

**Exploring the experiences of siblings of young people diagnosed
with an 'eating disorder'**

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Abstract

Background and Aims: Research focused on the families of children and adolescents diagnosed with an 'eating disorder' has long suggested an impact on the family and individual family members. It is increasingly acknowledged through research and clinical practice that siblings can play an important part in the support and recovery of young people diagnosed with an 'eating disorder'. However, less is known about the views of siblings in this context and the ways in which they might experience the situation. The use of the sibling perspective in qualitative psychological research is emerging however, a limited number of studies specific to the field of 'eating disorders' have used such methods. The current study therefore aimed to find out what siblings said about the experiences of living with a brother or sister diagnosed with an 'eating disorder'. The study aimed to hear about their experiences; the ways in which they felt the situation might impact on their lives; and their views about professional support.

Method: Semi-structured interviews were carried out with six siblings all aged between 11 and 18 years. All had a sibling diagnosed with an 'eating disorder' who had, or was receiving professional support for this. Verbatim interview transcripts were analysed using Thematic Analysis.

Results: The analysis produced five main themes. These were: 'Making sense of it all'; "Home's not how I remember"; "It impacts me too"; "To talk or not to talk?"; and "Life goes on". A description of these themes and associated sub-themes is presented.

Conclusion: Siblings report experiencing impact in a number of aspects of their lives and within family life. The results of the analysis offer support for previous findings within the sibling literature and further justify the need for on-going, wider research using sibling accounts. Clinical implications and directions for future research are discussed.

List of abbreviations

'AN'	-	'Anorexia nervosa'
'BN'	-	'Bulimia nervosa'
CAMHS	-	Child and adolescent mental health service
'ED'	-	'Eating disorder'
'EDNOS'	-	'Eating disorder not otherwise specified'
FT	-	Family therapy
LD	-	Learning disability
MFT	-	Multifamily therapy
NHS	-	National Health Service
QOL	-	Quality of life
UK	-	United Kingdom

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CHAPTER ONE: INTRODUCTION

The experience of being a sibling is common to most individuals - research has indicated that around 90% of the world's population are siblings (Milevsky, 2011) and children in the United States are more likely to grow up in a home with a sibling than with a father (McHale, Kim, & Whiteman, 2006). The sibling relationship (SR) is considered unique compared to other relationships in terms of permanency and longevity (Bank & Kahn, 1982; Noller, 2005) and is likely to be the longest relationship a person will experience in their lifetime (Nolbris, Enskar, & Hellstrom, 2007).

Prior to the 1980's, the focus of most family research was placed on the mother (Stoneman, 2005). Research exploring the impact of child and adolescent mental health difficulties was often focused on this parent-child relationship (Feinberg, Solmeyer, & McHale, 2012), leaving little space for understanding the experience of the family and specifically siblings. With the development of systemic thinking and intervention approaches during the late 20th century, the family system has become a key area of psychological research and clinical intervention; the family is now often considered an integral part of support within child and adolescent mental health services (CAMHS). Attention to research on siblings in this context has increased over the past 30 years however, this is marginal when compared with other family-based research and especially so within the UK (Pike, Kretschmer, & Dunn, 2009).

One area where the understanding of the family has become particularly emphasised is with young people diagnosed with an 'eating disorder' (ED)¹. Diagnoses of 'EDs' in childhood and adolescence are likely to have a significant impact on family life and individual family members (e.g. Whitney & Eisler, 2005; Tierney, 2005; Halvorsen & Heyerdahl, 2007). Visible and often rapid changes to weight and related physical concerns can often be intensely alarming for those around (Brown, 2011), as can the increase in distress and conflict around the

¹ Given the debate surrounding the use of diagnostic categories (see Boyle, 1999), and specifically with young people diagnosed with 'EDs' (Bravender et al., 2010; Bryant-Waugh & Nicholls, 2011; Eddy, Hertzog & Zucker, 2011) direct references to diagnoses will be placed in inverted commas. For the same reasons the terminology 'young person diagnosed with an ED' will be used.

imperative daily act of eating (Zucker, Leob, Patel, & Shafer, 2011). Much research has focused on the experience of caregivers in this context (e.g. Treasure et al., 2001; Highet, Thompson, & King, 2005). However, it is thought that siblings in this context can be at increased risk of developing difficulties with eating (Abraham & Llewellyn-Jones, 2001), or themselves being diagnosed with an 'ED' (Garley & Johnson, 1994). Although literature is emerging in this area, little remains known about siblings in this context (Halse, Honey, & Boughtwood, 2008; Tierney, 2012). Furthermore, relatively less is understood from the perspective of siblings themselves. Such accounts can be seen to offer a source of understanding relevant both to 'ED' research and clinical intervention with young people and their families.

Overview of chapter

This chapter will briefly outline definitions and classification of diagnosed 'EDs'². This will be followed by a review of theory and research relevant to siblings and their relationships. Next, the development and current status of family-based interventions with young people diagnosed with an 'ED' will be explored. This will be followed by a review of research exploring the experiences of young siblings. Given the dearth of sibling literature, this will include research from other fields where the sibling experience has been given greater attention. This is followed by an outline and critical examination of the sibling 'ED' literature. The chapter will conclude with the rationale for this study and outline of the research questions.

'Eating disorders'

Definition and classification

The term 'ED' refers to a collection of diagnoses characterised by a common theme of disturbance in eating behaviour and distress and preoccupation with body shape and/or weight (Goss & Fox, 2012). Within the Diagnostic and Statistic Manual of Mental Disorders – version IV Text Revision (DSM-IV-TR, APA, 2000) 'ED' classification is divided into three categories: Anorexia Nervosa ('AN'),

² For further information, see Le Grange and Lock (2011) and Goss and Fox (2012).

Bulimia Nervosa ('BN') and Eating Disorder Not Otherwise Specified ('EDNOS')³. Although these diagnoses are construed as discrete categories, in reality overlap of symptoms is common. Individual presentations are likely to 'move' between the categories (Palmer, 2005) and therefore attempting to diagnose is complex and thought to often be unrepresentative of a complete clinical picture (Waller, 2008). Furthermore, Garfinkel (2002) notes the unhelpful level of descriptive rather than explanatory language used in defining categories, and the complexity of diagnosing 'EDs' in younger populations, males, and those from non-Western cultures. Further information relevant to epidemiology and outcome of diagnosed 'EDs' can be found in Appendix 1.

Literature search

A review of the existing literature on siblings in the context of diagnosed 'EDs' was conducted using a narrative review approach. Jones describes the narrative review of literature and narrative concepts as 'natural allies' of qualitative research (2004, p.108). Systematic reviews of literature have often been considered the more robust form of review however, arguably the prescribed method of this approach offers a narrow focus and therefore does not always allow for comprehensive coverage of the literature (Collins & Fauser, 2004). In contrast, the use of a narrative review allows for awareness of theoretical background within research and offers analysis and critique that can be discussed in the context of a current research study.

Four databases were searched for relevant literature: Academic Search Complete, PsycINFO, PsycARTICLES and CINAHL Plus. The search was limited to work written in the English language but included studies from across all countries. Note was taken of the country of origin and where siblings lived in relation to the person diagnosed (e.g. same or different home). Criteria for this search included year of publication (1983 to January 2013) and age group of the non-diagnosed individual (defined as childhood/school age, adolescence, and

³ Revisions to 'ED' classification are anticipated within the proposed DSM-V (May, 2013). For further information on current and suggested criteria, readers are directed to <http://www.psychiatry.org/mental-health> and <http://www.dsm5.org/Pages/Default.aspx> respectively.

young adulthood). Academic journals, reviews, dissertations and books/chapters were included. Search terms used were derived from words including 'sibling/s' and 'eating disorder/s' combined with 'children' and/or 'adolescents' (see Appendix 2 for a review of the search terms). The search also included a review of key references of retrieved studies and books, Internet searches and correspondence with researchers.

The initial search yielded 44 results. These were initially reviewed according to their relevance to the research and contribution to further understanding of the wider context. Results were varied and included literature reviews, single and mixed methods research studies, research focused on the impact of the diagnosed 'ED' on the family as a whole and the experience of being a carer for an individual diagnosed with an 'ED'. Nine of these studies focused specifically on aspects of the sibling experience including adult retrospective accounts.⁴ None of these studies were based on a UK sample and of these, only three focused directly on hearing young siblings' subjective accounts of their experiences (Garley & Johnson, 1994; Ross & Handy, 1997; Areemit, Katzman, Pinhas, & Kaufman, 2010).

The lack of sibling 'ED' research has been previously noted (Tierney, 2012). Given the limited literature available, the search was expanded to include literature exploring the experience of siblings within other contexts. Broader searches⁵ of literature from the fields of mental health, chronic physical health problems and learning disability (LD) highlighted a larger focus on the experience of young siblings in these contexts. Therefore literature from these areas has also been considered in this review.

Siblings and the sibling relationship

Siblings, especially during childhood and adolescence, are likely to spend more time with one another than with anyone else, including their parents (McHale &

⁴ These studies will be reviewed in detail later in this chapter (see Table 1)

⁵ A similar search strategy to that described earlier was used in this search (see Appendix 3 for search terms).

Crouter, 1996; Sanders, 2004). Siblings can serve as a confidant, provide companionship (Updegraff, Thayer, Whiteman, Denning, & McHale, 2005) and offer emotional support to one another (Furman & Buhrmester, 1985). Siblings can help shape individual personality (Latzer, Ben-Ari, & Galimidi, 2002) and provide a unique space for relational development (Cicirelli, 1982; Dunn, 2007).

The sibling relationship

The SR can be one of complex and varied dynamics (Furman & Buhrmester, 1985), experienced differently across families and time (Goetting, 1996; Dunn, Deater-Deckard, Pickering, & Golding, 1999). The SR is likely to be impacted by, and in turn will impact upon other relationships within the family system (Cox & Paley, 1997; Pike et al., 2009). Feinberg et al. describe the relationship as “like the third rail on a subway track that carries the electrical current” (2012, p.44), highlighting the often intense dynamics as well as importance and relevance of the relationship within the wider family system. SRs experienced during child and adolescent years are thought to largely influence relationships formed in later life (Gotteting, 1996). Furthermore, the quality of a SR is thought to impact on psychosocial functioning (Noller, 2005), individual psychopathology (Buist, Deković, & Prinzie, 2013) and serve as a long-term predictor of mental health in later life (Waldinger, Vaillant, & Orav, 2007).

Influences on the sibling relationship

As with all relationships, the SR can be impacted upon by a number of influences. These can be seen to be especially prominent during child and adolescent years when change is occurring frequently for both individuals and families. Research suggests structural factors such as birth order and gender can influence the relationship (Furman & Buhrmester, 1985). However, this is thought by some to be secondary to the influence from within the family system (Furman & Lanthier, 2002) and, in particular, family functioning (Buist et al., 2013). Additionally, generational stories and family scripts (Byng-Hall, 1998) about the role of siblings may influence how the SR is developed and experienced across families (Sanders, 2004).

Wider influences such as culture and religion can impact on the SR (Bank & Kahn, 1982). For example, certain cultures place greater importance on older siblings providing care-giving for younger siblings (Updegraff et al., 2005). Discourses present in society can also influence the SR; siblings are often portrayed within media or literature as either an 'ally' or 'rival' (Sanders, 2004). Additionally, terms such as 'sisterhood' and 'brotherhood' are often used to imply cohesion and loyalty amongst groups in social, cultural or religious contexts (Feinberg et al., 2012).

The sibling sub-system and SR can be impacted by external factors such as physical illness, mental health difficulties or disability in the family. This is related to what some have referred to as a 'reorganisation' of the family around a diagnosis (Eisler, 2005; Whitney & Eisler, 2005). When one sibling is unwell, the other sibling/s may need to adapt or change their own roles to accommodate this (Jessop & Stein, 1989; Edwards & Davis, 1997). At such times, parental attention is naturally likely to shift meaning siblings may be required to be more responsible and independent in their lives (Blessing, 2007). Furthermore, siblings may choose, or need, to take on a carer role for their sibling, which can carry on into later life once parents are no longer able to do this (Dimitropoulos, Klopfer, Lazar, & Schacter, 2009).

Theoretical perspectives on siblings and their relationship

Arguably the SR remains one of the most neglected relationships in psychological research (Sanders, 2004; Buist et al. 2013). Blessing notes how "siblings have always been part of the clinical picture, but without an adequate theoretical hook on which to hang their significance." (2007, p.37). Caspi (2011) further identifies how this lack of any defined sibling theory has posed a challenge to sibling research. However, aspects of the SR can be understood through a number of theoretical perspectives, including attachment and social learning theories (see Whiteman, McHale, & Soli, 2011 for a review of this). In particular, family system and systemic theories have provided some of the most helpful perspectives on siblings within the family system. Such ideas have contributed to the continual development and use of family-based interventions within CAMHS and other therapeutic services. The following section will outline

some key aspects of this perspective, and its relevance to interventions with families of young people diagnosed with an ED.

Family system and systemic theory

The focus on the family in relation to childhood eating difficulties has been acknowledged from as far back as 19th century (Hepworth & Griffin, 1990). At this time, the family were often positioned as a causal and maintaining factor for difficulties. This contributed to the exclusion of the family from therapeutic intervention. Instead, an 'individual psychotherapy' approach was most often used.

Early psychoanalytic and family theories appeared to understate the role and position of siblings (Bank & Kahn, 1975). Families were often viewed as hierarchal, with children positioned as displacements of parents. Therefore no early accounts appeared to focus on how siblings may be able to influence one another (Bank & Kahn, 1975). The developments of family systems theory can be seen to mark a shift in how different members of the family might be understood. Furthermore, this helped in acknowledging the role of the family within intervention, and contributed to the subsequent development of Family Therapy (FT) models.

The family as a system

The notion of the family as a system has its origins in General Systems Theory (Bertalanffy, 1968). This aimed to understand and unify aspects of all sciences through the principles of systems. A system refers to a complex set of elements that interact with one another and the wider environment. Systems are able to maintain stability by self-regulating and changing, depending on feedback and the wider context (Dallos & Draper, 2000). In order to understand a system, Bertalanffy considered the importance of examining the interactive nature of a system rather than individual aspect, noting, "It is necessary to study not only parts and processes in isolation, but also to solve the decisive problems found in the organization and order unifying them." (Bertalanffy, 1968, p.31).

These ideas were attributed to family functioning, helping to position the family as a self-regulating body rather than collection of individuals. Originally developed following work with families of individuals diagnosed with Schizophrenia, Bowen's Family Systems Theory (1978) further helped define the family as a complex and dynamic system, giving importance to the context and those around an individual in the context of mental health. Arguably, family systems theory helped to challenge the previous cause-and-effect approach in understanding individuals and illness (Kerr, 1988). Bronfenbrenner (1979) later suggested the family system could be influenced from outside, through wider factors such as culture, society and environment. Furthermore, the acknowledgment of subsystems existing within the family system allowed for a specific focus on siblings and their positioning within the family.

Family subsystems

Within the family system, core subsystems were thought to exist; these being the spousal, parent-child, and sibling systems (Minuchin, 1974). Each subsystem was thought to evolve over time, and affect and be affected by events and interactions within other subsystems (Yu & Gamble, 2008). Within the family system and subsystems, individuals may take on specific 'roles' that work to regulate the system and relationships between them (Bowen, 1978). Change to the system, or sub-system, may therefore require individual roles to shift or be adapted in order to accommodate for this (Jessop & Stein, 1989; Dell-Clarke, 2009).

The family life cycle

The understanding of the family as a system comprising of smaller subsystems remained at the forefront of psychological thinking and contributed to the development of distinct schools of FT during the late 20th century (Dallos & Draper, 2000). The ongoing development of social constructionist ideas provided greater acknowledgment of a 'multi-contextual lens', which had arguably been given little prior acknowledgment. Carter and McGoldrick's (1980) family life cycle model emphasized how development and change in families followed common patterns and appeared shaped by demands from various system levels. The model allowed for greater acknowledgment of wider influences, both those

defined as vertical (e.g. generational stories or family scripts (Byng-Hall, 1998) and horizontal (e.g. untimely death or illness). Families were considered as inevitably needing to move through various stages of the life cycle, which required critical changes to be made to family structure, beliefs and dynamics.

The family in the context of diagnosed eating disorders

The development of systemic theory and practice has provided support for the role of the family within intervention with children and adolescents diagnosed with an ED. Although a number of different family-based approaches to intervention exist, all aim to develop a collaborative and shared understanding of the experience within the family (Dallos & Draper, 2000). Most schools of FT have given focus to understanding and developing approaches and models related to a diagnosed 'ED' and family support in this context (Dallos & Draper, 2000). Young people diagnosed with an 'ED' are thought of as existing within a system and sub-systems and unable to be understood in isolation from these. The wider family is viewed as a solution, able to offer useful resources in supporting the young person (Lock, Le Grange, Argras, & Dare, 2001). The following section will further explore aspects of family-based interventions with young people diagnosed with an 'ED'.

Diagnosed 'eating disorders' and family-based interventions

This section will outline family and multifamily therapy (MFT) interventions with young people diagnosed with an 'ED' and their families. It is beyond the remit of this research to discuss all family-based interventions however, MFT is an example of one approach that utilises principles of systemic therapy and in which siblings are often included. Therefore it felt relevant to discuss this approach in more detail.

Family therapy

FT has become an integral part of support with young people diagnosed with an 'ED' within child and adolescent services. Growing empirical evidence supports

the role of the family, in particular with those diagnosed with 'AN'⁶. However, further research is warranted given that few studies have provided comparisons with other interventions and most have included only adolescents with a diagnosis of 'AN'.

The National Institute for Health and Clinical Excellence (NICE, 2004) recommends FT as a treatment of choice for young people diagnosed with 'AN' and furthermore suggest "Family members including siblings should normally be included in the treatment of children and adolescents with eating disorders." (p.63)

Although siblings are included in this recommendation and are often invited to FT, clinical and research findings suggest they often do not attend (Abrams, 2009). In considering this, Bryant-Waugh and Lask (2007) suggest that this can relate to parental concern about siblings and the impact of taking time away from other aspects of their lives, such as school or social activity. It has also been suggested this can be a result of parents aiming to protect both siblings; the privacy of the young person diagnosed and the protection of their sibling from the situation (Abrams, 2009). Furthermore, parents and young people diagnosed with an 'ED' have suggested siblings themselves express reluctance to attend (Honey, Clarke, Halse, Kohn, & Madden, 2006), although reasons for this view were not outlined in the study.

Multifamily therapy

MFT represents a relatively new approach to working with families of young people diagnosed with an 'ED'. It was initially developed through the work of Laqueur, La Burt, and Morong (1964) with families of individuals diagnosed with schizophrenia. The intervention has since been used within a range of fields, including with families of young people diagnosed with chronic medical illness (Gonzales, Steinglass, & Reiss, 1989), as well as those diagnosed with an 'ED' (Dare & Eisler, 2000; Scholz & Asen, 2001; Colohan & Robinson, 2002). A growing body of evidence can be found in support of MFT as a therapeutic

⁶ For a review of this research, see Lock (2012).

intervention for young people diagnosed with an 'ED' (Dare & Eisler, 2000) however, it is acknowledged that ongoing research is warranted (Fairburn, Simic, & Eisler, 2011). MFT shares many aspects of FT, the main variation being that it is conducted with a number of families over a series of often one-day sessions. Although a number of MFT approaches exist, most include aspects of psycho-education, FT and group therapy techniques. All MFT approaches share a core belief in the benefit of sharing experience across families (Asen & Scholtz, 2010). MFT has allowed for a greater focus on the whole family (e.g. Dare & Eisler, 2000), with an aim to decrease isolation families can often experience. Within the approach, siblings are welcomed and often sessions are tailored around their attendance. However, as with FT, groups often consist only of the diagnosed sibling and parents. Therefore although acknowledged within both these approaches, there remains comparatively less focus on siblings. This leads to questions around the needs, experiences and perspective of siblings during this time.

The next section will explore current sibling research from a general perspective, within other fields of research and more specifically in the context of being a sibling of a young person diagnosed with an 'ED'.

Siblings within research

The sibling perspective within research

Compared with adult research, few studies have explored the experiences of young siblings and specifically from their perspective. This is perhaps a result of psychological research historically being focused on children, rather than with them (Darbyshire, MacDougall, & Schiller, 2005). Furthermore, it may be a reflection of an operating discourse that children's perspectives can provide a less worthy or 'valid' account than adults. However, growth in support of the validity of child testimonials, for example in the courtroom, has allowed for children to be greater acknowledged as individual to one another and experts in their own life (Greene & Hill, 2005). This has helped to better establish young people's voices within research and encouraged researchers to consider new and creative ways of hearing them (Pike et al., 2005; Pascal & Bertram, 2009).

Mental health difficulties and the young sibling experience

Siblings have been considered at risk of being affected by sibling mental health difficulties through an impact on behavioural and/or emotional functioning (e.g. Abrams, 2009). Most sibling research in the field of mental health has been focused on the experience of adult siblings of individuals diagnosed with what authors have referred to as 'severe mental illness' (Lukens, Thorning, & Lohrer, 2002), for example a diagnosis of 'schizophrenia'. Amongst other findings, siblings in this context have indicated deterioration in their SR (Barak & Solomon, 2005), emphasised the importance of being given information about the diagnosed illness and their sibling's progress (Lukens et al., 2002), and reported having developed a number of personal coping strategies to manage the situation (Friedrich, Lively, & Rubenstein, 2008). Such findings can provide useful direction for research with younger aged siblings. However, given the variance in developmental stage, child and adolescent sibling research requires specific attention within the literature.

The current literature search identified only five empirical studies exploring the experiences of siblings of young people diagnosed with mental health difficulties. All used either a quantitative or mixed-methodology design. Kelvin, Goodyer, & Altham (1996) used quantitative measures with a sample of 31 siblings of young people diagnosed with depression or anxiety disorders, finding 42% of these siblings themselves met criteria for such diagnoses. Using a similar approach with 65 siblings of young people diagnosed with anxiety disorders, Dia & Harrington (2006) concluded that scores from 12% of the sibling sample were indicative of a diagnosed anxiety disorder. Kilmer, Cook, Taylor, Kane, & Clark (2008) used quantitative measures to study the impact of having a young sibling diagnosed with what authors referred to as a 'severe emotional disturbance' (2008, p.1). Using a sample of 56 sibling participants, they reported siblings could show poor levels of adjustment and increased risk of emotional or behavioural difficulties. However, as noted by Kilmer et al. (2008), such results require caution in interpretation, especially given that all measures were reliant on caregiver reports alone. Aremit et al. (2010) later reported a greater likelihood of

impaired quality of life (QOL) for siblings of adolescents diagnosed with an 'ED'⁷ and most recently, Barnett and Hunter (2012) explored adjustment in the context of sibling mental health difficulties using a large sample of siblings of children referred to a CAMHS team in New South Wales, Australia. They reported significantly higher rates of sibling psychopathology and poorer 'QOL', compared with children in the general population, with siblings either meeting criteria for diagnoses or experiencing what they defined as 'adjustment difficulties' (p.262).

Although helpful in acknowledging the sibling experience and the importance of siblings within in mental health services, these studies employed approaches of identifying aspects of the experience that fit with pre-existing symptoms and diagnostic criteria, leaving little space for exploring the subjective account. Only one of these studies (Areemit et al., 2010) employed aspects of a qualitative methodology, although this was through a mixed-method approach. Given the on-going debate around suitability of diagnostic categories in the context of younger populations, further qualitative research with a focus on hearing individual accounts can provide additional understanding.

Findings from clinical practice can offer further understanding about the sibling experience. In Abrams' (2009) reflections from clinical work with families of young people diagnosed with mental health difficulties or a LD, siblings appeared to her to: take on care-giving roles in the family, make attempts to disassociate from their sibling, appear to feel neglected by parents, and experience neglect by professional systems. However, given that professionals are often likely to have relatively limited contact with siblings compared with their diagnosed sibling and parents, the importance of hearing the subjective experiences again seems especially relevant.

The limited number of sibling studies of direct comparability to the present study led to searching in two further areas where the sibling perspective has been more frequently used and with a greater variability of research methodology; the fields of LD and chronic physical health. Initial searches yielded over 300 findings from

⁷ This study will be later reviewed in greater depth.

across both fields. Following review, 65 results appeared relevant to the current research. These included articles, reviews, book chapters and dissertations. Some key findings will be reviewed in the following section. For more detailed reviews of this literature, see: O'Brien, Duffy, and Nicholl (2009); Rossiter and Sharpe (2001); and Sharpe and Rossiter (2002).

Physical illness, learning disability, and the sibling experience

The sibling experience has begun to be increasingly recognised within both the field of LD and physical illness, through a number of published studies and larger scale reviews. O'Brien et al. (2009) reviewed literature on the impact of childhood chronic illness or disability on siblings⁸. Findings suggested a key importance of healthcare providers having an awareness of the impact illness and disability can have on siblings. Key themes appear to emerge from these literature bases, with some identified across both fields. Main themes emerging have included: (1) findings suggestive of a negative impact to sibling psychological wellbeing (e.g. Rossiter & Sharpe, 2001; Sharpe & Rossiter, 2002; O'Brien et al., 2009); (2) siblings feeling they had been given little information about their brother or sister (e.g. Barerra, Chung, Greenberg, & Fleming, 2002); (3) siblings experiencing an impact to multiple aspects of their lives (e.g. Rossiter & Sharpe, 2001; Sharpe & Rossiter, 2002); (4) siblings feeling loyalty toward their siblings while at the same time feelings of wanting to move on with their own life (e.g. Nolbris et al., 2007); (5) siblings experiencing worry and/or distress with change to family life (e.g. Chesler, Allesewede, & Barbarin, 1991; Woodgate, 2006); and (6) siblings experiencing positive gains such as personal growth, stronger sibling bonds and increased maturity and independence (Wilkins & Woodgate, 2005; Nolbris et al., 2007).

In their meta-analysis of LD sibling literature, Rossiter and Sharpe (2001) reported a small but statistically significant negative effect of LD on sibling functioning. Factors thought to impact on this effect included the nature of disability, role of extended family, and experience of the peer group. Authors reported how many studies had failed to find any negative impact, which led them

⁸ Studies included siblings of young people diagnosed with Down's Syndrome, cancer and autism.

to conclude a possible overemphasis of this in previous literature. The authors went on to quantitatively review the literature on siblings and chronic physical illness between 1976 and 2000, finding a larger and significant negative effect on siblings (Sharpe & Rossiter, 2002). However, findings appear to remain inconsistent, contributing to the confusion about the sibling experience in both these contexts (Sharpe & Rossiter, 2002). Wilkins and Woodgate's (2005) review of 27 qualitative studies exploring the experience of siblings of young children diagnosed with cancer found parents tended to report a more negative impact on siblings than siblings themselves. This discordance between sibling and parent accounts has also been reported within LD research (Lobato, Kao, & Plante, 2005). One possible reason for the presumed overemphasis of a 'negative-impact' story (Rossiter & Sharpe, 2001) may be a result of previous literature being predominantly driven by parental accounts given the discourse that adult data sources can have more credibility than child accounts.

Given this lack of consistency in research findings, questions can also be asked about the research approach taken. Stoneman highlights how much research in the field of LD has been approached from a 'negative impact' point. Often the assumption held is that being a sibling in this context is thought of as "a problem to be understood and then solved" (2005, p.347), and that such experiences will negatively impact on a sibling's development and psychological wellbeing. This assumption can be seen to reflect the similar questions raised in the field of child trauma, where there remains debate over the often presumed negative impact of trauma versus research indicating post-traumatic growth for example in bereaved children (e.g. Meyerson, Grant, Carter, & Kilmer, 2011). Furthermore, the importance of cultural meaning of the SR is often given minimal attention, with most sibling research being approached from a Euro/American view of what a SR, and indeed QOL, should look like (Bank & Kahn, 1975; Stoneman, 2005).

Summary

The increase use of sibling accounts in research from the fields of LD and physical illness have allowed for recognition of general themes of the sibling experience, while at the same the often-inconsistent findings raise additional questions and debate. Furthermore, research has brought to light questions

about the process and design of sibling research and further justified the importance of researchers taking a neutral position in this. They have also allowed for greater acceptance of the importance of the sibling voice being heard through individual accounts of their experiences (Rowe, 1992) and the usefulness of qualitative methodology in doing this. Such findings can therefore help inform the design and approach taken in future sibling research.

Comparatively fewer studies have explored the sibling experience in the context of a diagnosed 'ED'. Garley and Johnson (1994) note how although diagnosed 'EDs' are often chronic and potentially fatal, unlike physical illnesses such as cancer, the consequences for some can be hidden behind a "socially desirable slim female form" (p.158). Therefore, questions arise about to what extent these findings can be generalised. The following section will review and discuss the experience of siblings in the context of a diagnosed 'ED'.

Siblings in the context of a diagnosed 'eating disorder'

In their review of sibling literature, Vandereycken and Van Vreckem noted how "In the voluminous literature on families of eating disorder patients, siblings are a relatively forgotten group." (1992, p.273). Their review suggested findings at the time were inconclusive, with most research being focused on the problematic rather than possible positive aspects of the experience. Since this time, a small number of empirical studies exploring the sibling experience have emerged. Adult and young siblings have taken part in quantitative and qualitative research exploring both current and retrospective experiences. Additionally, research has explored views of parents and young people diagnosed with an 'ED'. This section will provide an outline and critical review of this literature. Studies found from a review of the existing literature are outlined in Table one. This is followed by a discussion of some of the key overarching themes from across this research.

Table 1: Studies of siblings of individuals diagnosed with an 'ED'

Study and location	Aim	Participants	Outcomes/findings	Conclusions	Limitations
Areemit et al., (2010) North America	To explore the experience and QOL of siblings of adolescents diagnosed with an 'ED'.	<p>20 siblings (14 female) of 17 adolescents diagnosed with an 'ED' ('AN' or 'EDNOS').</p> <p>Mean age; 13.65 (SD = 2.06).</p>	<p>PedsQL average scores above cut-off for risk of impaired QOL. Siblings reported change in QOL; no sibling reported improvement and 80% reported a negative impact.</p> <p>Themes: (1) A desire to understand the 'ED'; (2) Acute awareness of 'ED' behaviours and thoughts; (3) Challenges in understanding 'non eating-related' behaviours; (4) Increase in family conflict and arguments; (5) compassion/concern for their sibling; (6) Feelings of loss and sacrifice; (7) Overwhelming sense of responsibility for their sibling; and (8) Sense of pervasiveness of the 'ED' across aspects of their lives.</p>	Siblings can experience an impact to their lives and be at risk of a 'negative' impact to perceived QOL.	<p>Small sample size.</p> <p>PedsQL subject to recall bias.</p> <p>Consent for participation required by diagnosed sibling.</p>

Bachner-Melman, (2005) Israel	Exploring the relationship between individuals diagnosed with 'AN' and siblings.	Four women in various stages of recovery from diagnosis of 'AN'.	Participants described antagonism, rivalry and little warmth in SR while growing up.	Siblings described as a useful resource within recovery.	Small sample size. Retrospective reporting on experience
Dimitropulos et al., (2009) North America	Exploring experiences and challenges for siblings of women diagnosed with 'AN'	12 female siblings with sisters diagnosed with 'AN'. Mean age; 25.6 (SD = 7.85)	Themes: (1) Sibling role as protector and mediator; (2) Familial factors influencing and reinforcing these sibling roles; (3) Consequences and benefits of 'AN' to non-affected sibling; (4) Coping strategies; (5) Current/future intentions of care giving and (6) Professional and informal support.	Siblings can take on new roles, experience a sense of loyalty toward their parents and develop coping strategies.	Results cannot be generalized to child and adolescent populations. Participants all identified themselves as caregivers.
Garley and Johnson, (1994) North America	To develop an increased awareness of the sibling experience in families where one child is diagnosed with an 'ED'.	Five female adolescent siblings (aged 15 -18) of sisters diagnosed with 'AN'.	Themes (see Appendix 4): (1) Perspective of the illness; (2) Disruption; (3) Role strain; (4) Special status; and (5) Coping with the illness. Two overarching constructs; 'pervasiveness' and 'intense and conflicting emotions'.	Importance of professionals being mindful of siblings when supporting families.	Small sample size Siblings of adolescents diagnosed with 'AN' only

Honey et al., (2006) Australia	Exploring perspectives of adolescent girls diagnosed with 'AN' and parents about siblings influence on diagnosed siblings' experience.	24 girls (aged 14 - 20) diagnosed with 'AN', and 24 parents. Inpatient and outpatient samples.	Siblings described as having a positive and negative influence on diagnosed sibling through their presence within the family, response or reaction to diagnosis, and indirectly through impact on parents/parents' actions. Further contributing factors identified (see Appendix 5).	Conceptual framework describes sibling roles and influences. Importance of awareness of siblings in this context.	Large variance in sibling demographics. No indication of cultural or social factors.
Honey and Halse (2006) Australia	Exploring parent efforts in helping 'well' siblings adapt to a sibling diagnosis of 'AN'.	In-depth interviews, 24 parents (16 mothers and eight fathers) of adolescent girls diagnosed with 'AN' and receiving support.	Grounded Theory analysis. Most parents considered potential of negative impact on siblings. Efforts to support siblings included: maintaining normality; compensating for changes to family life; providing emotional support; protecting siblings; and managing arising problems.	Most parents reported making efforts to minimise any negative impact on siblings. Support for inclusion of parents in sibling support programmes.	Large age range of siblings. All were parents of adolescent girls diagnosed with 'AN'.
Latzer et al., (2002) Israel	To describe experiences of younger sisters of individuals diagnosed with 'AN'.	Nine sisters (aged 11 – 18) of individuals with a diagnosis of 'AN'.	Six categories (see Appendix 6): (1) Structural processes; (2) Family dynamic processes; (3) Emotional processes; (4) Change in life functions; (5) Body image; and (6) Narrative of the illness. Two theoretical concepts presented, 'The illness as a	Suggestion of siblings being 'at risk' of developing 'pathological' symptoms.	Only focused on siblings of those diagnosed with 'AN'.

			new member of the family' and 'duality'.		
Moulds et al., (2000) Australia	Investigating relationship between perceived Expressed Emotion (EE) of siblings and parents of and its effect on weight gain and psychological functioning for hospitalised siblings diagnosed with 'AN'.	19 individuals (mean age; 20.9), and closest aged sibling completed: Level of Expressed Emotion Scale Eating Disorder Inventory 2 (EDI-2) and Family Attitudes Scale	Perceived EE not predictive of BMI change. Composite perceived family EE score significantly predicted change on three EDI-2 subscales; interpersonal distrust, maturity fears and perfectionism.	SR suggested as poor short-term predictor of treatment response.	Initial measures may have been impacted by emotional and/or cognitive response to hospitalisation.
Ross and Handy, (1997) New Zealand	Exploring family experiences of living with a diagnosis of 'AN'.	Two families (with one brother in each) with daughter diagnosed with 'AN'. One male sibling from each.	Key themes: childhood and family relationships and professional treatment.	Authors note 'enormous' effects of the illness on the family and marginalization of siblings.	Lack of cultural variance. Focus on diagnosis of 'AN' only.

Accounts from parents of and individuals diagnosed with an 'eating disorder'

Retrospective accounts from women in various stages of recovery from a diagnosis of 'AN' suggest that the quality and nature of the SR is of relevance to the development, prevention and treatment of an 'ED' (Bachner-Melman, 2005). Similarly, young people diagnosed with an 'ED' report how siblings can influence the experience of having an 'ED' diagnosis. Parents and adolescents diagnosed with an 'ED' have described siblings as having positive and negative influences on the situation with factors such as sibling relations prior to the diagnosis, professional involvement and family characteristics impacting on this influence (Honey et al., 2006). Findings supported previous literature identifying structural sibling factors as a framework (Circirelli, 1995), under which other individualised factors can operate (Honey et al., 2006). Such research suggests the importance of clinicians being mindful of the sibling experience when supporting families during therapeutic interventions.

Accounts from family members have provided useful findings about how siblings might be viewed by others in the family. However, as with much research within the field of 'ED', the focus of these accounts remains on female adolescents diagnosed with 'AN'. Such research has also highlighted variation in adolescent and parent accounts (Honey et al., 2006), consistent with findings from sibling research within the field of LD (Wilkins & Woodgate, 2005). This again supports the need to accommodate multiple perspectives within sibling research including that of the siblings themselves.

The sibling perspective

Although limited, previous studies using the sibling perspective within the context of a diagnosed 'ED' appear to suggest recurrent themes across findings, which have been outlined below.

The role of the sibling

Parents have reported that siblings are able to provide a role in communicating between parents and young person diagnosed with an 'ED' (Honey et al., 2006). Similarly, adult siblings have described taking on a role of mediator between their diagnosed sibling and parents (Dimitropoulos et al., 2009), although it is worth

noting that some reported having always had aspects of this role in their family. This echoes previous research findings suggesting the sibling role and may reflect family dynamics that predate the diagnosis of the 'ED' (Garley & Johnson, 1994). Such a view could be suggestive of the sibling experience being appropriately conceived of as a slowly evolving situation. Siblings have also identified having a protective role and feeling a sense of responsibility toward their diagnosed sibling (Garley & Johnson, 1994; Dimitropoulos et al., 2009). Additionally, adolescent siblings have suggested they can take on aspects of a 'parental' role (Areemit et al., 2010). Siblings have also reported wanting to support their diagnosed sibling, although feeling unsure about how to do this (Garley & Johnson, 1994). Findings have also suggested siblings may experience 'role strain', feeling burdened or conflicted with expectation and demands from parents and family members to be supportive toward their sibling (Areemit et al., 2010).

Siblings may be positioned by family members as a role model, or as able to provide motivation for their sibling's recovery. Parents have identified siblings as a source of support with respect to their parenting abilities; they may draw confidence in their parenting skills when siblings are seen to be 'coping' with the experience (Honey et al., 2006). Perhaps unhelpfully within research, terms such as 'well child' (Dimitropoulos et al., 2009; Honey & Halse, 2006; Abrams, 2009) have been used, which can be seen to demonstrate or encourage this discourse.

Sibling lifestyle and identity

Siblings report changes to day-to-day living, including perceived impact upon daily functioning and lower motivation for social or academic activity (Latzer et al., 2002). Findings also suggest siblings can feel pressure from their diagnosed sibling to eat (Tierney, 2005), and more frequently compare themselves to their sibling in terms of body image and diet (Garley & Johnson, 1994). Adolescent siblings have identified losses and gains in their life, with a perceived 'loss' in time spent with parents (Whitney & Eisler, 2005), aspects of a 'normal' childhood and time engaged in other activities (Areemit et al., 2010). Gains have been identified as closer sibling and family bonds and greater awareness of supportive friendships (Garley & Johnson, 1994; Areemit et al., 2010).

Similar to previous suggestions from fields of LD and physical illness, Areemit et al. (2010) suggested siblings' QOL may be negatively affected by having a brother or sister diagnosed with an 'ED'. Qualitative data from the study suggested siblings experienced either no improvement in perceived QOL, or for most, a perceived negative impact to this. Authors concluded how findings were suggestive of the "enormous impact" (2010, p.573) the situation could have on siblings.

This study appears to have provided the first published account of a group of siblings inclusive of male and female siblings and siblings of young people diagnosed with an 'ED' aside from 'AN'. The research design and variance in findings highlights some of the challenges with measuring a subjective experience such as perceived QOL, in particular with young people (Harding, 2001). Furthermore, Areemit and colleagues (2010) themselves questioned the appropriateness of the quantitative measures used in the study. The use of a qualitative aspect to the study appeared useful; authors attributed siblings' willingness to talk and share experiences to the use of a focus group design. Such an approach has been previously used with siblings in other fields (e.g. Woodgate, 2006). While allowing for shared experiences and perspectives to be heard, it can perhaps be equally limiting for those who may feel unable to express views within a larger group (Lewis, 1992). A final feature of the study is that it did not appear to consider the age of participants present in the focus groups. This could be seen as important to findings since language, confidence in expressing views and understanding about a perhaps previously un-encountered situation are likely to vary with age.

Sibling understanding and involvement

Siblings have reported having increased understanding about diagnosed 'EDs' although have expressed difficulty in making sense of this (Garley & Johnson, 1994). Studies have suggested siblings might view the 'ED' as 'a new member of the family' (Latzer et al., 2002, p.278). Siblings have reported being aware of their sibling's behaviours and thoughts - both those they associated with the diagnosis and those described as non-related, such as obsessional behaviours (Areemit et al., 2010).

Siblings can be thought of as a resource in recovery and therefore may have/be given a role in family-based interventions (Le Grange, Binford, & Loeb, 2005). Various factors can influence the extent of this involvement. While some parents may choose to involve siblings in FT or through other means such as attending appointments, others may discourage this, choosing to keep siblings separate from the situation (Honey & Halse, 2006). Additionally, the young person diagnosed with an 'ED' may decide who in the family attends FT appointments. This has been understood by some as a desire to keep hold of their own identity, separate from their siblings (Perkins et al., 2005).

Adult siblings of individuals diagnosed with an 'ED' have shared retrospective views about how parental minimising of the situation can contribute to increased sibling concern (Dimitropoulos et al., 2009). Studies have found parents of young siblings are aware of a possible negative impact on siblings of young people diagnosed with an 'ED' (Honey & Halse, 2006) and will actively aim to promote 'normality' through a number of methods, such as eliciting support from their extended family and intentionally withholding information as a way to protect siblings. This can be seen to reflect findings with young people in research with families where one member is critically unwell (Kean, 2010). However, questions arise around whether such strategies may be perceived differently, or seen as counterproductive, by siblings themselves. For example, strategies identified, such as 'shielding' might be viewed by parents as protective, while siblings may experience this as parents withholding information, which has been found to contribute to a feeling of being 'left out' (Areemit et al., 2010 p.572).

Family life and sibling relationships

Siblings have reported increased tensions and conflict with their diagnosed sibling (Latzer et al., 2009; Areemit et al., 2010) and within their family and sibling sub-systems (Garley & Johnson, 1994; Latzer et al., 2009; Areemit et al., 2010). Siblings have made reference to their diagnosed sibling as being privileged over them within the family (Garley & Johnson, 1994) and feeling they could be overlooked. This was especially in relation to their mothers, with authors questioning whether this contributed to siblings experiencing a lack of perceived identity, aside from being the "sister of an anorectic sibling" (p.161). However,

research also suggests siblings can feel unable to express such views about change in family and their lives to parents (Dallos & Denford, 2008).

Eisler (2005) refers to the impact of families needing to reorganise themselves around a diagnosed 'ED', which can result in this becoming the centre of family life. This can be seen to dominate and restrict aspects of family life and the lives of those within the family. One possible result of this can be an increased challenge in meeting the needs of the family life cycle, in particular for family members such as siblings who are likely to be developing through childhood and adolescence (Whitney & Eisler, 2005).

Little research has looked directly at how siblings perceived the influence of a diagnosed 'ED' upon their SR (Blessing, 2007). However, when asked about their experiences, siblings have expressed having various feelings and emotions towards their diagnosed sibling. For example, some siblings describe the experience as having drawn them apart, while others report feeling closer (Dimitropoulos et al., 2009; Latzer et al., 2002; Garley & Johnson, 1994). Carers have reported observing SRs as strained, with the non-diagnosed siblings appearing hypersensitive and unsure about the situation (Highet et al., 2005).

Emotions and coping strategies

Findings suggest siblings can experience a range of emotions related to their situation; sibling accounts have been previously linked with a key theme of 'intense and conflicting emotions' (Garley & Johnson, 1994). Siblings have expressed feelings of hopelessness (Dimitropoulos et al., 2009), fear, anger and worry about their sibling (Highet et al., 2005) and/or in further aggravating the situation (Latzer et al., 2002). Siblings may also have concerns about long-term outcomes for their diagnosed sibling and express worry for the family system as a whole (Garley & Johnson, 1994). Sibling accounts have previously been described as being at times filled with contradictions and conflicting views (Areemit et al., 2010). Related to these apparent conflicting emotions, a further theme reported across literature has been the 'duality' of emotions (Latzer et al., 2002; Areemit et al., 2010).

Parents have described siblings experiencing a range of emotions, including confusion, self-blame and worry about worsening the situation (Tierney, 2005). This may relate to findings from carers who expressed feelings siblings had detached from the family unit (Highet et al., 2005). Parents report being aware that siblings may feel neglected (Honey & Halse, 2006) and they themselves have reported feeling increasingly distressed when witnessing or feeling there had been a negative emotional impact on siblings (Honey et al., 2006).

Studies suggest siblings may employ a range of coping strategies, such as seeking support from those outside of their family (Garley & Johnson, 1994; Areemit et al., 2010), distancing themselves and/or taking on new roles (Areemit et al., 2010). Asked retrospectively about what might have constituted helpful support for siblings at the time their sibling was diagnosed, adult siblings identified discussions with therapists about roles and responsibilities of the siblings, reassurance and information about 'EDs', and forums such as support groups (Dimitropoulos et al., 2009).

Conclusion and justification for the current study

Studies using the sibling perspective in the context of a diagnosed 'ED' have offered a range of useful findings related to sibling identity and lifestyle, relations, and coping and support strategies. Some themes appear to have been previously identified as having resemblance to research with siblings of children with cancer and chronic illness (Garley & Johnson, 1994). However, as with sibling research in other fields, findings appear varied and inconsistent at times, perhaps reflecting the individuality of families and the sibling experience.

Studies have made reference to challenges and limitations of sibling research most notably the dearth of literature. Within previous studies, samples have included those who identify as caregivers for siblings (Dimitropoulos et al., 2009) or whose sibling diagnosed with an 'ED' consented to their taking part (Areemit et al., 2010). Both are arguably likely to be relevant when considering views expressed. Furthermore, most studies have focused on sisters of females diagnosed with 'AN', who remain a group more commonly researched than

siblings of young people diagnosed with 'BN' or 'EDNOS'. Finally, the increased support for qualitative sibling research, both in the field of 'ED' and beyond has contributed to the support for such methods in future research.

Three major features demonstrate the need for the current study: (1) There is currently only a small body of research in 'ED' literature focusing on siblings and within this, very few studies using the sibling perspective. Authors of the most recent sibling study noted, "future research is needed to further develop the existing knowledge base concerning the sibling experience of living with an 'ED'. (Areemit et al., 2010, p.575); (2) Much of what is understood about siblings in this context has been provided through accounts from the diagnosed sibling, parent or adult siblings. Although offering understanding about how the sibling experience is viewed by others in the family, such accounts do not allow consideration of what young siblings' themselves might report; and (3) No published research appears to have been conducted using a UK-based sample.

Research questions

Based on a review of the existing literature, this study will aim to explore the experiences of siblings from the UK living with a brother or sister diagnosed with an 'ED'. In light of existing research and gaps identified in the literature, the study will be directed by the following research questions:

- What is the experience of being a sibling of a young person who is diagnosed with an 'ED'?
- In what ways might siblings view having a brother or sister with a diagnosed 'ED' as impacting on sibling lifestyle, family and sibling relationships?
- What do siblings say about the support given to their family at the time of intervention?

The next chapter will outline the methodology, design and analysis used in the current study.

CHAPTER TWO: METHODOLOGY

This chapter outlines the epistemological position and rationale for the methodology of the present study. This will be followed by a description of the research design, ethical considerations, recruitment process and participant sample. Methods of data collection and analysis will then be outlined, followed by reflections on the positioning of the researcher in the context of the study.

Epistemology

Epistemology refers to the study of how individuals come to know information and acquire knowledge. It is defined by Willig as, “a branch of philosophy concerned with the theory of knowledge” (2008, p.2). Research methods provide ways to try and understand individuals and their views about world around them. Different research methods reflect different claims and assumptions about knowledge, how individuals come to know and make sense of this, and the role and implication of the researcher (Willig, 2008). In relation to this, epistemology links closely to decisions made about research design and the methods with which this is carried out (Carter & Little, 2007). Research methods should therefore be outlined with reference to the researchers’ epistemological stance and reflexivity (Miles & Huberman, 1994; Willig, 2008), both of which can be seen to influence data collection, analysis and findings.

Epistemological position

The current research is approached from a critical realist epistemological position. Critical realism rejects views held by traditional positivist approaches about the acquisition of knowledge and suggests there is reality independent of our thinking. A positivist epistemology implies research can provide objective and unbiased findings, which the researcher remains outside of. Such views are often dominant within quantitative research methods (Maxwell, 2012). In contrast to this, the critical realist perspective postulates that there is no one truth, but instead multiple perspectives or “knowledges” (Willig, 2008, p.7). In line with ideas of social constructionism (see Burr, 2003), historical and social factors can impact on this knowledge and experience, as can an individuals’ own concepts

and expression of language. Therefore in the context of research, a critical realist position acknowledges the researcher does not remain 'outside' the research but instead brings their understanding and assumptions to the method, analysis, and findings (Maxwell, 2012). This places importance in acknowledging the researcher's own contribution to the construction of meaning.

Rationale for methodological approach

The current research aimed to explore how siblings of young people diagnosed with an 'ED' view and make sense of the experience. Qualitative approaches provide a means of attempting to open up such routes of enquiry through discussion, allowing for rich descriptions of experience to be heard (Willig, 2008).

Qualitative research methods have long been compared with quantitative approaches. Antaki, Billig, Edwards, & Potter (2002) highlight how qualitative approaches are seen by some as overly broad in nature, and therefore critiqued on the level of interpretation and subjectivity involved. Willig (2008) highlights how, unlike quantitative research, the goal is not to generate and test predictions of outcomes but instead to explore the process. Furthermore she notes how "qualitative researchers tend to be concerned with meaning...quality and texture of experience" (2001, p.9). Qualitative approaches offer a method of analysis that allows for in-depth study of phenomena not easily quantifiable. It can therefore allow for the emergence of unanticipated findings (Barker, Pistrang, & Elliott, 2002) and lends itself well to exploring sensitive and complex issues. Although a number of qualitative methodologies exist, all can be seen to, at some level, acknowledge that there is no ultimate truth in experience, but instead multiple truths impacted upon by subjectivity (Berger & Luckman, 1967).

Although qualitative 'ED' research is continually emerging, there is a comparatively smaller literature base compared with quantitative research (Colton & Pistrang, 2004). Qualitative methods of research have offered a useful approach for hearing the sibling perspective, of which relatively little is known (Stoneman, 2005). Specific to 'EDs', much sibling research has employed quantitative methods to study the impact, influence, or genetic and environmental

factors related to siblings in this context. More recently, qualitative studies have begun to emerge using the sibling perspective (e.g. Garley & Johnson, 1994; Areemit et al., 2010), providing helpful findings and further support for the continued use of such methods. With this in mind, and with consideration of the research questions of this study, it was judged appropriate to adopt a qualitative method and analysis. It is hoped this will allow for the emergence of a rich description of the sibling experience from which themes can be generated.

Thematic analysis

Thematic Analysis (TA) involves eliciting salient patterns (themes) from data, from which inferences about meaning and process can be made (Boyatzis, 1998; Braun & Clark, 2006). TA has aspects of approach grounded in content analysis however, aims to move beyond the observed aspects of a data set (Joffe, 2011). TA was chosen as a method, primarily because it allows the researcher to approach and examine data in a flexible way, rather than working from a theoretically driven framework (Joffe, 2011; Braun & Clarke, 2006). This can also allow for recognition of the impact of a wider social context. Secondly, TA can be approached from different epistemological positions, allowing acknowledgement and flexibility of the researcher's theoretical positioning.

Why not a different qualitative analysis?

When considering the most appropriate methodology for this research, other qualitative approaches were considered and reviewed. These included Grounded Theory (GT) and Interpretative Phenomenological Analysis (IPA). All approaches share similarities in their framework and in aiming to represent a view of reality through the identification of aspects of data. However, they vary in how the data might be approached epistemologically.

IPA is a method of analysis closely attached to a phenomenological epistemology (Smith & Osborn, 2003). Based on the assumption that people will try to make sense of their experiences, IPA aims to hear people's experiences of reality in order to understand a particular phenomenon and provide a description of how this might be done (Smith, Flowers, & Larkin, 2009). Arguably this approach can

allow the researcher to both understand the participant's view, while at the same time add interpretation and ask critical questions of the data (Smith & Osborn, 2003).

GT can be seen to involve aspects of a more sociological approach (Willig, 2008), focusing on patterns within data that can support broader conceptual explanations. A GT analysis can be approached in a number of ways (Charmaz, 2002) however, the overall aim is to generate a theory that remains 'grounded' in the data (McLeod, 2001). GT therefore follows an inductive approach to analysis, where data collection and analysis are undertaken simultaneously (Strauss & Corbin, 1990).

As with TA, both IPA and GT seek to find patterns within data. However, unlike these approaches, TA is not theoretically bound and stands independently from any particular epistemology. Braun and Clarke (2006) argue that as TA does not rely on any pre-existing theory, it can be used within a wide range of theoretical frameworks, and avoid being driven as much by the researchers' own interests or pre-designed criteria. Themes can therefore occur which may not appear directly linked to questions asked. Additionally, guidelines and stages of analysis outlined in the approach allows for clarity and transparency in the analysis process (Braun & Clarke, 2006).

The aim of the current research was to develop an understanding of particular aspects and views about living with a young person diagnosed with an 'ED'. Siblings in this study were not seen as a homogenous group, varying in age, gender and their sibling's diagnoses. Therefore the focus of the research was aimed to be broader than that of the individual experience. Siblings in this context and wider, are a group whom relatively little is known about. Therefore it was felt the flexible nature of TA could allow for greater emergence of unanticipated findings and understanding of siblings within a wider context (Marks & Yardley, 2004), including their sub and family systems.

Design

This study employed a qualitative research design. In line with guidance on the number of participants involved in professional doctorate research (Smith et al., 2009), the study aimed to recruit between six and ten siblings to take part in individual semi-structured interviews. Participants were recruited both from within the NHS and outside of this. All were identified, either by themselves or professionals involved in supporting their sibling and/or family, as siblings of an individual diagnosed with an 'ED'. Following Areemit et al. (2010), a focus group design was initially considered in the research proposal. However, review at NHS Research and Ethics committee level determined that focus group design raised concern about confidentiality in relation to the ages of participants, and approval was made conditional upon undertaking data collection using individual interviews, adjudged by the committee to guarantee greater confidentiality of information.

Focus groups would have provided data collection through informal group discussion 'focused' on the research topic (Wilkinson, 2006); they are well suited to explore 'sensitive topics' (Frith, 2000) and compared to individual interviews, provide a more 'naturalistic' setting where natural communicative process can be observed. The researcher is positioned to facilitate discussions between the group members, and explore the interaction between them. It was decided that the focus groups would be formed based on the age of the participants. This was decided firstly to ensure participants were able to engage in age-appropriate conversations, and secondly to allow for possible comparisons from across the groups. It was felt that such comparisons could provide interesting findings related to the experiences of siblings from across an age range.

As it was, the interview design protected a higher level of confidentiality, but it was obtained at the expense of analysing and comparing such shared conversations and group ideas about the sibling experience.

Participants: Inclusion and exclusion criteria

Potential participants were siblings of young people (defined as aged between 11 and 18) who had been given a diagnosis of an 'ED' and were receiving support for this. Diagnoses included 'AN', 'BN' and 'EDNOS'⁹. Both male and female siblings were invited to participate. Additionally, it was anticipated that participants could be either older or younger than their sibling diagnosed with an 'ED'.

Participants were required to be of secondary school age (between 11 and 18 years). This was decided upon in order to allow for a more focused range of cognitive and language ability and general understanding. Additionally, whereas the experiences of younger children may arguably be more appropriately accessed through a parental account, this age range would allow for all siblings to offer their own account. Siblings were required to be living in the same home, although it was acknowledged participants could be siblings of young people who were receiving inpatient support at the time.

Siblings who were non-English speaking were excluded from the study. This was decided upon due to the qualitative analysis relying heavily on language. It was felt that had a translator been present, some meaning of discussions might have been lost. Due to the need to consent to participate, young people diagnosed with a significant LD who were unable to provide consent were also excluded.

Recruitment sites

Participants were recruited from inpatient and outpatient services. Although these experiences are varied, it was felt both experiences could provide useful accounts of the sibling perspective. Furthermore, siblings of young people receiving inpatient support are most likely to have had previous experience of their sibling receiving outpatient care prior to admission. An NHS CAMHS team was approached in relation to recruitment. A clinical psychologist based in the 'ED' team at this service was later involved in introducing the research to siblings

⁹ It is acknowledged that there is ongoing debate regarding the classification and specific aspects of these diagnoses when used in this population, (e.g. Eddy et al., 2011).

and their families. Additionally, a clinical psychologist based at a non-NHS inpatient service was involved in the recruitment process from this site.

Ethical considerations

Ethical considerations for this research were guided by professional codes of ethics (British Psychological Society BPS, 2009) and guidance on research (BPS, 2010), as well as literature specific to ethical considerations of research with young people (Alderson; 1995; Hill, 2005).

Ethics approval

Prior to recruitment, registration and ethical approval was granted for the study by the University of East London ethics committee (see Appendices 7 and 8). Additionally an application to an NHS Research and Ethics Committee was made. Following requested amendments being made, a favorable opinion from the committee was given (see Appendix 9). The research also needed approval from the NHS trust ethics committee (see Appendix 10) and Research and Development team (see Appendix 11). Managers from the non-NHS site reviewed the research proposal and gave approval for recruitment (see Appendix 12).

Informed consent

Informed consent to participate was ensured through participant and parent information sheets explaining: the purpose of research, what participation would involve, and what would happen to information given and recordings of interviews. Consent and assent forms were given when the study was initially introduced, allowing participants and parents to review these before deciding whether to participate. Prior to interviews taking place, the researcher reiterated to both the participant and parent that they were not under any obligation to take part. Participants were aware they could terminate the interview at any point without needing to give a reason for doing so.

Confidentiality

Participants were fully informed about confidentiality. They were aware that interviews would be transcribed and that anonymous transcripts might be read by supervisors. Participants knew that although quotes would be used in the write-up, all identifying information would be removed and names changed.

Participants and parents were also informed of the limits of confidentiality and that should the researcher feel it necessary, information would be shared with the appropriate people and services.

In accordance with the 1998 Data Protection Act, participant identity, including identifying data such as consent forms were stored separate to all other material related to this study. Each participant was assigned a research number, linked to a pseudonym. This document was also stored separately. Aspects of confidentiality were explained again at the start of the interview.

Affiliation of the study

Information sheets given to siblings and parents made clear that participation would not affect any support their family received from services. Participants and their parents were made aware that the researcher had no current affiliation with either recruitment site, although, had previously been employed as an assistant psychologist in one of the services.

Potential distress

The researcher was mindful of potential distress for participants given their age and discussion about a potentially sensitive topic. Participants were given clear, age-appropriate information beforehand about participation and the topics that would be covered in the interview. They were also made aware that they could break from the interview at any time, had the right not to answer questions they did not want to and could withdraw from the study at any time without reason. Following the interview participants were asked about the experience of being interviewed, offered debriefing information, and participants and parents (if present) were given the opportunity to ask questions.

Recruitment process

Siblings and families were initially informed of the research by the local collaborator at the site. They were provided with an information pack¹⁰ containing: an age appropriate information form about the study for sibling participants (see Appendix 13), an information form for parents and family members (see Appendix 14), an age appropriate consent form for sibling participants (see Appendix 15), and an assent form for parents/carers (see Appendix 16). Information sheets contained contact details for the researcher, local collaborator and the university chair of ethics.¹¹ Recruitment from both the inpatient and outpatient sites followed the same process. Families contacted through the NHS were made aware that their GP's would be informed of participant involvement by letter (see Appendix 17).¹² Parents and siblings were aware they could contact either the researcher or a local collaborator to arrange interviews.

Following delays with ethics approval and after discussion with supervisors, it was felt appropriate to expand recruitment to siblings from outside of NHS or other services who were within a wider age range (aged 18 to 30). Approval for this was given by the university ethics committee chair. It was acknowledged that participants' siblings diagnosed with an 'ED' might be over the age of 18 and not currently receiving support from a child and adolescent service (as initially defined in the inclusion criteria). However, it was felt these siblings could offer relevant current and/or retrospective accounts of their experiences of living or having lived who was a young person diagnosed with an 'ED' and receiving support for this. Separate information sheets and consent forms were used (see Appendices 18 and 19).

Participant sample

The sample of participants was recruited through an NHS CAMHS team, an inpatient setting and for siblings over the age of 18, from outside of services. A

¹⁰ Specific details in the information packs varied in nature depending on the service. Forms presented in Appendices are based on those used within the NHS service.

¹¹ For families approached through the NHS, Patient and Advice Liaison Service (PALS) details were also included.

¹² For participants recruited outside of the NHS, the researcher was not required to inform GPs of participant involvement.

total of six interviews took place. Table two provides a summary of demographics of the sample.

Table 2: *Participant sample*

Name	Age	Ethnicity	Number of siblings	Age, gender and diagnosis of sibling diagnosed with an 'ED'	Support being received by diagnosed sibling.
Hannah	18	White British	1	16-year-old female diagnosed with 'AN'	Diagnosed sibling receiving inpatient support
Rachel	15	White British	2	17-year-old female diagnosed with 'AN'	Diagnosed sibling receiving inpatient support
Nina	14	British Pakistani	1	11-year-old female diagnosed with 'AN'	Diagnosed sibling receiving outpatient support
Emma	18	White British	2	24-year-old female diagnosed with 'AN'.	Diagnosed sibling currently receiving support from adult services. Previous inpatient and outpatient support through CAMHS.
Michelle	16	White British	1	18-year-old female diagnosed with 'AN'	Diagnosed sibling receiving outpatient support
Priya	11	British Pakistani	1	14-year-old female diagnosed with 'EDNOS'	Diagnosed sibling receiving outpatient support

Data collection

Based on the study's research questions, an interview schedule was developed (see Appendix 20). This process was informed by discussions with supervisors,

guidance from related literature on developing interview schedules (Willig, 2008) and guidance on research and interviewing with children and adolescents (Howitt & Cramer, 2005; Tinson, 2009). The schedule contained prompt questions and was used flexibly to allow for discussions of unanticipated areas.

Interviews took place in a private room, either at the service where recruitment took place or the participant's home¹³. Interviews lasted between 30 and 90 minutes. They were audio recorded and later transcribed verbatim, with all identifying information removed. Debriefing information was offered following the interview (see Appendix 21).

Data analysis

As detailed above, TA was used to analyse the data. Supervision of the analysis was provided by a university research supervisor.

Themes were developed following analysis of each interview and the whole data set. While some participants expressed more ideas than others, all views were of equal importance and therefore themes chosen were those which captured important elements from across the data (Braun & Clarke, 2006). The researcher used an inductive/bottom-up approach in developing themes. This meant the analysis aimed to be driven by the data rather than the interest of the researcher and views expressed by participants therefore remained central to the analysis. However, as with all qualitative research it is important to note the influence of the research questions, context and assumptions held by the researcher, which remain present throughout the interviews, coding and analysis (Braun & Clarke, 2006; Willig, 2008). Furthermore, it is acknowledged that analysis of each interview contributed to the development of ideas, which then shaped and guided subsequent interview analyses.

The analytic process was informed by guidelines set out by Braun and Clarke (2006) and guidance on ensuring quality in qualitative research (Yardley, 2000).

¹³ This was the case with Michelle who was recruited via the general public.

Although TA guidelines form a framework with which to approach the data, Braun and Clarke (2006) note the flexibility of these and the importance of adaptation to best suit the research. Furthermore, Hunter, Lusardi, Zucker, Jacelon, and Chandler (2002) make reference to growing agreement amongst researchers in going beyond prescribed methods of analysis in order to generate new and creative insight. In the current study, stages of analysis did not follow the exact order outlined by guidelines. Delays in ethical approval and subsequent recruitment difficulties meant four interviews were carried out some time before the final two. Given the time constraints, analysis therefore began prior to all interviews having been conducted. Four interviews were transcribed, coded and initial ideas for themes considered. Following the final interviews, codes and initial ideas for themes were reviewed. Details of each stage of the analytic process (as outlined by Braun & Clarke, 2006) are further described below.

Phase one: Familiarisation with the data

In familiarising oneself with the data, Braun and Clarke highlight the importance of the researcher being immersed in the data in order to establish the “depth and breadth” of the data (2006, p.87). This phase began early on in the data collection process, with all interviews being conducted by the researcher. Transcription of interview data has been considered a core initial process in familiarisation with qualitative data and meanings (Bird, 2005; Kvale & Brinkmann, 2009) and was therefore carried out solely by the researcher. Interviews were analysed individually with recordings listened back to at least twice, once following complete transcription. Transcripts were line numbered and initial annotations made by hand. Notes were made about anything thought relevant, including initial thoughts about codes, content and language. Appendix 22 contains a section of annotated transcript from this stage.

Phase two: Generating initial codes

At this stage, each transcript was read with attention to the researcher’s initial comments. Patterns and features of the data were again noted, with a view to developing codes to describe these. Coding was initially carried out by hand on the transcripts. Coded transcripts were then re-read to ensure all data segments had been included. Where needed, segments were given multiple codes.

Reflections and analysis were included at this point to help the researcher develop a better understanding of the data (see Appendix 23 for an example of initial coding and analysis of data extracts from one transcript). Following all interviews having taken place, all codes were organised into a spreadsheet to form a 'coding manual' (Joffe, 2011) with associated data segments from across the data set (see Appendix 24 for the list of codes, and Appendix 25 for examples of coded extracts from across the data set).

Phase three: Searching for themes

Initial ideas for themes had been considered prior to completion of recruitment and were reviewed once the complete data set had been coded. This phase then involved the researcher analysing all codes and initial theme ideas to be able to group them into provisional themes. Some codes developed into themes, while others were merged to form themes. As suggested by Braun and Clarke (2006) a list of miscellaneous codes that appeared not to fit within initial themes was kept.

All data relevant to a provisional theme was collated. Visual representations of the data (see Appendix 26 for an example) offered useful ways to think about grouping codes within specific themes, considering possible variations, defining potential main and sub-themes and considering how they might relate. At the end of this phase, provisional themes had been identified while some codes and themes were discarded. Braun & Clarke (2006) note how in TA, themes can be determined by salience within each data item and prevalence across the whole data set. However, they also emphasize how the "keyness" (p.82) of a theme may not necessarily depend on the frequency of its occurrence but additionally its relevance to the research question as well as researcher judgement. Therefore, although repetitions of themes were assumed to be reflective of salience, these other factors contributed to theme development. By the end of this stage a list of 15 provisional themes had been identified (see Appendix 27).

Phase four: Reviewing themes

In order to review provisional themes, attention was given to the associated codes and related data extracts. A challenge at this stage was to ensure the data extracts accurately represented the themes. To do this, the researcher again

referred back to the whole data set, leading to some extracts being re-coded and others being discarded.

Thematic maps were then developed (see Appendix 28), outlining themes and possible connections between them. During this stage, themes were merged and discarded and sub-themes developed. These themes were then reviewed across the whole data set. This was carried out with the aim of developing a set of themes that provided an accurate representation of the data. At the end of this phase, the five themes were identified, each with sub-themes within them.

Phase five: Defining and naming themes

The next stage involved further analysis of the themes, allowing for refinements and definition with quotes from the data. At this point changes were made to themes and final names decided upon. Themes were further defined through writing a 'memorandum' for each (see Appendix 29). They were then reviewed in relation to the coded extracts from the entire data set. This allowed for consideration of whether the themes reflected the meaning within the data set as a whole. Once the analysis had been conducted, validity and reliability of themes were checked based on guidance outlined by Elliott, Fischer, and Rennie, (1999) and Joffe (2011). This process included a review carried out by a peer who matched initial codes and a selection of quotes with potential themes developed by the researcher.

Phase six: Producing the report

The final stage of the analysis was the production of the report, which is found in the following chapter. Excerpts of text were used to provide examples of themes. These were further analysed with the research questions kept in mind.

Reflexivity

Yardley (2000) notes the importance of acknowledging the impact of the researcher on the research process. It is understood that within qualitative research, beliefs and assumptions held by the researcher will have an influence throughout the data collection and analysis process. It is therefore important to

remain clear about ownership of individual beliefs and assumptions (Elliott et al., 1999). The following section aims to outline some of these perspectives through personal reflexivity with respect to the current research.

I am a twenty eight-year-old white British woman and have lived in England all my life. I am a Trainee Clinical Psychologist in the final year of Clinical Psychology training at the University of East London. I have worked in the field of mental health and clinical psychology for the last six years. I have never been diagnosed with an 'ED'. I have, however, been interested and aware of the impact of difficulties with eating and discourses in society that promote an 'ideal' female form. I believe attending a same-sex school, where I saw the effect of restricting food on a number of individuals made these discourses more prominent. My interest further developed while researching dieting behaviours during my undergraduate degree and subsequently working with young people diagnosed with 'EDs'. It is important to highlight my previous employment (prior to clinical training) in one of the services I recruited from. I was mindful of how families and participants may make sense of this and was keen to establish my independence from the service. Prior to starting an interview, I explained my previous employment and that I was now a 'trainee psychologist' and not connected to the service through employment or any other means.

My theoretical orientation could be considered as integrative. My views have been influenced by social constructionist and critical psychology ideas during my training (e.g. Burr, 2003; Harper & Spellman, 2006). I would describe my epistemological positioning as built on social constructionist and critical realist ideas. I consider diagnoses of mental health difficulties, including diagnosed 'EDs', as existing within a context of psychological, social and biological factors, which can impact on anyone regardless of society, class, race or gender. A range of models and theories have impacted on my thinking, in particular systemic theory and approach. Part of my rationale for researching the sibling perspective developed from my interest in systemic and family system ideas. In terms of research and data collection, I expect there to be multiple possible interpretations of one data set and accept I offer one description of the sibling perspective in the context of a diagnosed 'ED'.

CHAPTER THREE: ANALYSIS

This chapter will present the themes derived from the analysis of data from the six participant interviews. Using TA, initial codes were grouped into five main themes, each with sub-themes (see Table 3). Each theme will be outlined with attention given to meaning and content. Excerpts from the data have been used to illustrate aspects of each theme. This chapter aims to present findings of the current study; further interpretation, relevance to existing literature and assumptions held by the researcher will be discussed in the following chapter.

Table 3: *Themes and sub-themes*

Main themes	Sub-themes
Making sense of it all	Developing understanding Getting information A broader context
“Home’s not how I remember”	The main focus Impact on parents Changed relationships
It impacts me too	Pervasiveness New roles and responsibilities Deep feelings but sometimes contradictory
To talk or not to talk?	Hearing and being heard Difficult talk
Life goes on	Separate lives It’s my life, it’s now or never

Transcription conventions used in this research were guided by what Potter and Heburn (2005) refer to as 'Jefferson lite' transcription. In presenting extracts and quotes from interviews, minor changes have been made to improve readability. Words omitted to shorten quotes are indicated by dotted lines within brackets (...).¹⁴ Where text has been added to help provide explanation, the researcher has used square brackets [text]. Pauses are indicated by dotted lines - .. to represent a brief pause and ... to represent an extended pause. All identifying information has been removed or changed to protect the anonymity of participants. The initials 'DM' indicate the interviewer's speech.

Making sense of it all

This theme refers to the process of siblings developing an understanding of the experience of living with a sibling¹⁵ diagnosed with an 'ED'. Participants described the ways in which they were making sense of the diagnosis and the broader concept of 'EDs'. They also discussed their sister in relation to these concepts and their individual experiences in understanding what was going on at the time. Making sense of the situation also appeared to involve being aware of wider contextual factors that might impact on the situation. To encapsulate the broad elements of this process of meaning-making, the theme was explored on three levels: (1) Developing understanding; (2) Getting information; and (3) A broader context.

Developing understanding

Rather than expressing fixed views, for most participants understanding about the situation appeared to be continually developing. This process involved questioning previous ideas and beliefs, as well as making sense of new information.

When giving explanations about their understanding, participant accounts were at times filled with language reflective of this ongoing questioning and curiosity. This

¹⁴ Some repetitions of 'filler' words within interview extracts (e.g. words such as 'like', and hesitations such as 'er...') have been removed for the sake of reader clarity.

¹⁵ All participants had a sister diagnosed with an 'ED'.

could be seen to reflect both confusion about information and the emergence of individual views:

I don't really; I don't like them [diagnostic words]. Like, they sound like really harsh things to say. And I don't like hearing people say she's got an eating disorder or anything, just..coz..I dunno. I don't know what I'd rather hear - I don't really know how to explain what it is apart from anorexic or whatever. But I don't really know. (Rachel)

Developing what might be thought of as an accurate understanding of the 'ED' seemed to be contingent on having had personal experience of living with a young person diagnosed with an 'ED'. This was compared with theoretical knowledge about 'EDs'. Having obtained information through education, media and/or peers, participants felt there were missing elements of understanding that could be obtained only through lived experience. This experience could offer new insight and challenge previous ideas and/or wider dominant discourses about the diagnosis. These elements appeared to be key aspects, suggestive of participants not feeling they previously had a 'complete' picture about the diagnoses until this time:

I heard a lot from there [school] but then I kind of got a true understanding I guess from seeing it first-hand...Whereas maybe if I just learnt about it at school, just seeing it as like a mental health problem but didn't really understand what it's fully about. But yea, definitely from seeing it happen to [sister] I kind of got more of an understanding. (Michelle)

For others, this understanding gained from lived experience allowed them to make sense of the 'ED' in a different way, for example, the diagnosis not being solely a physical illness but instead including a mental health component. This could also impact on understanding about the approach needed for supporting recovery:

I think it's given me a different understanding in the sense that before I thought it was all about..I didn't realise so much it's a mental illness because it's related to..not a product but because you think it's as simple as like if someone's not

eating or whatever then you just give them some food and they'll be better. But because it's mental...I don't think I realised the mental impact. I think everyone assumes it's that easy, like if my sister suddenly ate, or ate more, or more of the right things then it would just go. (Emma)

In developing understanding through personal experience, participants reflected on not just their own previous ideas but also on dominant societal discourses and perceived misconceptions about 'EDs'. One aspect that appeared to be a challenge was explaining their understanding to those who may have not had personal experience of the situation. For some this was a complicated, if not impossible task:

Rachel: (...) coz they're just words and people will always expect that it's just people wanting to be skinny and going too far, but it's more than that. It's like there are reasons behind everything, but people won't see that unless they know, they've been through it.

DM: Do you think that your views about it have changed?

Rachel: [Rachel nods head] coz I always used to think it's something that could be got rid of easy and it can go really quick. But it takes...it's not just about eating again, and just eating back to health. It's more about your mind and how you think of yourself.

Another way participants appeared to be developing this understanding was through comparisons with physical illness. This could help in evaluating the experience, and perhaps offer further justification for the confusion they felt. Comparisons also highlighted the perceived lack of order or structure, as well as questions about how much control one had over the situation. In the extract below, Emma draws on personal experience of physical illness in her family to explain this:

(...) if you're ill there's kind of a checklist and even if you stay ill at the end, at least you know you've crossed off all the normal steps and that means, well I don't know, even with cancer or whatever, that you've done everything that you can and then you're like 'oh well there's nothing more I can do' kind of thing. (Emma)

In the extract below, Hannah suggests how these comparisons might be made by others outside of the situation:

(...) any way you put it, it doesn't sound that bad. It's like okay so she doesn't eat, so she's gone somewhere where she is going to eat. Ok. (...) it's not like you know, like she's..I think if she was physically ill, people could be like know 'oh G-d that's awful', but at least there is a set treatment for that and you know it works. I think in a way this is worse (...). But you can't make people understand. You can't expect people to understand if they're not in the position. (Hannah)

Developing understanding was identified as a core aspect of how participants made sense of the experience. However, in contrast to the extracts presented above, it was interesting to hear an account about understanding from a sibling relatively younger than the others. Priya (aged 11) gave a brief and succinct account of her understanding, which contained no questioning about the situation:

She doesn't like food. She doesn't like spicy food. She doesn't like stuff. (Priya)

This contrast to the views of the older participants could be seen to perhaps reflect her age and/or level of knowledge about the situation.

Getting information

Participants spoke about acquiring information from others about what was happening. Having this information shared seemed to contribute to how participants made sense and understood their experiences. Information could be accessed through various means: their parents, their sister, peers, school, and/or in professional settings such as FT:

It [family therapy] has given me some insight into what other people think a bit. (Nina)

But I didn't find it [family therapy] annoying or anything, I quite liked it, like to find out about stuff. (Rachel)

For most, participants, parents appeared to be viewed as 'gatekeepers' of information; they had greater access to information and were positioned to pass this onto siblings. For some participants there was a sense that this information may not have always been as accessible as they would have liked, and even for those who felt it was, there was some acknowledgment this may not be true for other siblings:

(...) he's [dad] passed quite a lot onto me, he was giving me advice about what to say if she says 'this', which is good, but some people might not have that passed on as well as I have (...). (Hannah)

Age was often spoken about as a barrier to what information siblings might be given from parents. The extract below captures this, as well as the sense that having information could enable siblings to feel more involved:

I think, obviously it depends on the family but they [parents] probably can choose what they filter through to you. And I think that probably if you're younger, you feel like they won't tell you everything. But then at the same time you want to know, and you feel like you're being, you might feel like you're being kept out of the loop. I always wanted to feel like I knew what was happening because it made me feel less helpless, I felt involved in her treatment and more like [in] her progress. (Emma)

When discussing what would be helpful for siblings in terms of getting information, most participants gave ideas about having someone to talk to. This seemed especially important during the early stages, when there was perhaps more confusion about the situation. Talking with someone was seen as potentially being a helpful way of getting information about what was going on:

Um, maybe at the beginning (...) to go talk to someone about it coz, you know, I just knew that she had anorexia, I didn't really know what next was going to happen, I knew she was going into hospital, but not what next..and maybe that would be helpful like, you know, so you could talk to someone about it. (Michelle)

This was also suggested in comparison to what one might be able to access from books or online sources:

There's probably good literature on it, but maybe more talking about it might be good. (Hannah)

A broader context

In making sense of the experience, participants spoke about a wider context for both the ED' and the impact it had on others, including themselves. This included an awareness of other relevant factors within their family. Questions were also raised in relation to what was attributed to their sister's 'nature' versus the result of the 'ED' diagnosis:

(...) there are certain things she says to them [parents], like I know she's ill but some of the things she says to them are unforgivable I think. Then they say 'oh it's not her, it's the illness talking' and all this. But I'm not sure how much I buy of this 'the illness is a separate physical entity'. I don't really buy into that (...) (Hannah)

One participant described being especially aware of a broader context in conversations within FT sessions, which she felt could detract from her sister's difficulties:

[In family therapy sessions] you'd end up discussing these other things, and they were probably like real issues that were hard to resolve. Then you end up giving therapy for those other things. (Emma)

There was also questioning talk about what aspects of their own experience might be related to a bigger context of 'expectable' changes as they develop through adolescence, versus the diagnosed 'ED'. Changes such as greater time spent away from their sister and parents were discussed:

But again, how much of that [spending less time with parents] is because you know, like I've had a big change as well [university] so it's hard to pin things to you know like which. what's caused them. (Hannah)

This could again contribute to a difficulty in separating the illness from their sister, the situation, and developmental changes in relation to their SR:

(...) we [participant and sister] argue, but I think we're either really close or we argue a lot and...I think that's just like, I don't know if that's all to do with the eating disorder or... just like, just being teenagers. (Michelle)

Similarly, for some there was a greater awareness of eating-related talk among peers that could be perceived as in relation to these 'expected' changes:

(...) obviously at this age most, my friends are all, all kind of trying to be on a diet [and] failing and stuff like that. And they're all...like it's quite based around food coz they don't want to get fat, they want to be skinny. So my friends are also talking about food. (Nina)

Overall, most participants' articulation of this 'broader context and role of external influences did not appear to widen out as far as society, culture and media or a perceived pressure in glorifying thinness.

“Home’s not how I remember”

This theme refers to the impact and change siblings identified to home and family life. The name given to the theme is an extract from a participant's (Hannah) interview with reference to having left home to begin university and noticing change when returning during the holidays. Participant accounts suggested that aspects of home life were impacted by their sister and/or the 'ED' diagnosis. For the siblings, home seemed to have changed on a number of levels, and was identified in this theme through three sub-themes: (1) The main focus; (2) Impact on parents; and (3) Changed relationships.

The main focus

Participants discussed a notable change in the focus within the family. Living with a young person diagnosed with an 'ED' had contributed to the main aim and purpose of the family now being about their sister and the diagnosis. This

appeared to permeate much of family life through talk, lifestyle, and behaviour. Activities participants had considered enjoyable and 'normal' (such as walking the dogs, going for meal or family holidays) were now dominated by this one topic:

(...) it was always about her eating, and when she's going to eat, and making sure she got the right amount. (Rachel)

The following extract further highlights this focus on the 'ED', with a view suggestive of a change or shift in the whole family's 'centre of gravity':

(...) I just feel...kind of the whole thing revolves around it. (Nina)

While this focus was present in conversations within the family, it could also be present in more subtle ways without being spoken about. The extract below refers to this sense of a main, ongoing focus in a family who had been experiencing the situation for a number of years:

It's been quite hard coz it's quite a main thing in your head now, like around you know...we don't talk about it in the house but it's still kind of quite present (...).
(Michelle)

For siblings, this focus could sometimes result in an overshadowing of other important parts of life:

(...) it just contracts your life down to just, you know, remember when you had other things in your life? (Hannah)

For some, the impact of the main focus being on their sister and the diagnosed 'ED' was described in relation to their own life. Some spoke about what had been occurring for them at the time, such as leaving home to begin university or sitting exams. With the main focus of the family on their sister and the diagnosis, some participants felt these important transitions in their lives were spoken about or shared differently within the family:

I think I always did talk about things that were happening for me, but I just feel she became like the centre of attention. Not, they [parents] didn't care about us, but she was like where everyone's focus lay I suppose. (Emma)¹⁶

Impact on parents

A notable aspect of participants' talk about home and family life were their views about how their parents had been impacted by the situation. Throughout accounts, there was a clear awareness for siblings of how parents had been impacted by the situation. For some, the impact on parents was described or implied as having been to a greater degree than the impact they perceived on their own life:

I mean because I've had to go to uni, I've kept other things in my life. But mum and dad's lives have completely just gone to...like this is their sole kind of aim. I suppose it's just changed everyone's perspective really. Like not in a good way. (Hannah)

For others there was a greater sense of having noticed a more general impact on parents with less of a direct focus on either their sister or the situation as the cause of this:

I don't know, he's [father] always stressed and tired and stuff. (Rachel)

A number of participants expressed awareness that their parents had greater conflict in their own relationship as a result of the difficulties and changes at home. This could impact on their relationship, for example by being unable to spend as much together as a couple. One participant spoke about her parents considering a 'break' from one another as a way to help the situation, while Emma gave a retrospective view of the situation having in some way contributed to her parent's later separation:

¹⁶ It is relevant to note that Emma offered an account which when compared with other participants, had a greater degree of retrospectiveness.

It [the situation] had a massive impact on my parent's relationship as well because they'd always be discussing my sister and they'd have conflicting views about how her treatment should be, and they couldn't really reach a compromise and then it consumed...like they'd spend all their time worrying about her, or my brother or whoever rather than focusing on their time as couple. (Emma)

Changed relationships

Participants reported experiencing change in their relationships with both their sibling and parent/s. With respect to the SR, this was often described by participants through a historical closeness, which was used as a comparison to their current relationship. The frequent use of the phrase 'used to' in relation to their closeness was apparent across most accounts. As outlined in the sub-theme 'A bigger context', some participants did acknowledge developmental change as a contributing factor to this. However, often the cause of the changed relationship was related to the experience itself. More specifically, this was described as a change outside of the participant's control and instead a result of their sister having in some way changed:

She doesn't really have any interests anymore, apart from don't make me eat. So. And I obviously don't share in that [Hannah laughs], so there's not a lot to talk about. (Hannah)

I felt quite like our relationship wasn't very good at that point because I felt like she told me like what I should eat. (Emma)

This change to the SR was spoken about by some as temporary. Priya spoke about a later positive change to her SR at the time when her sister was managing recovery:

DM: (...) what's your relationship like with you sister [now]? Do you get on?

Priya: Now we do (...) she bought me that present.

For those in families with multiple siblings, there was some talk about having found support through, and developed closer bonds with other siblings during the experience, which is suggestive of positive outcomes of the situation. Participants

who were in families with no other siblings appeared to indirectly support this, through views about what having another sibling could be like. This appeared to reflect feelings of usefulness in connecting and sharing with others:

I could talk to them [another sibling] and ask them what we should do. And I'd be less lonely because they would be another person in my position who I could spend time with and I could talk to, and we could share our opinions on what to do and stuff like that. (Nina)

Relationships with parents were identified as another key relationship change for siblings. This seemed to be linked to the ideas outlined in the sub-theme 'Impact on parents'. For some, the change to parent relationships was met with understanding, with siblings being mindful of what their parents may be experiencing. However, for others this was a source of distress or frustration. Changed relationships with parents could be a result of change to communication, with siblings appearing aware of wanting to avoid further conflict or upset:

(...) we [Rachel and her father] don't talk as much because we [Rachel and her twin brother] know that he's stressed and we don't want to start any arguments or anything. (Rachel)

This could also be attributed to spending less time with parents, one reason being that their sister required more of their parents' time. While for some this appeared to be acceptable, others expressed a sense of unfairness in the situation:

She [sister] takes she takes up the time of my mum and my dad. And then I don't get to spend much time with them. (Nina)

Time spent with parents may have also reduced as a result of families needing to make use of extended family support with increased appointments for the diagnosed sibling. For the youngest participant Priya, this seemed to impact on time she spent with her mother. The change she described in the interview was a

positive one; as her sister began to improve in health, there seemed to be a reduction in the time she needed to spend with extended family. As a result, more time could be spent with her immediate family:

We [Priya, sister and mum] do stuff together [now] and that's how I like it. (Priya)

With changes at home, and specifically to family relations, siblings appeared to be affirming their own position within the family system. One way was to feel included in what might be happening and perhaps in being part of a solution:

I'm part of the family so I think everyone should be involved [in family therapy].
(Nina)

This affirmation of positioning appeared to connect to a salient aspect of the participant's accounts; the apparent alignment they held, or sought to hold with parents. In conversations about home life and their sibling, language used appeared to imply an aligning with parents, suggestive of forming an 'us and her' dynamic. Of particular interest was the frequent use of 'we' in this context:

We've done that [monitored food] for quite a while, and we know that if (...) she chooses to do stuff on her own then she'll lose quite a bit of weight. But I guess coz she's going to university we're gonna have to let her choose (...). I feel like we should, you know tell her, but then at the same time we need to let her learn, you know, to choose the right amount on her own. (Michelle)

But we know she feels guilty about everything...and she's like blaming everything on herself. But we were telling her (...) that none of it's her. We don't blame her for anything, it's not her fault. (Rachel)

It impacts me too

This theme focuses on the ways participants experienced change or impact within their own life and lifestyle. The name of the theme aims to capture the sense that this impact was often felt as though it might be unseen or not always realised by others around them. Within this theme, participants provided a

number of examples of times when the impact had seemed particularly prominent. The use of such examples often seemed to serve as justification or proof for what participants had experienced and were expressing. The theme consists of three sub-themes: (1) Pervasiveness; (2) New roles and responsibilities; and (3) Deep feelings but sometimes contradictory. Both names for sub-themes (1) and (2) closely reflect findings in previous literature.¹⁷ The latter sub-theme refers to the intense emotions expressed, which at times could appear conflicting through what was said and the language used.

Pervasiveness

Participants described a range of areas of their lives that may be impacted by living with a young person diagnosed with an 'ED', leading to the sense of a pervasive impact. This included their school life, social relations and/or thoughts and behaviours around food. The impact was described by some as a result of change to their routine, such as increased time needing to be given to their sister. This seemed especially true for those whose sisters were receiving support from inpatient services:

I think before maybe it was a bit hard with like schoolwork coz if we were going to visit [sister] in hospital, you know, [there was] not enough time. (Michelle)

The impact on schoolwork and ability to concentrate on aspects of their own life could also be due to perceived changes at home. One reason was due to an increase in conflict or tension at home:

I was revising for my end of year exams [and] all I heard was my sister like screaming in the background. I still did well but obviously I would prefer if I don't have that. And it does make me upset. (Nina)

It could also be especially felt at times of transition or points of change for the sibling. For example, for one participant leaving home and beginning university was an experience that may have been altered as a result:

¹⁷ This will be discussed in the following chapter.

It's not that I haven't enjoyed it [university] or anything; it's not ruined it but it's been different. (Hannah)

Another aspect of sibling life described as being impacted upon was social life and relations. Some participants spoke about the usefulness of keeping social interactions separate from the situation, perhaps as a way to distract from what could be happening at home. This could also be suggestive of siblings wanting to protect space for themselves outside of the situation. Some spoke about ways of preventing peers from knowing what was happening due to concerns about how they might perceive it. However, social relations and activity could still be impacted as a result of their sisters' difficulties:

When I was younger, if you went to someone's house you'd invite them back to yours the next time but I didn't really feel like that principle worked in the same way coz I was always like embarrassed, like I didn't really want, not I didn't want people to know but, I didn't really want...it felt like an uncomfortable atmosphere (...). And also I didn't want them to see how skeletal she was. (Emma)

For some participants this impact was felt as a direct result of their sister and/or her behaviour. One example was the idea of this being an obstacle or barrier for siblings:

She stops me from doing things (...) I like going out with my friends and having them over, she [sister] gets kind of jealous and (...) stops me doing what I want (...). (Nina)

Another area of life participants described as having been influenced and impacted upon was their thoughts and attitudes towards food. While participants acknowledged this could also be impacted by social discourses and an increased focus on this throughout adolescence, living with their sibling had led to greater awareness of food and increased comparisons of their eating to that of their sibling's:

(...) if we're having dinner and [sister] doesn't want to have what we're eating, then I think 'oh, what's wrong with what we're eating'? You know you think 'oh

this is just really unhealthy' but...I try not to think about it. But obviously you see, it's like really healthy food and then I'm there like eating biscuits and stuff [Michelle laughs] so you just think, 'oh maybe I should be eating a bit healthier' (...). (Michelle)

Some expressed greater frustration at this increased awareness, which seemed outside of their control and unhelpful in their own lifestyle:

I don't really like the conversations [about food], but because my sister has an eating problem, it's made me think more...when I'm at home I kind of think, 'ok I'm not gonna eat this, I'm gonna eat that (...). (Nina)

She made me like resent...not resent food, but I hated talking about food, um like I used to want to learn how to cook. (Emma)

At times, this could be seen to further impact on their eating behaviours:

A few years ago I became quite, well not like aware, but I started kind of being aware of what I was eating myself. And I lost, a bit of weight. And my parents were starting to get worried. But...um, luckily I kind of realised before (...) what I was doing. (Michelle)

One participant expressed that she had not previously spoken about this impact on her relationship with food before. Through our discussion she spoke about how she had, and continued to have, concerns about whether her sister's difficulties would inevitably be passed on to her:

Emma: I've never really admitted this [Emma laughs], but I'm still kind of paranoid to ever eat like people who eat completely healthily and get really obsessed with exercise (...). I feel like I'd always have to have like a bag of crisps or a chocolate bar (...). I don't think anyone ever understands that though (...). I think they think it sounds quite weird (...).

DM: So (...) you worry that it [difficulties eating] might happen [to you]?

Emma: I think like that that's where the root of it is.

New roles and responsibilities

This sub-theme refers to the roles participants had taken on as a result of the situation. Roles related to their sister included being a 'watcher', 'messenger' and/or 'encourager'. Another role was with respect to parents and 'making it easier' for them. These roles were identified both directly through what participants described and also in what was suggested through their accounts. Along with these new roles there was now a greater sense of responsibility, or duty for siblings. This was apparent in different contexts and in respect to both the whole family and individual family members. One context where responsibility was often thought about was with sibling participation in FT:

Well, obviously a bit's changed because before I didn't have that much responsibility, I didn't have to come to like sessions and stuff. But now I feel like I have more responsibility. (Nina)

It seemed that some roles taken on were specific to siblings; they required something that participants appeared to suggest parents, or other people, were not always able to do. For example, siblings appeared well placed (perhaps due to closeness in age) to take on a role of 'watcher' and being extra vigilant around their sister. This could be at the request of parents:

(...) mum and dad said just keep an eye on her. (Hannah)

However, for other this role was might be on through their own choice and appeared to provide an additional function in allaying concerns or anxieties they might have about their sister and her health:

It [monitoring sister] kind of made me feel better knowing that she was safe. It didn't really bother me that it took..that I had to do it, it helped me as well. (Rachel)

Another role appeared to be that of 'messenger'. This could often be about passing on information to parents which was felt to be of a more concerning nature, or secrets their sister had asked them to keep, for example about

restricting food. Whereas the role of 'watcher' appeared a role which could be *given* by parents, some accounts were suggestive of the role of 'messenger' and passing information to parents could often come from a decision made by the participants themselves:

Rachel: I wanted her to get better so I told him what the truth was [her sister restricting food], so it would help her in the long run.

DM: And how did [sister] deal with that?

Rachel: Um...she didn't really say anything to me about that, but she's probably annoyed.

Some siblings also appeared to take on a role of 'encourager' or supporter of their sister, although this appeared less significant when compared with the other roles outlined. Encouragement was usually in the context of mealtimes and again could be a result of siblings feeling well placed to take this on:

(...) when she was first out and she'd refuse to eat some stuff, I'd go up to her room, you know, talk to her and try and help her through it. I do feel like..sometimes I could chat to her coz [we're] a similar age (...) obviously I didn't know what was going through her mind but, [I could] maybe [be] a younger person that she could talk to. (Michelle)

For some, giving support could be immensely challenging and at times appear ineffective:

When she's sitting there, you're saying 'come on [sister] you know, why don't you just try to eat a bit of that?' And she goes 'no'. And what can you say [Hannah laughs] you can't make her eat it. (Hannah)

This encouragement could also be through smaller gestures, which for the sibling, could hold great value:

DM: Are there things that you do..that help that [sister's recovery]?

Priya: [nods head and smiles]

DM: There are?!

Priya: Yea. She likes Millie's cookies and I bought her one today.

Siblings also had a role in 'making things easier' for their parents and reducing perceived stress or burden they felt their parents had as a result of the situation. This could be done through supporting their sister:

I try and calm my sister, I kind of try and get her away, kind of... reassure my parents (...). (Nina)

For some, this was thought possible by being more present in the home, reflected in the extract below. This could also be suggestive of the responsibility felt by some siblings and/or worry about their absence at the time:

[While living at university] I've sort of felt more drawn to home because I feel like there's stuff I need to sort out there, so I've gone [home] (Hannah)

This was also reflected in monitoring communication; there appeared to be a risk of further burdening parents with their views and opinions and therefore some participants actively held these back:

(...) If he's [father] not in a good mood we just agree with him, and not try to disagree. (Rachel)

Deep feelings but sometimes contradictory.

This sub-theme aims to capture the intense feelings experienced by participants. These were identified in relation to their sister, the situation in general, and the impact on themselves and their family. At times these appeared to be contradictions, with siblings acknowledging different feelings, sometimes being felt at the same time. Feelings included: care and empathy towards their sister and the challenges she faced; worry about her health and whether she would recover; and as described with the extract below, anger or frustration, not

necessarily aimed at their sibling but instead the situation and the impact it had on others:

I do feel really angry (...) not with her, but with what's happened because its been so unfair on everybody. (Hannah)

At times, intensity of feelings was expressed clearly in participants' talk. For some, these feelings were felt towards their sister and her behaviour. For Nina, they appeared overwhelming, at times to the point that they could prevent her from being able to maintain a relationship with her sister:

(...) to be honest after everything she's done (...) I don't really want her, I don't really care if I don't spend time with [her], like I'd (...) rather spend time with my friends or parents, I'm not really that like affected that our relationships isn't that good. I just think I'm affected by everything she does...she's driven me to the point where I can't stand what she does anymore, I just can't...[as] hard as I try to be nice to her and be with her, I can't really I just can't really do it. (Nina)

One participant talked about an intense worry at seeing her sister stop eating. This was expressed in a relatively more direct manner than others, perhaps more appropriate to her age:

DM: Do you remember what you were scared of?
Priya: That she would die.

Priya later gave another direct example of how not being able to spend as much time playing with her sister left her feeling:

DM: And how did that [spending less time with sister] make you feel?
Priya: A bit scared and left alone.

Through the interviews and analysis, the expression of some feelings and views through contradictions was apparent. At times, participants expressed contradictory and/or multiple views when talking about the emotions they

experienced. This appeared to reflect both the level of complexity of emotions they might be feeling and the experience as a whole:

I am excited for her [to go to university], but I'm just worried. I think...when she first comes back after the first term, like if she's, you know, lost a lot [of] weight, then obviously I'll get more [worried]. (Michelle)

The following extract further demonstrates a contradiction of emotions and highlights the fluid nature of feelings, suggesting an almost cyclical process of thought:

(...) first I feel really sad for her, really sorry for her when she's sad and stuff and you know just wish I could take it away. But then when she's being...she can be quite cruel, some of the things she says are really upsetting and it's not like she just sits there being all sad. She can say some really hurtful things and then I feel really angry with her. Then I feel bad for feeling angry with her and then I feel sorry for her again, it kinds of goes round like that. (Hannah)

To talk or not to talk?

The theme 'To talk or not to talk?' encompasses the conversations and aspects of talk that siblings identified as helpful and unhelpful. The name of the theme aims to represent the challenge of siblings often wanting to talk and feeling talking was of value to them, whilst at the same time being a challenge and at times even unhelpful. This appeared true in a number of settings; with their family, peers, and/or in a professional context. The question over whether talk would be helpful for siblings brought about a number of views about who and what the talk was about. These could then contribute to the decision of whether siblings spoke or held back. The theme is composed of two sub-themes, 'Hearing and being heard' and 'Difficult talk'.

Hearing and being heard

Participants expressed views about aspects of talking that could help and be a source of support for them, as well as for the family as a whole. Talk that allowed

participants to feel listened to and heard, and in turn allowed siblings to hear from others was seen as helpful. This could be with both family and professionals. Talking to others about their concerns allowed participants to share feelings and worries. In the extract below Priya explains how, after initially not wanting to talk about her worry, she found doing so helped in reducing it:

DM: Do people know now that you were worried?

Priya: Yea

DM: How did they find out?

Priya: Um, I told them.

DM: Ok. And who did you tell?

Priya: My mum.

DM: Ok. And what was that like?

Priya: A bit...better.

Although they may want to talk, siblings might hold back with what they talk about in their family. This was suggested as being a result of a fear of upsetting others. With relation to parents, this could link to the previously described role of 'making it easier'. However, for some, being heard could have a negative rather than helpful outcome for the sibling:

(...) I don't really talk to them about how I feel much, because I don't want them to be upset (...) once you start talking it just upsets you, I would just prefer not to think about it, I just kind of push it under the carpet quite a lot. There's only a couple of times I've got really upset and cried in front of them, and it [has] never really gone well. (Hannah)

Being heard not only related to feelings but also information they had, that they felt was helpful for others to know. However, feeling heard within the family could be complicated, one factor reason being their age. Emma provided an example of this, from an account of a time when it felt as though adults had chosen to not hear her views because of her age, even though she had been able to offer something she felt was important:

But I almost think like, I was right you know, if they'd listen to me about the guidelines becoming rules, would things have been different? And then it just frustrated me like why didn't they listen me at the time (...) I know it's coz I was young. (Emma)

As with being heard, it could be equally hard for participants to feel they could hear from others within the family setting. Participants questioned whether parents might hold back or censor information they gave for a similar reason of not wanting to upset them:

I'd ask them [parents] what happened, but I don't think they wanted to like talk about it a lot with me, maybe in case it made me upset or anything. (Michelle)

One participant described how it was unhelpful not to be able to hear from her sister, whom she believed could offer useful information for both their understanding:

(...) they [diagnosed sibling] have to actually talk about it, rather than, keep it inside, coz then it helps you and them as well. (Rachel)

Conversations within therapeutic settings could often fit the criterion of 'hearing and being heard' better than the talk at home. Having a space where talk was facilitated and people were made to hear others seemed to let siblings feel more heard:

I liked it coz it helped us talk about it more instead of holding it in and stuff.
(Rachel)

At the same time, this setting could also give them access to hearing other views and perspectives:

It was interesting to go along and see, you know, what was happening for [sister].
(Michelle)

Although generally helpful, the talk within the FT setting did not always appear to fit this criterion. Sometimes siblings could feel they had not been able to have

their views heard in this setting. It seemed that although they knew the family was there to talk, siblings hesitated in talking openly in front of family for fear of upsetting them:

(...) it was quite tough in front of my parents well...coz they were already going through a lot with [sister]. I didn't want them to feel they had to...not like worry about me, but if I expressed how I felt, I didn't want them then to be worried [and think] 'oh no, what about Michelle' coz they've already got a lot on their plate with [sister]. (Michelle)

The challenge to talk in a professional context was also reflected in the views siblings had about what might have been, or would be, helpful in allowing siblings to have felt, and feel heard in the context of professional support. Suggestions were indicative of wanting a space to talk but without worry about protecting parents:

I think the family therapy is really good, but I think sometimes the sibling on their own should talk to someone, because there are things you can't say because they would upset the family. There [is] some stuff that I probably would have said if mum and dad hadn't been there. (Hannah)

Maybe [having] session without your parents, maybe even just for me and [sister], or you know just me on my own, yea that would have been quite helpful I think. (Michelle)

Difficult talk

The other identified aspect of the theme 'To talk or not to talk?' related to talk and conversations that had become difficult as a result of the situation. This was especially relevant in conversations between the siblings. Challenges were present for siblings, both in deciding what to talk about and in engaging in conversations that were now notably different. Some participants discussed how conversations with their sibling had previously been viewed as being 'open' and without constraints, but as a result of the situation, had become more difficult due to not always knowing what to say. For some, the main change had been in having to monitor, or pay close attention to what was said:

It's hard to talk to her, coz you always have to be really precautionous [sic] of what you say in case you say something wrong. (Rachel)

There was some concern as to what aspects of their own lives the siblings could share through conversations with their sister and what aspects needed to be censored. This seemed to be a prominent aspect of 'difficult talk', especially for those whose sisters were receiving inpatient support:

Talking about stuff that I do, like at weekends and stuff would make her annoyed coz she'd think that she could do it, but she's in here so she can't. (Rachel)

For some siblings, sharing stories from their own lives also felt unhelpful for their sister:

And whether...not she'd want to know [about Emma's life], but [whether she would] understand, or whether it would make her feel uncomfortable. (Emma)

At times, the challenges of such talk appeared to have become too difficult. There was a sense of this impacting on previous connections between siblings. For some participants this could lead to making less effort to talk with their sister.

(...) you can't really say them [stories from her life] to someone who doesn't really respond. You can't have a monologue (...). There are plenty of people I could tell. There are some funny stories we could have shared, but she's not interested. So that's..that's up to her. (Hannah)

Difficult talk was also identified within the wider family system. With much talk being focused on the situation, it seemed that some of it could have no element of positive outcome. Emma referred to the difficult nature of talk within her family about the situation, which eventually seemed pointless:

(...) that conversation, it never had an end point, so it would just be conversation that went in circles (Emma)

Life goes on

This final theme encompasses what participants spoke about in relation to aspects of coping and moving forward. The name of the theme aimed to encapsulate the sense of needing to look beyond their current situation and the strategies siblings were actively choosing to do this with. The theme was understood on two levels, 'Separate lives' and 'It's my life, it's now or never'.

Separate lives

Siblings appeared to make conscious efforts to keep aspects of their lives separate from their sister's and the changes they felt at home. Notable strategies used were distraction from the situation and differentiation from their sister. This could perhaps allow a distinction between them and the diagnosis of an 'ED'. Accounts often had clear descriptions of this process, with siblings naming many of these strategies themselves. Methods of distraction involved trying to think less about the situation. For some this could not only allow them to focus on their own lives but also reduce escalating worry about what was happening:

[It helps] having lots of distractions to not make you think about it. Thinking about it is the worst thing to do. Coz it gets you worried about stuff that you shouldn't be worried about, coz it's going to be fine in the end. (Rachel)

One way of doing this was through a greater focus on what was going on in their lives. By doing so it could again serve to minimise upset:

Obviously I was focusing on trying to get everything ready [for university] and sort of, trying to separate myself a little bit so that I could go without it being quite so upsetting. (Hannah)

Another method of distraction used was through occupying time with academic work. This could serve two purposes; it allowed for them to not fall behind with schoolwork often at an important time in their secondary school education (which was a concern expressed by some and furthermore offered a useful alternative focus:

I just give myself time to do revision and..if stuff like that was going on, it almost helped to get away from maybe stresses at home and just focus on my work (...) to give me something to focus on instead of that. So it was quite good (...).
(Michelle)

Some siblings also increased the time spent away from the home by spending more time with friends. While some participants found support through telling peers, for others, not telling friends about what they were experiencing allowed them to maintain a setting where there was less, or no focus on the difficulties or food. This could serve to minimise any impact the situation might have on their thoughts and behaviours around food:

When I'm with people who don't know, I kind of forget about all of this. (Nina)

There was, however, acknowledgement that distancing themselves from the situation was at times a challenge. This was in part due to the expectable focus adolescents had on food and diet at this stage of development. A contrasting approach for one participant was to let peers know about her sister's difficulties, and in doing so, she found they would actively avoid such talk for fear of upsetting her:

I don't think they [friends] mention a lot to me, like (...) if they're worried about their body, I don't think they'll want to mention it too much to me, just coz it's quite a sensitive topic I think. (Michelle)

Another method of creating separate lives was through differentiation. Participants described differences they identified between themselves and their sisters. In doing so, they seemed to perhaps position themselves as distinct from their sibling and ultimately the diagnosis:

Now I just try not to really think about it [dieting] because I saw what it's done to [sister] and I am aware of it, but I just try not to think about it and I just try to be healthy. (Michelle)

In the extract below, Emma explains her reasoning behind her active avoidance of dieting and healthy eating. This highlighted the often-intense level of active choice in this differentiation from her sister:

It's like I've tried to rebel against, not against it, but because she was such [an], I don't know if advocate's the right word, but like [example of] healthy eating (...), I think I've wanted to differentiate myself from her. (Emma)

It's my life, it's now or never

This sub-theme felt especially focused on the sibling participant rather than relating to others in the family, including their sister. The name reflects the determination of siblings in maintaining their focus on future aspects of their life. Siblings identified this being a time for them where important tasks and/or decisions for their own future would be made and for some this was the one chance to experience that aspect of life. There appeared a sense of ongoing commitment to this, regardless of what else might be going on around them.

Participants expressed rationale and justification to support what felt like an important choice to focus on their own life, perhaps mindful that this determination could be interpreted by some as siblings having less care about their sister:

(...) I'm looking forward to going back to uni, I try and see my life as kind of separate from this because, you do only get to go through uni once. I really want to try and enjoy it so I try not to let it cloud it too much. I try to think of [sister's] progress as separate from my life, which sounds a bit cold but that's sort of the way I try to think about it. (Hannah)

Much of this determination was centred around education, with most siblings studying for exams or embarking on further academia. The importance and seriousness of being able to reach their own potential came across in a number of accounts, which suggests needing to put things into context within their own life:

They're [studies] as good as they can be I guess..but yea, I'm not like letting what's happening with [sister] affect them. Coz that would just ruin like everything.
(Rachel)

For others, this involved making a conscious decision to prioritise aspects of their life above their sister's:

I really don't want to miss school [for family therapy] coz it's quite an important time for me to work and stuff, and I can't really sacrifice half my Tuesday and stuff. (Nina)

Having experienced her sister's difficulties with eating from a young age, Emma reflected on the challenge of having gone through education, moving from home and entering adulthood. While her sister continued to experience difficulties with eating and living with a diagnosis of an 'ED', Emma spoke about having focused on forming new relationships and the start of a career; things she saw her sister as unable to do at this point. In explaining this experience, she spoke about having had to 'accept' her sister's situation and look towards her own future:

Well life, there is other life, life carries on apart from just this thing. (Emma)

CHAPTER 4: DISCUSSION

Overview

In this chapter, main themes from the analysis will be further explored and considered in relation to both the research questions and existing relevant literature. Next, a review of methodological considerations and limitations of the study will be presented. This is followed by a discussion of wider implications of findings and possible directions for future research. The qualitative methodology and design will then be evaluated. The chapter will conclude with a reflective account of the research process.

Research questions

This study aimed to address the following research questions:

- What is the experience of being a sibling of a young person who is diagnosed with an 'ED'?
- In what ways might siblings view having a brother or sister with a diagnosed 'ED' as impacting on sibling lifestyle, family and sibling relationships?
- What do siblings say about the support given to their family at the time of intervention?

These questions will be considered in the following section through a discussion of main themes and relevance of findings.

Discussion of themes¹⁸

Making sense of it all

The theme 'Making sense of it all' refers to aspects of participant accounts that relate to the experience of siblings and how they might view the situation as

¹⁸ It is noted there was some disparity in the proportion of quotes used from participants. Although evidence substantiating the themes is to be found across all the data, some participants articulated themes more than others. Furthermore, the youngest participant's interview (Priya) was comparatively shorter in length, mainly due to her age and briefer responses given.

impacting on them. Rather than appearing to be fixed and decided upon, for most, this was an ongoing process.

For siblings, making sense of the situation could be a time of confusion and questioning. Previous studies, both with adult (Dimitropoulos et al., 2009) and adolescent siblings (Garley & Johnson, 1994; Areemit et al., 2010) have reported similar findings. Difference to this was seen with the youngest participant's account, which was less questioning of the situation; perhaps related to her age and the amount of knowledge she had about what was happening. Another variance seemed to be with the elapsed time since diagnosis. Emma's account was (chronologically) from a more retrospective position than other participants and at times suggestive of a more established account compared with others.

While making sense of the situation could be a time of confusion, it also seems to allow siblings to gather and collate information to help inform their understanding. The knowledge obtained from siblings' lived experiences of the situation seemed to be one of the most important contributions to this understanding, providing a measure with which previous theoretical knowledge and assumptions could be challenged. From the participants' accounts, it seems that once this new understanding was acquired, there was a sense of challenge or frustration in how to communicate it. By communicating these views grounded in individual experience, siblings may be continuing the process of developing understanding by further constructing meaning through talk and conversation (Anderson, 1997). This could hold relevance for families, professionals and researchers in thinking about how, and with whom, siblings can best communicate and further shape their views.

Reflective of previous findings (Garley & Johnson, 1994; Areemit et al., 2010), siblings in this study wanted to have information about the diagnosis passed onto them. Findings from studies with families experiencing physical and/or critical illness indicate how parents become the key source of information for siblings in such contexts (Barerra et al., 2002; Kean, 2010). This appears similar to findings from the current study; the main route of accessing information was via parents. However, for siblings this was identified as not always an easily accessible

source. Parents might filter what information siblings receive, which in turn could contribute to feelings of uncertainty and not knowing. This is in agreement with previous findings; Areemit and colleagues (2010) highlighted how siblings reported feeling left out as a result of not having information from parents. Parents themselves have indicated that withholding information can allow them to feel they are protecting siblings (Honey & Halse, 2006). This dynamic can be challenging; in attempting to protect siblings (and siblings in this study did acknowledge parents were acting with an aim to minimise their upset), withholding information was generally presented by participants as unhelpful.

Another possible factor in accessing such information could be related to siblings taking on a role of 'making it easier' for parents. Much like the concern of parents, siblings reported avoiding certain talk with parents for fear of upsetting them at time when they appeared heavily burdened. This could be suggestive of a conversation at risk of being silenced from both sides due to mutual concerns about how the other might respond.

Siblings in this study had acknowledgment of wider contextual factors around the diagnosis and impact to their lives. As found in Garley & Johnson's (1994) study, siblings were questioning which aspects of their sister's behaviour might be attributed to the diagnosis and which to long-established characteristics of their sister. For some, they attributed a larger amount to their sister, which might conflict with other views heard about the diagnosis. One example of particular interest was a participant who had heard it suggested that an 'ED' could 'take over' the individual. This brought about conflict with her own perception about her sibling's part in the difficulties experienced in the family. Using this example, strategies such as externalising difficulties can appropriately allow a diagnosis to be viewed by the family as outside the individual. Furthermore, parents and siblings in this context have suggested this as a helpful approach (e.g. Whitney & Eisler, 2005; Dimitropoulos et al., 2009). However, for some family members it may be interpreted as allowing the young person to 'hide behind' the diagnosis. This further highlights the complexities and questions raised about how individual members and the family as a whole might make sense of the situation and how

families and professionals can allow space for multiple views to be shared and questioned.

Related to this broader context, siblings seemed to be appealing to a discourse of 'natural' and 'expected' development within the family and sibling sub-systems, as well as in their own life. Part of making sense of the experience was establishing what resulted from the situation and what was related to their own development. For example, while siblings felt living with their sister had impacted on their eating attitudes, there was acknowledgment that the time of adolescence also brought an inevitable increase in awareness of body image. Equally, while family life could be impacted, siblings were questioning how much change might be linked to 'expected' development of the family. These questions are not necessary unique to siblings making sense of a diagnosed 'ED', but can be seen to reflect experiences of young people as a whole as they negotiate aspects of their own development within a wider context. However, the process might be seen as further complicated by external influences such as a diagnosed 'ED'.

"Home's not how I remember"

The constituent parts of this theme provide some answers to both the research questions focused on the experiencing of living with a sibling diagnosed with an 'ED' and ways this might impact on their life. Siblings in the current study identified a number of changes to their home life, aspects of which were attributed to living with someone diagnosed with an 'ED'. There seemed to be no indication of this impact being more or less relevant to siblings in terms of their ages or sibling position (i.e. older or younger than their sister).

Siblings viewed parents' lives as having been largely impacted as a result of the situation. This echoes findings from previous studies (Latzner et al., 2002; Dimitropoulos et al., 2009; Areemit et al., 2010). For some, there was awareness that parents were likely to experience the majority of the impact. The sense of this impact possibly being seen as greater than for the siblings themselves seems to offer an additional aspect to this finding. This can perhaps be conceptualised through sibling concern that parents may be less able to hold a position of responsibility during a time of change and unpredictability.

A central theme in Latzer and colleagues (2002) study was how siblings might metaphorically see the 'ED' as a new family member. Whitney and Eisler (2005) note how families may 'reorganise' around the 'ED' and research findings have alluded to a similar idea (Ross & Handy, 1997; Dimitropoulos et al., 2009; Areemit et al., 2010). Current findings support this view; siblings saw the family as having become centred around and focused on their sister and her eating difficulties.

This consuming focus was experienced by siblings across many aspects of home life. One area in particular, as previously suggested in literature (Cottee-Lane, Pistrang, & Bryant-Waugh, 2004; Whitney & Eisler, 2005; Dimitropoulos et al., 2009) was in relation to family mealtimes and the tension siblings can associate with this. While mealtimes may be viewed as family time associated with interaction and togetherness (Fiese, Foley, & Spagnola, 2006), current findings further support how for a family living in the context of a diagnosed 'ED', this can be an arduous task, characterised by conflict and tension and required several times a day.

Siblings voiced how family relationships had also changed; a finding reflective of previous sibling research from across fields (Garley & Johnson, 1994; Wilkins & Woodgate, 2005). Similarly, the SR was viewed as having changed. Change to the SR is understood as being impacted upon by the development of the family life cycle (Blessing, 2007). As siblings grow and move through stages of development, sibling contact can become more voluntary and aspects of the SR such as the level of interaction are likely to change (Goetting, 1986). Factors such as sibling diagnosis might further complicate how the SR is experienced through such transitions. This impact on the SR has been an area of mixed findings, with previous research suggesting elements of both positive and negative impact on the SR (Garley & Johnson, 1994) and others being more suggestive of a greater positive impact (Dimitropoulos et al., 2009). The current findings mostly reflect those of Areemit et al. (2010) and do not appear to support findings of a positive impact on the SR. However, siblings talked about the possibility of establishing stronger bonds with non-diagnosed siblings in the family. Similarly, those who had no other siblings hypothesised how having

another sibling could offer a chance for shared experience and support. Such ideas can be seen to reflect aspects of post-traumatic growth and family resilience literature (E.g. Walsh, 2006; Meyerson, et al., 2011).

Changes to relationships with parents and siblings have previously been interpreted by Areemit et al., (2010) through sibling losses. While some siblings expressed these changes through ideas linked to loss, across the current findings, relationships appeared to be most often reported simply as 'changed' or 'different'. One possible interpretation of this could relate to the slightly older average age of siblings in this study. Half of the current sample was over the age of 16 and accounts were suggestive of their developing individuality and lives outside of the home. This may contribute to a greater acknowledgement of transitional change and the inevitability of shift in family life and relationships. The family life cycle model (Carter & McGoldrick, 1980) conceptualises this through an awareness of how, during stages of development and transition periods, adolescents can begin to develop a differing perception of the self in relation the family. The quote used to name this theme felt appropriate in explaining how there could be elements of both; while home life and relationships could be seen as having changed as a result of the impact of the situation, this is in the context of ones own development and transitioning (i.e. leaving home), which could in turn influence how they viewed themselves in relation to home.

A striking finding was the apparent identification of siblings with their parents, suggestive of an 'us and her' dynamic being formed. Previous findings have indicated possible changes to and development of new sub-systems, one example being the metaphorical removal of the diagnosed sibling from the sibling sub-system (Latzer et al., 2002). Furthermore, literature has suggested siblings may become involved in parental splitting with relation to ideas about supporting the young person diagnosed (Whitney & Eisler, 2005). While this specific aspect of an 'us and him/her' dynamic is often informally reported in clinical settings, it appears less represented in existing sibling research within the field of 'EDs'. Findings from the current study could be seen as documenting this sense of togetherness through the creation of an additional system during a time of change to the family and sub systems. Although it is not clear from current

findings whether this was a mutual experience (i.e. also from a parent perspective), parents have previously reported how siblings might be seen as a role model or resource (Latzer et al. 2002; Honey et al., 2006) and therefore be given, or take on, greater responsibility in the family. This may be suggestive of a shared role between parents and sibling in developing this dynamic. One possible challenge to this potential dynamic might be parents additionally wanting to protect the sibling. In doing so, they may then be re-establishing a division between themselves and the non-diagnosed sibling.

It impacts me too

There was a general sense within the data of a sibling impact being at risk of going unnoticed by others, which has been previously suggested by Ross & Handy (1997) While parents have acknowledged being mindful of and noticing an impact, they have also identified feeling unable to give enough time and attention to siblings and being unsure about what would be helpful for them (Honey & Halse, 2006).

Of all themes identified in the study, the impact on sibling life appears most reflective of previous findings in the literature. The sub-theme 'Pervasiveness' relates directly to an overarching construct identified by Garley & Johnson (1994, p.159 see Appendix five). This was also identified through a theme within Areemit and colleagues study, as was the finding suggestive of siblings taking on 'new roles and responsibilities' (2010, p.532). The current findings offer strong support for these themes. In particular, siblings taking on roles such as 'messenger' between parents and the diagnosed sibling and a role in 'making things easier' for parents appear salient across studies (Garley & Johnson, 1994; Dimitropoulos et al., 2009; Areemit et al., 2010). Such roles may be result in siblings perhaps experiencing a sense of becoming 'parentified' through increased responsibility. This could contribute to the previously discussed aligning between parents and siblings. While previous findings indicate these may be seen by sibling as burdensome (Garley & Johnson, 1994), what remains less clear in previous and current findings is to what extent these roles and responsibilities are felt to be imposed by others (i.e. parents) and furthermore whether siblings might actively

reject these roles, perhaps seeing them a further focus on the already centralised topic of their sister and the 'ED'.

For siblings, the situation could affect a number of aspects of their own life including their focus on schoolwork and social relations, both previously reported on (Garley & Johnson, 1994; Latzer et al., 2002; Areemit et al. 2010). Another factor identified in this study was on thoughts and attitudes associated with food, as also outlined by Garley and Johnson (1994). Furthermore, one sibling in this study associated previous efforts to restrict her own eating as a direct result of seeing her sister do this. This finding is in slight contrast to those from Areemit and colleagues (2010) who found that whilst siblings talked about an awareness of their sister's attitudes towards eating, they denied an impact upon their own. Although thoughts and behaviours around eating may have been impacted, the data indicated an overwhelming sense of participants not wanting to go through, or cause a similar situation, perhaps suggestive of the magnitude of what they had witnessed being caused. This seems connected with current and previous findings of siblings disliking peer talk centred on dieting (Latzer et al., 2002). Armed with their lived experience, siblings are perhaps presented with a more 'accurate' and worrying picture compared with peers and cannot therefore treat such talk as light-hearted as peers might.

The strong/intense feelings and emotions expressed within this theme closely relate to previous findings (Garley & Johnson, 1994; Latzer et al., 2002; Areemit et al. 2010). Studies have alluded to a further aspect of these feelings being expressed through contradictions, previously conceptualised as 'duality' (Latzer et al., 2002; Areemit et al., 2010). While such contradictions were evident within the current findings, they seemed less prominent as conflict (as in previous studies) and narrated more as one part of a vast range of feelings that can be experienced in the situation.

To talk or not to talk?

The theme 'To talk or not to talk?' encapsulates findings relevant to answering the research questions focused on the experiences of siblings and how they might view professional support. Talk in a FT context could be a useful tool in

allowing siblings to feel heard and in turn hear from others. This can be linked to the finding that participants' expressed desire for information and knowledge about the situation. Whereas talking and getting information might be more complicated at home, FT appears to offer a setting where siblings feel more actively involved and perhaps part of a solution.

As previously identified (Honey et al., 2006), relatively little research exists exploring how siblings of young people diagnosed with an 'ED' experience talk in professional settings such as FT or MFT. All siblings in this study had some experience of FT, although for most this appeared significantly less than the rest of their family. Additionally, whilst some knew about MFT, none had attended such interventions. It was apparent that while FT could be useful, siblings did not always express their views, again through fear of upsetting parents or their sister. This is an occurring theme both in the current study and previous literature (Latzer et al., 2002; Dallos & Denford, 2008; Areemit et al., 2010). Additionally, attendance often seems contingent on other factors such as parental decision about who should attend (Abrams, 2009; Bryant-Waugh & Lask, 2007). One participant talked about how even though she had found FT useful, she was unsure whether the family would continue with this as her parents had not found it helpful. Given the relative lack of involvement siblings might have with such interventions there is likely to be a comparatively smaller space for siblings to access an aspect of support that previous and current findings suggest can be of use to them.

As with existing literature, current findings offer limited understanding about sibling views on professional support. Suggestions from adult siblings (through retrospective questioning) about professional support that might have been helpful for siblings at the time of initial diagnosis have included being able to talk about how they could communicate better with their sibling (Dimitropoulos et al., 2009). In relation to this, suggestions from the current study focused on talking openly within a professional therapeutic context without fear of upsetting parents. An implication of this could be a greater focus on research and evaluation of siblings in the context of intervention, providing further understanding for families and professionals working with these individuals.

For siblings in the current study, certain talk and communication had become more difficult, in particular in conversations with their sibling. Related to the previously discussed impact on the SR, siblings appeared to experience difficulty in talking with their sister about their own life and establishing commonalities and connections. This is perhaps linked to previous findings suggested siblings can express guilt about continuing with their own life while their sibling seemed unable to (Latzer et al., 2002). This perhaps has increased relevance for siblings of those being supported through inpatient admissions, given the level of and often-sudden change to their contact and communication.

Life goes on

The final theme offers findings relevant to the research questions about the sibling experience and views held about the impact on their lives. It refers specifically to coping strategies identified by siblings and is consistent with previous findings, (Garley & Johnson, 1994; Dimitropoulos et al., 2009; Areemit et al. 2010). Previous and current findings identify specific strategies as ways to actively separate participants' life from that of their siblings; Areemit et al. (2010) reported distraction, which current findings strongly support. Another coping strategy identified in the current study was actively differentiating from their sibling through their eating behaviour. Furthermore, the finding that siblings might want to distance themselves from their sister, for example by spending more time outside of the home can be linked to Garley and Johnson's (1994) finding that siblings expressed anticipation about a time when they could move out and live independently. Additionally, parental accounts suggest that parents themselves may encourage this separation (Honey & Halse, 2006). Distance, be it physical or metaphorical, can allow siblings to identify as different from their sibling and ultimately the diagnosis, while also serving as a reminder of additional aspects of their lives.

Although aspects of the experience for siblings were filled with questioning and confusion, one contrasting finding was in relation to how siblings expressed views about their life and future; voicing drive and determination to prioritise aspects of their own life. Whilst this has been expressed with previous sibling accounts about coping strategies (Garley & Johnson, 1994), the current findings seem to

imply a greater sense of importance and urgency to this. Participants, especially older ones voiced being mindful of being at points in their own development that are likely to impact on their future (e.g., academically). Therefore, certain aspects of their life might be seen as demanding their full attention regardless of what was happening at home. It might be considered that this could be reflective of a further distraction strategy. However, the findings of this study indicated a greater sense of ownership and willingness of siblings in this process.

Summary of new contributions to the literature

The themes developed in this study appear reflective of previous findings both within 'ED' sibling research and findings from sibling research in wider fields. However, certain unexpected aspects of current findings can be seen to contribute new understanding about the sibling perspective. Firstly, the sub-theme reflecting sibling views about changed relationships within the home was suggestive of a specific 'us and her' dynamic being developed between participants and parents. This appears to contribute a new aspect of understanding about how sibling relationships with parents might be experienced at the time. Given this, future research could focus on exploring and comparing this with the perspective of parents in this context. Secondly, the theme 'Life goes on' reflects an unanticipated finding related to siblings' active and conscious efforts to separate and differentiate themselves from their diagnosed sibling and the situation as a whole. While previous literature has highlighted coping strategies employed by siblings such as distraction and separation in this context, the current findings appear to suggest a greater importance and urgency for siblings in being able to use these to move on with aspects of their own lives. Finally, although current findings offer less understanding related to siblings views about professional support, the unexpected finding relating to how FT can at times be both helpful and unhelpful provides a useful foundation from which further sibling research, and specifically around their experience of support, can be approached. Furthermore, the emergence of unanticipated findings from the current study further supports the overall value of ongoing qualitative research in exploring the sibling perspective within what remains a relatively under-research group.

Methodological considerations

Design and analysis

Qualitative research has been critiqued through comparisons with quantitative research on the basis of small sample sizes, increased researcher bias and challenges in establishing validity (Mays & Pope, 1995). However, it is also argued that qualitative research allows for a more detailed and in-depth understanding of data (Flick, 2009) and can be especially suitable with younger participants (Galambos & Leadbeater, 2000). Given that sibling research, in particular within 'ED' literature, is an emerging field, it is important to allow for unanticipated findings - another key aspect of qualitative research. Furthermore, whereas quantitative research will often exclude outliers or findings thought inconsistent with a data set, a qualitative approach sees all data as demanding equal attention and able to contribute to findings (Willig, 2008). This seems especially relevant to the current study where data from one interview was, at times comparable to the others due to participant age and language. With relation to the method of analysis chosen (TA), the approach appeared to fit well with data obtained from younger participants and offered a flexible framework from which data could be explored both in respect to similarities and variances. Furthermore, as a novice qualitative researcher, the approach was accessible and findings could be offered in a clear format.

Interview schedule

The interview schedule provided a useful framework for interviews. However, most participants engaged in conversations without additional prompting needed. Efforts were made to avoid leading questions and the researcher found it helpful to provide a space for participants to suggest areas of discussion not yet addressed, both in the middle and at the end of the interview. The schedule was comparatively less of a guide during the interview with the youngest participant (Priya). As seen through extracts in the previous chapter, conversation was varied to other accounts in terms of elaboration of views and questioning style. On reflection, it may be that a greater focus on additional creative methods when setting up the interview could have helped in establishing a more relaxed environment (Veale, 2005).

Retrospective accounts

A further methodological consideration of the current study relates to the extent of retrospective nature of the data collected. This was greatest for Emma in the account of her experiences, both from growing up and her current situation. Slight variations in her account compared to others were identified, namely her acknowledgement of hindsight altering some of the views she had previously held. Such accounts can contribute to a greater understanding of longer-term aspects of the experience. Reflecting on the process as a researcher, one challenge was navigating the interview across past and present experience. This might have been better approached by developing an additional interview schedule that had greater relevance to this context.

Developmental issues

In the current study, the participant sample was representative of a wide age range (11 to 18 years). Given considerations noted above in relation to the use of interview schedules with younger-aged siblings and retrospective accounts with older-aged siblings, another interesting consideration would have been to explore the relevance of developmental issues from across this age range. The initial proposal of a focus group design, with groups developed based on participant age, could have allowed for a greater focus on this through possible comparisons of findings from siblings of different ages. Future research employing such a design may therefore be of relevance in understanding this.

Furthermore, four of the siblings in the current study were younger than their sibling diagnosed with an 'ED'. Although current findings did not appear to reflect variance in experiences between younger older siblings, further exploration of this could provide useful understanding about possible differences in the experience when a sibling diagnosed with an 'ED' is either younger or older in age. Finally, another interesting aspect related to developmental issues is exploring whether and/or how siblings might experience the situation differently as a result of the degree of chronicity of their experience compared with their age and level of understanding.

Limitations

One of the main limitations of this study is the sample size. Persistent delays from ethical approval bodies meant recruitment was not able to begin when initially intended. As a result, and given the time constraints on the project, the final number of participants was smaller than planned and hoped. Although accounts have provided a data set rich in detail and from a range of siblings (in terms of birth order and age), a larger sample size might have offered broader support for themes identified. However, Guest, Bunce, and Johnson (2006) discuss the challenges of defining a specific number of participant interviews as a marker of a purposeful sample. In their study, they documented stages of qualitative analysis in deriving themes of data from 60 semi-structured interviews. Authors reported how following the initial six interviews, enough data appeared to have been obtained to support “meaningful themes and useful interpretations” (p.78).

Another limitation with respect to sample size was the low response rate from siblings. At one site, 27 siblings (and families) were initially sent information about the study, with only one subsequently contacting the researcher. One possible factor in this low uptake might be attributed to the use of lengthy information sheets. Although a requirement of ethical approval, these may have given the impression of a more ‘formal’ research process than intended and perhaps deterred adolescents and families from reading and/or taking part. Similarly, all documentation used within the NHS service was marked with NHS and service logos. Although arguably this may have added credibility to the study, it is possible this raised questions for families about who was conducting the research and why they had been asked to participate.

Finally, another limitation of the current study is the lack of variance of participants in terms of culture, gender and sibling diagnoses. The study initially aimed to recruit male and female siblings of brothers and sisters diagnosed with an ‘ED’ (non-specific) in order to allow for multiple diagnoses and views from across genders. However, the sample included only female participants with sisters diagnosed with an ‘ED’, and all but one this was ‘AN’. This reflects all previous studies, where female siblings and the diagnosis of ‘AN’ have

predominated. Furthermore, although some, there was little cultural variance across the sample. Specific to gender differences, this could be reflective of findings related to young people's help-seeking behaviour, which indicates males are often less likely to talk about sensitive topics (Rickwood, Deane, Wilson, & Ciarrochi, 2005). (During recruitment for this study, a male sibling approached me back to the researcher that he would have been willing to participate had it been a 'yes no' task rather than discussion).

Wider implications of findings

Research implications

Current findings have implications both in relation to the understanding of siblings in the context of an 'ED' and in broader sibling research. The findings support the use of qualitative approaches in hearing accounts from a group who have remained relatively unheard, despite increased acknowledgment of their importance to both family research and involvement in intervention (Pike et al., 2009).

Although the recruited sample was small, those who participated appeared willing to talk and open in their accounts. This could be linked to current and previous findings that siblings can feel unable to express their views to family (Dallos & Denford, 2008) and/or in professional settings. Participants' willingness to talk in this study could be interpreted as having been given an opportunity to talk through a new and confidential conversation, with a researcher who had identified themselves as interested in hearing these ideas. Mindful of the challenges in recruitment and the emerging literature base, it may be useful for future research to consider other ways of talking with siblings. One possibility might be through a different setting (i.e. school) rather than their home or a therapy service, both which may be seen as affiliated with their sibling. Another approach might be the use of focus groups with younger children. While focus groups are sometimes considered as limiting to conversation with young children, my experience of interviewing Priya left me curious about whether younger children may feel able to talk more openly in a less formal setting.

Professional implications

Current findings also have implications for professionals working in clinical settings with siblings and their families. All participants had, to some degree, been involved with family-based interventions, although attendance and views about this were mixed. Ideas suggested by siblings themselves included both FT appointments to talk with professionals on their own and appointments with their diagnosed sibling to allow them to talk to separately from their parents. While such ideas might often be used within FT practice, these hold relevance for all professionals working with such families. Furthermore, they are suggestive of the importance of remaining aware of sibling positioning and understanding, in particular at early stages, as well as being mindful of how the SR can be supported through a professional context.

A further implication is in relation to how professionals might support siblings in making sense, talking about and sharing their own experiences. This seems especially relevant given findings suggest a potential mutual protecting or censoring occurring between parents and siblings possibly resulting in reduced dialogue. Previous findings have suggested the use of sibling groups (Dimitropoulos et al., 2009), which may offer a useful space for hearing shared experiences. Although current findings offer relatively less understanding about how siblings experience support, they do suggest siblings may find it useful to have space either individually or with their sibling to talk about their own experiences within a professional context. This highlights the need for professionals working with families to remain mindful and curious with families about identifying what might be helpful for siblings, both for those who appear to be asking for support and others who may feel less able to directly request this, perhaps due to worry about whether this might 'burden' parents and family. Finally, given this specific aspect of the sibling experience remains relatively under-explored, professionals working clinically with siblings and their families are well-placed to provide ongoing development, research and evaluation of possible sources of sibling support such as sibling groups and/or specific information for siblings.

Future directions

In light of the current findings, future research could focus on investigating the perspective of brothers of diagnosed sisters and both male and female siblings of boys diagnosed with an 'ED'. Equally, hearing from siblings of young people diagnosed with 'BN' will offer new understanding about diagnoses that comparatively less research has focused on.

Sibling accounts in this study involved a strong emphasis on making sense of the situation. Linked with previous studies (Garley & Johnson, 1994), current findings suggest siblings' understanding can involve negotiating and developing appreciation of a balance between the role of wider contextual factors and their sister's characteristics. With this in mind, a future study using discourse analysis to investigate the development of how siblings draw upon medical and characterological discourses to understand their sisters might offer further contribution.

Research and evaluation focused on MFT is continuing to emerge. Hearing from siblings who have taken part in such interventions would be a useful avenue to explore in relation to developing understanding about how siblings might experience such support. Furthermore findings warrant greater focus on the SR in this context. Exploration of factors such as age, gender and culture could be of value in further understanding the varied findings associated with the impact on the SR.

Evaluation of current research

Assessing the quality of qualitative research requires a varied approach compared with assessing validity and reliability of quantitative work (Barker et al., 2002). To seek quality in analysis and remain aware of possible pitfalls, I referred to guidelines set out for qualitative research analysis (Elliott et al., 1999; Yardley, 2000). Yardley (2000) outlines criteria relating to quality of research, with which the current study is be evaluated below:

Sensitivity to context

Sensitivity to context can be developed through an awareness of relevant literature, theory and the socio-cultural setting of the study (Yardley, 2000). Additionally, an awareness of ethical issues and implications allow for greater understanding of the context. I have aimed to address these aspects of sensitivity through a review of the existing literature and theory surrounding siblings in the first chapter of this thesis. Furthermore, the review processes required for ethical approval of this study has allowed me to remain aware of the ethical issues and potential impact of participation. Attending two committees to discuss the research allowed me to consider additional issues of context I had not previously accounted for. I have aimed to demonstrate sensitivity to the data through conducting and describing an in-depth analysis and supporting my arguments with verbatim extracts, with the hope of allowing for participants to be given a voice within the project (Smith et al. 2009).

Commitment and rigour

Commitment and rigour can be demonstrated through maintaining in-depth engagement with the topic and developing skill in the research method used (Yardley, 2000). I have aimed to demonstrate this through examples of each of the research stages within the Appendices. This was my first experience of using TA, and additionally being constrained by time and length of the project, I am aware of the impact these factors may have upon the rigour of the study. I have aimed to develop my skills in research through attending lectures and reading relevant sources of information. I have also used the experience of my supervisors, which has allowed for development of both my analytic skills and research ideas within the field of 'EDs'.

Transparency and coherence

Yardley (2000) outlines the importance of transparency and coherence within qualitative research, especially in presenting approaches and findings. With this in mind, I have aimed to focus on detailing the specific approach taken in the collection and analysis of data through the Appendices. Early on in the analysis I felt challenged in moving away from pre-existing guidelines of the approach. I experienced concern about the sample size and moving between phases of

analysis. However, delays with recruitment indirectly led me to develop an approach to analysis the fit with my own data set, which I feel led to a greater focus on the individual nature of the data.

Impact and importance

This final criterion relates to the impact and utility of the research. I have sought to remain aware of what this research might contribute to the literature base, as well as to service delivery. Given that siblings remain a relatively under-researched group both in the field of 'EDs' and wider, the importance of continuing research through varied approaches can be seen to contribute to support and justification for ongoing sibling research. The clinical relevance of the research has also been kept in mind, with the hope that findings can be heard by those working with siblings and their families in a therapeutic context. As such, it is anticipated findings will disseminated to participants and their families as well as members of the Eating Disorders Research Consortium.¹⁹

Reflections

In reflecting on developing and carrying out this research, there are three aspects of the process that I feel have been especially relevant to my own professional development.

The process of interviews for research rather than clinical purposes was novel to me, as was the analysis of interview transcripts. In carrying out the interviews, I was mindful of the challenge in not confusing clinical and research roles, either for participants or myself. However, through the process of interviewing I was reminded of the possibility of managing both; with clinical experience being especially helpful in engagement. Equally, having carried out the research, I feel this has contributed to my developing clinical skills through greater awareness about the role and meaning of language.

¹⁹ This is group of clinicians who work with children and young people diagnosed with 'EDs' from both NHS and private settings across the UK, with an interest in developing research in this population.

Secondly, I have reflected on questions about assumptions participants might have related to my gender, age and status as a trainee psychologist. One of the reasons for thinking this was that through conversations it became apparent that two of the participants were, or were intending to pursue further study in psychology. I wondered about whether this had any influence in their decision to participate in the study and on their views and responses but refrained from enquiring outright.

Finally, through conducting this research, I have learnt about specific aspects of conducting research with young people, both in respect to recruitment and ethical procedures. The process of seeking NHS ethical approval is something I feel I have benefited from. However, at times, I felt it was a challenge to present a rationale for psychological research within an NHS approval process that appeared more weighted towards the ethical requirements of medical research. Additionally, the application process did conflict with time constraints of the project, the delay being partly due to the younger age of participants proposed in this study. However, reflecting overall on the NHS ethical application process, I feel it allowed for conversations to be had during the developing stages of the research about aspects of ethical consideration I had not yet considered. Furthermore, it has been a useful introduction into the process of research with young people, which I have become increasingly aware of in doing this project.

Conclusion

The aim of this study was to contribute to understanding sibling views and perspectives of siblings about living with a young person diagnosed with an 'ED'. The use of TA provided a useful framework with which themes could be identified and placed in the context of current literature. Given that no published studies appear to have been conducted in the UK, the current findings are therefore able to offer some indication of sibling views about support from within NHS services, although it is acknowledged further research focused on the experience of siblings within support and interventions offered through NHS services is warranted. Findings from this study can be placed in the context of family-system

and life cycle theories and provide further support for family-based intervention with families living with an individual diagnosed with an 'ED'.

It is hoped that this study has contributed the evidence-base, offered additional support for an ongoing commitment to the development of sibling research in the context of a diagnosed 'ED' and further justified the use of the sibling perspective within this.

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APPENDICES

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* Information and formatting of this document has been adapted for thesis guidelines. Information about research sites and those involved has been removed and additional text to replace information is placed in brackets (e.g. [name])

Appendix 1: 'Eating disorders': Epidemiology, outcome and intervention.

Epidemiology

Approximately one and a half million people in the UK are diagnosed with an 'ED' at a given time (Lipczynska, 2005). Estimates of female-to-male ratios have ranged from 6:1 to 10:1 (Carr, 2006). Diagnosis of an 'ED' remains most common in females aged between 15 and 19 (Smink, Hoeken, & Hoek, 2012), although comparatively less research exists looking at rates of diagnoses other than that of 'AN' (Norris, Bondy, & Pinhas, 2011). Furthermore, although there has been an increase in epidemiological research across cultures, the most researched group remains white women in Western societies (Treasure & Schmidt, 2002).

Polivy and Herman (2002) have estimated an incidence rate for diagnosed 'EDs' of between 3-10% in females aged between 15 and 29. It has been estimated that between 20% and 60% of individuals presenting to services will meet criteria for 'EDNOS' (Turner & Bryant-Waugh, 2004). Although most commonly diagnosed, the 'EDNOS' classification has raised a number of questions with regards to overlap with other categories and approaches to intervention (Fairburn & Bohn, 2005; Noring & Palmer, 2005).

Understanding about classification and epidemiology within child and adolescent populations remains relatively limited (Norris et al., 2011) and debate about suitability of classification for this population is ongoing (Bryant-Waugh & Nicholls, 2011; Eddy et al., 2011). It has been suggested that rates of diagnoses and access to services have increased in child and adolescent populations (Watkins & Lask, 2002; Bryant-Waugh & Nicholls, 2011). However, challenges exist when considering the suitability of diagnostic criteria (Rosen, 2003) and difficulty for both families and professionals in defining normal eating during childhood (Bryant-Waugh & Nicholls, 2011). It has been suggested that proposed revisions to the DSM-IV-TR ED categories are intended to allow for greater relevance to child and adolescent populations (Bravender et al., 2010).

Outcome

Outcome of a diagnosed 'ED' has been viewed as extremely variable, impacted

by a number of factors related to the nature of the difficulties and wider context (Steinhausen, 2002). Diagnoses of 'EDs' have long been associated with low rates of recovery (Pritts & Susman, 2003) and high mortality (Carr, 2006; Fairburn & Brownell, 2002). Furthermore, the diagnoses are thought to carry the highest mortality rate of any of the psychiatric disorders (e.g. Herzog et al., 2000). Research with children, defined by most in this field as under the age of 13 or 14, suggests the outcome may be worse than when compared with adolescents, although the dearth of literature in providing support for this is acknowledged (e.g. Noris et al., 2011). Some evidence exists to support lower mortality rates within younger populations (Nielsen et al., 1998) although again, research is limited.

Intervention

Diagnoses of 'EDs' can often be complex and in particular within child and adolescent populations, much remains unknown. Diagnosis is most common within the adolescent to young adult population therefore the impact on the family and their role in intervention has become a growing focus of research and clinical practice. A large body of literature exists exploring the experience of families and empirical-based evidence for family-based intervention. As a result, UK clinical guidelines advocate such family-based approaches to intervention within services supporting young people and their families (NICE, 2004).

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Appendix 2: Literature search terms

Four databases were searched for relevant literature. These were, Academic Search Complete, PsycINFO, PsycARTICLES and CINAHL Plus. The search was limited to those written in the English language, however, included studies from across all countries. Note was taken of the country of origin and where sibling's lived in relation to the person diagnosed (e.g. same or different home). Criterion for this search included, year of publication (1983 to January 2013) and age range of the non-diagnosed individual (defined as childhood/school age, adolescence, and young adulthood). Academic journals, reviews, dissertations and books/chapters were included. Search terms used were derived from words including 'sibling/s' and 'eating disorder/s' combined with 'children' and/or 'adolescents':

1. Sibling, brother, sister, sub-system, older sibling, younger sibling, sibling relationship/s
2. Family, family system, family sub-systems, family-based interventions, family therapy, multifamily group therapy
3. Mental health illness, eating disorder, diagnosis of eating disorder, Anorexia, Anorexia Nervosa, Bulimia, Bulimia Nervosa, Eating disorder otherwise not specified, child and adolescent eating disorders, CAMHS,
4. Sibling perspective, sibling experience, impact on sibling, impact on brother/sister, sibling research

Appendix 3: Additional literature search terms

1. Sibling, brother, sister, sub-system, older sibling, younger sibling, sibling relationships
2. Family, family system, family sub-system, family-based interventions
3. Chronic/physical illness, cancer,
4. Learning disability, intellectual disability, childhood illness,
5. Sibling perspective, sibling experience, impact on sibling, impact on brother/sister, sibling research

Appendix 4: Research model outlined by Garley & Johnson (1994 p.159).

Image taken from Garley, D. & Johnson, B., (1994). Siblings and eating disorders: a phenomenological perspective. *Journal of psychiatric and mental health nursing*, 1(3), 157–64.

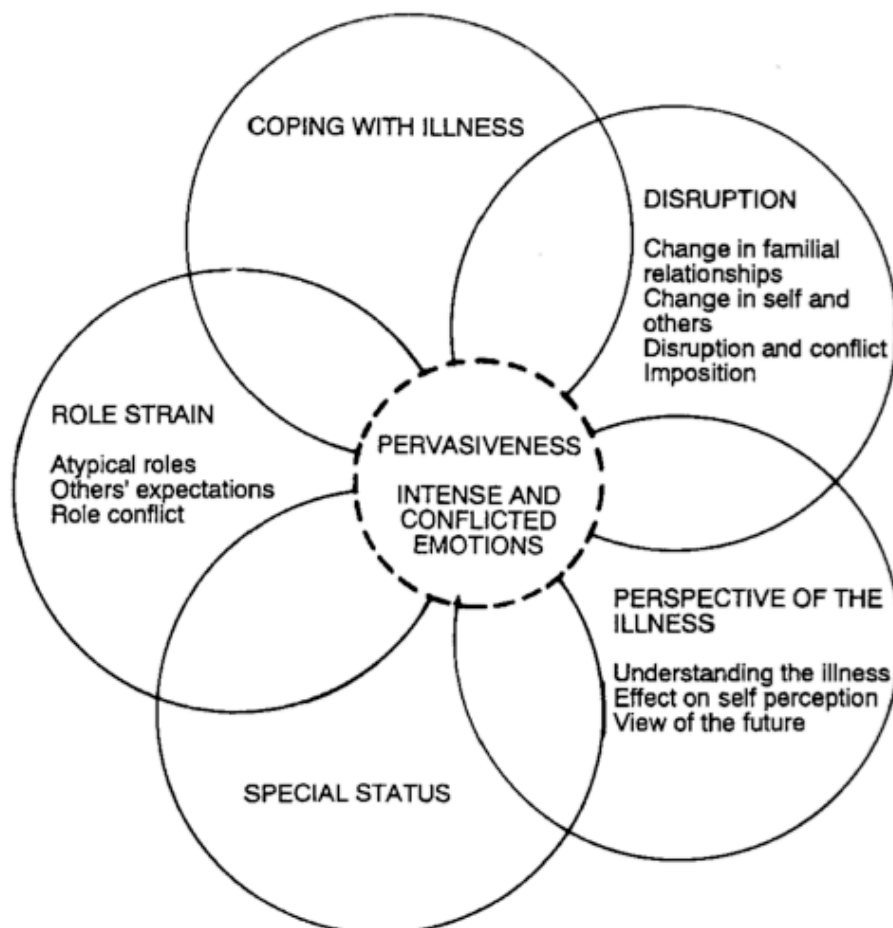


Figure 1

Schematic representation of the sibling experience in individuals with an eating disorder. (Subthemes that appear in Fig. 1 have not been specifically developed in this paper).

Appendix 5: Conceptual framework identified by Honey et al. (2006 p. 317)

Image taken from Honey, A., Clarke, S., Halse, C., Kohn, M., & Madden, S. (2006). The Influence of Siblings on the Experience of Anorexia Nervosa for Adolescent Girls. *European Eating Disorders Review*, 14(5), 315–322.

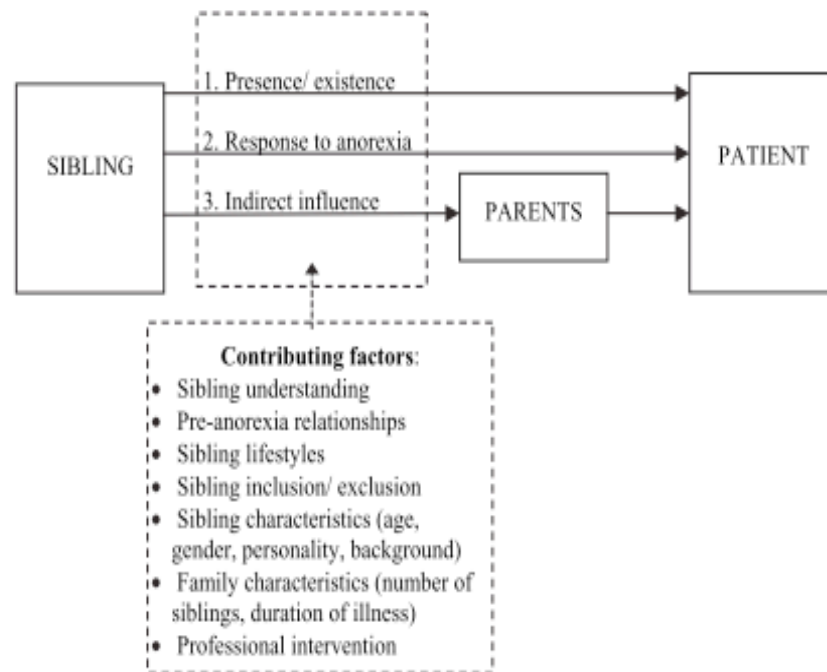


Figure 1. Conceptual framework for the influence of siblings on girls with anorexia

Appendix 6: Research model outlined by Latzer et al., (2002 p.278).

[Image taken from Latzer, Y., Ben-Ari, A., & Galimidi, N. (2002). Anorexia nervosa and the family: The effects of younger sisters to anorexia nervosa patients. *International Journal of Adolescent Medicine and Health*, 14(4), 275–281].

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ANOREXIA – EFFECT ON YOUNGER SISTERS

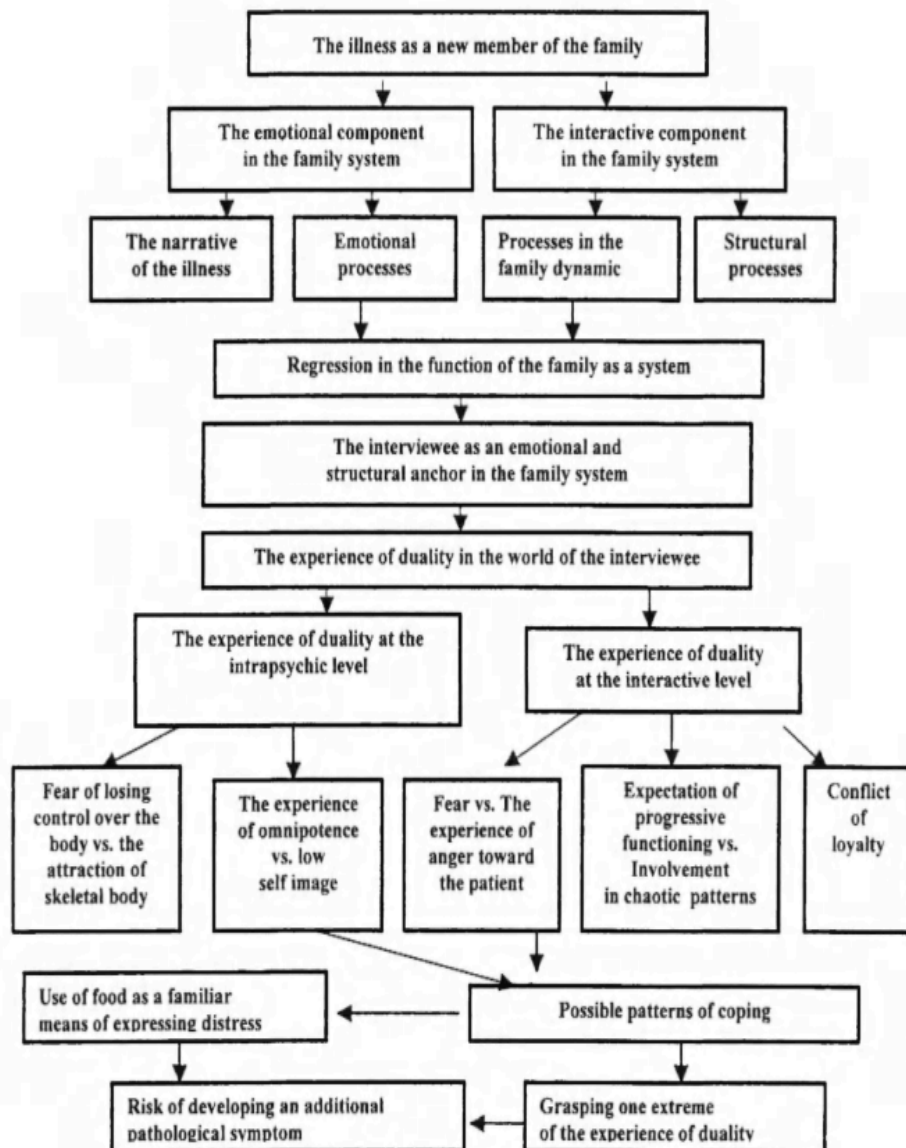


Figure 1: The effect of anorexia nervosa on the family as a system, and especially on the sister.

Appendix 7: Confirmation letter for university registration of research

February 2012

Dear Davina

Re: Registration Board

Thank you for your amended research proposal and for your letter detailing your response to the points raised in relation to your original proposal. I am satisfied that you have successfully addressed the issues identified in my previous letter to you, and I am writing to inform you that your proposal will now be considered at the Clinical psychology Sub-Group of the School Research Degrees Sub-Committee on 20th February. You are now permitted to proceed to apply for approval from the UEL School of Psychology Research Ethics Committee and any other relevant ethics committee(s).

Best wishes for every success with your research.

Yours sincerely

Research Director

Appendix 8: Ethical approval document from University of East London

ETHICAL PRACTICE CHECKLIST (Professional Doctorates)

SUPERVISOR: Name

ASSESSOR: Name

STUDENT: Davina Moses

DATE (sent to assessor): 26/03/2012

Proposed research topic: Exploring the experiences of siblings of young people diagnosed with an eating disorder.

Course: Doctoral degree in Clinical Psychology

- | | |
|--|------|
| 1. Will free and informed consent of participants be obtained? | YES |
| 2. If there is any deception is it justified? | N/A |
| 3. Will information obtained remain confidential? | YES |
| 4. Will participants be made aware of their right to withdraw at any time? | YES |
| 5. Will participants be adequately debriefed? | YES |
| 6. If this study involves observation does it respect participants' privacy? | NA |
| 7. If the proposal involves participants whose free and informed consent may be in question (e.g. for reasons of age, mental or emotional incapacity), are they treated ethically? | NA |
| 8. Is procedure that might cause distress to participants ethical? | NA |
| 9. If there are inducements to take part in the project is this ethical? | / NA |
| 10. If there are any other ethical issues involved, are they a problem? | NO |

APPROVED

YES

MINOR CONDITIONS:

REASONS FOR NON APPROVAL:

Assessor initials: XX Date: 11/5/12

RESEARCHER RISK ASSESSMENT CHECKLIST (BSc/MSc/MA)

SUPERVISOR: Name

ASSESSOR: Name

STUDENT: Davina Moses

DATE (sent to assessor): 26/03/2012

Proposed research topic: Exploring the experiences of siblings of young people diagnosed with an eating disorder.

Course: Doctoral degree in Clinical Psychology

Would the proposed project expose the researcher to any of the following kinds of hazard?

- | | | |
|----|--|----|
| 1 | Emotional | NO |
| 2. | Physical | NO |
| 3. | Other
(e.g. health & safety issues) | NO |

If you've answered YES to any of the above please estimate the chance of the researcher being harmed as: HIGH / MED / LOW

APPROVED

YES

MINOR CONDITIONS:

REASONS FOR NON APPROVAL:

Assessor initials: **XX** Date: 11/5/12

Please return the completed checklists by e-mail to the Helpdesk within 1 week.

SCHOOL OF PSYCHOLOGY

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.



School of Psychology Professional Doctorate Programmes

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

Stratford Campus, Water Lane, Stratford, London E15 4LZ
tel: +44 (0)20 8223 4966 fax: +44 (0)20 8223 4937
e-mail: mno.davies@uel.ac.uk web: www.uel.ac.uk/psychology



The University of East London has campuses at London Docklands and Stratford
If you have any special access or communication requirements for your visit, please let us know. MINICOM 020 8223 2853



Appendix 9: Approval document from NHS Ethics Committee



13 August 2012

Dear Miss Moses

Study title: Exploring the experiences of siblings of young people diagnosed with an eating disorder.
REC reference: [number]
Protocol number: n/a

Thank you for your letter of 26 July 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

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

Ethical review of research sites

NHS sites

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

Non-NHS sites

Conditions of the favourable opinion

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

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

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

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

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

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

Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>	
Covering Letter		17 May 2012	
Covering Letter		22 June 2012	
Covering Letter		26 July 2012	
GP/Consultant Information Sheets	2	26 July 2012	
Interview Schedules/Topic Guides	1	26 March 2012	
Investigator CV			
Other: Supervisor Dr XXX's CV			
Other: Debriefing information	1	26 March 2012	
Other: Investigator XXX's CV			
Other: UEL registration of research letters		08 February 2012	
Other: Confirmation of research ethical approval from university of East London Ethics Committee	1		
Other: Ethical Practice Checklist (Professional Doctorate)		11 May 2012	
Other: Researcher Risk Assessment Checklist (BSc/MSc/MA)		11 May 2012	
Participant Consent Form	3	26 July 2012	
Participant Consent Form: Parent/carer assent	2	26 July 2012	
Participant Information Sheet	4	26 July 2012	
Participant Information Sheet: Parent/Family	3	26 July 2012	
Protocol	1	23 March 2012	
REC application		17 May 2012	
Response to Request for Further Information		04 July 2012	

Response to Request for Further Information		26 July 2012	
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Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

[ref no.]	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Yours sincerely

Chair

Appendix 10: Ethical approval documentation from NHS site

Dear Dr [REDACTED]

PROJECT TITLE	Exploring the experiences of siblings of young people diagnosed with an eating disorder
Protocol version	Version 2
Protocol date	[REDACTED]
REC Reference	[REDACTED]
R&D Reference	[REDACTED]
CSP Reference	N/A
Sponsor	University of East London
Chief Investigator (CI)	Miss Davina Moses

Notification of [REDACTED] NHS Permission.

The research approval process for the above named study has been completed successfully. I am pleased to issue approval on behalf of [REDACTED] for the above study to proceed.

All research carried out within this Trust must be in accordance with the principles set out in the Research Governance Framework for Health and Social Care (April 2005, 2nd edition, Department of Health (DoH)).

This approval is issued on the basis of the project documentation submitted to date. The approval may be invalidated in the event that the terms and conditions of any research contract or agreement change significantly and while the new contract/agreement is negotiated.

The conditions for host site approval are as follows:

- The Principle Investigator (PI) must ensure compliance with protocol and advise the [REDACTED] of any change(s) to the protocol. Failure of notification may affect host approval status.
- Under the terms of the Research Governance Framework (RGF), the PI is obliged to report any Serious Adverse Events (SAEs) to the Sponsor and the [REDACTED] in line with the study protocol and Sponsor requirements. Adverse Incidents (AIs) must also be reported in accordance with the Trust Adverse Incident Reporting Policy & Procedures.
- The PI must ensure appropriate procedures are in place to action urgent safety measures.
- The PI is responsible for the set up and maintenance of the Investigator Site File (ISF) generated to store all documentation relating to this project.
- The PI must ensure that all named staff are compliant with the Data Protection Act (DPA) 1998, Human Tissue Act (HTA) 2005, Mental Capacity Act (MCA) 2005 and all other applicable statutory guidance and legislation.
- The PI must allow monitoring and auditing by the Sponsor and the [REDACTED]
- The PI must report any cases of suspected research misconduct and fraud to the [REDACTED]
- The PI must provide an annual report to the [REDACTED] for all research involving NHS patients, staff and/or resources. The PI must notify the [REDACTED] of any presentations of such research at scientific or professional meetings, or on the event of papers being published and any direct or indirect impacts on patient care.

Failure to comply with the above conditions and regulations will result in the suspension of the research project.

Please contact the [REDACTED] if you require any further guidance or information on any matter mentioned above. We wish you every success in your research.

Yours sincerely,

Appendix 11: Research and Development department letter of access

Dear Davina Moses,

Letter of access for research

Study: [REDACTED] Experience of siblings living with young people with eating disorders

This letter confirms your right of access to conduct research through [REDACTED] NHS Trust for the purpose and on the terms and conditions set out below. This right of access commences on 25th January 2012 and ends on 31st October 2013 unless terminated earlier in accordance with the clauses below.

The information supplied about your role in research at [REDACTED] has been reviewed and you do not require an honorary research contract with this NHS organisation.

You are considered to be a legal visitor to [REDACTED] premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through [REDACTED] you will remain accountable to your employer, but you are required to follow the reasonable instructions of [REDACTED] in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with [REDACTED] policies and procedures, which are available to you upon request, and the Research Governance Framework.


You are required to co-operate with [REDACTED] in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on [REDACTED] premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and

premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer/educational institution is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

 will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

We wish you well with your research.

Yours sincerely

Appendix 12: Letter of approval from non-NHS site

December 2012

Dear Davina,

Re. Research Proposal

I write to confirm that I have taken your proposal to our local governance committee. We decided we would forward this to our regional director for approval.

Our regional director has given the proposal ethical consideration and consulted with our lead clinician, Dr xxx

Having considered your proposal, I am delighted to confirm that we are able to participate in the project as outlined.

Thank you for your patience.

Yours sincerely,

For and on behalf of xxxx

xxx

Service Manager

Appendix 13: Information for sibling participants



INVITATION TO TAKE PART IN A STUDY

Talking about what it's like having brother or sister who has difficulties with eating.

We are asking if you would like join in a study to help us learn about what it's like being the brother or sister of someone who has difficulties with eating. Before you decide if you want to join in, it's important to understand why the study is being done and what it will involve for you. So please consider this leaflet carefully. Talk to your family, friend or doctor if you want to.

Why are we doing this research?

We would like to hear from you about what you think it is like to have a brother or sister who has difficulties with eating.

Why have I been invited to take part?

We know that you have a brother or sister who has difficulties with eating, and that people from [site name] sometimes meet with you and the rest of your family about this. We know that you may have met with these people before to talk about what things are like for you, but we would really like to be able to hear a bit more about this.

To do this, we are asking brothers and sisters to take part in a study. You will be invited to take part in an interview. An interview is just like a discussion. This will be between just you and the researcher, Davina Moses. The researcher will ask some questions about what you think it is like having a brother or sister who has difficulties with eating. You don't have to answer anything you don't want to, and you can choose to finish the interview early if you don't feel you want to carry on. We have invited other siblings to take part in the study, so there will be other people your age also having interviews, but you won't meet them.

What will I have to do if I decide to take part?

If you agree to take part, you and your family will be given some more information about where the interview will be. You and your family can let us know when a good day or time might be, and we can decide together on the best time to have the interview.

The interview will be in a quiet room and last for about one hour. We will be able to have time after the interview to talk about what it was like, and answer any questions you have. Our discussion will be recorded on a recording device. This is to help us remember all the things we spoke about.

Will anyone else know I'm doing this?

We will let your GP (that's your doctor) know that you are taking part in this study. The people at [site] who work with your family will also know that you are taking part in the study. Anything you talk about during the interview will be kept confidential. This means we will only tell those who have a need or right to know.

What will happen to the things I say?

The things you say in the discussion will not be spoken about with anybody else. I may want to write some of the things you say in the interview, but I will not use your name. **I will treat anything you say as private and confidential** -- the only exceptions to this would be if you said something that made me think that you or

Is there anything to be worried about if I take part?

No, there is nothing which you need to be worried about, but if you do have any worries, or want to ask any questions before you make your decision, you can contact us on the phone number at the bottom of this form

Can I change my mind about coming?

Yes, it's fine to decide you don't want to come to the interview; you or your parent or carer can phone and let us know you have changed your mind.

Who has reviewed the study?

Before any research goes ahead it has to be checked by two Research Ethics Committee's. They make sure that the research is fair. This study has been checked by a University of East London Committee, and NRES Committee [reference number]

What do I do next if I want to be involved?

If you would like to be involved, there is a form enclosed for you (and one for your parent or guardian) to sign and bring with you to the interview. You can contact us using the contact details in this pack for more information or any more questions you have about the study.

For more information about taking *part* or if you have any other questions, please contact: [contact details]

For general advice about taking part in research, you can contact the Patient Advice Liaison Service on [number]

Thank you for reading about this study, and we look forward to meeting you if you decide to take part.

Appendix 14: Information for parents/carers and family members



Information for family members about the study

We are looking for young people to take part in a study about what it's like being a brother or sister of someone diagnosed with an eating disorder, and would like to invite your child to take part in the study. Before you decide about whether you are happy for child to participate, we would like you to understand why the research is being done, and what it would involve. Please feel free to contact the researcher (details below) or a member of the team involved with your family [site name], to answer any questions you have.

What is the purpose of the study?

There is a lack of research that looks exclusively at the experiences of siblings who live with brothers or sisters diagnosed with an eating disorder. This study will be looking into this experience by asking siblings about what it is like living with a brother or sister with an eating disorder, and the support given to the family by professionals. We hope for this research to help services understand more about what it is like to be a sibling in a family where a young person is diagnosed with an eating disorder.

The researcher is a Trainee Clinical Psychologist, carrying out this work as part of a doctorate qualification. The research is supervised by [name], senior lecturer at the University of East London, and clinical psychologists [name] and [name].

Why has my child been invited?

We are looking for young people aged 11 to 18 years who would be happy to take part in an individual interview about what it is like for them being the sibling of a child or young person diagnosed with an eating disorder. There is a separate information sheet enclosed in this pack for your child to read about the study.

Does my child have to take part?

No; your child can choose not to participate. If you agree and give consent for your child to take part, they can withdraw at any point without giving a reason and without any disadvantage to them or your family. Enclosed are consent forms for you and your child with more information about this.

What does taking part involve?

If you and your child agree to take part, further information about the dates, times and location of the interview will be given. If the time is not convenient for you or family, we can think together about when may be more appropriate for you. The interview will be held in a quiet room and last for up to one hour. Only the researcher and your child will be present. During the interview, your child will be asked about their experience of being a sibling of a child diagnosed with an eating disorder. They do not need to answer anything they do not want to, and free to end the interview if they feel they do not want to continue. Anything your child speaks about in the discussion will be treated as confidential unless it is felt they, or someone else, may be at risk of harm.

The interview will be recorded on a recording device for the purpose of writing the research. Quotations from the interview will be used in the write up of the study, however, these will be anonymous; no personal identifiable information will be used in the write up of the study.

What are the benefits to taking part?

Taking part in the study and the interview may provide an opportunity for young people living with siblings diagnosed with an eating disorder to communicate and share their experience and views. It is hoped that these views can provide some understanding of the experience of siblings, and lead to some suggestions of how to further improve support for siblings during what can be a very difficult time for the whole family.

Who will know my child is taking part?

We will inform your child's GP about the study, and let them know that you and your child have given consent for them to take part. Members of the team at [site name] involved in your families' care may also know about your child's participation.

How does my child take part?

Enclosed is an information form about the study for your child to read, and consent forms for both you and your child to sign and bring with you on the day of the interview. For further information about taking part or if you have any other questions, please do not hesitate to contact:

[Contact details for researcher and supervisor]

Ethical Approval

This study has been approved by the University of East London Ethics Committee and NRES [name] Committee [reference number]

For general advice about taking part in research, you can contact the Patient Advice Liaison Service on:

[Contact details]

Many thanks for taking time to read about the study.

Appendix 15: Participant consent form



Centre Number:

Study Number:

Participant Identification Number for this study:

CONSENT FORM FOR YOUNG PERSON TAKING PART IN THE STUDY

Title of Project: Experience of living with a sibling diagnosed with an eating disorder

Name of Researcher: Davina Moses

This consent form is a way of agreeing that you are happy to be involved in the study. Please read the form and if you are happy to, put your initials in the boxes and then sign at the bottom of the page.

Please put
your initials in
the boxes

1. I have read the information leaflet about the study. The study has been explained to me, and I have been able to ask questions about what I will be doing. I know how to contact someone to ask for more information if I want.
2. I understand that I will take part in an interview with the researcher, Davina Moses. This will be a discussion that will last for about one hour. We will be talking about what it is like to be a brother or sister of someone who has difficulties with eating. I understand that our discussion will be recorded.

3. I understand that what I say will be kept private, unless the researcher hears something that they are worried about. I understand that my GP (doctor) will know that I am taking part in this study. ☐
4. I understand that the researcher will make sure that no one will be able to know I was involved. This would mean (for example) that my name would be changed, and any information which could be used to tell who I was, or who my family or anyone else working with us, would not be used. ☐
5. I understand that I do not have to agree, or give consent (I can say yes or I can say no, it's up to me). ☐
6. I understand that some things I say might be used when the study is written about, but that no one will be able to tell who I am (the extracts will be anonymised). ☐
7. I have read this form and I am happy to take part in the study.

_____	_____	_____
Name of young person	Date	Signature
_____	_____	_____
Name of person taking consent.	Date	Signature

Appendix 16: Parental assent form



Centre Number:

Study Number:

Participant Identification Number for this study:

PARENTAL ASSENT FORM

Title of Project: Experience of living with a sibling diagnosed with an eating disorder

Name of Researcher: Davina Moses

Please initial all

boxes

1. I confirm that I have been consulted about’s participation in this research. I have read and understood the information sheet for the above study, dated 26/07/2012. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. I agree to their taking part in this research.

☐

2. I understand that I am not obliged to give assent for my child to participate in the study. I understand that I am free to withdraw assent at any time without giving any reason, and without their, or my family’s care or legal rights being affected.

☐

3. I understand that this study will involve my child taking part in a discussion about their sibling who is diagnosed with an eating disorder. **I confirm that my child diagnosed with an eating disorder has been made aware of this, read the relevant information about the research, and is in agreement with their siblings’ involvement in the study.**

☐

4. I understand that the study will be conducted through an interview with my child, and will last for up to one hour. I understand that this discussion will be recorded using audio equipment.

☐

5. I understand that that relevant sections of his/her contributions in the discussion used in the write-up of this study (e.g. academic assessment, possible publication in a professional journal) but my child or family will not be personally identifiable (the extracts will be anonymised).

☐

6. I am aware that their GP or other care professional will be informed of their participation in the study.

☐

7. I hereby freely and fully assent to allow my child..... to participate in this study.

☐

_____	_____	_____
Name of Parent/guardian	Date	Signature

_____	_____	_____
Name of Person taking assent	Date	Signature

Appendix 17: GP letter for NHS site



Davina Moses
University of East London
School of Psychology
The University of East London
Stratford Campus
Water Lane
E15 4LZ

[GP name and address]

[Date]

Dear Dr.....,

Re: Research study exploring the experiences of siblings of young people diagnosed with an eating disorder

I am writing to inform you that has agreed to take part in a research study which is being conducted as part of a Doctoral Degree in Clinical Psychology. This study is exploring the experience of being a young person living with a brother or sister diagnosed with an eating disorder.

There is currently only a small body of research looking at the experience of siblings of young people diagnosed with eating disorders. This study is designed to try and understand what it is like for a child or young person growing up in a home with a brother or sister with an eating disorder. The study will also try to understand the ways in which siblings feel supported by their families and services.

..... has agreed to take part in the study. They will take part in an individual semi-structured interview with the researcher, Davina Moses, which will last for up to one hour. They have been provided with information about the study and having read this, have given written consent to take part. Their parent/carer has also been given information regarding the study, and provided assent for their child to take part. Both and their parent/carer are aware that you have been informed of the study and their participation.

The study has been developed through discussions with local collaborators at [site name], and Dr [name], Senior Lecturer in Clinical Psychology at the University of East London. The study has been approved by the University of East London Ethics Committee and NHS Research Ethics Committee [reference number]

Should you have any questions regarding the research, please do not hesitate to contact me on the above number.

Yours sincerely,

Davina Moses
Trainee Clinical Psychologist
University of East London

Appendix 18: Information form for participants recruited from outside of services

Information about the study

We are looking for young people to take part in a study about what it's like being a brother or sister of someone diagnosed with an eating disorder, and would like to invite you to take part in the study. Before you decide about whether you are happy to participate, we would like you to understand why the research is being done, and what it would involve. Please feel free to contact the researcher (details below) to answer any questions you have.

What is the purpose of the study?

There is a lack of research that looks exclusively at the experiences of siblings of young people diagnosed with an eating disorder. This study will be looking into this experience by asking siblings about what it is like living with, or previously having lived with, a brother or sister with an eating disorder, and the support given to the family by professionals. We hope for this research to help services understand more about what it is like to be a sibling in a family where a young person has been diagnosed with an eating disorder.

The researcher is a Trainee Clinical Psychologist, carrying out this work as part of a doctorate qualification. The research is supervised by [name], senior lecturer at the University of East London, and clinical psychologists [name] and [name].

Why have I been invited?

We are looking to hear from people aged 18 to 30 years about their experiences as a sibling of someone diagnosed with an eating disorder and who currently or have previously received support for this. We would like to hear from people who are living with, or have previously lived with their sibling diagnosed with an eating disorder to find out more about their experiences.

What does taking part involve?

If you are interested in taking part you will be invited to an interview with the researcher. The interview will last for up to one hour. Only you and the researcher will be present. During the interview, you will be asked about your experience of being a sibling of someone who has been diagnosed with an eating disorder. You do not need to answer anything they do not want to, and are free to end the interview if you do not want to continue. Anything you speak about in the discussion will be treated as confidential unless it is felt you, or someone else may be at risk of harm.

The interview will be recorded on a recording device for the purpose of writing the research. Quotations from the interview will be used in the write up of the study, however, these will be anonymous; no personal identifiable information will be used in the write up of the study.

What are the benefits to taking part?

Taking part in the study and the interview may provide an opportunity for siblings of people diagnosed with an eating disorder to communicate and share their experience and views. It is hoped that these views can provide some understanding of the experience of siblings, and lead to some suggestions of how to further improve support in the future for siblings during what can be a very difficult time for the whole family.

How do I take part?

Enclosed is a consent form for you to sign and bring with you on the day of the interview. For further information about taking part or if you have any other questions, please do not hesitate to contact Davina Moses on:

[contact details for researcher]

Ethical Approval

The study has been approved by the University of East London Ethics Committee and NHS Research Ethics Committee [reference number].

Many thanks for taking time to read about the study.

Appendix 19: Consent form for participants recruited from outside of services

CONSENT FORM

Title of Project: Experience of living with a sibling diagnosed with an eating disorder

Name of Researcher: Davina Moses

Please initial all boxes

8. I confirm that I have been my participation in this research. I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
9. I understand that I am not obliged to give consent to participate in the study. I understand that I am free to withdraw at any time without giving any reason. ☐
10. I understand that this study will involve taking part in a discussion about my experiences of being a sibling of someone who is or has previously been diagnosed with an eating disorder. ☐
11. I understand that the study will be conducted through an interview and will last for up to one hour. I understand that this discussion will be recorded using audio equipment. ☐
12. I understand that that relevant sections of my contributions in the discussion will be used in the write-up of this study (e.g. academic assessment, possible publication in a professional journal) but that this will not be personally identifiable (the extracts will be anonymised). ☐
13. I hereby freely and fully consent to participate in this study. ☐

Name of Parent/guardian	Date	Signature
Name of Person taking assent	Date	Signature

Appendix 20: Interview schedule

Interview schedule: What is the experience of living with a sibling diagnosed with an 'eating disorder'?

Semi-structured framework, following participant

Introduction

- Explain to the participant the nature of the questions, the aim and the length of the interview, the tape recording and issues of confidentiality.
- Ensure they know they can take a break or withdraw at any point.
- Rapport building and time for participant to ask any questions
- NB: Ask participant mid-way whether there is anything they want to talk about that has not been asked.

Topic areas and questions used to generate discussion

- Can you tell me about your experiences of being a brother/sister of someone who has difficulties with eating? *Prompt if necessary – How do you feel about having a brother or sister who has been told they have an ED? How long have you known about it? What was it like hearing about it? Are there things that you find difficult/heard about it?*
- Are there any differences you notice in your life since your brother/sister began having difficulties with eating, or was given a diagnosis of an ED? *Prompt if necessary – Have you noticed differences at home/school/with your parents/family/friends?*
- Can you tell me about your relationship with your brother/sister? *Prompt if necessary, what is your relationship like? Do you feel things about it have changed? Are there things you notice that are different in your relationship with your brother/sister since they were diagnosed with an ED?*
- Sometimes families meet with professionals to talk about their family and the diagnosis of an ED; is this something you have done? Can you tell me a bit about what you thought/think of that? *Prompt if necessary – what's it been like meeting with people here? What's it like having conversations with your family and sister when other people have been there? Sometimes families are invited to meet with*

other families and professionals all together; have you attended anything like this before? Can you tell me a bit about that?

- Is there anything you would like to tell me that I have not asked you about?
- **Ending** Ask participant how they are feeling/ what their experience was of the interview process. Do you they have any questions? Talk through debriefing information. Thank participant and explain feedback. Take participant back to parent (if present) and ask parents if they have any questions.

Appendix 21: Debriefing information

Dear participant and family,

Thank you for taking part in this study and giving up your time today to attend the interview

I would like to remind you that any information you have given today will be treated as private and the recordings from the discussion will only be accessible to myself. As mentioned before the discussion, if I use information from our discussion, names and other personal information will not be used or will be changed. Other people may read the research but will not be able to identify people who took part.

The next part of the research will be about thinking how your comments today can be used to help services think about what it is like being a brother or sister of someone who has difficulties with eating, so we can continue to think about ways to support siblings during this time. If you have any questions you would like to ask, you can contact me on the email address or phone number below:

Name: Davina Moses

Telephone:

Email:

I am aware that during the discussion, you may have spoken about things that are upsetting. I would like to pass on details of places or people you can contact for support or advice should you wish to. You can also speak to your GP at any time or the people involved with your family at [site name].

Contact details for information and support:

B-eat

Website: <http://www.b-eat.co.uk/>

Telephone: 0845 634 7650

Text message service: 07786 20 18 20

Email: fyp@b-eat.co.uk

Child Line

Website: <http://www.childline.org.uk>

Telephone: 0800 1111

Thank you again for giving up your time today and for your help with this study.

Davina Moses

Appendix 22: Annotated extract of transcript

- 567 if you try to eat a little but more, just so you can get back to doing the things
 568 you enjoy, just so you can have a bit more of a fulfilled life kind of thing (.)
 569 But if you try, you can't really reason with it. You try and reason with her
 570 and she just goes all off the handle.
 571 DM: What's it like for you as her sister seeing her at mealtimes or, at those
 572 seeing difficult times / P1: oh awful, awful /. That's why I'm glad she's here
 573 it's so much easier now she's not at home, coz it's just, it makes me feel so
 574 depressing when she just sits there with a tiny bit of vegetable she's agreed
 575 to eat and then just pushes it around the plate. It's just so depressing. And
 576 she just sits there like the condemned man, you know as she kind of, as if it
 577 the most awful thing anyone's ever tried to make her do. And she just you
 578 know, you trying to kind of, what do you talk about round the table? When
 579 she's sitting there are you're saying "come on [sister's name] you know, why
 580 don't you just try to eat a bit of that?" and she goes "no". And what can you
 581 say [P1 laughs] you can't make her eat it.
 582 DM: What sort of things did you used to do?
 583 P1: We used to try and say you know "come-on its only a little bit, we need to
 584 put fuel in our body, you know just think of it like that, you need to just eat
 585 it and then it then its done, and then we can go. Just eat that and then you
 586 can go and do that or this", you know do a distraction. But in the end we all
 587 just sort of gave up because you can't just the hours of kind of tantrums and
 588 stuff - tantrums, that sounds awful, but the sort of, she was in so much
 589 emotional pain after she ate, just this kind of self loathing, it just all such (.)
 590 it just becomes (.) not too much effort but too exhausting. So eventually you
 591 just give up because you can't make her, she's a big girl you cant force her to
 592 eat. So I think everybody sort of got exhausted by it. And that sort of
 593 becomes the point where she needs to not be at home anymore, because
 594 when you haven't really got the reserves to have that fight anymore is when
 595 she needs to sort of not be at home.
 596 DM: And what was that like for you (.) when you knew she was not going to be at
 597 home?
 598 P1: I was quite relieved. I was the one pushing for it to be honest. Mum was
 599 saying at this meeting (.) the one before the time she was coming in, mum
 600 was saying oh "no she needs to be at home, I don't want her to be
- vs. unfulfilled life now.
- P1 (or family) are offering "reasoned talk"
- How is she identifying the ED?
- RELIEF
Relief at this being over.
- IMPACT ON MOOD
She's impacted by her sister's eating behaviour
- Earlier accounts ref. to Prison "her release date"
- Nothing works? come on [sister's name] you know, why
- Is her laughter representative of it being a 'joke' - she's fed up?
- HOW SHE HELPS
Encouragement
- P1 & her parents as one.
- P1 & PARENT AS UNIT
childlike
- P1 talks a lot about 'distraction'
- She's also little sister
- POINT WHERE YOU NEED OUTSIDE HELP
- Previous exhaustion
- SIBLING ROLE OF NOTICING & VOICING
- She's giving Parents an alternative view - rational? or fed up?

601 PI IS
602 DOING
603 A GOOD
604 THING?
605 MEDICAL
606 FACTS TO
SUPPORT IT

owns this
sectioned, and all this". And I was the one that was say no this is ridiculous
now, she's tried to kill herself, she weighs something like 30kg, this is
③ ridiculous. She had this kind of physically exam and her heart rate was down
to 50, or something, so I said you know this is getting physically dangerous
now, this is ③ ridiculous. So I was the one pushing for it, I was relieved ① in a
way. It was awful when she went it was awful, but I was quite relieved ①

Sort of
Palindrome?
[1, 2, 3, 3, 3, 2, 1]

PARENTS
WONT NOTICE
ALL THIS
WITHOUT
SIBLING SAYING
IT?

Appendix 23: Example of initial coding and analysis of data extracts from one transcript

Themes	Codes	Line Number	Extract	Reflection/analysis
	Impact on home life	57	The worst bit was when she was at home.	<i>The impact of her presence was felt most at home.</i>
		61	...when you're homesick, home seems like the perfect place, and that, and I couldn't wait to go home. Then I'd go home and it would just be awful, like just like fights, and just horrible, and then I would think "I cant wait to go back"	<i>Home is no longer a safe space for Hannah. Sister as cause of home not being home...(developmentally, Hannah went away from the safe base and when she got back it wasn't a safe base any more</i>
		67	...home's not, how I remember	<i>How much of this is changes with being at university?</i>
		573	It makes me feel so depressing when she just sits there with a tiny bit of vegetable she's agreed to eat and then just <u>pushes</u> it around the plate. It's just <u>so depressing</u> .	<i>Coded also for impact on emotions/feelings – the act of not eating (after saying she would?) has caused change in feeling for Hannah.</i>
	Impact on sibling relationship	109	it was quite gradual, there was no kind of massive point where we stopped speaking or anything	<i>Coded also for a natural change to the relationship – would this have happened anyway?</i>
		352	I haven't really missed her that much when she's been away	<i>Quite a bold statement, interesting as she has also been away so would she have equally not missed her had she been at home?</i>
		135	I don't really have much of a relationship with her anymore	<i>Reference to past relationship – historical closeness</i>
		351	Well (..) I hope we can get it back on track	
		358	I think we can sort of get back once she's better. I don't think it's a permanent kind of damage; I hope not anyway	<i>Hopeful for the future – just a 'blip?'</i>
	Impact on parent	130	It's obviously hard for mum and dad, like they're obviously much more stressed upset everything	<i>Obviously - statement to acknowledge/understand parents. But perhaps justification for her?</i>
		135	...obviously they've got a lot of stresses, so that's changed in a way	<i>Again obviously – justification for change in her time with them?</i>
		278	I feel angry for what she's done to mum and dad	<i>Plus emotional impact – feelings of anger</i>
		371	Yea it's a really depressing atmosphere. You can't really blame them. But it is quite depressing	<i>Is she suggesting she maybe has some blame for them?</i>

Appendix 24: List of codes from the 'coding manual'

1	Acceptance and understanding	51	Family support wasn't helpful
2	Acceptance of situation	52	Family therapy as helpful
3	Acknowledgment of sister's emotions	53	Fear
4	Active choice in relationship change	54	Finding out information - having questions
5	Active choice to not let it impact	55	Finding out information through family therapy
6	Active role in avoiding impact	56	Focus is on sister
7	Affirming position within the family	57	Focused on own life
8	Age brings knowledge	58	Frustration at sister's behaviour
9	Age impacts on understanding	59	Gaining from personal experience
10	Always the focus at home	60	Gender differences
11	Anger	61	Giving in for sake of parents
12	Attending family therapy	62	Gradual development
13	Avoiding talking about it	63	Grasping the severity of it
14	Awareness in society	64	Growing up quickly
15	Balancing the approach	65	Growing up vs. impact of diagnosed 'ED'
16	Being nice to her	66	Guilt
17	Being the only child at home	67	Hard being around her
18	Boyfriend sees less than sibling	68	Hard to access support
19	Change in context of their 'normal' relationship	69	Hard to talk
20	Change to sibling relationship	70	Hard to trust her
21	Changing the subject	71	Hard to watch her not help herself
22	Cheering the family up	72	Hard work
23	Consuming topic	73	Having other interests
24	Contrasting feelings	74	Hearing about the 'ED'
25	Contrasting views	75	Helpful label
26	Controlling	76	Helpful listening in family therapy
27	Conversations with sibling are not mutual	77	Helpful talk
28	Coping - distancing	78	Helpful talk in family therapy
29	Cycles of feeling	79	Helpful to express feelings and feel heard
30	Developing an understanding	80	Helplessness
31	Developmental changes vs. impact of eating difficulties	81	Historical/past closeness
32	Differences to sister	82	Holding back
33	Differing views to parents	83	Holding things in
34	Difficulty explaining it	84	Hostile sibling relationship
35	Difficulty of living with the situation	85	How much you tell others
36	Difficulty of transitioning to adult, not knowing enough	86	How others might see things
37	Difficulty talking with diagnosed sibling	87	'ED' has a function
38	Dislike of talk about food and weight	88	Impact from society
39	Distance is helpful	89	Impact of sister's mood on participant's mood/tolerance
40	Distancing	90	Impact of wider context
41	Distraction	91	Impact on family life
42	Duty and responsibility	92	Impact on home life
43	Duty to be part of therapy.	93	Impact on mealtimes
44	Empathy toward sister	94	Impact on parent's relationship
45	Exhaustion	95	Impact on parents
46	Extended family support	96	Impact on relationship with parents
47	Families' focus	97	Impact on school life
48	Family adapts to diagnosed sibling	98	Impact on sibling relationship
49	Family can't do it all	99	Impact on sibling's life
50	Family role in intervention	100	Impact on social life

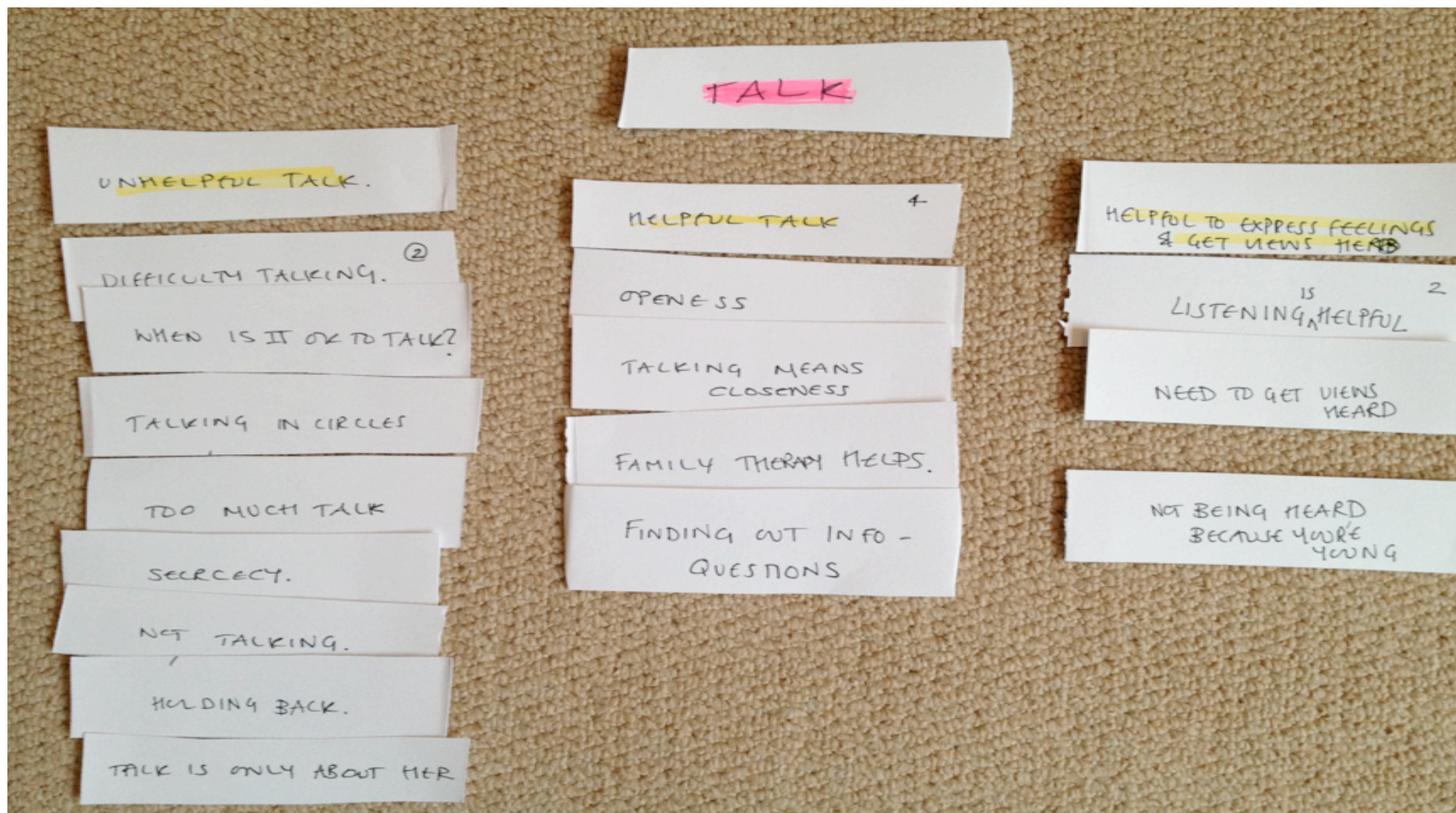
101	Impact on the family system	154	Out of the loop
102	Impact upsets sibling	155	Parent able to do more
103	Improved relationship with other siblings	156	Parent and participant as a unit
104	Increased awareness of food and eating	157	Parent and participant as unit
105	Increased responsibility at home	158	Parent feels guilt
106	Increased responsibility with diagnosed sibling	159	Parent knows more
107	Information helps understanding	160	Parent provides information
108	Information kept from younger siblings	161	Parent vs. sibling understanding
109	Initial denial of 'ED'	162	Parent's are more involved in support
110	Intense emotions	163	Parent's not as aware of it
111	Intense fear	164	Parent's taking a hard line
112	Isolation	165	Parents are aware of impact
113	It's the main focus	166	Parents as 'gatekeepers' of information
114	Just a phase	167	Parents don't always comment on eating
115	Keeping it in the family	168	Participant and parents as a unit
116	Keeping separate aspects of life	169	Peers can't always support
117	Knowing was a shock	170	People will gossip
118	Label leads to identity	171	Personal vs. theoretical knowledge
119	Lack of support	172	Physical vs. mental illness
120	Learning as a family	173	Reassuring sister
121	Less impact when distanced	174	Recovery needs a different approach
122	Life goes on	175	Recovery' does not mean she's ok
123	Listening is helpful	176	Relief
124	Living without sister at home	177	Retrospective/ hindsight
125	Long process	178	Role of sibling as secret keeper
126	Looking out for parents	179	Roles blurred
127	Making it easier for parents	180	Secrecy
128	Making sense of it	181	Separate life
129	Manipulating	182	Sibling as a messenger
130	Meeting professionals	183	Sibling as role model
131	Mental health component to it	184	Sibling is the golden one
132	Messenger	185	Sibling relationship impacted by diagnosed sibling's mood
133	Misconceptions of 'ED'	186	Sibling role of responsibility
134	Monitoring sister	187	Sibling role is different to parent
135	More arguments with sister	188	Sibling role of being 'rational'
136	Mutual coping skills for siblings	189	Sibling role of being present
137	Natural differences between siblings	190	Sibling role of being proactive
138	Need to get your view heard	191	Sibling role of offering perspective
139	Negative impact on the family system	192	Sibling role reversal
140	Not being heard because you're young	193	Sibling sees something different to parent
141	Not burdening parents	194	Sibling's can have a specific role
142	Not initially concerned	195	Sibling's focus changed not participant
143	Not keeping things inside	196	Sibling's own relationship with food
144	Not talking	197	Sister as different
145	Not talking to anyone	198	Sister in charge, getting what she wants
146	Not wanting to know more	199	Spending time with others
147	Noticing	200	Stage in development where diet/food talk is present
148	Noticing change gradually	201	Stigma of accessing help
149	Ongoing difficulties	202	Sudden change in the situation
150	Only parents notice some things	203	Suddenly finding out
151	Openness	204	Support -ideas for helpful talk
152	Other focuses in life	205	Support - how you talk
153	Others can't change -diagnosed sibling needs to		

206	Support for siblings	226	Unseen risk to siblings
207	Support from peers	227	Unsure about how to manage the situation
208	Support outside of family therapy - their own support	228	Unwell sister aware of impact
209	Talking helps	229	Unwell sister causes changes to sibling relationship
210	Talking in circles	230	Visiting sister
211	Talking means closeness	231	Wanting a structure to it
212	Telling and letting people know	232	Wanting to know more
213	Telling parents information	233	Watchful eye
214	Things you don't talk about	234	Watching is helpful for participant
215	Time of not knowing	235	Watching/keeping an eye on her
216	Too much talk	236	What is her and what is the 'ED'?
217	Trying to be less watchful	237	When is it ok to talk?
218	Trying to help diagnosed sibling	238	Wider context around difficulties
219	Trying to normalise the situation	239	Wider family context
220	Unable to watch her	240	Words and diagnoses
221	Uncertainty is upsetting	241	Work as a distraction
222	Understanding of support	242	Worry
223	Understated worry	243	Worry about what impact might be
224	Understating		
225	Unhelpful talk in family therapy		

Appendix 25: Examples of coded extracts from across the data set

Initial code	Extract (line number)
Distraction (41)	I sort of like try and think of other things, coz like exams and stuff, I don't want to be thinking about that the whole time. (Rachel, 279 – 281)
	It's hard, it's a bit of a rollercoaster like my emotions are very kind of up and down. Like when I'm, if I'm at uni and I'm busy in the day and stuff its great coz I <u>literally</u> completely forget about it. Then at night I sort of think about it. Then I come home and it's really down and stuff. But, I don't know, yea it's very up and down. Um, I'm quite kind of a coping person, I just try and like keep busy get on with it, I don't really stop and think that much (coughs), otherwise you get nothing done, you just sit around moping, that's completely not me. (Hannah, 492 – 501)
	Like talking to someone about it, like therapy or family therapy. And having lots of distractions / DM: Ok / to not make you think about it. Like I don't think... Thinking about it's like the worst thing to do. Coz it gets you worried about stuff that you shouldn't be worried about, coz it's going to be fine in the end (Rachel, 767 – 772)
	Well yea. When I'm with people who don't know, I kind of forget about all of this. (Nina, 536 – 542)
	I just give myself time to do revision and..if stuff like that was going on, it almost helped to get away from you know, maybe stresses at home and just you know, focus on my work (...) you know, to give me something to focus on instead of that, so it was quite..it was quite good, yea. (Michelle, 724 – 727).
	I just got on with (...) it (Emma 1086)

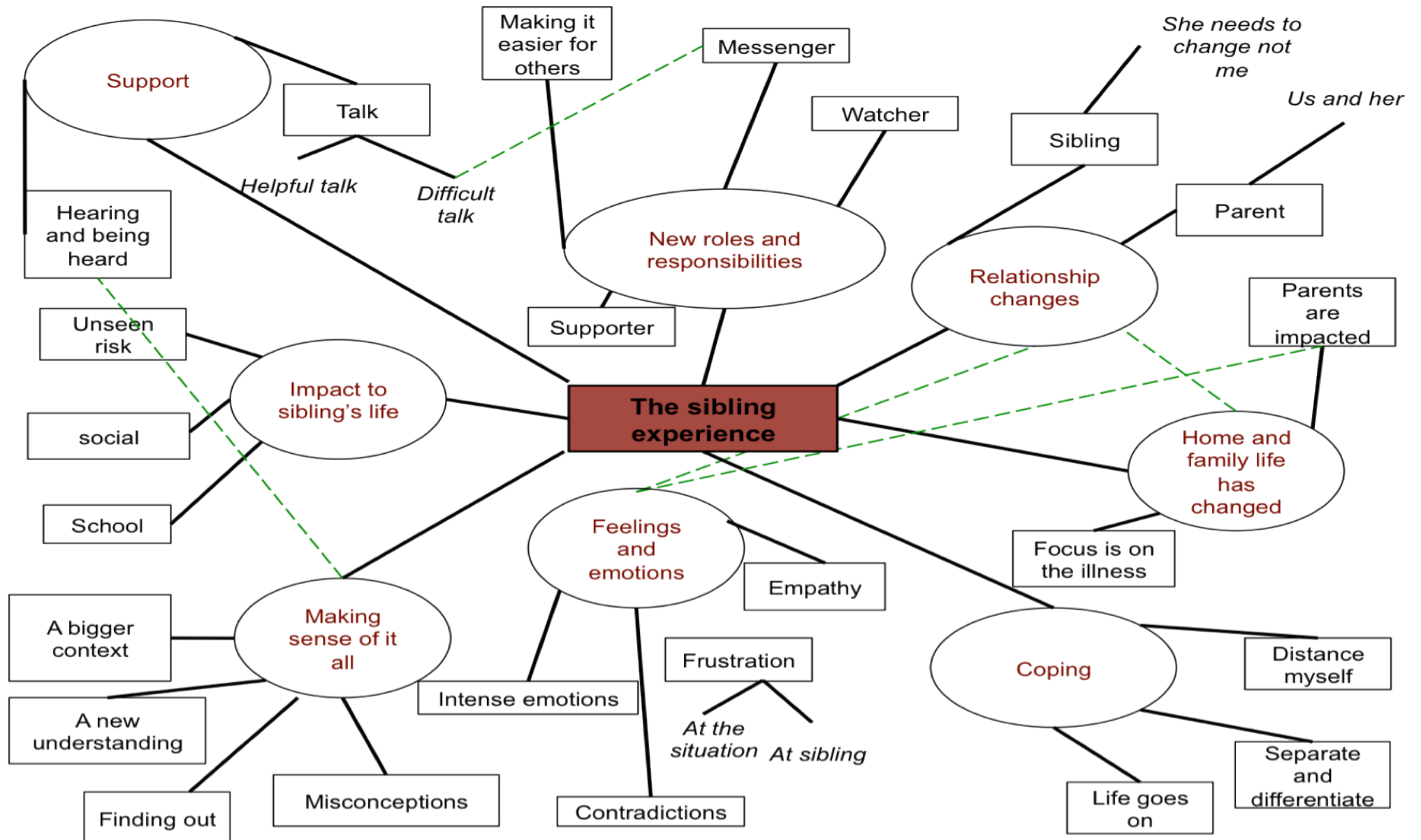
Appendix 26: Example of visual representation of initial themes



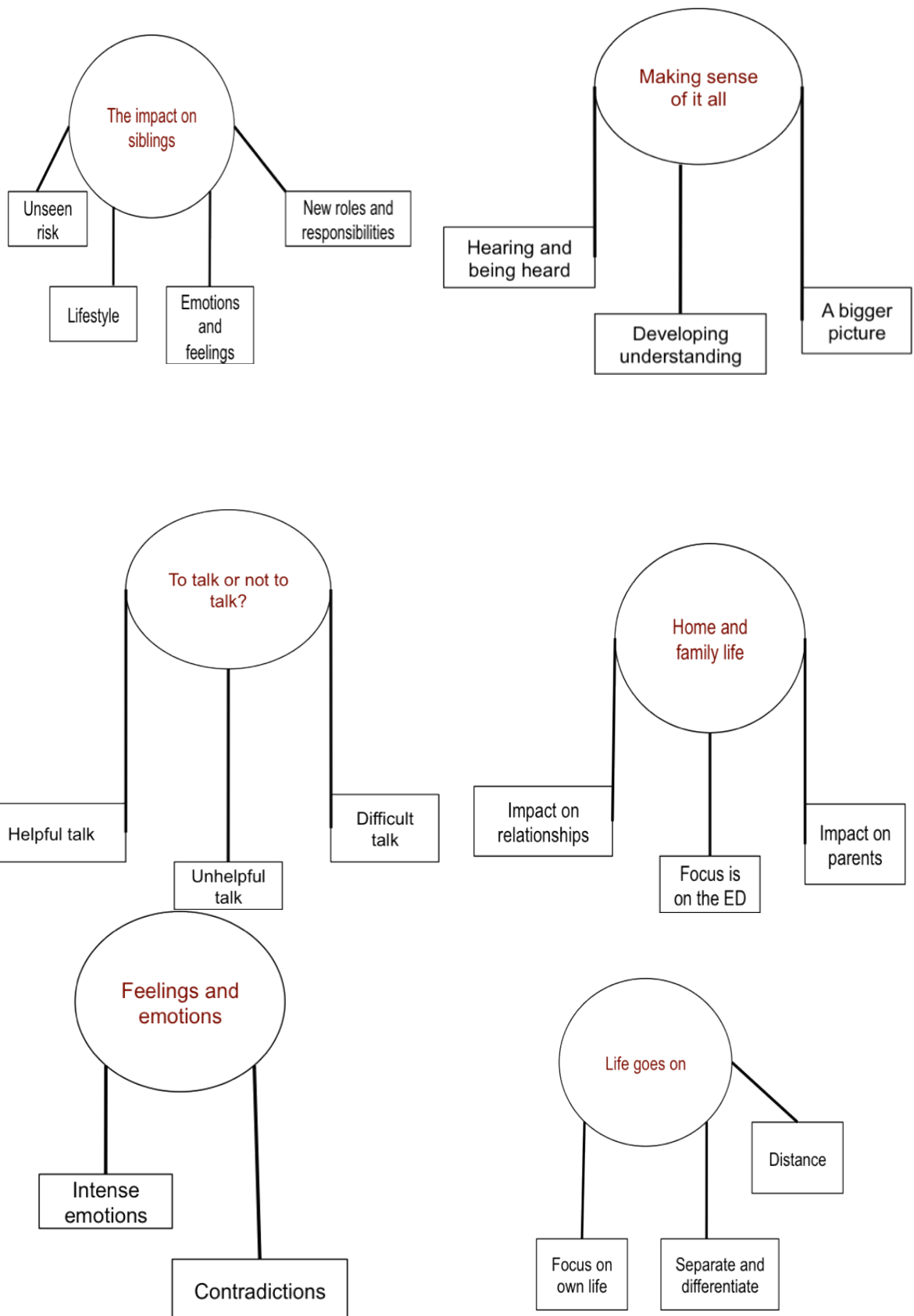
Appendix 27: Provisional themes

1. Finding out
2. Making sense of the situation
3. New understanding
4. The context around the 'ED'
5. Home and family life has changed
6. Relationships have changed
7. Impact on sibling's life
8. Impact on parents' lives
9. New roles and responsibilities
10. Talk
11. Hearing and being heard
12. Feelings and emotions
13. Contrasting views and feelings
14. Coping and getting on with it
15. Support

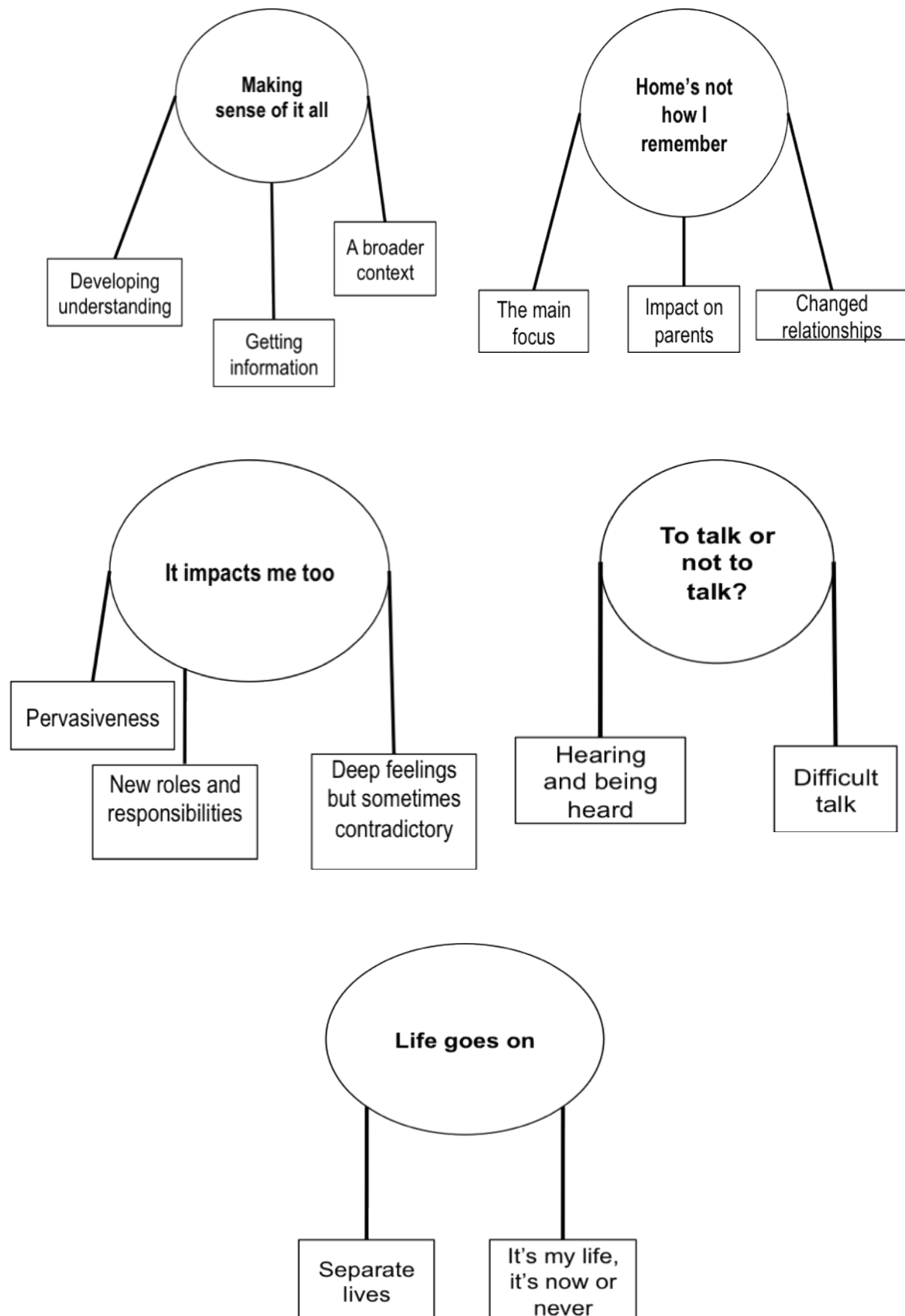
Appendix 28: Thematic maps (1)



Appendix 28: Thematic maps (2)



Appendix 28: Thematic maps (final map)



Appendix 29: Theme memorandums

Name of Theme	Definition	Interest/relevance to research question
1. Making sense of it all	The process of developing an understanding about the diagnosis and their sister in relation to this.	Personal experience had challenged previous ideas siblings held. It seemed there were a number of aspects of understanding that sibling's were trying to make sense of within their own situation and diagnoses of 'ED' in general. They were mindful of the wider context and other difficulties impacting the situation as well as misconceptions of others.
<i>Developing understanding</i>	<i>Refers to the continual, ongoing process of understanding.</i>	<i>Participants' spoke about their understanding as continually developing rather than being fixed. 'Accurate' understanding seemed to be contingent on having had personal experience (vs. theoretical knowledge). Participants also spoke about the challenges of explaining it to others.</i>
<i>Getting information</i>	<i>The importance of acquiring information and ways in which this was done. This contributed to how siblings made sense and understood the experience.</i>	<i>There were challenges to this including parent's not always passing on information for fear of 'upsetting'. Equally not being able to hear from their sister diagnosed with an 'ED' could be a challenge to this.</i>
<i>A broader context</i>	<i>Refers to what else may be going on, firstly around their sister's difficulties, and secondly the impact on their (the participant's) life.</i>	<i>Siblings spoke about their sister's difficulties in the context of other events, such as family difficulties. There was also questioning talk about the impact they experienced as perhaps being related to the wider context of developmental changes</i>

2. Home's not how I remember	An extract from an interview. Refers to the prominent changes sibling's experienced at home and in family life.	The impact on home and family life appeared to be felt as much as the impact on the siblings themselves. In many ways the two can be seen as linked. However, the theme highlights specific influences on the system experienced by a member from within. It also relates to the possible natural family life cycle changes, as siblings grow.
<i>The main focus</i>	<i>Family talk, lifestyle and behaviour all focused on sister and the 'ED'.</i>	<i>The family was seen as 'consumed' by the experience. Regardless of what was going on the participants life, it felt as though the focus was on their sister and the 'ED'.</i>
<i>Impact on parents</i>	<i>The changes to and impact on the lives of parents.</i>	<i>Participants expressed a range of emotions in relation to the impact of the difficulties on their parent's lives and marital relationship. This could be seen by some as a more prominent impact compared with how they viewed the impact on their own life</i>
<i>Changed relationships</i>	<i>The changes siblings experienced to family relationships, both with parents and siblings.</i>	<i>The sibling relationship was often described in relation to a 'historical closeness', but had changed as a result of their sister being different. Whereas some participants hoped for this closeness in the future, siblings felt this was out of their control and dependant on their sister changing. Some acknowledged the change being related to natural developmental change. Parent relationships had also changed; mostly as a result of reduced time spend with them. I was interested in the use of "we" to describe parent and participant views. Siblings appeared to want to align themselves with parents, perhaps related to their new roles and responsibilities, or wanting to feel 'part of the family'.</i>

3. It impacts me too	Refers to the impact on siblings.	The name aims to capture the view that often the impact is felt as though it is 'unseen' by others.
<i>Pervasiveness</i>	<i>The impact spoken about across many aspects of life.</i>	<i>This included school life, social relations and activities and eating thoughts and behaviours. This was present in previous literature.</i>
<i>New roles and responsibilities</i>	<i>This sub-theme refers to the new roles or duties siblings took on, and the responsibilities which came with these.</i>	<i>Siblings took on roles of messenger, watcher, and/or supporter of their sibling. They also had a role in 'making things' easier' for their parents by taking on more responsibility and not burdening them.</i>
<i>Deep feelings but sometimes contradictory</i>	<i>The range of intense emotions siblings could experience toward their sister and/or the situation.</i>	<i>Siblings experienced a range of emotions, which were at times expressed through contractions.</i>
4. To talk or not to talk?	The aspects of talk that could impact on whether siblings felt able to be heard and hear from others, and the challenges associated with talking.	Talk could be thought about as helpful, unhelpful, and at times, difficult. This included talk with professionals, with their family and with their sister. The question aspect of the theme name aims to reflect a process of deciding whether it would be helpful to talk or refrain from doing so.
<i>Hearing and being heard</i>	<i>Situations and conversations that allowed siblings to feel their views had been heard, and equally they could hear from others.</i>	<i>This related to both family and 'professional' talk. Talk in settings such as family therapy could allow for more assurance that people would listen to each other's views, allowing siblings could feel able to get their point across. However the opposite could also be true, with siblings mindful of talking in front of parents. Age may also be a challenge to feeling heard. Siblings wanted to be able to hear from others, although this could again be challenging given perceived concerns about causing them upset.</i>

<i>Difficult talk</i>	<i>The talk that was necessary but had become difficult.</i>	<i>This related to feeling things needed to be said but could not be expressed for fear of upsetting others. This often related to talk between the siblings, which felt as though it required the participant to 'hold back' in conversation. This also related to talk that could be consumed with the 'ED' or with no resolution.</i>
5. Life goes on	Defines coping skills	The name aims to capture the determination felt what sibling's were expressing.
<i>Separate lives</i>	<i>Methods of separating out their life from their sisters.</i>	<i>Siblings aimed to view aspects of their life as separate, and seemed to want to identify their sister (and the diagnosis) as different from them. The use of distraction and differentiation helped with this. Often this was heard through what participants directly said, as well as through more subtle accounts.</i>
<i>It's my life, it's now or never</i>	<i>An active approach to coping with the experience, siblings made efforts to focus on their own future.</i>	<i>Almost a sense of 'urgency' in doing this, because the impact could be worse if they did not focus on their own lives. Siblings were clear about focusing on aspects of their own future.</i>