants gift voucher.	
February 2018	Recruitment Site Confirmed: Imago/ Kent Young Carers (London & Kent)	Purposive sampling based on demographic details held by organization. 166 potential families identified	Plan to send information out in stages. Two batches of letters (based on geographical areas) were sent. Subsequently due to sudden staff/organizational changes the charity did not continue to support this study and the final batch of letters were never sent. Number of participants recruited: 5
February 2018	Recruitment Site Confirmed: Social Arts for Education (London)	Opportunity sampling	Number of participants recruited: 0
March 2018	Recruitment Site Confirmed: Body and Soul Charity (London)	Opportunity sampling	Number of participants recruited: 0
November 2018	Recruitment Site Confirmed: Confident Children (operates across the UK)	Opportunity sampling	Number of participants recruited: 0
December 2018	Recruitment Site Confirmed: Fegans (Kent)	Opportunity sampling	Number of participants recruited: 0
December 2018	Recruitment Site Confirmed: Barking and Dagenham Young Carers (London)	Opportunity sampling	Number of participants recruited: 0
December 2018	Recruitment Site Confirmed: Wandsworth Carers (London)	Opportunity sampling	Number of participants recruited: 0
December 2018	Recruitment Site Confirmed: Bromley Wellbeing (London)	Opportunity/Purposive sampling	Number of participants recruited: 2

Appendix H: Information Sheet for Parents/Guardians



PARENT/GUARDIAN INFORMATION SHEET

Understanding the experiences of young people who have a brother or sister with a mental health condition.

The research study aims to explore young people's experiences of having a brother or sister (referred to as sibling from here on) with a mental health condition. Participants will be interviewed about their own personal experiences and the nature of their relationship with their sibling. There is existing research looking at the experiences of those who have a sibling with a health condition but these have tended to focus on physical conditions or have looked at this area from an adult sibling perspective. This project may allow us to gain an understanding of what it is like for these young people and the knowledge gained can be used to provide avenues for support or to inform professional practice in the arenas of health care, social care and education.

We are writing to parents/ guardians to inform them of this project and to ask for their consent to approach their child. If you consent to your child being approached, your child will be given more information about the project and they can then decide whether or not to participate. Your child will need to show that they fully understand the project and they will need to provide their own written consent to participate.

To participate in this research your child must be:

- **Aged 11- 14 years old**
- **Have a sibling, who is aged under 18, who has a mental health condition (which affects every day functioning, where its impact can be seen or felt such as anxiety, low mood, unusual experiences or experiences that are not easily understood, eating disorders or other difficulties. This can be experienced without a mental health diagnosis or ongoing contact with health services)**
- **Not have their own mental health diagnosis**
- **Be able and willing to understand what the study involves and also talk about their thoughts and experiences**

The researcher will liaise with you and your child to find a suitable time and place to meet, which may be at your home, at their school or elsewhere in the local community. It is important that your child feels comfortable whichever location is chosen, the privacy of the child will be ensured.

The interview session will last no longer than 45 minutes and they will then be asked a number of questions. The session will be audio recorded. Participants are free to skip certain questions or to end the session early if they wish.

The researcher will approach the session sensitively and will alter the pace or direction of the interview session if any distress or concerns are noted. The session will remain confidential, however if any concerns arise regarding the welfare of your child or anyone else these will be raised in line with the recruiting organisation's Safeguarding policy. At the end of the study, both you and your child will be given an information pack which outlines further sources of

support. After the interview, your child will be offered a £10 gift voucher to thank them for their participation.

If your child decides during the interview that they no longer want to take part, we will ask if we can still use their interview. If they decline, we will delete the audio recording. If after the interview is completed your child decides that they don't want to be involved in the project, they can contact the researcher up until (date) and all their information will be erased.

Unfortunately after (date) we will not be able to erase the information from the interview as it will have already been used for analysis.

The researcher will write up the findings into a formal report that will be submitted to Canterbury Christ Church University as part of a doctoral degree. The findings may also be published in an academic journal and shared with other psychologists. Any information or quotes used with reports will be anonymous. None of the participants' names will be in any report. No one reading the report will be able to identify who the participants are.

Your child will be given a code which links them to their interview so that their name is not stored with their interview. The audio-recording will be erased after the study has finished. A password protected CD containing the anonymous written record of the interview will be kept in a locked filing cabinet in a specified office in Canterbury Christ Church University for 5 years (in accordance with the Data Protection Act 1998 and the University's own data protection requirements).

If you are worried about your child's involvement in the study you can speak to the researcher, directly and she will try and address your issues. If you remain unhappy and wish to complain, you can do this by contacting: *Professor Paul Camic, Research Director, Salomons Centre for Applied Psychology, Canterbury Christ Church University, 1 Meadow Road, Tunbridge Wells, TN1 2YG*

If you have any further questions, please contact the researcher, Lauren Bryan, using the details below

- 24 hour research voicemail: 01227 92 7070. Leave your contact details and the name of the project on the voicemail and your call will be returned as soon as possible.
- Email: l.bryan808@canterbury.ac.uk
- By post: Lauren Bryan, Salomons Centre for Applied Psychology, Canterbury Christ Church University, 1 Meadow Road, Tunbridge Wells, TN1 2YG

Thank you for taking the time to read this information sheet.

Lauren Bryan, Trainee Clinical Psychologist

Appendix I: Summary of Study for Young People



A study of brother and sister relationships

My name is Lauren and I am training to be a psychologist.



As part of my psychology course I am doing a project to find out what it is like to have a brother or sister with a mental health condition. I hope you can help by talking to me about your experiences.

We will meet for no longer than 45 minutes in a place that you choose, such as your home, your school or somewhere else in your local community. I will have some questions to ask you and I will record what you say on a tape recorder. If you don't want to answer some of the questions you can just say no. If you would like to leave before we finish the questions that's also ok. You can ask to stop and leave at any time.

Our talk would be private. I will not tell your teachers or your family what you say, unless you ask me to. The only time I would break this rule was if I were concerned that you or someone else was not safe.

You can choose to join the project or not. If you do not want to take part it is ok. If you would like to join in the project, please read the Information Sheet. It might be helpful to read the information sheet with your parents/guardians or someone else that you trust so you can understand what you will do in the project.

If you have any questions about the project you or your parents/ guardians can speak to me.

When the project is finished, I will give you some information which explains what the project discovered. We will also share what we have found with other people who might like to know about what it's like for young people who have a brother or sister with a mental health condition. All the information you tell me will be anonymous, that means it won't identify you or use your name, so no one will be able to tell what information is yours.

Thank you for reading this letter, if you would like to know more please read the Information Sheet.

Appendix J: Information Sheet for Young People



Information sheet: A Study of Brother or Sister Relationships

What is the research about?

We are interested in finding out the experiences of young people who have a brother or sister with a mental health condition (which affects every day functioning, where its impact can be seen or felt such as anxiety, low mood, unusual experiences or experiences that are not easily understood, eating disorders or other difficulties. This can be experienced without a mental health diagnosis or ongoing contact with health services). When we understand more about these experiences, we may be able to think of ways to support these young people better. You have been invited to take part because your parents/guardians have given their permission for us to contact you.

Do I have to take part?

No- you do not have to take part. It is important that you read this information and think carefully whether you would like to share your experience. This is your decision, but you may wish to talk with people whom you trust before deciding. You are free to drop out of the study at any time, without giving a reason.

What will happen to me if I take part?

If you decide that you would like to share your experiences, we will go through the research information again and you will have a chance to ask questions. You will need to give your written permission on a consent form, to show that you have understood the study and that you wish to take part.

We will meet somewhere convenient to you and where you will feel comfortable to talk about your experiences; this might be your home, your school or somewhere else in your local area. We can refund your travel costs up to £10.00 and you will be asked to sign a form to get this money back.

You will meet with the researcher, Lauren Bryan, and she will ask you some questions about your experiences. You will have a private space in which you can talk and this session will not last more than 45 minutes.

After the interview, you will be offered a £10 gift voucher to thank you for your participation.

What are the good things about taking part?

At the moment, there aren't enough studies that ask young people who have a brother or sister with a mental health condition about their experiences. We cannot promise that the study will help you but the information we get from this study should help improve our understanding so that in future we can give better support to young people in your position.

Are there any bad things about taking part?

It is possible that by discussing some of your experiences you may feel uncomfortable or it might remind you of unhappy times. It is important that you consider this before agreeing to take part. The interview will go at your pace and you can ask for a break or to stop the whole session. You do not have to answer any questions you do not want to. There will be time for you to ask questions both before and after the interview.

Will you tell anyone about what I said in my interview?

No, not unless you ask the researcher to. The researcher will not tell your parents what you have said. There are some situations when we would have to break this rule, which are explained later.

What will happen if I don't want to carry on with the study?

If you decide during the interview that you no longer want to take part, we will ask you if we can still use information from your interview. If you say no, we will delete the audio recording. If after you complete the interview, you decide that you don't want to be involved you can contact the researcher up until (date) and all your information will be erased/deleted. That means it is wiped out completely. Unfortunately, after (date) we will not be able to erase your information as it will have already been used for our analysis – and we won't be able to identify your bits and pull them out.

How will you keep all my information safe?

Your interview session will be audio recorded. This recording will then be kept on a secure device, protected by a password. Your interview recording will be typed into words and the names of anyone you talk about, including your own, will be changed so no one can identify you. Only the researcher, Lauren Bryan, and the research supervisor Professor Margie Callanan will be able to look at the written version of your interview.

You will be given a special code which links you to your interview – any information that says who you are or identifies you will not be stored with your interview. No one else will have access to information that identifies you. The audio recording will be erased after the study has finished. All research information will be kept in a locked filing cabinet in a specified office in Canterbury Christ Church University for 5 years. After this time, it all gets destroyed and deleted. No one would be able to look at it except the administrator in charge of the cabinet and the researchers, Lauren Bryan and Professor Margie Callanan.

When would you need to tell someone else about something I said in my interview?

Any information you give will remain anonymous, that is without any names attached, and confidential – that is completely private - unless you say something during your interview that might mean either you or someone else is at risk or not safe. If this happens, this information will be shared with the research supervisor Professor Margie Callanan and the Child Safeguarding Lead at the recruiting organisation. This would be discussed with you and would be done to keep you and others safe.

What will happen to the results of the research study?

The results of this project will be used to form part of Lauren Bryan's report for her studies to become a doctor in Clinical Psychology at Christ Church Canterbury University. A report about the study will also be submitted to a journal that publishes research into mental health. It will not be possible to identify you in the results or in the report. When the project is finished, we will send you information about what we have found in the study.

Do you want some more help before you make a decision?

It would be good if you could talk this information sheet through with your family, a friend or someone else that your trust, for example your teacher. If you want any help to understand anything in this information sheet or you want to ask some more questions, please contact the researcher using the details below:

Write to: Lauren Bryan, Canterbury Christ Church University, Salomons Centre for Applied Psychology, 1 Meadow Road, Tunbridge Wells, TN1 2YG

Email: l.bryan808@canterbury.ac.uk

You can leave a message on a 24-hour voicemail phone line at 01227 92 7070. Please say that the message is for Lauren Bryan and leave a contact number so that your call can be returned.

Who is organising and paying for the research?

The study is being organized and paid for as part of a training programme in Clinical Psychology at Canterbury Christ Church University.

Who has reviewed the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee to make sure that it is fair. This study has been checked by Canterbury Christ Church university research panel.

What if there is a problem?

If you have any problems during the interview, please let the researcher know so that she can try and sort it out. If you feel like the problem really hasn't been sorted out, you or your parents can make a formal complaint. You can do this by contacting the Research Director for the Doctorate in Clinical Psychology:

Dr Paul Camic Research Director, Doctorate in Clinical Psychology Salomons Centre for Applied Psychology, Canterbury Christ Church University, 1 Meadow Road, Tunbridge Wells, TN1 2YG

Thank you for reading this information. You will be given a copy of this sheet and one of your signed consent forms to keep.

Appendix K: Consent Form for Parents/Guardians



Consent Form

Title of Project: A study of brother or sister relationships

Name of Researcher: Lauren Bryan

Participant ID:

Please write your initial in each box if you agree:

1. I confirm that the above study has been explained to me by the researcher.

2. I confirm that I have read and understand the Information Sheet (Version__, dated__) for the above study and have had the chance to ask questions.

3. I understand that my child has the choice whether to take part in this research or not and that they are free to withdraw or stop at any time, without giving any reason.

4. I agree to my child's research interview being voice recorded.

5. I understand that any personal information that I or my child provides to the researcher will be kept strictly private and confidential, unless there is a risk to myself, my child or someone else.

6. I agree to my child taking part in the above study and understand that doing so will mean that their responses may be included in a report, but that they will not be able to be identified in ay.

7. I agree to my child's responses being used within published research, but being presented without any identifying information about them personally.

OR

1. I do not give consent for my child to take part in this research.

Name of Child

Name of Parent

Signature

Date

Name of Researcher

Signature

Date

Contact details:

Lauren Bryan

Salomons Centre for Applied Psychology, Canterbury Christ Church University

1 Meadow Road

Tunbridge Wells

TN1 2YG

Email: l.bryan808@canterbury.ac.uk

Appendix M: Semi-structured Interview Guide

Thanks for coming in to speak with me today. Today, we are going to discuss a few things. If there's anything that you don't want to speak about or if you want to have a break or stop our session, that's ok you can just let me know. I won't tell anyone about our discussion today so everything we talk about will be private. The only time I would break that rule would be if I was worried about your safety or someone else's safety and even then, you and I would discuss a plan before I spoke to anyone else.

So, to start with, I just want to get to know you a bit better

Can you tell me a little bit about you?

Possible Prompts

- *What you like/dislike?*
- *What area do you live in?*
- *How school is going?*

Can you tell me about your family, who lives with you at home or who you see regularly?

Possible Prompts

- *How many people live at home?*
- *What are your family like?*
- *Who do you spend most time with at home?*

Thanks for letting me all about you and your family, so now I'd like to know a little bit more about you and (sibling)

Can you tell me a bit about (name of sibling)?

Possible Prompts

- *What things do you like/ appreciate most about (name of sibling)?*
- *What are their hobbies and interests?*

Are you and your (brother/sister) similar in any way?

Possible Prompts

- *Do you have the same interests?*
- *Would you say you behave or think in similar ways?*
- *If I were to ask your (sister, brother, mother, father) about this what do you think they would say?*

In which ways are you different?

Possible Prompts

- *Are there things you like that they hate?*

- *Are there things that are very different about the two of you?*
- *Do you disagree or clash about certain things?*
- *If I were to ask your (sister, brother, mother, father) about this what do you think they would say?*

So thinking about (sibling), can you tell me about their illness/condition?

Possible Prompts

- *How would you explain or describe their illness/condition?*
- *What things does their illness/condition affect e.g. school, family, holidays?*
- *How has (sibling) illness/condition made you feel or affected your life?*
- *Was there a time when (sibling) didn't have this illness/condition or when their illness/condition was a bit different to how it is now?*

So we've spoken about the ways in which you and (sibling) are similar and different and also a little bit about their illness/condition but what about the activities and time you spend with them?

What things do you enjoy doing with your sibling?

Possible Prompts

- *Are there some activities that you enjoy doing together?*
- *Would you turn to your sibling for advice or support?*

Are there things that you used to enjoy doing with your sibling that you don't do anymore?

Possible Prompts

- *Has the amount of time you spend alone, just the two of you, changed?*
- *Did you both used to really enjoy a particular hobby or activity?*

How do you think (name of sibling) feels about how you two get along?

Possible Prompts

- *Do you think your sibling would agree with some of the things we have talked about today?*
- *Do you think your sibling values the time you have together?*

Ok, thanks for letting me know about that. We've spoken a little bit about how things are for you and your brother/sister at the moment, but can we have a think about how things might be in the future?

How do you think you and your sibling will get along as you get older?

Possible Prompts

- *Do you think things will change or stay the same as they are now?*

- *What kind of relationship would you like to have with your sibling?*

So just a couple more questions before we finish up.

Can you tell me about a fond memory or time that you shared with your sibling?

Possible Prompts

- *Is there an event or holiday that sticks in your mind?*
- *Is there a funny story you remember?*

Is there anything else you'd like me to know about you or your family?

Possible Prompts

- *Anything you think it's important for me to understand?*
- *Anything you thought I would ask about that I haven't?*

Appendix N: List of Support agencies for Participants/Parents

If you are experiencing any distress or would like advice, please find below a list of organisations that offer support:

Childline

0800 1111

childline.org.uk

Free 24-hour helpline for children and young people in the UK

The Mix

themix.org.uk

Online guide to life for 16-25 year olds. Straight-talking emotional support is available 24 hours a day. Chat about any issue on our moderated discussion boards and live chat room.

NSPCC

helpline (adults): 0800 800 5000

helpline (children and young people): 0800 1111

help@nspcc.org.uk

nspcc.org.uk

Specialises in child protection and the prevention of cruelty to children.

Samaritans

24-hour helpline: 116 123 (freephone)

jo@samaritans.org

samaritans.org

Emotional support for anyone feeling down, experiencing distress or struggling to cope.

Young Minds

020 7089 5050 (general enquiries)

0808 802 5544 (parents helpline, for any adult concerned about the mental health of a young person)

youngminds.org.uk

National charity committed to improving the mental health of all babies, children and young People

Appendix O: Example of Coded Transcript

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Appendix P: Examples of concept/theory development

Progression from open codes to focussed codes to concepts

Open coding	Focussed coding	Theoretical concepts
<ul style="list-style-type: none"> ● Access to family members ● Acknowledging different perspectives ● Acknowledging limits on being together ● Acknowledging own feelings ● Acknowledging siblings interests ● Being made fun of ● Being sensitive ● Comparing self to sibling ● Being together ● Making decisions ● Describing impact on own activities ● Describing other people's reactions ● Disagreeing with others ● Going from together to separate ● Keeping to self ● Leaving each other alone ● Noticing consequences ● Quantifying experiences ● Speaking or not 	<p>Relationships to others</p>	<p>Establishing connections</p>

speaking		
<ul style="list-style-type: none"> ● Accessing family members ● Acknowledging different perspectives ● Acknowledging own feelings ● Acknowledging sibling interests ● Comparing self to sibling ● Describing decision making ● Describing own interests ● Feeling unacknowledged ● Going from together to separate ● Linking to others ● Recalling how difficulties are shared ● Speaking or not speaking 	Family positions	
<ul style="list-style-type: none"> ● Acknowledging own feelings ● Being made fun of ● Making decisions ● Describing other peoples' reactions ● Feeling unacknowledged ● Holding onto earlier feelings ● Speaking or not 	Communication styles/patterns	

speaking		
<ul style="list-style-type: none"> ● Acknowledging own feelings ● Attempting to understand ● Being found out ● Being sensitive ● Feeling confused ● Feeling unacknowledged ● Labelling the problem ● Not remembering ● Not understanding ● Speaking or not speaking 	Knowing and not knowing	Gathering information
<ul style="list-style-type: none"> ● Attributing change to something specific ● Going from together to separate ● Noticing change in family interaction ● Noticing variability ● Quantifying experiences 	Noticing change	

Overlapping codes

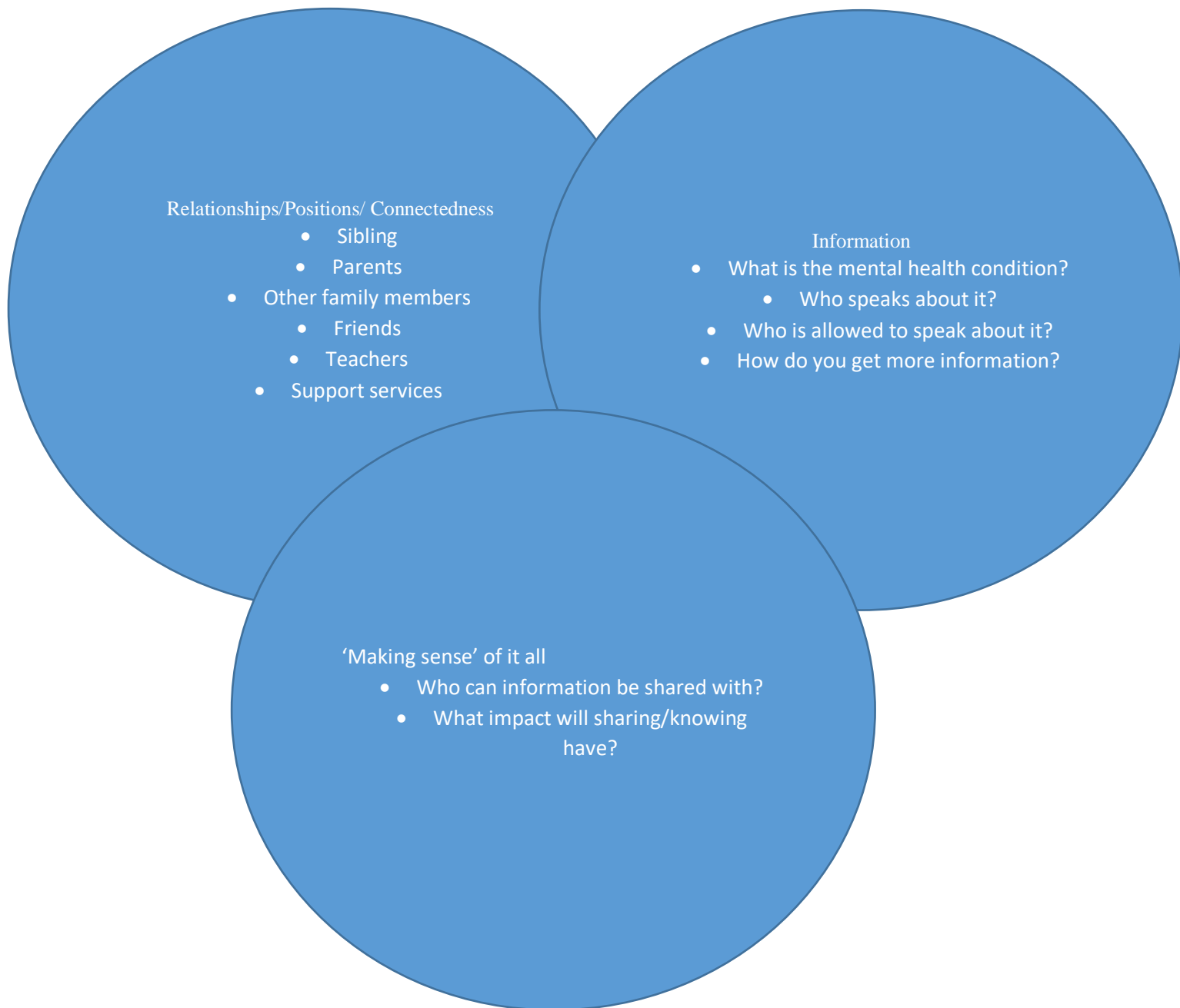
Access to family members	relationship to others
	family positions
Acknowledging different perspectives	relationship to others
	family positions
Acknowledging own feelings	relationship to others
	family positions
	communication styles/patterns
	knowing
Acknowledging sibling interests	family positions
	relationship to others
Being made fun of	relationship to others
	communication styles/patterns
Being sensitive	relationship to others
	communication styles/patterns
	knowing
Comparing self to sibling	relationship to others
	family positions
Describing being together	relationship to others
	family positions
Describing decision making	relationship to others
	family positions
	communication styles/patterns
Describing other people's reactions	relationship to others
	communication styles/patterns
	knowing
Describing own interests	relationship to others
	family positions
Describing the level of emotion	relationship to others
	communication styles/patterns

Feeling unacknowledged	family positions
	communication styles/patterns
	knowing
Going from together to separate	relationship to others
	family positions
	noticing change
Quantifying experiences	relationship to others
	noticing change
Recalling how difficulties are shared	relationship to others
	family positions
Recalling how difficulties are shared	communication styles/patterns
	knowing
Speaking and not speaking	family positions
	communication styles/patterns
	knowing
	relationship to others

Examples of Memos

- Does connection to others (including parents, friends, aunts/uncles) mean better information and better understanding?
- Pairings in family. How do two members show other that they are aligned? Who links with who? How is this determined?
- A process of child making sense of the information they have. Thinking about what is true/ false? What is right or wrong? Process of making sense of themselves and also making sense of other people's behavior
- Communication codes can be both about establishing connections and gathering information
- Communication is a way to keep close. Having no communication can keep siblings distant. Relationship between communication and level of connection.
- Making sense happens on a spectrum e.g. good/bad or right/ wrong. Making sense is not only about the position on the spectrum but also how it feels to move up/down the spectrum

Initial conceptual ideas:



Appendix Q: Excerpts from research diary

December 2017

I've been watching lots of YouTube videos about Grounded Theory and its origins. I was already leaning towards a constructivist approach but these videos have helped to clarify this position. Grounded theory seems like a really useful and interesting methodology; seems like it can be used across lots of research areas too. I think I'll need to be really immersed in the whole process of data collection and analysis so I'm hoping things will go to plan to allow for that.

June 2018

I met with my very first participant today and it was a really interesting discussion. I was really struck by how articulate and open he was with me, despite his young age. It was interesting how a lot of discussions were about his concerns about other members of the family, particularly his mum. As he also had other siblings, it was interesting to see how he made comparisons to his relationships with his other brothers/sister.

Today's session made me consider how I explain and describe things in an age appropriate/kid friendly way. I struggled at points to really explain what it is I do as a trainee psychologist or what alternative words I could use for things like 'impact' or 'relationship'.

I feel very lucky to have had kicked things off on such a good note and I'm hoping the other interviews will be equally as rewarding as this one.

June 2018

I met with my second participant today and this experience was quite different to the first interview. It felt a bit more difficult to get details from him and there were lots of prompting questions from me. It reminded me of what my manager had said; that children are either very chatty or very quiet and the participants I've seen so far have been a good example of that. On reflections, I perhaps could've spent much more time laying foundation and getting to know him as much of the in depth discussions were had with him towards the end of the session after he felt more comfortable.

A couple of things of note from this interview were about the impact of the sibling relationship at school, he spoke about observing things with his sisters friend's, having trouble with his own friends making fun and also confiding in teachers about worries. It seems like that can be quite a heavy burden to bear, particularly when things seem so up in the air! He also mentioned about how the relationship between his dad and sister had changes, he feels that since they've both got a diagnosis of depression that they perhaps have more in common.

November 2018

I arranged to meet with a fellow trainee today to do some joint coding of our transcripts. I think we're both having a bit of doubt about our ability to 'do grounded theory right'. I purposely selected an interview that I initially thought was 'less rich' than others, so I could get her help to really stay close to the data. We both found coding of each other's transcripts easier than our own- perhaps being a bit removed from the interview helps with the 'quick and dirty' initial coding! I've also come away feeling that there is actually much more richness to the interview than I had originally thought.

December 2018

I met with the director of Bromley wellbeing today. I feel a little less anxious than before as she's hopeful that they can support with research. They are the single point of access for mental health/ well-being in the whole of the borough and they also do triage before cases go to CAMHS- hopefully that means there will be many potential participants from this location.

February 2019

The anxiety about recruitment is rising again, the deadline is rapidly approaching. I've repeatedly reached out to lots of the clinicians at Bromley wellbeing and the key worker at Barking and Dagenham Carers; I'm starting to feel like a real nuisance. People are saying that they can't think of any suitable clients/ families and I'm unsure of how true this is. Perhaps there is a reluctance to support the project as there are concerns that this will possibly uncover the additional needs of these siblings or maybe others don't share my passion about the sibling perspective. Perhaps there has been a lot of naivety on my part about the limitations of doing research with children. What I've found thus far is really interesting and it would be a shame to lose momentum because of these recruitment setbacks

March 19

Today I met with another participant, who I've been trying to arrange a meeting (via school) since last year. I'm glad that we did get to meet in the end as her account was really valuable. She spoke of how not knowing about certain details of her sister's experience, particularly when things got more serious, really affected her wellbeing. Her account was really powerful and the emotion she felt was palpable. She definitely is an example of how a more information/ support could prove very valuable.

March 2019

I've been thinking a lot about these concepts and really felt that I needed to plot some things out in a more visual way. I got some A3 paper and started to draw lines linking ideas to the other. It really helped to see it all laid out and to get things out of my head.

April 2019

I met with my supervisor today to speak about my emerging theoretical model. Last night I drew it out for my mum and sister to make sure I could articulate it properly and show them the progression of my ideas.

My supervisor said I really need to think about the arrows on the model- whether they were one directional or bi directional and what processes they are describing.

She also mentioned the work of Gilbert and the concepts from Compassion focused work relation to an 'old brain' and 'new brain'. She noted parallels between this and my emerging model. I don't know much about Compassion focused approaches so I'll have to look into this. Perhaps Compassion focused therapy is an avenue of intervention for these young people?

Appendix R: Summary of Bracketing Interview

Discussion of aims

- To explore sibling relationships in context of mental health conditions.
- How does it impact a sibling?
- What does the sibling relationship look like? How has it been changed?
- Using Grounded Theory to explore this phenomenon. Looking at the impact/change in sibling dynamics as a result of mental health conditions.

Origins of Project

Project emerged out of curiosity about:

- The role of siblings within work within CAMHS health services. Are siblings seen when a young person has a mental health condition? How much does a sibling know or understand about mental health?
- Vicarious effects on one sibling to another more generally e.g. if one sibling has a positive mood does that have a positive effect on the other sibling?

Remit of Project

Acknowledge that it might have been useful to get both siblings perspectives e.g. through a joint interview or by interviewing one then another. However beyond what I thought I could do within MRP.

Focus on 11-14 (pre-adolescence)

- Existing knowledge of role of siblings in adolescent development
- Knowledge of stages of development influenced cut off for age for instance at this stage of adolescence young people are perhaps starting to make meaning but not so engrained.
- Also based on my views from adolescence in terms of expressive ability e.g. for primary school aged children.
- Assumed that there might be difficulties in processing things for younger children
- There might be a reason for lack of qualitative research with children (based on these factors).
- My manager had told me young people either are very chatty or not (nothing in between) and that was demonstrated in my first two interviews.

Reflections on first two interviews

- Thinking about demographics: affluence of areas, being seen in a school context, gender e.g. mixed schools.
- Noticing similarities and differences in my own experiences.

Assumptions/ Points to consider/ Blind spots

- When people describe dynamics such as disagreements etc. I'm thinking 'Is this just part and parcel of what siblings go through' - largely based on my own sibling experience.
- I hadn't really considered the role of family structure and the wider constellation e.g. young peoples' concerns about parent health/wellbeing
- I had thought that parental attention might be diminished for the sibling without a mental health condition but hadn't really thought of other implications
- Views/Conceptualisation of mental health condition- unsure about my own view. I tried to refrain from psychiatric diagnosis/ pathologising.
- My own views are changing, particularly in relation to mental health difficulties in young people as I feel that in the large these 'difficulties' are usually a response to context.
- I wanted to be broad when thinking about mental health conditions so have not defined certain conditions, but acknowledge that different conditions might elicit different response.
- I am wondering how my own natural curiosity influences interviews and also aware that I am training to be a clinician so that no doubt has an impact on interviewing style. I've been considering to what extent I am influencing discussion, torn between validating and being a researcher e.g. not offering too much of an emotive response.
- Reflecting on my own sibling relationship, such as fluctuations in our relationship e.g. initially looking up to my sister and then having more arguments as we got older. Mindful that I might be looking at other sibling interactions through that lens.
- Awareness of other influences on my own views about siblings e.g. my mother and aunts, friends who have siblings
- Acknowledging that I haven't had experience of a sibling with a mental health condition but wondering if there are parallels between other experiences such as loss etc.
- Noticing that I haven't really thought about my view on family more generally, what constitutes a sibling (half, step, foster/adopted, living together or apart)

Appendix S: End of Study Letter to Ethics Panel

Dear members of the ethics panel,

Re: Exploring the experiences of children who have a sibling with a mental health condition

I am writing to provide you with an update on the progress of my research as recruitment and analysis has now been completed.

Aims

The study examined the experiences of children who have a sibling with a mental health condition. It aimed to examine the perspectives of the child, the core features of their sibling relationship and the impact of the mental health condition on the sibling relationship and other areas of the child's life.

Method

Participants were recruited from charitable organisations across London and Kent between March 2018 and April 2019. Seven interviews were conducted with young people and a grounded theory methodology was employed to build a theoretical model from the data.

Findings

Participants gave details about their interactions with their sibling; many noted that there could be fluctuations within this dynamic as sometimes they were unsure of how their brother or sister may behave or react.

Participants spoke of how their relationship with their sibling impacted upon their relationships with others including other family members, friends and teachers.

Participants spoke of their knowledge about their sibling's condition; many noted that information usually came from sources other than their sibling and in some cases there were limits to how much details were discussed with them.

Three main concepts were identified:

Establishing Connections

This describes the nature of the sibling relationship, as experienced by participants. It also notes how this relationship is situated in the context of other connections within the family and in other areas such as school.

Gathering Information

This refers to the knowledge held by participant's about mental health conditions, including the sources of information and gaps in understanding.

Developing an understanding of sibling

This refers to the internal processes of integrating and evaluating experiences and information to form an understanding of the sibling.

There was an interaction between establishing connections and gathering information, with the nature of relationships with others (sibling, parents) determining the quality and level of information held about mental health conditions and vice versa.

Participants developed an understanding of their sibling through an internal process of reviewing and evaluating these connections and information. It was found that both the process of developing this understanding, as well as the conclusions drawn, impacted upon the participant's overall view of the relationship and how they related to their sibling.

The enclosed diagram, provides a visual representation of this theoretical model.

Conclusion

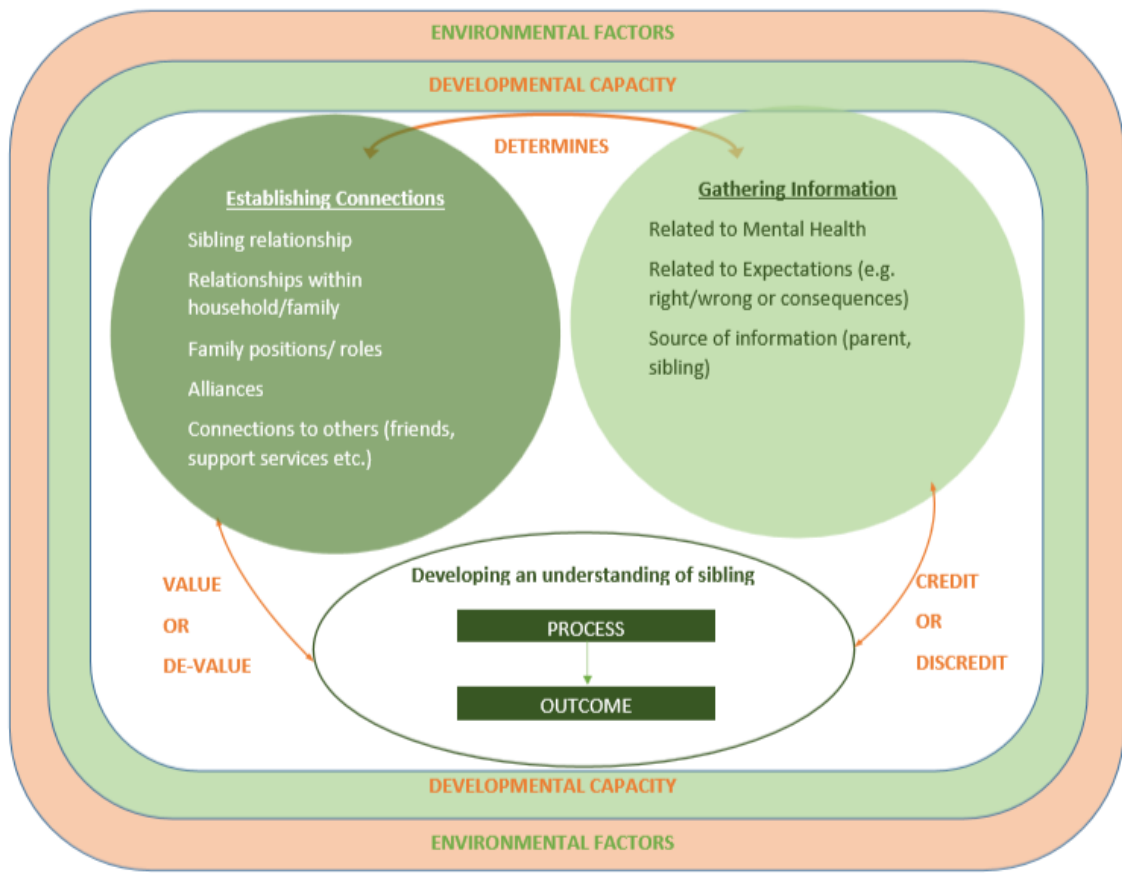
Participant's connection to others (sibling, other family members and significant figures) was affected by their knowledge of mental health conditions, similarly the level of information held affected the nature of these relationships. The process and outcome of evaluating these areas influenced the overall view of the sibling relationship.

When this process of developing an understanding feels unsettling or a coherent understanding cannot be formed, this can have a negative impact on a child's own wellbeing as well as their evaluation of the sibling relationship. There is scope for interventions to be employed to support all family members of children with mental health conditions (including siblings) and it would be beneficial for research in this area to continue.

Dissemination

A summary of these research findings will be shared with all participants and their parents, efforts will be made to ensure this information is provided in a manner appropriate to the participants' age and understanding.

Yours sincerely,
Lauren Bryan
Trainee Clinical Psychologist
Salomons Institute for Applied Psychology
Canterbury Christ Church University



Appendix T: End of Study Letters to Participants

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Appendix U: Author Guidelines for submission to Journal of Child Psychology and Psychiatry

Manuscript preparation and submission

Papers should be submitted online. For detailed instructions please go to: http://mc.manuscriptcentral.com/jcpp_journal. Previous users can check for an existing account. New users should create a new account. Help with submitting online can be obtained from the Editorial Office at publications@acamh.org

1. The manuscript should be double spaced throughout, including references and tables. Pages should be numbered consecutively. The preferred file formats are MS Word or WordPerfect, and should be PC compatible. If using other packages the file should be saved as Rich Text Format or Text only.
2. Papers should be concise and written in English in a readily understandable style. Care should be taken to avoid racist or sexist language, and statistical presentation should be clear and unambiguous. The Journal follows the style recommendations given in the *Publication manual of the American Psychological Association* (5th edn., 2001).
3. The Journal is not able to offer a translation service, but, authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found [here](#). All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

Layout

Title: The first page of the manuscript should give the title, name(s) and short address(es) of author(s), and an abbreviated title (for use as a running head) of up to 60 characters.

Abstract

The abstract should not exceed 300 words and should be structured in the following way with bold marked headings: Background; Methods; Results; Conclusions; Keywords; Abbreviations. The abbreviations will apply where authors are using acronyms for tests or abbreviations not in common usage.

Key points and relevance

All papers should include a text box at the end of the manuscript outlining the four or five key (bullet) points of the paper. These should briefly (80-120 words) outline what's known, what's new, and what's relevant.

Under the 'what's relevant' section we ask authors to describe the relevance of their work in one or more of the following domains - policy, clinical practice, educational practice, service development/delivery or recommendations for further science.

Headings

Articles and research reports should be set out in the conventional format: Methods, Results, Discussion and Conclusion. Descriptions of techniques and methods should only be given in detail when they are unfamiliar. There should be no more than three (clearly marked) levels of subheadings used in the text.

Acknowledgements

These should appear at the end of the main text, before the References.

Correspondence to

Full name, address, phone, fax and email details of the corresponding author should appear at the end of the main text, before the References.

References

The JCPP follows the text referencing style and reference list style detailed in the *Publication manual of the American Psychological Association* (5th edn.)i.

References in text

References in running text should be quoted as follows:

Smith and Brown (1990), or (Smith, 1990), or (Smith, 1980, 1981a, b), or (Smith & Brown, 1982), or (Brown & Green, 1983; Smith, 1982).

For up to five authors, all surnames should be cited in the first instance, with subsequent occurrences cited as et al., e.g. Smith et al. (1981) or (Smith et al., 1981). For six or more authors, cite only the surname of the first author followed by et al. However, all authors should be listed in the Reference List. Join the names in a multiple author citation in running text by the word 'and'. In parenthetical material, in tables, and in the References List, join the names by an ampersand (&). References to unpublished material should be avoided.

Reference list

Full references should be given at the end of the article in alphabetical order, and not in footnotes. Double spacing must be used.

References to journals should include the authors' surnames and initials, the year of publication, the full title of the paper, the full name of the journal, the volume number, and inclusive page numbers. Titles of journals must not be abbreviated and should be italicised.

References to books should include the authors' surnames and initials, the year of publication, the full title of the book, the place of publication, and the publisher's name.

References to articles, chapters and symposia contributions should be cited as per the examples below:

Kiernan, C. (1981). Sign language in autistic children. *Journal of Child Psychology and Psychiatry*, 22, 215-220.

Thompson, A. (1981). *Early experience: The new evidence*. Oxford: Pergamon Press.

Jones, C.C., & Brown, A. (1981). Disorders of perception. In K. Thompson (Ed.), *Problems in early childhood* (pp. 23-84). Oxford: Pergamon Press.

Use Ed.(s) for Editor(s); edn. for edition; p.(pp.) for page(s); Vol. 2 for Volume 2.

Tables and Figures

All Tables and Figures should appear at the end of main text and references, but have their intended position clearly indicated in the manuscript. They should be constructed so as to be intelligible without reference to the text. Any lettering or line work should be able to sustain reduction to the final size of reproduction. Tints and complex shading should be avoided and colour should not be used unless essential. Authors are encouraged to use patterns as opposed to tints in graphs. In case of essential colour figures, authors are reminded that there is a small printing charge. Authors will be contacted during the proofing stage of their accepted paper. Figures should be originated in a drawing package and saved as TIFF, EPS, or PDF files. Further information about supplying electronic artwork can be found in the Wiley electronic artwork guidelines [here](#).

Nomenclature and symbols

Each paper should be consistent within itself as to nomenclature, symbols and units. When referring to drugs, give generic names, not trade names. Greek characters should be clearly indicated.

Supporting Information

Examples of possible supporting material include intervention manuals, statistical analysis syntax, and experimental materials and qualitative transcripts.

1. If uploading with your manuscript please call the file 'supporting information' and reference it in the manuscript.
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