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University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

**Title:** Eating Disorders: Sibling Experience and Implementing Externalisation in FBT

**Systematic Review:** The Experience of Healthy Siblings of People with Eating Disorders: A Systematic Review and Thematic Synthesis

**Empirical Study:** Mental Health Clinicians' Perspectives on Implementing Externalisation in Family-Based Treatment

Katie Lonergan

Under the Supervision of Dr Christian Ryan

Wordcount: 28, 561




University College Cork

School of Applied Psychology

May 2020

**Declaration**

*This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism.*

**Signed:**  **Date: 07/05/2020**

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## Abbreviations and Terminology

| | |
|---|---|
| ED | Eating disorder |
| AN | Anorexia nervosa |
| BN | Bulimia nervosa |
| EDNOS | Eating disorder not otherwise specified |
| FT | Family therapy |
| SR | Systematic review |
| MRP | Major Research Project |
| Healthy sibling | In this paper to clearly differentiate between siblings, the sibling without the ED will be referred to as the 'healthy sibling' (or 'participant' within the results section) |
| YP's | Young Person's |
| YP | Young People/Young Person |

# Chapter One

## Background Literature

This portfolio aims to explore aspects of family therapy (Major Research Project; MRP) and the family member experience (Systematic Review; SR) in families where one individual has an eating disorder (ED). This chapter will give a brief introduction to family therapy development in the context of EDs. This will include a discussion of the initial "psychosomatic families" explanatory model (Minuchin, Rosman & Baker, 1978), its reformulation over time (Eisler, 2005), and a review of the current day gold-standard approach to family therapy in EDs, family-based treatment (FBT; Lock & Le Grange, 2013).

Since the earliest development of psychological research focusing on children and adolescents, the parent-child relationship has been recognised as important in understanding the aetiology, maintenance and experience of mental health difficulties in young people (YP; Feinberg, Solmeyer & McHale, 2012). Over the past forty years, systemic theory has influenced the field of mental health. For instance, through family systems theory (Bowen, 1978), which posits that individuals can not be understood in isolation but as part of a complex and dynamic family group; ecological systems theory (Bronfenbrenner, 1979) which suggests that the family system can be affected by events from the external environment, society and culture; and the idea that within the family system, core subsystems exist which influence each other and change over time (Dodge, 2016; Minuchin et al., 1978; Yu & Gamble, 2008). These theories led researchers and clinicians to begin to look at the family as a system which encompassed several different, influential subsystems, which interacted and impacted on one another (Dodge, 2016). Research on the mental health of children and YP slowly began to focus on other relationships in the YP's life including the interparental and sibling relationships (East, 2009; Feinberg et al., 2012).

This shift in understanding YP with mental health difficulties within the context of their families was apparent in the area of EDs. In the past, interventions and therapies for targeting EDs favoured working with the affected person individually and did not include the family in treatment (Dodge, 2016; Eisler et al., 2016). Family (namely, parents) were viewed as "harmful" to the individual and as having contributed to both the cause and maintenance of the ED (Dodge, 2016, p. 220). This resulted in interventions where the affected person was separated from their family throughout treatment (Dodge, 2016; Lock & Le Grange, 2013). The move away from therapy aimed only at the affected individual and towards family-based interventions began with Minuchin et al's. (1978) work on "psychosomatic families". Minuchin et al. (1978) developed an explanatory model of family functioning in which they reported that the transactions and patterns which existed within families led to the development of ED symptoms and subsequent diagnosis (Dodge, 2016). Their way of working included intervening with the whole family to change patterns they identified as causing and maintaining the ED such as enmeshment, overprotectiveness, rigidity, conflict avoidance/lack of resolution (Minuchin et al., 1978). Although influential, the empirical basis of this explanatory model was not validated and it was largely challenged within the field (Dodge, 2016). A 2014 systematic review which focused on family functioning suggested that families with an ED have poorer family functioning than control families (Holtom-Viesel & Allan, 2014). However, the majority of studies included within the review did not support the psychosomatic family model of ED development and found no consistent type of family organisation in families where one member had an ED (Dodge, 2016; Eisler, 2005; Holtom-Viesel & Allen, 2014).

While Minuchin et al's. way of working with family systems rather than with individuals was challenged, it continued to play a central role in interventions aimed at treating EDs in young people (Minuchin et al., 1978). Over time this explanatory model was

reformulated and the family began to be viewed as a "resource in treatment" rather than a "dysfunctional system to be treated" (Eisler, Wallis, Dodge, Le Grange & Lock, 2015, p. 6). This new model of understanding was developed in line with the perspectives around how families accommodate to chronic physical illness (Steinglass, 1998). Eisler (2005) posited that rather than being part of the aetiology of the disorder, the family system played a role in the maintenance of the ED through reorganisation and reinforcement of the ED behaviours (Dodge, 2016). This theory underpinned Maudsley Family Therapy (MFT; Eisler, 2005) and later FBT (Lock & Le Grange, 2013), two family therapy interventions developed specifically for EDs. MFT and FBT combined principles and techniques from family therapy approaches such as structural family therapy (Minuchin et al., 1978), Milan Systems therapy (Selvini & Palozzoli, 1998; Selvini-Palazzoli, 1978) and Narrative therapy (White, White, Wijaya & Epston, 1990; Simic & Eisler, 2018). One key difference of the MFT/FBT approach was that rather than using an explanatory model which viewed the family as dysfunctional, they viewed the family from a new perspective of accommodating to the ED rather than causing it (Eisler et al., 2016; Lock & Le Grange, 2013). This explanatory model suggested that family reorganisation resulted in the ED becoming a central part of family life, a narrowing of focus on the present or here-and-now for family members which caused distress and overwhelm, patterns of daily life becoming rigid and inflexible, and a dominant feeling of helplessness within the family (Eisler, 2005; Simic & Eisler, 2018).

The first intervention (MFT) based on Eisler's reorganisation model was developed by a team of clinicians in London's Maudsley Hospital in the 1980s (Eisler et al., 1997). This model was introduced by Daniel Le Grange (a member of the team in the Maudsley hospital) to clinicians and researchers in the United States in the 1990s and was consequently renamed FBT, manualised, and involved in much clinical effectiveness research (Loeb & Le Grange, 2009). FBT is a short-term intervention that has been shown to be effective in working with

children, adolescents and young adults with anorexia nervosa (AN) and adolescent bulimia nervosa (BN; Le Grange & Chen, 2007; Le grange & Lock, 2009; Lock & Le Grange, 2013). Current guidelines for the treatment of adolescent AN by the National Institute for Health and Care Excellence (NICE, 2017), the American Psychiatric Association (APA, 2006) and the Health Service Executive's Model of Care for Eating Disorders (HSE, 2018) suggest the use of family therapy as a first line intervention. This model recommends that therapy is a whole family process and that both parents and siblings are involved throughout.

FBT encompasses three main phases and is carried out over twenty sessions (Lock & Le Grange, 2013). Phase I is focused on restoring the YP's weight with a focus on reducing parental guilt and supporting the refeeding process. The focus of phase II is to support the family to give control of eating back to the YP. ED symptoms and weight gain are the main focus in this phase, however, other family issues can be discussed and explored throughout. The family then transition to the final stage of treatment once the YP has achieved a stable weight within normal levels. The final phase focuses on supporting healthy adolescent – parent relationships, exploring autonomy, and boundaries (Lock & Le Grange, 2013). The FBT model takes an agnostic view of the aetiology of the eating disorder with little interest being paid to how or why the ED developed (Loeb & Le Grange, 2009). Responsibility for feeding the YP is handed over to parents, and therapists try to encourage, empower and support parents in this role (Lock & Le Grange, 2013). The FBT therapist takes a neutral position within the family and tries to maintain a therapeutic relationship with all family members (Eisler et al., 2016). Finally, the model aims to separate the YP from the ED through a process of externalisation (Lock & Le Grange, 2013).

This portfolio sets out to understand two important areas relating to the family within the context of EDs: (i) the experience of healthy siblings when a sibling experiences AN through systematic review of the literature within the field and (ii) clinicians' perspectives

and views on the use of externalisation (in the context of FBT) through an original, empirical study. The chapters which follow will include: an extended review of the methodological choices and decisions made for both the SR and the MRP; an SR of the experiences of healthy siblings in the context of EDs; an MRP which focuses on the perspectives of clinicians using externalisation, an important therapeutic technique within FBT; and a final discussion and conclusion chapter.

**References**

American Psychiatric Association. (2006). Treatment of patients with eating disorders, American Psychiatric Association. *The American Journal of Psychiatry*, *163*(7 Suppl), 4.

Bowen, M. (1978). Family therapy in clinical practice. Northvale, NJ: Jason Aronson. *Social Interest*, *291*.

Bronfenbrenner, U. (1979). *The ecology of human development*. Harvard university press.

Dodge, E. (2016). Forty years of eating disorder-focused family therapy–the legacy of 'psychosomatic families'. *Advances in Eating Disorders*, *4*(2), 219-227.

East, P. L. (2009). Adolescents' relationships with siblings. *Handbook of adolescent psychology*, *2*, 43-73.

Eisler, I. (2005). The empirical and theoretical base of family therapy and multiple family day therapy for adolescent anorexia nervosa. *Journal of Family therapy*, *27*(2), 104-131.

Eisler, I., Dare, C., Russell, G. F., Szmukler, G., le Grange, D., & Dodge, E. (1997). Family and individual therapy in anorexia nervosa: A 5-year follow-up. *Archives of general psychiatry*, *54*(11), 1025-1030.

Eisler, I., Simic, M., Blessitt, E., & Dodge, L. & Team. (2016). Maudsley service manual for child and adolescent eating disorders (Revised). London: Child and Adolescent Eating Disorders Service, South London and Maudsley NHS Foundation Trust. Available at: http://www.national.slam.nhs.uk/services/camhs/camhs-eatingdisorders/resources

Eisler, I., Wallis, A., Dodge, E., Le Grange, D., & Lock, J. (2015). What's new is old and what's old is new: The origins and evolution of family therapy for eating disorders. *Family therapy for adolescent eating and weight disorder: New applications. Florence, KY: Routledge*.

Feinberg, M. E., Solmeyer, A. R., & McHale, S. M. (2012). The third rail of family systems: Sibling relationships, mental and behavioral health, and preventive intervention in childhood and adolescence. *Clinical Child and Family Psychology Review*, *15*(1), 43-57.

Holtom-Viesel, A., & Allan, S. (2014). A systematic review of the literature on family functioning across all eating disorder diagnoses in comparison to control families. *Clinical Psychology Review*, *34*(1), 29-43.

Health Service Executive (2018) *Eating disorder services HSE model of care for Ireland* Available at: https://www.hse.ie/eng/about/who/cspd/ncps/mental-health/eating-disorders/ [Accessed 06 December 2019]

Le Grange, D., & Chen, E. (2007). Family-based treatment for young adults with anorexia nervosa. *Unpublished Manual. Chicago: Univ Chicago*.

Le Grange, D., & Lock, J. (2009). *Treating bulimia in adolescents: A family-based approach*. Guilford Press.

Lock, J., & Le Grange, D. (2013). *Treatment manual for anorexia nervosa: A family-based approach*. Guilford Publications.

Loeb, K. L., & le Grange, D. (2009). Family-based treatment for adolescent eating disorders: Current status, new applications and future directions. *International Journal of Child and Adolescent Health*, *2*(2), 243.

Minuchin, S., Rosman, B. L., Baker, L. (1978). *Psychosomatic families: Anorexia nervosa in context*. Cambridge MA: Harvard University Press.

National Institute for Health and Care Excellence (2017). *Eating disorders: recognition and treatment* (NICE guideline NG69). Available at: https://www.nice.org.uk/guidance/ng69/chapter/Recommendations [Accessed 06 December 2019].

Selvini-Palazzoli, M. (1978). Self-starvation: From the intraphysique to the transpersonal approach. *Londres: Chaucer*.

Selvini, M., & Palazzoli, B. (1998). *Paradox and counter-paradox*. Jason Aronson Incorporated.

Simic, M., & Eisler, I. (2018). Maudsley Family Therapy for Eating Disorders. In *Encyclopedia of Couple and Family Therapy* (pp. 1-9). Springer, Cham.

Steinglass, P. (1998). Multiple family discussion groups for patients with chronic medical illness. *Families, Systems, & Health*, *16*(1-2), 55.

White, M., White, M. K., Wijaya, M., & Epston, D. (1990). *Narrative means to therapeutic ends*. WW Norton & Company.

Yu, J. J., & Gamble, W. C. (2008). Pathways of influence: Marital relationships and their association with parenting styles and sibling relationship quality. *Journal of Child and Family Studies, 17*(6), 757-778.

# Chapter Two

## Extended Methodology

The purpose of this chapter is to give a detailed account of the methodology followed in both the MRP and the SR which goes into more depth than was possible in the individual research papers. Aspects of the methodologies that overlapped e.g. epistemological positioning will be discussed first, followed by a section which describes the specific methodological considerations for each piece of research.

### Qualitative Framework

Both the SR and the MRP within this portfolio aimed to explore the experiences, perspectives and views of individuals within the context of either working with YP who have an ED or having a sibling with an ED. Qualitative research/synthesis was seen as most fitting for both pieces of research in order to gain detailed and rich descriptions of the experiences of these individuals (Stainton-Rogers & Willig, 2008). When beginning a qualitative study, it is important to locate the study in a qualitative paradigm and to define the methodological approach that will be used when collecting, analysing, and producing the research (Braun & Clarke, 2013). Within a qualitative paradigm, several assumptions are made about the generation and analysis of qualitative data. These include: an understanding that insightful knowledge can be generated by focusing on the meanings that are attributed to experiences in small cohorts of participants; that the focus of the research is not to prove a hypothesis but to understand the meaning of the experience or phenomenon for the participant; that the subjective experience of the researcher involved carrying out the qualitative research becomes part of the research process and they cannot be seen as separate from the development, analysis and write up of the research; and that knowledge is viewed as contextual i.e. a reality of the context which it was generated within (Braun & Clarke, 2013;

Terry, Hayfield, Clarke & Braun, 2017). The current research approached the data with an experiential focus. Theoretically, the views, thoughts and feelings expressed by participants were viewed as reflecting the reality of their experience and that of their clients. The theoretical assumption which underpins this approach views language as reflecting reality rather than creating reality, as seen in critical approaches to research (Braun & Clarke, 2006; Terry et al., 2017).

**Rationale for Qualitative Methodology**

The current research studies aimed to review a) the experience of siblings of people diagnosed with an ED through a systematic review and b) to explore the perspectives and views of clinicians using externalisation with adolescents in the context of FBT. A qualitative methodology was deemed most appropriate to the research aims as the methods used allow for in-depth discussion of topics of interest that are not easily researched within a quantitative framework. Furthermore, a qualitative framework facilitates the development of rich description and understanding of individuals' experiences (Braun & Clarke, 2013; Stainton-Rogers & Willig, 2008). While there is a wealth of research in the area of EDs, many of these studies use a quantitative framework (Colton & Pistrang, 2004). Within the areas specific to this research study i.e. FBT (MRP) and siblings' experiences (SR) there are many quantitative studies focusing on the effectiveness of the model, clinician fidelity to manualised FBT, and studies which focus on factors such as genetics, personality, and environment on the development of an ED. However, less qualitative research has been conducted within these areas (Fjermestad, Espeland, Halvorsen & Halvorsen, 2019). Where qualitative research has been carried out, for example in studies focusing on the YP's experience of FBT or siblings' experiences of EDs, helpful insights and understandings have been developed. Considering the above information alongside the nature of the research

question, and aims of the research for this study, a qualitative methodology was considered most appropriate.

## Epistemology

The branch of philosophy which is related to understanding how individuals come to acquire information and knowledge is known as Epistemology (Braun & Clarke, 2013). Research allows us to gain information on human experiences and gain access into how they understand the world around them. The research method that is chosen to generate and analyse data often comes with a number of assumptions related to how knowledge is understood, the impact of the researcher on the process of research, and how individuals make sense of their experiences and the world around them (Willig, 2012). Willig (2013) suggests that the epistemological positioning of the research, the role of the researcher and the assumptions made within the research should be outlined clearly prior to addressing specific methods (e.g. data collection methods, analysis) of the research to ensure the philosophical grounding of the study fits with how the study is approached.

### *Epistemological position*

This research project (SR and MRP) was approached from the position of critical realism. Maxwell (2012) described critical realism as combining "a realist ontology with a constructivist epistemology" (p. vii) and described this position as an understanding that there is a real world that is outside of individuals' experiences but that our knowledge of this world is understood and filtered through our own, independent perspective. The current research falls into this middle ground between realism and constructivism and views knowledge as accessible and attainable through research but also acknowledges the influence that individuals' perspectives, views, and experiences can have on this knowledge. Furthermore, in the context of the current studies, a critical realist perspective assumes that the researcher's

own experiences, perspectives and views will also be brought into the research process and will have an influence on the meaning derived from the data. For this reason, importance is placed on the subjectivity and reflexivity of the researcher undertaking the study.

*SR*: Siblings within the qualitative studies were viewed as giving reliable accounts of the experience of having a sibling with a diagnosed ED while it was also acknowledged that personal factors e.g. gender, education, socioeconomic status would influence how they perceived the world. Furthermore, it was acknowledged that the researchers who carried out the studies included in the SR would have brought their own perspectives, views, and experiences to the research as well.

*MRP*: Clinician participants were viewed as giving reliable accounts of both their own, and their clients experiences and perspectives of externalisation within the context of FBT. This knowledge was viewed as representing an objective reality that was shaped and moulded by the lens that the clinician viewed the world with. The researcher interpreted ideas and concepts about the data which were viewed as reflecting a truth related to the area of study while also acknowledging that the researcher's experiences and views would shape the collection, analysis and findings of the research.

## MRP methodology: Specific Considerations

Due to the restrictions on word count within the main MRP article, much of the detail related to the research process could not be comprehensively described. The next section gives additional information and context to the reader in relation to the research process for the MRP.

### *Development of semi-structured interview schedule*

Semi-structured interviews (see table 1, P. 92) were chosen as the method of data collection for this piece of research. Semi-structured interviews give space for participants to

openly explore ideas and concepts within the context of a focused set of interview questions (Galletta, 2013). Both opened-ended questions, and questions that relate to existing ideas and concepts can be used within a semi-structured interview format. This generates data that is based on both the experiences of the participants and the existing literature within the field (Kallio, Pietila, Johnson & Kangasniemi, 2016). Semi-structured interviews present some disadvantages when used in qualitative research such as the possibility of the interview being shaped or biased by the use of pre-decided questions. However, this method of data collection allows for flexibility and the exploration of new, unanticipated ideas that arise leading to the emergence of rich data from participants (Galletta, 2013).

When developing the semi-structured interview framework, the literature relating to FBT, externalisation, and the field of EDs more broadly was consulted. Initial drafts were reviewed, and feedback was received from a senior clinician working in the field. Further feedback was received from the research supervisor involved with this study. The semi-structured interview was used as a guide only during interviews with clinicians, with participants often beginning to explore areas included within the interview before the questions were asked. Questions outlined within the interview were open ended and exploratory in nature which allowed clinicians the space to consider, reflect on, and develop ideas throughout the interview (Galletta, 2013).

***Participant identification, recruitment and consent***

1. Once ethical approval for the study was given by the Clinical Psychology Research Ethics Committee (CPREC) in University College Cork, identification and recruitment of potential participants began. Potential participants were clinicians who had been trained in the FBT model and were working in CAMHS services in Ireland.

2. Recruitment of participants followed a protocol which had been developed by the research team and aimed to protect participant confidentiality. Initially, eligible participants received a letter of invitation which was composed by the main researcher. This letter of invitation (Appendix 6) was attached to an email and sent to all eligible clinicians by the clinical research supervisor involved with the study. Both in the letter of invitation and the main body of the email it was outlined that interested clinicians should email the main researcher (KL) directly and that throughout the research process the identities of the participants who took part in the research would not be known to anyone else involved in the research (i.e. the research supervisors).
3. Eight emails were received from interested participants and interviews were arranged at a time and place of their suiting. All interviews were carried out in the CAMHS services where the clinicians worked.
4. As part of the recruitment procedure, participants were informed about the voluntary nature of the research during initial phone contact. Following this, when meeting the clinician to conduct the interview they received an information leaflet (Appendix 7) which outlined the purpose of the study, the voluntary nature of the involvement, the method of interview recording (audio), and a time frame relating to withdrawal from the research.
5. After reading the information leaflet, participants read and signed a consent form relating to the above information. All participants signed the consent form prior to being involved in the research (Appendix 7).
6. Clinicians were then asked to complete a brief demographic questionnaire (Appendix 8). Following this, the interview took place.

### *Thematic Analysis*

While researchers working qualitatively with scientific data have been describing the identification of themes since the beginning of the twentieth century, guidelines on the use of thematic analysis (TA) have only been available over the past 30 years (Aronson, 1995; Terry et al., 2017). Even after the development of guidance for TA, explicit referencing of TA as a method and the process that was followed when conducting TA research was poor within the field of qualitative research (Braun & Clarke, 2006). A paper which had a significant impact in this area was published by Braun and Clarke (2006) and gave detailed guidance on the procedure involved in using TA to analyse qualitative data. Braun and Clarke's (2006) method has now become the most commonly used method of TA and was chosen as the guidance for this research project (Terry et al., 2017).

### *Rationale for choice of method*

Braun and Clarke's (2006) TA was used as the method of data analysis for this piece of research. This method of analysis involves identifying and extracting patterns from a dataset (in this case semi-structured interviews) to create themes that can then be interpreted by the researcher to understand and give meaning to data. This method consists of six phases of data analysis which are systematic and structured (Braun & Clarke, 2013). One advantage of TA is that it is a flexible method of analysis; TA is independent of any theoretical framework, ontological or epistemological positioning and does not come with any pre-defined method of data collection (Terry et al., 2017). It is reported to be accessible to researchers who are less advanced in using qualitative methodology, with access to a number of guidelines and phases that can be followed to ensure research quality and transparency throughout the process (Braun & Clarke, 2013).

Interpretive Phenomenological Analysis (IPA; Eatough & Smith, 2008) was considered as an alternative methodology for this research. However, while the current research aimed to produce knowledge which related to the human experiences of clinicians, it was not focused on gaining a deep understanding of their subjective, personal experiences or how they made sense of the phenomenon being researched. Instead the current research endeavoured to get a broader understanding of the patterns which were prevalent across the data relating to ideas and concepts about the use of externalisation, the experience for the family when a clinician uses externalisation and the participants clinical experience of using this technique. Furthermore, IPA relates closely to a phenomenological epistemology, an alternative position to that of critical realism taken in this study (Braun & Clarke, 2013; Eatough & Smith, 2008)

The aim of the current study was to gain an understanding of the views and perspectives of the clinicians using FBT, and specifically using the technique of externalisation. Clinicians in this study were not a homogenous group and had backgrounds in different professional disciplines e.g. social work, psychology and nursing. They also varied in years of experience and time using the FBT model. Therefore, the focus of this research was not on individual experience but the broader themes and concepts across the dataset. Little research has been carried out on how clinicians use the interventions outlined in the FBT model and therefore the research team felt that the flexibility that is inherent in TA would best suit the research aims, allowing for an understanding of the context within which the clinicians work to emerge and also leave space for findings which were not anticipated prior to conducting the research (Marks & Yardley, 2004)

### *Phases of Thematic Analysis*

Phase 1: Data familiarisation

The first phase of data analysis for this piece of research was familiarisation with the data. This stage of data analysis has been referred to as an "opportunity for ... immersion in the dataset" (Terry et al., 2017, p. 13). Familiarisation with the data began at an early stage, with the main author conducting and transcribing the eight individual interviews, making observational notes throughout this process, and reading through the transcribed data. The procedure of conducting and transcribing interviews began a process of engaging at a deeper level with the data and allowed for early identification and emergence of provisional patterns and ideas. This part of the process was supported using a Microsoft Word programme and using the comment function. Within Braun and Clarke's (2006) framework for TA, there is acknowledgment of the subjective nature of TA and the impact of the researcher's knowledge and skills, conceptual and theoretical lens, and life experiences, on the data. Considering this, time was given to building an awareness of the researcher's personal and professional experiences which may have led to an interest in the area of EDs. This positioning of the researcher, documented in a subsequent section of this chapter, supported an understanding of the context within which the data would be analysed.

Phase 2: Generating codes

This stage of data analysis involved the researcher systematically working through each transcript and creating meaningful codes for specific data segments which related to the research question. Codes were often presented as short sentences of a few words (e.g. "externalisation gives language to parents") ensuring that enough information was captured within the code to be able to easily refer to it at future points of analysis, and to support theme development. At this point of analysis, all data segments were viewed as relevant and codes were given to any segment of data which related to the research question or appeared meaningful to the area of research. Coding of the transcripts was flexible with the researcher moving back and forth between transcripts revising initial codes and developing new codes.

This stage of the process was supported using Nvivo, a qualitative research software package. A coding framework (Appendix 10) was created at the end of this process which listed all final codes identified throughout phase 2. A total of 148 codes were generated during this phase of TA.

Phase 3: Theme development

At this point in the process of data analysis, a deep and rich understanding of the data had been gained through familiarisation and coding. The process of identifying provisional themes involved searching through codes and identifying patterns and relationships that related to the overarching research question. Using the coding framework, codes which could be merged or clustered together were identified, with some individual codes becoming stand-alone provisional themes that could then encompass several codes within them. A method of identifying a "central organising concept" (Braun, Clarke & Terry, 2015, p. 102) was used when merging codes together. This involved the researcher identifying a clear underlying concept across codes which drew them together under one main provisional theme. Codes which did not relate to the research question were discarded to support data management. Working titles were given to provisional themes. To support the process of theme development and identify how provisional themes may relate to one another, thematic maps were used (Braun & Clarke, 2013; an early stage example of a thematic map can be seen in appendix 12). Thematic maps supported the researchers understanding of the relationship between codes and themes and supported the development of levels within the data i.e. themes, sub-themes. At the end of this phase, 10 provisional themes were identified (Appendix 11).

Phase 4: Reviewing and defining themes

This phase of the research process included reviewing all provisional themes developed in phase three. The central organising concept for each provisional theme was further defined and the relationships between themes were explored and developed. Furthermore, provisional themes were scrutinised to ensure that they each had distinctive, yet related concepts linked with them. The provisional themes were then compared against the codes which they were created from and against the whole data set to ensure the meaning captured in the theme related back to the initial, entire dataset. During this phase transcripts were re-read to make sure the provisional themes had not moved too far away from the meaning communicated by participants throughout the interviews or from the research question. Following this, brief theme definitions were produced to ensure there was a clear and defined central organising concept for each and to ensure themes captured something important about the data that was not described elsewhere. The previous list of 10 provisional themes were merged or discarded if they were no longer considered relevant to the final analysis. These themes were then reviewed by the research supervisor for this study. Following research supervision, three main themes, each with several subthemes were identified as most relevant to the research area and aims of the study.

Phase 5: Defining and naming themes

This phase involved moving into a position of interpretation of the data. Rather than viewing the data as many separate parts, a narrative was developed based on the separate ideas and how they related to one another (Terry et al., 2017). As themes were finalised, the working titles which had been created for them were checked to ensure that they spoke to the meaning of the theme. Where themes were better described by alternative titles, changes were made.

Phase 6: Producing the report

The final stage of the TA process involved writing up the findings of the research into a narrative. One consideration which was made in relation to reporting of the findings was whether the use of numbers would be supportive to the write-up, for example when reporting on the number of participants who references a theme or subtheme. A decision was made by the researcher, based on reading in the area and personal preference, that numbers would not consistently be reported within the study. While themes and sub-themes that are reported within this research were often reported by numerous participants, reporting the number of participants does not necessarily give the reader much additional information about the findings (Braun & Clarke, 2013). For example, if a participant does not report on a certain issue, it does not mean they agree or disagree with it, instead it may just not have emerged within the interview on the day. Therefore, numbers were reported only where illuminating to a certain point.

***Quality of Research: Trustworthiness***

Throughout all phases of the research process, steps were taken to ensure that the study was carried out in a systematic and methodologically rigorous way. "Trustworthiness" should be demonstrated within qualitative research paradigms to assure readers that findings are valuable and benefit the area of research (Lincoln & Guba, 1985; Norwell, Norris, White & Moules, 2017). When ensuring trustworthiness within the research, the criteria of credibility, transferability, dependability, and confirmability were considered and the framework outlined by Norwell et al., (2017) was followed. Credibility relates to how well the researcher's analysis and interpretations fit with the initial raw data. Initially, to ensure credibility across the whole research process, the main researcher defined and outlined her epistemological position and acknowledged her subjective positioning in relation to the

research question (further developed in subsequent section of this chapter). Credibility was further addressed through peer-debriefing with the research supervisor. Methodology, transcripts, and analysis write-up were reviewed by the supervisor, feedback was received, and any issues outlined were addressed enhancing the credibility of the findings.

Transferability within qualitative research relates to the generalisability of the findings and was addressed within this study by ensuring a thick description of the participants involved was reported. Dependability of qualitative research is demonstrated through ensuring that the research is "logical, traceable and clearly documented" (Norwell et al., 2017). Within this study a number of steps were taken to ensure dependability of the research findings, this included: the use and documentation of regular research supervision; the use of a coding framework which documented and kept track of code and theme development (Appendix 10); documentation of the process of analysis and the development of subthemes and global themes using an audit trail; and the use of checklists to ensure the reporting of quality qualitative research (Braun & Clarke, 2006; Appendix 14).

## SR methodology: Specific Considerations

A thorough description of the methodological considerations and processes for the SR are contained within the SR article. Below, information relating to the methodology that could not be included in the main article due to word count restrictions or relevance to a scientific journal are outlined.

### *Qualitative Thematic Synthesis*

Systematic reviews contribute to our understanding of an area or topic by identifying, appraising, and combining all research within an area. While the majority of SRs carried out over the past forty years synthesise quantitative research, with a particular focus on Randomized Control Trials, interest in qualitative synthesise is growing (Butler, Hall &

Copnell, 2016; Evans & Pearson, 2001; Thomas & Harden, 2008). Qualitative synthesis supports the scientific understanding of an area, and the significance of findings, through increasing participant numbers and combining findings leading to the emergence of new interpretations and understanding within an area of research (Sherwood, 1999).

The synthesis used for the current research was based on Thomas and Harden's (2008) thematic synthesis technique. This method allows a researcher to compare and contrast research and also "go-beyond" the findings in primary studies to describe new interpretations of the data (Thomas et al., 2008, p.10). A detailed description of the stages of analysis can be found in the main SR paper. Thematic synthesis was the method of choice for the current SR for several reasons and has been suggested as a technique which can be used to address research questions which relate to the perspectives and views of individuals or groups (Barrett-Page & Thomas., 2009; Thomas & Harden, 2008). One of the main ways in which qualitative systematic analyses differ is in the epistemological position they are ground within. Thematic synthesis is one of the methods of synthesis that is grounded in a critical realist epistemological position, in line with the views of the researcher and the epistemological position of the current piece of research (Barrett-Page & Thomas, 2009). Furthermore, thematic synthesis is viewed as a synthesis which produces information that can support policy, practice, and intervention in health-related services (Barrett-Page & Thomas, 2009; Thomas & Harden, 2008). One of the aims of this research was to better understand the experiences and perspectives of siblings whose voices are often not heard within research, and as such whose views do not inform interventions (Jungbauer, Heibach & Urban, 2015). The findings of the thematic synthesis, based on healthy siblings' experiences across multiple studies, could therefore lead to practical clinical recommendations that could support this group of individuals.

***Search Strategy***

Studies for the SR were located in September 2019 following a multi-step process which included: searching the research databases; reference list searching; searching for related work by authors of studies identified in this process; and consulting grey literature. The first step included consulting the research databases and searching for relevant studies using a specified set of search terms, developed in consultation with a subject librarian at University College Cork (UCC). Seven databases were searched from their inception to September 2019: MEDLINE, PsychINFO, psycARTICLES, Psychology & Behavioural Sciences Collections, CINAHL, Social Sciences Full Text (H.W Wilson) and SocINDEX with Full Text. Keywords included in the search strategy were as follows: (Eating disorder* OR Anorexi* OR disordered eating) AND (Famil* OR Sibling* OR brother* OR sister* ) with data-base specific search terms (e.g. medical subject headings (MeSH terms)) used for each database (Appendix 2). The next step in this search process included consulting the reference lists of each study included in the SR. Where more information was needed on a study, the authors were contacted by email to request information. Following this, the work of authors of studies identified for inclusion was consulted to check for any related work not found in the initial search. Finally, in order to reduce the risk of publication bias, grey literature databases i.e. Google Scholar (GS) were searched for doctoral theses, dissertations and non-peer reviewed studies which may not have been identified by the initial search strategy or which may not have been published on a database. Guidance on using GS in evidence reviews were followed and the first 30 pages (200 – 300 hits) of GS were searched (Haddaway, Collins, Coughlin & Kirk, 2015).

Studies had to meet the following inclusion criteria: one of the primary informants was a sibling of a person with AN and the study had to use either a qualitative or mixed method design. Exclusion criteria included: studies which focused primarily on siblings of a

person experiencing any ED that was not classified as AN e.g. BN; studies that used a quantitative methodology only; non-English language papers, as it was outside of the scope of this review to carry out translation of studies; and non-empirical work such as opinion pieces and book reviews. One study could not be located online and was not available through local library sources. In this instance, UCC inter-library loan service was used, and the study was accessed through a university in the United Kingdom. The titles and abstracts for all retrieved studies were reviewed by the main author (KL). Full-text articles were retrieved for any study which appeared to fit the inclusion criteria from the title and abstract review. Full-text articles were reviewed by two team members (KL and PT) and studies that fulfilled the inclusion criteria were included in this review. The PRISMA flowchart (figure 1 p. 46) documents the selection process.

***Data Extraction***

Key areas of interest, including information relating to the study (country, year of publication), demographic data (participant characteristics i.e. age range, gender, information on sibling with ED), methodological data (data collection method, analysis used) and results were extracted from each study. One difficulty that has been reported when carrying out qualitative SRs is in specifying what counts as results in each paper. This is due to various reporting styles and the use of participant quotations and author interpretations across qualitative research (Thomas & Harden, 2008). The current review addresses this by following Thomas and Harden's (2008) guidance on qualitative synthesis and extracting all data labelled as "results" or "findings". QSR's Nvivo software was then used to organise and code this data. Where electronic files were available, these were imported directly to Nvivo, where electronic files were not available (in one case), data was typed into Nvivo verbatim. Data were coded using a line-by-line method with both first order constructs (participant quotations) and second order constructs (researcher interpretations) analysed.

### *Quality of articles*

An important stage of completing an SR within quantitative research is carrying out a quality assessment of all articles to be included. However, within qualitative research, the use of quality assessments is not well defined, and debate is ongoing about the appropriate criteria to apply and how it should be applied (Atkins, Lewin, Smith, Fretheim & Volmink, 2008; Campbell et al., 2012; Garside, 2014). One of the main aims of quality assessments within SRs is to assess for rigour and to ensure that the studies included follow sound methodologies (Butler et al., 2016). However, when appraising qualitative research, there is little agreement on what constitutes a quality study, whether quality appraisals are helpful and the most effective appraisal tools to use (Campbell et al., 2012). The researchers involved in the current review felt the use of an appraisal tool which identified the quality of each study in relation to the methodology used was necessary. Furthermore, the researchers decided that original studies which did not meet quality criteria cut-offs would be excluded from the SR (further discussed in the methodology section of the SR). The current SR used the Critical Appraisal Skills Program (CASP, 2014) to assess article quality. The CASP appraisal tool was chosen for its brevity and as it was used in studies of a similar nature previously (Butler, 2016). One downfall of the CASP checklist is its lack of a scoring system. To overcome this difficulty, the current review used a CASP scoring system used and published by authors of a similar SR (Butler et al., 2016; Fox et al., 2015).

## Subjectivity and reflexivity

As noted previously, when working within a qualitative paradigm, researcher subjectivity is seen as an essential part of the research process and has been described as "something created by the researcher, at the intersection of the data, their theoretical and conceptual frameworks, disciplinary knowledge, and research skills and experience" (Terry et al., 2017, p. 7). One assumption that underlies qualitative research is that the researcher's

views, experiences, and beliefs will impact and shape the collection and analysis of the research. For this reason, this section outlines some of the experiences and beliefs held by the researcher, and considerations on how the researcher's perspectives may have shaped the data process. Following this, a description of how the researcher approached reflexivity throughout both pieces of research is discussed.

I feel it is important to acknowledge the influence that my professional experiences and views may have had on shaping the research process. I am a thirty-year-old, Irish woman who is currently in the final year of Clinical Psychology training in University College Cork. I have worked in mental health for the past six years both in primary, secondary and tertiary settings. I have never worked in a setting where FBT was used with clients. My professional experiences throughout clinical psychology training have supported a move from viewing mental health difficulties through a biomedical lens (i.e. DSM diagnostic categories) to a formulation-based model which considers the biological, psychological, and social aspects of a person's experience.

Personally, while I have never experienced an ED, I live with a chronic health condition which requires constant tracking and management of food, exercise, and medication. Societally, this condition is poorly understood by the general public and this can often lead to blame being placed on the individual in terms of the aetiology of the condition but also in the daily choices made by people living with the condition. The misunderstanding of this condition, at times, can lead to internal feelings of shame and blame, particularly during adolescent years. Although this research focused on siblings of those with an ED and clinicians working with those with an ED, my personal life experiences may have made it more likely that I would consider the findings from the perspective of the YP with the ED.

At the beginning of the research process, I explored ways of documenting my subjective experiences, thoughts and feelings relating to the research to ensure a reflexive approach was taken throughout. Reflective journals are widely used in qualitative research (Ortlipp, 2008) and were deemed appropriate for the current research project. Initially, I documented the areas of my life and the experiences I have had that I felt may influence the way I processed the data (documented above). Prior to beginning the research, I considered how these subjective experiences and views would potentially influence the research process. In addition to this, experiences, thoughts and feelings were documented throughout the research process in a research journal, this included views, opinions or thoughts that occurred during the interview process (when interviewing clinicians on their experience of externalisation), during analysis, and write-up of both pieces of research. If I felt some form of bias was emerging or if I felt stuck with a particular idea or avenue, I teased this and sought feedback through research supervision.

**References**

Atkins, S., Lewin, S., Smith, H., Engel, M., Fretheim, A., & Volmink, J. (2008). Conducting a meta-ethnography of qualitative literature: lessons learnt. *BMC medical research methodology*, *8*(1), 21.

Aronson, J. (1995). A pragmatic view of thematic analysis. *The Qualitative Report*, *2*(1), 1-3.

Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: a critical review. *BMC Medical Research Methodology*, *9*(1), 59.

Bondas, T., & Hall, E. O. (2007). Challenges in approaching metasynthesis research. *Qualitative Health Research, 17*(1), 113-121.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101.

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage.

Braun, V., Clarke, V., Terry, G. (2015). Thematic analysis. In Rohleder, P., & Lyons, A. C. (Eds.). (2014). *Qualitative research in clinical and health psychology*. Macmillan International Higher Education.

Butler, A., Hall, H., & Copnell, B. (2016). A guide to writing a qualitative systematic review protocol to enhance evidence-based practice in nursing and health care. *Worldviews on Evidence-Based Nursing*, *13*(3), 241-249.

Campbell, R., Pound, P., Morgan, M., Daker-White, G., Britten, N., Pill, R., ... & Donovan, J. (2012). Evaluating meta ethnography: systematic analysis and synthesis of qualitative research.

CASP, U. (2014). Critical Appraisal Skills Programme (CASP) 2014.

Colton, A., & Pistrang, N. (2004). Adolescents' experiences of inpatient treatment for anorexia nervosa. *European Eating Disorders Review: The Professional Journal of the Eating Disorders Association*, *12*(5), 307-316.

Eatough, V., & Smith, J. A. (2008). Interpretative phenomenological analysis. *The Sage handbook of qualitative research in psychology*, *179*, 194.

Evans, D., & Pearson, A. (2001). Systematic reviews of qualitative research. *Clinical Effectiveness in Nursing*, *5*(3), 111-119.

Fjermestad, K. W., Rø, A. E., Espeland, K. E., Halvorsen, M. S., & Halvorsen, I. M. (2020). "Do I exist in this world, really, or is it just her?" Youths' perspectives of living with a sibling with anorexia nervosa. *Eating Disorders*, *28*(1), 80-95.

Fox, J. R., Dean, M., & Whittlesea, A. (2015). The experience of caring for or living with an individual with an eating disorder: A meta-synthesis of qualitative studies. *Clinical Psychology & Psychotherapy*, *24*(1), 103-125.

Galletta, A. (2013). *Mastering the semi-structured interview and beyond: From research design to analysis and publication* (Vol. 18). NYU press.

Garside, R. (2014). Should we appraise the quality of qualitative research reports for systematic reviews, and if so, how? *Innovation: The European Journal of Social Science Research*, *27*(1), 67-79.

Haddaway, N. R., Collins, A. M., Coughlin, D., & Kirk, S. (2015). The role of Google Scholar in evidence reviews and its applicability to grey literature searching. *PloS one*, *10*(9).

Jungbauer, J., Heibach, J., & Urban, K. (2016). Experiences, burdens, and support needs in siblings of girls and women with anorexia nervosa: Results from a qualitative interview study. *Clinical Social Work Journal*, *44*(1), 78-86.

Kallio, H., Pietilä, A. M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: Developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing*, *72*(12), 2954-2965.

Lincoln, Y. S., & Guba, E. G. (1985). Establishing trustworthiness. *Naturalistic Inquiry*, *289*(331), 289-327.

Marks, D. F., & Yardley, L. (Eds.). (2004). *Research methods for clinical and health psychology*. Sage.

Maxwell, J. A. (2012). *A realist approach for qualitative research*. Sage.

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies* (Vol. 11). sage.

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, *16*(1), 1609406917733847.

Ortlipp, M. (2008). Keeping and using reflective journals in the qualitative research process. *The qualitative report*, *13*(4), 695-705.

Sherwood, G. (1999). Meta-synthesis: merging qualitative studies to develop nursing knowledge. *International Journal of Human Caring*, *3*(1), 37-42.

Stainton-Rogers, W., & Willig, C. (2008). The SAGE handbook of qualitative research in psychology. *London: Sage. doi*, *10*(9781848607927), n3.

Terry, G., Hayfield, N., Clarke, V., & Braun, V. (2017). Thematic analysis. *The Sage handbook of qualitative research in psychology*, 17-37.

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*(1), 45.

Willig, C. (2012). Perspectives on the epistemological bases for qualitative research.

Willig, C. (2013). *Introducing qualitative research in psychology*. McGraw-hill education (UK).

# Chapter Three

## Systematic Review

**Title:** The Experience of Healthy Siblings of People with Eating Disorders: A Systematic Review and Thematic Synthesis

Prepared in accordance with submission guidelines of the International Journal of Eating Disorder (Appendix 1)[1]

Word Count: 8, 532 (excluding abstract, highlights, tables and references)

[1]Although figures and tables are usually included as separate files for the journal, they are inserted in the text for ease of examination

**The Experience of Healthy Siblings of People with Eating Disorders: A Systematic Review and Thematic Synthesis**

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*Personally, I'm only just beginning to see what affects it has had on my life (….) it's only in the last five years that things have really started happening for me. Life is great now, but the anorexia will probably remain with me, in some shape or form, forever (A sibling's perspective on the impact of AN; Ross and Handy, 1997, p. 237).*

**The Experience of Healthy Siblings of People with Eating Disorders: A Systematic Review and Thematic Synthesis**

*Background:* Within the area of eating disorders (EDs), research on carers has predominantly focused on the experience of parents and partners of those diagnosed with EDs. This led to siblings being referred to as the "forgotten" kin. Sibling relationships play an important and often long-standing role in peoples' lives. Having a sibling with an ED can impact on healthy siblings in many ways including negatively affecting their quality of life, their sibling bond, and their physical, mental and emotional health. *Aim:* A meta-synthesis of qualitative studies was conducted to explore the experiences of healthy siblings of people who have EDs. *Method:* Seven databases (MEDLINE, PsychINFO, psycARTICLES, Psychology & Behavioural Sciences Collections, CINAHL, Social Sciences Full Text (H.W Wilson) and SocINDEX with Full Text) were searched for qualitative studies reporting on the experience of healthy siblings who have a brother or sister with a diagnosed ED. Thematic synthesis was used to analyse the studies included in this review. *Results:* 10 studies were included. Five core themes and twelve subthemes were identified. Themes related to the impact of the ED on both interpersonal and intrapersonal aspects of the healthy siblings' lives. This included disruption to the sibling relationship and family life, experiencing difficult emotions, changes in the healthy sibling's relationship with their own body, and coping skills. *Conclusions:* These findings are discussed in relation to the existing literature within the area and the implications for clinical practice.

*Keywords: systematic review, thematic synthesis, sibling, eating disorder, anorexia nervosa.*

**Highlights**

- Healthy siblings are a heterogeneous group, practitioners should endeavour to work with this group in a personalised way that fits with the experiences of the individual in the context of their family.
- Many intrapersonal and interpersonal aspects of healthy siblings' lives are affected by the experience of their sibling's ED.
- Many siblings report "feeling invisible" and suppressing their own needs to reduce stress on the family. Building parental awareness of this process may facilitate parents to support healthy siblings within the family.

**Introduction**

Sibling relationships are often one of the most prominent and enduring relationships in a person's life (McHale, Kim & Whiteman, 2006). Although siblings play a prominent role in family life, research into the nature of the relationship between siblings is limited when compared to other relationships within the family system (East, 2009). In the existing research, there is a growing understanding of the significant developmental impact that the sibling relationship has on a person across the lifespan (Feinberg, Solmeyer & McHale, 2012; McHale et al., 2006). Influential aspects of the sibling relationship on a person's development include shaping social and emotional development in childhood (Bank, Burraston & Snyder, 2004); influencing one another's beliefs, behaviours and scholastic attainments (East, 2009); impacting on the relationships and attachments formed throughout the lifespan (Feinberg et al., 2012); and protecting against mental health difficulties in later years (Waldinger, Vaillant, & Orav, 2007). When one sibling within a family experiences a physical illness or mental health difficulty, the roles and relationships within a family system change (Eisler et al.,

2016). The experience of healthy siblings in response to these changes are not as often the focus of research as the experiences of other family members (Feinberg et al., 2012).

There is a paucity of qualitative research on the experience of growing up with a sibling who is unwell (Garley & Johnson, 1994; Jungbauer, Heibach, & Urban, 2016). Areas where the qualitative experience of siblings has been a focus include siblings of people with intellectual disability, autism spectrum disorder (ASD), psychosis, schizophrenia, cancer and chronic pain (Amaresha, Venkatasubramanian, & Muralidhar, 2014; Angell, Meadan & Stoner, 2012; Friedrich, Lively & Rubenstein, 2008; O'Brien, Duffy, & Nicholl, 2009; Rossiter & Sharpe, 2001; Sharpe & Rossiter, 2002; Yang, Mu, Sheng, Chen, & Hung, 2016). Themes which are evident within this literature include healthy siblings experiencing mental health difficulties, behavioural difficulties and problems with social relationships; feeling they lack important information on their sibling's illness/diagnosis; experiencing conflicting emotions towards their affected sibling; and experiencing distress in relation to the changing roles and dynamics within the family. Additionally, some healthy siblings across these studies reported that they experienced positive outcomes as a result of their sibling's difficulties including stronger sibling relationships and personal growth (Mascha & Boucher, 2006; Moses, 2013; Nolbris, Enskar & Hellstrom, 2007; Wilkins & Woodgate, 2005; Woodgate, 2006).

### *The sibling relationship in the context of an ED*

These findings shed light on the experiences of siblings who have a sister or brother with a diagnosed physical illness, intellectual disability, developmental disorder or mental health difficulty. Although they help to clarify parts of the sibling experience, they may not be completely generalisable to the area of EDs (Honey & Halse, 2006). EDs present with their own set of complicating factors. This includes having the highest mortality rate of all

mental health disorders at 5-7%, a lack of understanding of the disorder within society, and sociocultural factors related to weight stigmatisation and the promotion of the "thin-ideal" across advertising outlets and social media platforms (Arcelus, Mitchell, Wales & Nielsen, 2011; Fox, Dean & Whittlesea, 2015; Harrison, 2000). Little research existed in this area prior to the 1990s, leading to healthy siblings within the context of EDs being referred to as the "forgotten group" (Vandereycken & Vreckem, 1992, p.273).

Over the past three decades a number of qualitative and quantitative studies have been carried out investigating the experience of healthy siblings in the context of EDs from the perspectives of the affected sibling (the sibling with the ED) or the parents (Jungbauer et al., 2016). Research on the parents of young people (YP) with AN suggests that they are aware of the negative impact that the disorder can have on healthy siblings such as affecting their daily lives and routines, their relationships, and impacting negatively on their emotions (Honey & Halse, 2006). Despite parents' need to focus on the affected sibling, they also reported protective behaviours towards the healthy siblings such as maintaining normal routines, providing emotional support and withholding information from them at times to protect them (Honey & Halse, 2006). In a different study by the same group, adolescent girls with AN and their parents were interviewed about the influence of a healthy sibling in the context of one child having an ED (Honey, Clarke, Halse, Kohn, & Madden, 2006). This study found that when healthy siblings had a poor understanding of the ED they were perceived as causing upset within the sibling relationship by rejecting their affected sibling. In contrast, many participants reported that the healthy sibling provided emotional and practical support and were a companion for their affected sibling throughout the ED (Honey et al., 2006). While the perspectives of other members of the family system are helpful, the personal experience of siblings within the context of EDs is still largely unknown. From the limited studies which focus specifically on the perspective of the healthy sibling, research suggests that they are

impacted in several ways. This includes the experience impacting on their quality of life, their relationship with their sibling and their mental, physical and emotional health (Areemit, Katzman, Pinhas & Kaufman, 2010; Callio & Gustafsson, 2016; Fjermestad, Espeland, Halvorsen &Halvorsen, 2019; Jungbauer et al., 2016). Some studies have also reported benefit-finding for siblings of those with an ED including experiencing an improvement in their sibling relationship and experiencing personal growth (Areemit et al., 2010; Fjermestad et al., 2019).

To the authors knowledge there has been no systematic review (SR) carried out which focuses on the experiences of siblings in the context of EDs. While Fox et al's., (2015; published online in 2017) review looked at the experience of caring for a person with AN, they had a broader focus on all carers i.e. parents, partners, and siblings. Their review included only four studies out of twenty which focused specifically on the experience of siblings, incorporating 36 siblings out of a total of 239 participants (15%). Fox et al's., (2015) review began the process of exploring and understanding the carer perspective through synthesis. However, siblings were not the primary focus of this previous review and therefore it may have missed out on some of the nuanced experiences of this group of individuals. This lack of focus on specific groups of individuals (i.e. exploring the sibling experience only rather than the carer experience) "limits the development of precise theories and models" for supporting the personalised needs of these groups as outlined by the previous review (Fox et al., 2015 p. 123). Furthermore, the authors of the current review are aware of several studies which have been published which relate to the sibling experience since the publication of this 2015 review (e.g. Callio et al., 2016; Fjermestad et al., 2019; Jungbauer et al., 2016).

This paper aims to systematically review the literature on the experience of healthy siblings who have a brother or sister with an ED, primarily AN. AN was chosen as a focus as

most the studies focusing on the sibling experience have been carried out in the context of AN. The research team felt that focusing on AN rather than EDs more generally was most appropriate given the possibility that siblings of those with EDs may not be a homogenous group i.e. the experience of having a sibling with AN may be different to that of BN due to the multitude of physical health and medical complications in AN.

**The research question for this review was:**

How do healthy siblings experience their brother's or sister's AN?

## Methodology

### *Search Strategy*

This study took place from May to December 2019. Seven databases including MEDLINE, PsychINFO, psycARTICLES, Psychology & Behavioural Sciences Collections, CINAHL, Social Sciences Full Text (H.W Wilson) and SocINDEX with Full Text were searched from their inception to September 2019 with specific algorithms adapted for each database. Keywords based on the research question and previous studies referred to anorexia nervosa, eating disorders, family, and sibling (see appendix 2 for detailed search strategy). Inclusion criteria were a primary informant within the study was a sibling of an individual with AN and the study had to use a qualitative or mixed method design. Exclusion criteria included articles which did not focus specifically on AN, non-English language papers and non-empirical work. After duplicate studies were excluded, the main author read the titles and abstracts of the remaining studies. Articles which met the inclusion criteria and were relevant to the research question were identified and full-text versions were retrieved. Two authors reviewed full-text articles (figure 1).

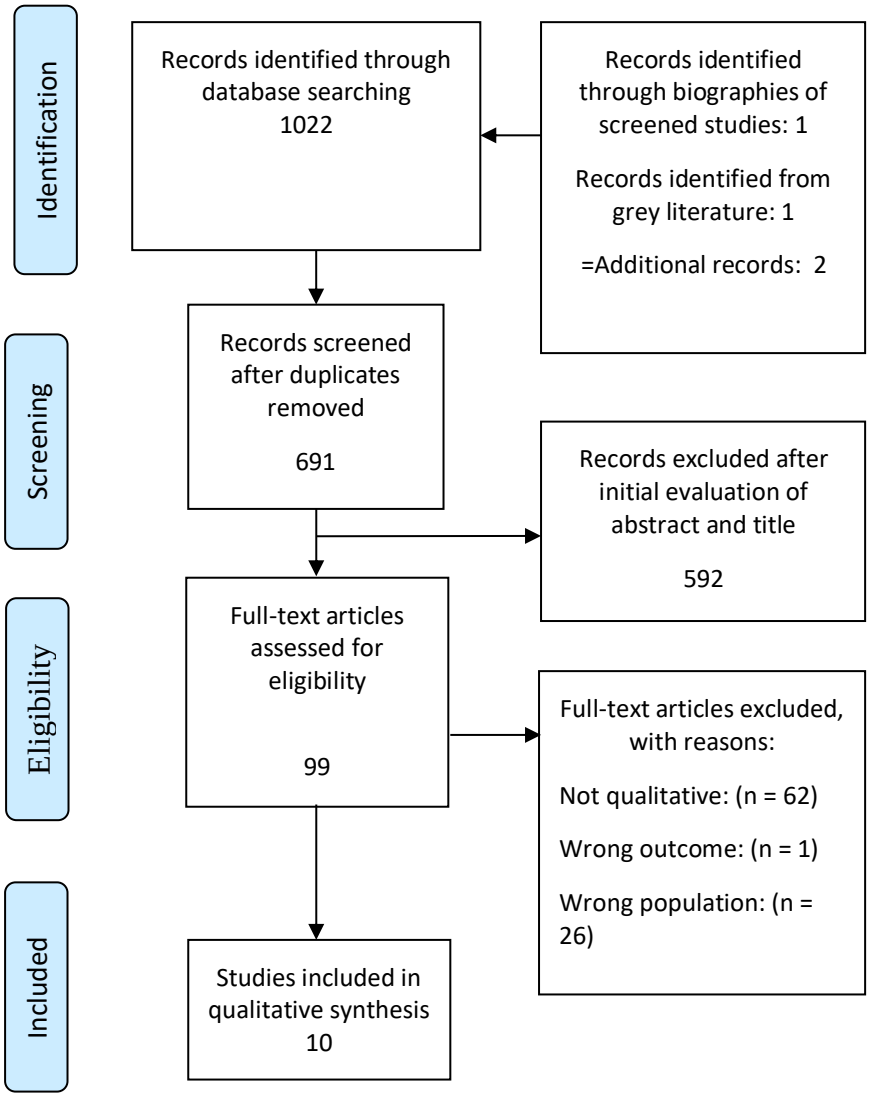



**Figure 1:** PRISMA flowchart

### *Assessment of article quality*

Quality assurance is essential in qualitative research, however the parameters for quality judgements are less well established than in quantitative systematic reviews (Atkins, Lewin, Smith, Fretheim & Volmink, 2008; Campbell et al., 2012; Garside, 2014). The Critical Appraisal Skills Program (CASP; Chenail, 2011) consists of ten questions: two screening questions which review the aims and methodology of the research followed by eight questions which focus on design, recruitment strategy, reflexivity, ethical procedures

and the value of the research. All ten articles included in this review were rated using the CASP quality assessment tool. A score of 0, 0.5 or 1 was awarded for each question and each article was scored out of a total of ten points. Articles were coded by the main author as A (high quality articles; 8.5 – 10 points), B (moderate quality paper; 5 – 8 points) or C (lower quality paper; < 5 points). Fifty percent of the articles were then re-rated by the second author and this process showed good strength of agreement between both authors using Cohen's Kappa (0.71; Brennan & Silman, 1992). All discrepancies between authors were reviewed and a final decision on scoring was made together by both authors.

***Data Analysis***

An inductive approach was used when deriving themes and subthemes from the data set. The extracted data was synthesised following guidance on thematic synthesis (Thomas & Harden, 2008) and followed a three-step process; line by line coding, drawing together initial codes into "descriptive themes", and developing "analytic themes" (Thomas and Harden, 2008, p. 4). The analysis began with reading and rereading the main articles in full, carried out by the main author. The main author then carried out line-by-line coding of the findings from each study included in the review. Each line of text was given a new code and entered into a coding database relating to the group of articles included in this review. Each sentence in the results section of each paper had at least one code connected with it. This stage allowed for ideas and concepts within studies to be translated and synthesised across studies through the development of a new set of codes which tied this group of articles together.

Some codes in the coding database formed part of a hierarchy while others were free, stand-alone codes. This process led to 72 initial codes being created. These codes were examined by two authors. Codes were grouped into nine descriptive themes, with new codes developed to describe groups of initial codes at this point. Codes which were focused on for

this SR were those which were evident across studies and those which addressed the review question.

At this point during the synthesis, the two authors were able to "go-beyond" the initial findings of the primary studies and produce new concepts which had not been as visible in the primary studies alone (see appendix 3 for example of analysis of code; Thomas & Harden, 2008, p.10). The final analysis resulted in five main themes, each with two to three subthemes (figure 2). A third author reviewed and gave feedback on the themes and subthemes. The final step in the synthesis was to express these results using text, table and figures as seen in results section below. The "Enhancing Transparency in Reporting the Synthesis of Qualitative Research" (ENTREQ) statement was used to support the reporting of our results (Appendix 4). The ENTREQ includes 21 questions, grouped into five domains, and is used to ensure transparency in research, a qualitative alternative to the "Preferred Reporting Items for Systematic Reviews and Meta-Analyses: the PRISMA statement" used in quantitative research.

Reflexivity was considered throughout the research process. Initially, the subjective personal and professional experiences and views of the researcher were explored in relation to how they might have impacted on data analysis. A research journal was used to document the researcher's experiences, views and feelings throughout the research process, and these were examined in research supervision (Ortlipp, 2008).

## Results

### *Studies and Participants*

691 records were identified through database searching (PRISMA flowchart; figure 1). Of this number, 592 were excluded after initial evaluation of the abstract and title only. 99 full-text articles were evaluated for inclusion in the final review, it was not possible to reduce

this number by narrowing the search strategy as this would have resulted in a loss of potential papers for inclusion. 89 papers were excluded on screening full-text articles (exclusion reasons included in figure 1). 10 studies were included in the final review. Qualitative methodology was used in nine studies. One study used a mixed methodology, however, the qualitative data for this study, i.e. the focus group results, were reported separately and therefore the study could be included (Areemit et al., 2010). All information relating to demographic and methodological characteristics of these studies can be found in table 2. The primary focus in the majority of the studies was on the experience of having a sibling with a diagnosed ED. One study had an additional focus related to the experience of being admitted to an inpatient unit with their affected sibling as part of a therapeutic intervention (Fjermestad et al., 2019).

98 participants in total were included across studies. Table 3 outlines further information related to participants. Of note, the gender of the affected sibling was not available in all the studies. Of those affected siblings where gender was available (n = 65), 98% were female. Ten participants (10%) across three studies were not categorised as AN specifically; five were categorised as EDNOS and five were categorised as ED only within the study. The authors of the study which did not specify ED type were contacted for more information but could not be reached (Callio et al., 2016). A number of factors were considered in collaboration with the research supervisor when deciding whether the papers with the unspecified/EDNOS participants should be included. Initially, the researcher looked at each of the three papers individually. Consideration was given to both the number of participants affected in each study and to the nature of the findings in each study i.e. were findings in line with similar studies where AN diagnosis was specifically identified for all sibling participants. A decision was made in collaboration with the research supervisor to include all three papers, see below table for outline of rationale for each study's inclusion.

**Table 1:** Rationale for study inclusion/exclusion

| Paper | Rationale for inclusion/exclusion |
|---|---|
| Areemit, Katzman, Pinhas and Kaufman (2010)<br>Participant Characteristics:<br>AN = 6<br>EDNOS = 4 | • Majority of cases in study were AN specific.<br>• On exploring the themes found in this study it was evident that they shared strong similarities with those of the studies that focused on AN only client.<br>• Themes related to the experience of AN specifically e.g. "compassion and concern for the sibling with anorexia". |
| Moses (2013)<br>AN = 5<br>EDNOS = 1 | • Majority of cases AN specific (83%) |
| Callio and Gustafsson (2016)<br>5 = ED unspecified | • Themes similar to that of AN specific studies with many relating to AN specific symptomatology. |

All articles included in this SR were categorised as either A or B in relation to their quality using the CASP quality assessment tool, this suggests that there is a low to moderate likelihood of methodological issues within the research included. The debate on whether to exclude studies with low quality ratings i.e. C and lower is ongoing (Atkins, et al, 2008; Campbell et al., 2012; Garside, 2014). However, due to all studies in this SR being categorised as A or B the authors did not need to decide on whether to exclude studies categorised as C. Quality assessment categories awarded to each article are outlined in table 2.

**Table 2:** Demographic and methodological information

| No | Reference | Country | Participants | Sample Size | Data | Analysis | QR | Summary of themes |
|---|---|---|---|---|---|---|---|---|
| 1 | Garley and Johnson (1994) | Canada | **Age range**: 15 – 18 years. **Gender**: Female sibling; sister with AN. **Birth order**: 3 older siblings, 2 younger siblings. **Living arrangement**: living in same household. **Diagnosis**: AN; active stage of illness. | 5 siblings | Unstructured interviews | Phenomenological approach | B | *Overarching Themes:* Pervasiveness; Intense and conflicting emotions. Perspective of the illness; Coping with the illness; Disruption; Role strain; Special status. |
| 2. | Ross and Handy (1997) | New Zealand | **Age range**: 20 – 30 years. **Gender**: Male sibling; sister with AN. **Birth order**: 1 older sibling, 1 younger sibling. **Living arrangement**: Information not available. **Diagnosis**: AN; recovery stage of illness. | 2 siblings | Semi-structured interview sent to participants through postal system, completed independently. | Grounded theory approach | B | Childhood; Family relationships during the illness; professional treatment; family relationships today. |
| 3. | Latzer, Ben-Ari and Galimidi, (2002) | Isreal | **Age range**: 11 – 18 years. **Gender**: Female sibling; sister with AN. **Birth order**: 9 younger siblings. **Living arrangement**: living in same household. **Diagnosis**: AN; active stage of illness. | 9 siblings | Semi-structured interviews | Layer system theory | B | *Two theoretical concepts presented:* The illness as a new member of family; Duality. Structural processes; Family dynamic processes; Emotional processes; Change in life functions; Body image; Narrative of the illness. |
| 4. | Dimitropoulos, Klopfer, Lazer and Schacter (2009) | Canada | **Age range**: 25.6 (SD = 7.85) **Gender**: Female siblings; sister with AN. | 12 siblings | Semi-structured interviews | Grounded theory approach | B | *Overarching concept:* Mediator and Protector; Familial factors that influence and reinforce the sibling role. Consequences and benefits of |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | **Birth order**: Information not available. **Living arrangement**: Information not available. **Diagnosis**: Chronic AN; active stage of illness. | | | | | the ED to the sibling; Coping strategies; Current and future interventions of caregiving; Professional and informal social support. |
| 5. | Areemit, Katzman, Pinhas and Kaufman (2010) | Canada | **Age range**: 10 – 18 years. **Gender**: 3 male, 7 female siblings; information on gender of person with ED not available. **Birth order**: 3 older siblings, 1 twin, 6 younger siblings. **Living arrangement**: living with sister during illness. **Diagnosis**: AN (n = 6), EDNOS (n = 4); information on stage of illness not available | 10 siblings | Mixed methodology. Qualitative: Focus group interviews | Grounded theory approach | A | *Overarching concept: Duality in relation to living with sibling with ED;* Struggling to understand the ED; Acute awareness of the ED behaviours and thoughts; Challenges in understanding non-eating related obsessive behaviours; Increase in family conflicts and arguments; Compassion and concern for the sibling with anorexia; Feelings of loss and sacrifice; Overwhelming sense of responsibility; Pervasiveness of the ED in all aspects of the sibling's life. |
| 6. | Moses (2013) | United Kingdom | **Age range**: 11 – 18 years. **Gender**: Female siblings; sisters with AN or EDNOS. **Birth order**: 2 older siblings, 4 younger siblings. **Living arrangement**: living with sister during illness. **Diagnosis**: AN (n = 5), EDNOS (N = 1);. | 6 siblings | Semi-structured interviews | Thematic Analysis | A | Making sense of it all; Home's not how I remember; It impacts me too; To talk or not to talk?; Life goes on. |
| 7. | Withers et al. (2014) | Australia | **Age range**: 12 – 18 years. **Gender**: 15 female, 5 male siblings; information | 20 siblings | Semi-structured interview | Thematic analysis | B | The sibling relationship; Knowledge of AN; Time out from AN; Emotional supports; Involvement in treatment. |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | on gender of sibling with AN not available.<br>**Birth order**: information not available.<br>**Living arrangement**: information not available.<br>**Diagnosis**: AN; active stage of illness. | | | | | |
| 8. | Callio and Gustafsson (2016) | Sweden | **Age range**: 15 – 20 years.<br>**Gender**: 2 female, 3 male siblings; sister with ED.<br>**Birth order**: information not available.<br>**Living arrangement:** information not available.<br>**Diagnosis**: ED (type not specified); active stage of illness. | 5 siblings | Semi-structured interview | Content analysis | A | The adolescent's feelings towards the ill sibling; The adolescent's perceptions that the ill sibling had changed since the onset of the ED; Impact on one's own body image and eating habits; Taking care of oneself; Consequence on the family; Being involved and not being involved in the ill sibling's treatment. |
| 9. | Jungbauer, Heibach and Urban (2016) | Germany | **Age range**: 12 – 52 years.<br>**Gender**: 12 female, 4 male siblings; sister with AN.<br>**Birth order**: 11 older, 5 younger siblings.<br>**Living arrangement**: information not available.<br>**Diagnosis**: AN; stable, non-life-threatening stage of illness, one sibling with AN had passed away 4 months previously. | 16 siblings | Semi-structured interview | Content analysis | B | Relationship to the affected sister; Burdens due to the ED; Impact on siblings' body image; The effects on family life; Positive aspects, learning experiences and meaningfulness; Support needs and experiences with helping professionals. |
| 10. | Fjermestad, Espeland, Halvorsen and Halvorsen (2019) | Norway | **Age range:** 12 – 23 years.<br>**Gender:**10 female, 3 male siblings; 9 sisters, 1 brother with AN.<br>**Birth order:** | 13 siblings | Semi-structured interview | Systematic text condensation | A | Anorexia is hard to understand; Anorexia evokes difficult emotions; Anorexia affects family dynamics and relations; Altered relations to food; Negative experiences as a road to |

| | | |
|---|---|---|
| | **Living arrangement:** siblings interviewed had been inpatients in a unit with their sibling with AN and had also lived with sibling for a mean of 3 years previous to inpatient admission. Interviews conducted 3 to 6 years post admission.<br>**Diagnosis:** AN; 3 people still in active stage of illness, 10 in recovery. | growth; Ways of coping with the situation; Ambivalence concerning inpatient treatment. |

*QR: Quality rating of each study A – C using the CASP*

**Table 3:** Information on participant group

| Characteristics | |
|---|---|
| **Total healthy siblings in SR** | **98** |
| *Gender of healthy sibling* | 78 female (74%); 20 male (26%) |
| *Age range of healthy sibling* | 10 – 52 years |
| *Gender of affected sibling* | 64 sisters with ED; 1 brother with ED; information not available for 30 participants |
| *ED type: AN* | 88 |
| *EDNOS* | 5 |
| *ED – unspecified* | 5 |

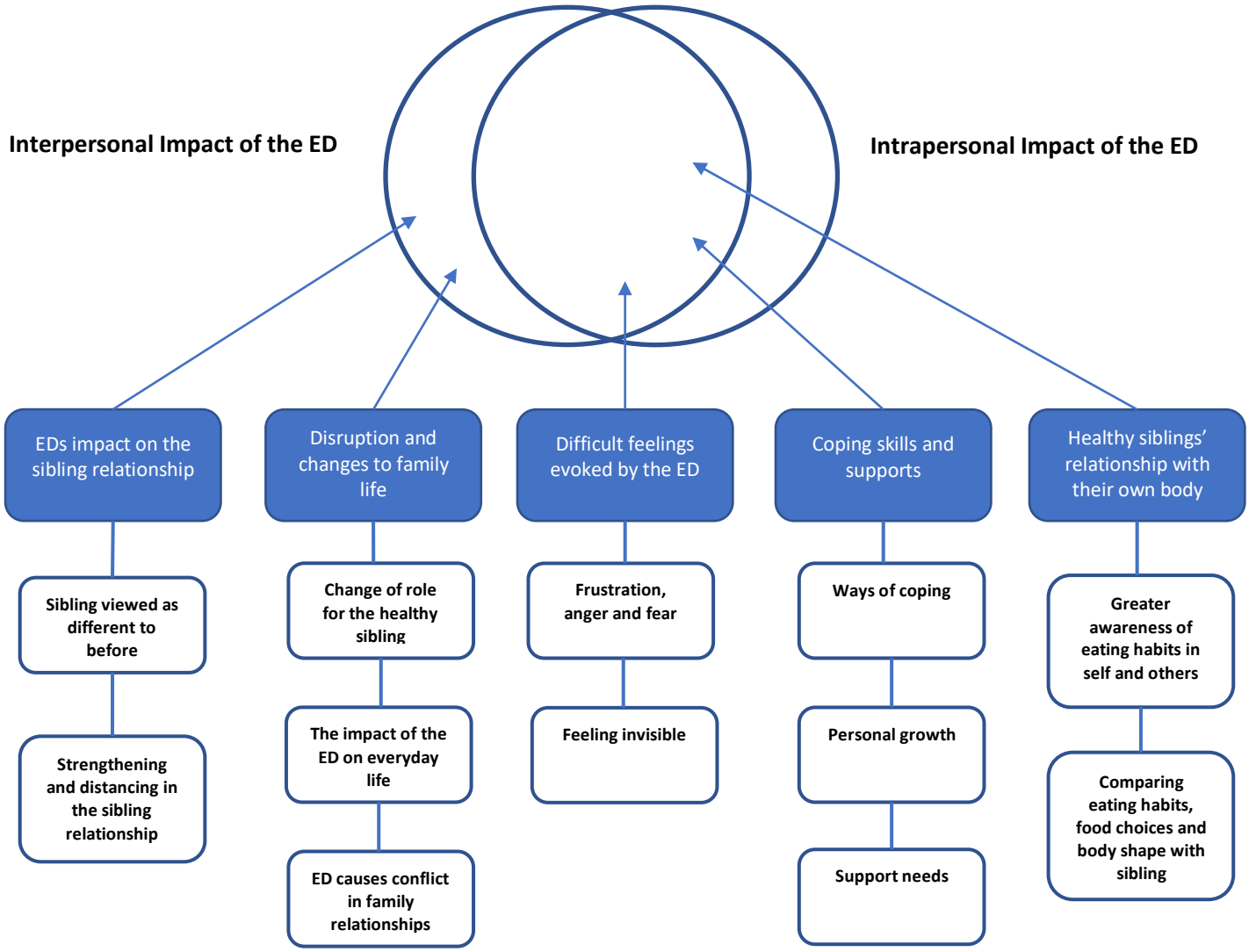



**Figure 2:** Flowchart of themes and subthemes

***Interpersonal and intrapersonal impact of ED***

Participants reported that the experience of having a sibling with an ED led to changes within their relationships (i.e. interpersonally) and also within themselves (i.e. intrapersonally; Areemit et al., 2010; Callio et al., 2016; Dimitropoulos et al., 2009; Fjermestad et al., 2019; Garley & Johnson, 1994; Jungbauer et al., 2016; Latzer et a., 2002; Moses, 2013; Ross & Handy, 1997; Withers et al., 2014). Two of the themes identified related mainly to the interpersonal lives of the participants ("ED's impact on the sibling relationship" and "disruption and changes to family life"). The other three themes highlighted how the ED had an impact on both the interpersonal (i.e. relationship between self and

others) and intrapersonal (i.e. changes within self) life of the healthy sibling (seen in figure 2 as the themes which connect to the middle of the Venn diagram). For example, in the theme "healthy sibling's relationship with their own body", participants reported greater self-awareness of their own eating habits and body shape, highlighting the intrapersonal impact of having a sibling with an ED. However, they also reported that these intrapersonal changes in perception led to comparisons being made with their sibling around body shape and food choices which impacted on their relationship and thus had interpersonal consequences as well. Results will be discussed in relation to the themes and subthemes identified in figure 2. Quotations from participants across studies can be found in table 4 at the end of the results sections.

### *Theme One: EDs Impact on the sibling relationship*

#### *Sibling is viewed as different to before*

In five of the studies participants spoke about the changes they saw in their affected sibling and how they felt their sibling was different to before the onset of the ED (Areemit et al., 2010; Callio et al., 2016; Fjermestad et al., 2019; Moses, 2013; Withers et al., 2014). Participants reported changes across several domains. One of the changes noticed was physical appearance with participants reporting that their sibling looked "tired" or "thin and haggard" (Callio et al., 2016, p. 618; Withers et al., 2014). Changes in behaviour were also noted. Some of these changes related to the ED, such as reduced food intake and compensatory behaviour, while others related to their sibling's behaviour in the home with participants reporting that their siblings said things which were "unforgivable" to their parents (Moses, 2013, p. 49). Mood changes were reported by many participants across studies and siblings were observed to be more "angry", "bad-tempered", "aggressive" and "agitated" than before (Callio et al., 2016, p. 618; Fjermestad et al., 2019; Withers et al., 2014, p. 57). There was a sense of loss evident across studies where participants reported on

the changes witnessed in their siblings, comparisons where made between the siblings premorbid nature and the sibling since the development of the ED (Areemit et al., 2010; Fjermestad et al., 2019; Withers et al., 2014). Participants across studies reported uncertainty in relation to the causes of the changes they had observed in their siblings (Areemit et al., 2010; Fjermestad et al., 2019; Moses, 2013). For some, it was hard to separate their sibling from their current physical, behavioural and mood changes and the sibling was viewed as having control over his/her ED (**Quotation 1**, table 4; Withers et al., 2014). Contrasting this, some siblings expressed their view of the ED as external to their sibling, feeling that the ED was an illness that had "taken over" and that as their sibling recovered, their old self would re-emerge (Areemit et al., 2010**; Quotation 2**; Fjermestad et al., 2019; Moses, 2013). One study reported that the participants' ability to externalise the ED played a role in maintaining the sibling relationship (Withers et al., 2014).

*Strengthening and distancing within the sibling relationship*

The majority of reviewed studies described a change in the sibling relationship (Callio et al., 2016; Dimitropoulos et al., 2009; Fjermestad et al., 2019; Garley & Johnson, 1994; Jungbauer et al., 2016; Latzer et al., 2002; Moses, 2013; Withers et al., 2014). Some participants reported a strengthening in their relationship while others reported a distancing, with almost all participants reporting that this change in the relationship was due to the impact of the ED. Where relationships felt stronger than before, participants reported that this was due to: greater awareness of one another and clearer communication within the relationship (Callio et al., 2016); going through difficult personal experiences together as a result of the ED (**Quotation 3**; Dimitropoulos et al., 2009); and becoming a confidant and support for their sibling (Fjermestad et al., 2019; Jungbauer et al., 2016). For those participants who reported a strong and valued relationship prior to the ED, sustaining that relationship throughout the ED was important, with some reporting that they felt their

relationship played an important part in their sibling's recovery (Withers et al., 2014). For those who experienced distancing within the sibling relationship, two studies reported that the relationship between participants and their sibling no longer felt normal as a result of the ED. Participants reported that normal sibling experiences, such as conflict about belongings or having lunch together, were no longer possible and this put a strain on their relationship (Dimitropoulos et al., 2009; **Quotation 4;** Garley & Johnson, 1994). Participants also reported that they felt their sibling avoided interactions with them and this led to distancing. Some participants reported that their sibling focused only on ED behaviours such as weight loss and reduced calorie intake with little interest in anything else leading to distancing between them (Fjermestad et al., 2019; Jungbauer et al., 2016; Moses, 2013; Withers et al., 2014). Finally, some reported that the physical changes they witnessed in their sibling, coupled with their sibling's denial of the ED, impacted on their ability to maintain a close relationship with them (Dimitropoulos et al., 2009).

### *Theme Two: Disruption and changes to family life*

#### *Change of role for the healthy sibling*

Six studies described a change of role for the healthy sibling within the family (Areemit et al., 2010; Callio et al., 2016; Dimitropoulos et al., 2009; Garley & Johnson, 1994; Jungbauer et al., 2016; Moses, 2013). Participants reported taking on responsibility for the affected sibling through monitoring their sibling's food intake and exercise (Callio et al., 2016; Garley & Johnson, 1994; Jungbauer et al., 2016), and protecting them in times of family conflict (Dimitropoulos et al., 2016). Participants in three of the studies identified or described the relationship in a way that suggested sibling-focused parentification since the onset of the ED, wherein the healthy sibling took on the role of a parent to the sibling with the difficulty (Dimitropoulos et al., 2009; Garley & Johnson, 1994; **Quotation 5**; Jungbauer et al., 2016). Various reasons for taking on responsibility for their siblings were reported

including providing support to their parents (Callio et al., 2016), feeling partly to blame for causing the ED (Areemit et al., 2010), and feeling that their parents were not responding adequately to the ED (Areemit et al., 2010; **Quotation 6;** Dimitropoulos et al., 2009;). Birth order did not seem to impact on this change of role and increased responsibility, with one study reporting that participants who were younger than their sibling took on this new role (Jungbauer et al., 2016). This role appeared to continue into adulthood for some of the participants, with one reporting that she had taken on legal custodianship of her sibling. This same study reported that female participants felt more responsibility for their affected sibling than male participants (Jungbauer et al., 2016).

*The impact of the ED on everyday life*

In four of the reviewed studies, participants reported that the ED had impacted on everyday family life (Callio et al., 2016; Jungbauer et al., 2016; Latzer et al., 2002; Moses, 2013;). Participants reported that the ED had a particular impact on family mealtime, which had become organized, structured and inflexible, where schedules were used, and meals were planned weeks in advance. Family life was reported as being more rigid due to the importance of adhering to mealtimes for their affected sibling, this led to less time doing enjoyable activities together (**Quotation 7;** Callio et al., 2016). They reported that carrying out important daily tasks such as completing homework could be impacted due to conflict between their sibling and their parents or by visiting their sibling in hospital (**Quotation 8**; Moses, 2013). Many of the participants reported feeling frustration and sadness in relation to the impact of the ED on everyday life (Callio et al., 2016; Moses, 2013).

*ED causes conflict in family relationships*

Seven of the included studies described conflict within the family arising from the ED (Areemit et al., 2010; **Quotation 9**; Callio et al., 2016; Dimitropoulos et al., 2009; Fjermestad et al., 2019; Garley & Johnson, 1994; Jungbauer et al., 2016; Moses, 2013;). Participants

across studies reported conflict arising between their affected sibling and their parents. In addition to this, participants also reported interparental conflict and conflict between parents and other family members (Dimitropoulos et al., 2009; Garley & Johnson, 1994; Jungbauer et al., 2016). Difficulty during mealtimes, response of family members to the ED, and ways to support the affected sibling were the most frequently reported as reasons for conflict arising (Callio et al., 2016; Dimitropoulos et al., 2009; Jungbauer et al., 2016). Participants in three studies reported that different family member response styles to the ED led to conflict and a sense of dividedness. For example, conflict arose when one family member had a detached response to the ED and one had an over-involved response (Areemit et al., 2010; **Quotation 10**; Dimitropoulos et al., 2009; Jungbauer et al., 2016).

### *Theme Three: Difficult feelings evoked by the ED*

*Frustration, anger and fear*

Difficult emotions evoked by the ED were discussed across all ten papers (Areemit et al., 2010; Callio et al., 2016; Dimitropoulos et al., 2009; Fjermestad et al., 2019; Garley & Johnson, 1994; Jungbauer et al., 2016; Latzer et a., 2002; Moses, 2013; Ross & Handy, 1997; Withers et al., 2014). Most regularly reported across studies were the participants experience of anger, frustration and fear. Participants reported being frustrated by the time spent by both their sibling and their family focusing on the ED (Fjermestad et al., 2019), some reported frustration towards their sibling's denial of the ED or their indifference to the recovery process (Callio et al., 2016; Fjermestad et al., 2019; **Quotation 11;** Jungbauer et al., 2016). Frustration in relation to their sibling's rigid behaviours and obsessions were also reported across studies (Areemit et al., 2010; Fjermestad et al., 2019). In two studies, participants reported anger towards their siblings. These participants reported that anger led to verbal conflict such as arguing and shouting and in one study physical aggression between siblings (Callio et al., 2016; **Quotation 12**; Jungbauer et al.,2016). In another study, a participant

expressed anger in relation to what she and her family had experienced. However, the focus of her anger was not directed at her sibling (Moses, 2013).

Fear was a dominant theme across nine of the reviewed papers (Areemit et al., 2010; Callio et al., 2016; Dimitropoulos et al., 2009; Fjermestad et al., 2019; Garley & Johnson, 1994; Jungbauer et al., 2016; Latzer et a., 2002; Moses, 2013; Withers et al., 2014). While some participants reported that their sibling's hospitalization provided them with relief (Withers et al., 2014), many reported that this experience was difficult and frightening and that they did not like being separated (Dimitropoulos et al., 2009; Withers et al., 2014). In three studies, participants reported that thoughts of their sibling dying evoked fear. These thoughts were related to fears about major weight loss, complications of the ED and fear that their sibling would die by suicide (**Quotation 13**; Callio et al., 2016; Fjermestad et al., 2019; Moses, 2013).

*Feeling invisible*

Over half of the studies described how participants experienced a feeling of invisibility as a result of the ED (Areemit et al., 2010; Callio et al., 2016; **Quotation 14** Fjermestad et al., 2019; Garley & Johson, 1994; Jungbauer et al., 2016; Moses, 2013). Participants in almost all of these studies reported that there was an intense focus within the family on the affected sibling which led to parents having less availability for them. Some participants reported that this led to feelings of grief and anger (Jungbauer et al., 2016). For some participants, having a sibling with an ED led them to supress their own emotional experiences and become the "un-demanding, silent child" (Areemit et al., 2010 p. 572), potentially reinforcing the "special status" of their sibling (Garley & Johnson, 1994 p. 161). Participants in one study reported that they felt there were higher expectation and demands placed on them in terms of awareness and responsibility towards their affected sibling (Jungbauer et al., 2016). Contrasting this, participants in one study reported that although

there was a focus on the ED, parents managed to continue to be available to all of the children in the family. Of note, these were participants who had spent time as an inpatient on an ED unit with their sibling and family during the ED (Fjermestad et al., 2019).

### *Theme Four: Coping skills and supports*

#### *Ways of coping*

Seven of the reviewed studies discussed participants' ways of coping with the experience of having a sibling with an ED (Callio et al., 2016; Dimitropoulos et al., 2009; Fjermestad et al., 2019; Garley & Johnson, 1994; Moses, 2013; Ross & Handy, 1997; Withers et al., 2014). Emotion-focused coping strategies such as distancing, avoidance and seeking social support were reported most frequently by participants. Participants discussed taking physical time-out from the home environment (Dimitropoulos et al., 2009; **Quotation 15;** Withers et al., 2014) distracting themselves from the situation by focusing on schoolwork (Moses, 2013) and taking up hobbies (**Quotation 16;** Dimitropoulos et al., 2009). The use of avoidance as a coping strategy was evident in two studies where siblings reported preferring when their sibling was not around as it reminded them of the difficulties the family were experiencing (Garley & Johnson, 1994; Dimitropoulos et al., 2009). In four studies, seeking social support by talking to their other siblings, external family members, friends or supports in school was used as a way of coping (Callio et al., 2016; Dimitropoulos et al., 2009; Fjermestad et al., 2019; Withers et al., 2014). Interestingly, several participants across 5 studies reported that they did not look to their parents for support (Callio et al., 2016; Dimitropoulos et al., 2009; Fjermestad et al., 2019; Garley & Johnson, 1994; Withers et al., 2014). Reasons for this included not wanting to add to their parents distress (Moses, 2013), not feeling like their concerns would be acknowledged (Dimitropoulos et al., 2009), and finding it difficult to seek emotional support from parents who had different response styles to the ED (Fjermestad et al., 2019). Contrasting this, some participants felt that their parents

were an important support to them during their siblings ED (**Quotation 17**; Callio et al., 2016; Withers et al., 2014).

*Personal growth and development*

Participants across five studies described how they were able to introspect and take meaning from their siblings ED (Areemit et al., 2010; Dimitropoulos et al., 2009; Fjermestad et al., 2019; Garley & Johnson, 1994; Jungbauer et al., 2016). Participants in three studies described having more understanding of, and compassion for, people and families experiencing mental health difficulties (Dimitropoulos et al., 2009; **Quotation 18,** Fjermestad et al., 2019; Jungbauer et al., 2016). Furthermore, participants reported that the experience of having a sibling who was unwell led to better understanding of the value of reliable friendships (Dimitropoulos et al., 2009; Garley & Johnson, 1994). Contrasting this, some participants reported adverse physical and mental health consequences as a result of their sibling's ED. Some participants reported more physical problems such a colds and infections, disturbed sleep and eating habits, and concentration problems in school. Some participants reported that they developed mood problems such as anxiety and depression (Fjermestad et al., 2019).

*Support needs*

Participants across five studies described and discussed what they needed in terms of support both when the diagnosis was received and afterward (Callio et al., 2016; Dimitropoulos et al., 2009; Fjermestad et al., 2019; Jungbauer et al., 2016; Moses, 2013). One support need which was discussed across several studies was the participants need for information. Many participants reported that access to personal information that was specific to their sibling and family situation would be beneficial to them. They reported that this should come from a professional within the mental health service and if possible, it should be delivered to the participants in a one-to-one session rather than within a family setting

(Dimitroupouls et al., 2009; **Quotation 19;** Jungbauer et al., 2016; Moses, 2013). Participants reported that one-to-one sessions with a profession would be useful not only for their information needs but also for emotional support. The following were outlined across studies as potential discussion points for one-to-one sessions: the roles and responsibilities of the participant and how best to support their sibling, information on what it is like to experience an ED, support with communication skills, and what has worked for other families (Dimitropoulos et al., 2009; Jungbauer et al., 2016; Moses, 2013).

Many participants who experience family therapy (FT) described it as supportive. FT was described as a place where participants could access information, express their views and gain a better understanding of their sibling's experience (Fjermestad et al., 2019; Jungbauer et al., 2016) However, some participants reported that FT sessions were not a place where they could open-up. Reasons for this included not wanting to further burden their parents with their emotion (Jungbauer et al., 2016; Moses, 2013) and feeling that their voices were not heard, and opinions were not considered within this setting (Jungbauer et al., 2016). A final support need reported by participants across studies was the need for sibling specific support groups. Participants reported that attendance at these groups would help to normalize the experience of having a sibling with an ED and would also be a place where they could gain practical and emotional support (Dimitropoulos et al., 2009; Fjermestad et al., 2019; Jungbauer et al., 2016). Although many participants wanted more involvement in their sibling's care through information and support, other participants were ambivalent about this. Some reported that they feared that more information and involvement would lead to more anxiety for the participant themselves. While others reported not wanting to be involved in their sibling's care at all (**Quotation 20:** Callio et al., 2016; Fjermestad et al., 2019).

### *Theme Five: Healthy sibling's relationship with their own body*

*Greater Awareness of eating habits in self and others*

Participants in four of the studies included in the review discussed having a greater awareness of eating habits and body shape in themselves, their sibling and in others outside the family unit (Areemit et al., 2010; Callio et al., 2016; Fjermestad et al., 2019; Moses, 2013;). Participants in one study reported that they had been the first person to become aware that their sibling's eating habits had changed (Callio et al., 2016), while other participants reported that they had become more aware of their sibling's behaviour around food since the ED which made them take more notice of what, and when their sibling was eating (Areemit et al., 2010; Fjermestad et al., 2019). One study reported that participants continued to pay attention to the eating behaviours of their sibling when they were in recovery for fear of them becoming unwell again (**Quotation 21;** Fjermestad et al., 2019). Participants in three of the studies reported that they had become more aware of the eating behaviours and attitudes of people outside of their family (Areemit et al., 2010; Fjermestad et al., 2019; Moses, 2013). This ranged from participants feeling angry when they heard people using certain language e.g. "fat" and "diet" to participants being more watchful over friends who were engaging in restrictive behaviour around food (Areemit et al., 2010, p.551; Moses, 2013).

*Comparing eating habits, food choices and body shape with sibling*

Comparison were made between siblings in relation to eating habits and body shape in four studies (Areemit et al., 2010 Callio et al., 2016; Garley & Johnson, 1994; Moses, 2013;). While some participants reported that they were the initiator of this comparison, observing differences in their "willpower, appetite and body image" when compared to their siblings (Garley & Johnson, 1994, p. 160), others reported that this comparison was initiated by their sibling and led to them feeling judged by them (Garley & Johnson, 1994; **Quotation 22;** Areemit et al., 2010). Participants reported that living with their sibling while they were

experiencing the ED intensified comparisons in these areas (Moses, 2013). Participants in one study reported that they had experimented with some of the disordered eating habits displayed by their sibling (Areemit et al., 2010). Several participants across studies reported that they compared their eating habits and body-image against their siblings in a negative way i.e. leading to negative appraisals about themselves, while two studies reported that this comparison did not lead to a negative view of their own self-image. Of note, Callio et al., (2016) found that two of the male participants in their study reported that their sibling's ED had no impact on their body-image. This finding was also reported by some participants in a study with a mixed gender participant group (Areemit et al., 2010).

**Table 4:** Quotations from participants by theme/subtheme

| **Theme/Sub-theme** | **Quotation** |
|---|---|
| **My relationship with my sibling** | |
| *My sibling seems different now* | 1. Her personality just changed. She would lose her temper at the smallest things and attack everybody…. it's totally the opposite to her nature (Withers et al., 2014, p.57).<br>2. But then mum and dad have always said it is just the illness, but to me the illness has been her (Fjermestad et al., 2019, p. 5). |
| *Strengthening and distancing in the sibling relationship* | 3. I think we have become more close because we know each other more and I guess you can say the darker sides even though it sounds dramatic…. and I think that has just brought us closer but I wish it would happen in a more positive way instead of this continual negative way (Dimitropoulos et al., 2009, p. 358).<br>4. It's not normal…I used to be living with a normal sister. We'd get into arguments over "No, don't wear my clothes tonight" those little things, but now over salt in the water! (Garley & Johnson, 1994, p. 160). |
| **Disruption of family unit and family life** | |
| *Change in role for healthy sibling* | 5. I've always felt responsible for my sister, that's why I never broke contact with her, even when it was difficult and burdensome. My sister is, then as now, like a daughter to me (Jungbauer et al., 2016, p 83).<br>6. My mother tries to not pay attention to it [the eating disorder] and my father not so much because he doesn't communicate and not my brother so [affected sibling] doesn't really have anybody to say look there's stuff going on here so I'm the most direct (Dimitropoulos et al., 2009, 354). |
| *Impact on normal family life* | 7. We have like a schedule about who is to do the cooking and then we have to plan one week in advance what to cook, and I think it's bloody frustrating and childish sort of … I don't understand why mum doesn't just say that today we prepare this and tomorrow we prepare that, but we have a schedule for everything, and every little detail is planned and can't be changed (Callio et al., 2016, p. 619).<br>8. 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 (Moses, 2013, p. 56). |
| *ED causes conflict in relationships* | 9. It becomes busy to have a person in the house who struggles with an eating disorder. … Already from breakfast, she did not want to eat, then there are arguments. Then you go to school and you come home again, then again, arguments. Then I go to practice, then it is supper, and they can manage to argue then as well (Fjermestad et al., 2019, p. 9).<br>10. Divided in how we would respond and divided in how we would react toward her....there were times when it was obvious she was on a downward spiral so some people would choose to completely ignore it and some people did not want to (Dimitropoulos et al., 2009, p. 355) |
| **The ED evokes difficult feelings** | |
| *Anger, frustration and fear* | 11. Well, the entire illness is pretty annoying because it is completely meaningless to waste so much time on something so silly. I think what annoys me the most is the fact that my sister has wasted so much of her life on something completely meaningless, which she could have used to something meaningful (Fjermestad et al., 2019; p. 6).<br>12. I felt helpless, but also aggressive because she was so indifferent. Our parents sat there, crying, and she just sat there and said, "just leave me alone!" I was so angry, and I screamed at her. One time I even resorted to violence (Jungbauer et al., 2016, p. 82).<br>13. You worry about it more or less all the time and I have also thought about whether she might take her life, you sort of never know. (Callio et al., 2016, p. 617). |
| *Feeling invisible* | 14. So when aunties and such ask; "How is your sister?" Your sister, your sister… what about me?... Do I exist in this world, really, or is it just her (Fjermestad et al., 2019, p.8). |
| **Coping skills and supports** | |
| *Ways of coping* | 15. …just when I get out of the house, it's like, I don't have to be around it anymore (Withers et al., 2014, p. 57).<br>16. I think keeping somewhat of a distance from it, don't deny it, just somewhat of a distance. Living fully in your own life... staying busy in your own life, and if it means having a specific hobby that's great (Dimitropoulos et al., 2009, p. 358).<br>17. Yeah, my mum and dad made sure that even though she's got a disorder and stuff that they really tried not to forget about me. So I was always talking with them (Withers et al., 2014, p.58). |
| *Personal growth and development* | 18. It is so incredibly important to live well with oneself, to do what makes you happy in a way … It is hard to explain, but you should just be satisfied. When you think about everything you have in life, it is incredibly much. I have gotten a very different view after this actually (Fjermestad et al., 2019, p. 10) |
| *Support needs* | 19. … It would have been good if the therapist had come to me and spoken with me about how I was doing. I think it would be nice to be better informed about the situation. My parents told me my sister was anorexic and needed to go to the clinic, but I never knew more than that (Jungbauer et al., 2016, p. 84).<br>20. I'm not all that interested, actually (Callio et al., 2016, p. 619). |
| **My relationship with my body** | |

| | |
|---|---|
| *Greater awareness of eating habits in myself, my sibling and others* | 21. It is like every time she is going to work out or eats a bit less than usual or she skips a meal, then of course I think: What if she still is sick? (Fjermestad et al., 2019, p.9). |
| *Comparing my eating habits, food choices and body shape with my sibling* | 22. I never lend her any of my clothes anymore because she'll say, "I couldn't wear the clothes because it was too big for me, it was just too big for me". I'll be like, okay, "You don't need to tell me that three times. Yes, I'm bigger than you" (Areemit et al., 2010, p. 574). |
| | |

**Discussion**

This SR was carried out to gain a better understanding of healthy siblings' experience of having a brother or sister diagnosed with an ED. Nine qualitative studies and one mixed method study were included in this review and a thematic synthesis revealed five core themes and twelve sub-themes (figure 2). The clinical implications of the five core themes will be discussed below. Of note, several novel concepts and sub-themes were evident within the data when it was synthesised, this included: healthy siblings feeling invisible; the concept of sibling-focused parentification within the context of the ED; healthy siblings not using parents as a support; and comparisons being made between siblings around body image and food habits. These findings emerged through the combining of data and were not stand-alone themes within individual studies.

This review found that the lives of healthy siblings were greatly impacted by their sibling's ED. Themes which were evident in the data related to both the impact on the interpersonal and intrapersonal aspects of the healthy siblings' lives, with many themes overlapping and impacting on both areas (figure 2). A further important overarching finding within this review was that healthy siblings were not a homogenous group. Across many themes and sub-themes participants reported different views on their experiences; for example, while some participants reported a strengthening in their relationship with their sibling, others reported a distancing as a result of the ED; some participants reported that their sibling's ED had a direct impact on their eating habits and self-image where others felt it

had no effect; and while many participants wanted more information and involvement in their siblings care, some reported not wanting to have any involvement at all. For this reason, when considering supporting healthy siblings within the context of EDs, it is important for clinicians and services to take a person-centred approach and take time to understand the individual support needs of each person.

A theme which was evident across many studies was the impact which the ED had on the sibling relationship. The affected sibling was viewed as different to before, participants reported the loss of "normal" sibling activities and changes in the quality of the relationship i.e. a stronger relationship or distancing within the relationship. This finding reflects the existing literature on other groups of healthy siblings who have brothers or sisters with physical or mental health problems where the illness has been diagnosed after a period of normal development e.g. cancer, psychosis (Amaresha et al., 2014; Wilkins & Woodgate, 2005), but not for those who have siblings with developmental disorders e.g. ASD (Marcha & Boucher, 2006). Healthy siblings reported that they struggled to understand the ED and the changes they observed in their sibling. Externalising the illness, a core technique used in family-based treatment, was reported as supporting the participants' understanding of the ED and in turn strengthening or maintaining the sibling relationship (Lock & Le Grange, 2013). However, participants reported that they were often torn between the externalised view of the ED and the feeling that their sibling could control the ED if she or he wished. This experience of simultaneously viewing the person with the ED as in control of their behaviour while also viewing the ED as a separate entity has been reported by other carers/relatives of those with EDs (Fox et al., 2015). Externalising the disorder has been reported by some carers to be a conscious decision which supports them to direct their negative feelings towards the ED rather than the person (Fox et al., 2015). If healthy siblings are willing to engage in treatment, clinicians should ensure that they are supported to externalise their sibling's ED which may

function to maintain the sibling relationship. Furthermore, future research focusing on the ways which family members, siblings and clinicians externalise the ED could be supportive to the field and could facilitate a better understanding of this important process.

The current findings also highlight the impact of the ED on normal family life for the healthy siblings. Participants reported that greater levels of responsibility were placed on them, with some comparing their new role to that of a parental role. Sibling-focused parentification, a process whereby a child/adolescent takes on the role of a parent to their sibling has previously been reported in healthy siblings of children with chronic illness and disability (Lamorey, 1999). Within these cohorts, research indicates that if the role of caregiving is too demanding on the healthy sibling they can display "extreme helpfulness, hyper-responsibility and pseudo-maturity" which can lead to emotional dysregulation, mental health difficulties and behavioural issues in the long-term (Lamorey, 1999, p. 76). The current review found that birth order did not necessarily impact on this change of roles with both older and younger healthy siblings reporting taking on roles which required them to be more responsible and independent. However, gender may play a role in the level of responsibility that healthy siblings feel is placed on them with this review suggesting that female siblings felt higher levels of responsibility and parentification. However, this link is tentative at present due to the small number of male participants included in this study. The male sibling perspective may benefit from further research to identify whether gender differences are evident and the causes of these differences.

These changes within the sibling role may be life long, with some participants reporting that as they moved into adulthood and onward, they continued to feel responsibility towards, and provide care for their siblings. These factors should be considered alongside information related to recovery rates in EDs. For AN, 30% of this population will only meet partial recovery, with 20% of these remaining "severely ill" (Mascolo, 2017; Hay & Touyz,

2015). For healthy siblings, a continued sense of responsibility into adulthood may lead to their taking on of caregiving duties into the future. Across several studies, participants reported that they feared that their affected sibling would die. These fears, held by healthy siblings, can be viewed as valid in terms of the mortality rates within EDs, previously stated (Arcelus et al., 2011) and may further reinforce feelings of responsibility towards their sibling. Consequently, healthy siblings may need emotional support with these difficult thoughts and emotions.

The sub-theme of "feeling invisible" was also evident in this review. Participants reported that the affected sibling became the parents main focus and that they would often supress their own needs to ensure no added stress was put on the family. The focus of the family being on the affected sibling is corroborated by the "Reorganisation of the Family Model" which underpins family therapy for EDs (Eisler, 2005). It is also reported in studies looking at the experience of the ED from other family members' perspective (Fox et al., 2015; Honey et al., 2006), and for families of children with other physical and mental health difficulties (Amaresha et al., 2014; Marcha & Boucher, 2006; Wilkins & Woodgate, 2005). For those participants who did not report feelings of invisibility, a number had experienced family therapy and an inpatient admission with their affected sibling. These participants reported feeling heard within the context of the ED. Reasons for this could include: parents feeling more supported by services and therefore having more capacity to care for healthy siblings; parents having access to better information from clinicians and therefore being aware of the potential impact that the ED may have on healthy siblings; or the families who choose to engage intensely with services i.e. through an inpatient admission, being more resourced to support the whole family within the context of the ED.

The finding which was most specific to this population (i.e. siblings of those with *EDs*) was related to healthy siblings eating habits and view of their body shape. The synthesis

of studies led to the identification of a theme which related to comparisons of food and body shape between siblings. Many participants, although not all, reported comparing themselves with their siblings, this included experimenting with their siblings eating habits and comparing shape and size. Quantitative studies investigating the rates of EDs, specifically AN, in healthy siblings suggest that approximately 6.6% of this cohort also experience an ED (Vandereycken & Van Vreckem, 1992). Furthermore, rates of lifetime prevalence in female siblings of people with AN have been reported to be 11.4% (when AN, sub-clinical AN and BN are combined) compared to 1.8% of a control group (Strober, Morrell, Burroughs, Salkin & Jacobs, 1985). As healthy siblings are at a higher risk of eating and weight problems (Vandereycken, 2002), it is important that those who endorse weight and shape comparisons with their affected sibling are identified, and that psychoeducation around healthy and unhealthy eating habits are offered. Early intervention and support for this vulnerable subgroup may lead to a reduction in the mimicking of ED behaviours and reduce the risk of the healthy sibling developing an ED.

Many siblings did not report parents as a form of support. For healthy siblings who do not approach parents for support, the "un-demanding, silent child" role may be reinforced (Areemit et al., 2010). Many participants reported benefit-finding and meaning-making as a result of their sibling's experiences with AN (Packenham, 2010). This included understanding the value of good friends, increased empathy towards others' suffering and development of important intrapersonal skills such as patience and tolerance. This finding is supported within the literature base which identified benefit-finding in siblings of people with physical illnesses such as cancer and mental health difficulties such as schizophrenia, borderline personality disorder, major depression and generalised anxiety disorder (Sanders & Szymanski, 2013).

Of particular importance and relevant to clinical practice were the support needs which were reported by healthy siblings across this review. This included access to personalised, individual information related to their family context. Of note, reporting of support needs tended to be in more recently published papers (from 2009 onwards) which could relate to the increased understanding of the role of the family in recovery of the YP and the increased sibling involvement in ED interventions (East, 2009). Healthy siblings acknowledged that families were not homogenous and therefore wanted information that would support them in coping with their sibling's difficulties. When supporting healthy siblings, clinicians should consider taking a personalised approach i.e. using clinical knowledge of the family and the affected sibling to support the healthy sibling. Siblings reported wanting support with communicating with their sibling and supporting them through their diagnosis. They also reported wanting one-to-one practical and emotional support outside the context of the family environment where they could open-up about their experiences, and sibling support groups with others who have had similar life experiences which they felt would help to normalize their experiences. Taking the results of this review into account, one-to-one clinical sessions for healthy siblings could also incorporate psychoeducation on eating and self-image. As stated above, healthy siblings are a heterogenous group and therefore what works for some may not work for all. Supports should be offered as optional to those who wish to be involved with their affected siblings care.

***Robustness of findings***

To the authors knowledge, this is the first SR focusing specifically on the healthy siblings' experience. Robustness of findings was supported by several steps taken by the authors throughout. The first was the use of reporting tools and quality assessments designed for use in qualitative synthesis (i.e. CASP and ENTREQ). In the interest of only including studies of good methodological quality, the CASP quality assurance measure, a published

framework for quality assessment was used to rate the quality of each study. Within qualitative research, debate is on-going on how to use the results of these quality assessments and whether studies should be excluded on their quality scoring (Atkins et al., 2008; Campbell et al., 2012; Garside, 2014). Within this SR, quality assurance was carried out by two authors and all studies included were rated as either category A (indicating a low likelihood of methodological flaws) or B (indicating a moderate likelihood of methodological flaws) studies, leading to no studies being excluded on the basis of quality. However, it is acknowledged that the use of a quality assurance measure does not guarantee quality but is an indicator only (Walsh & Downe, 2006). The robustness of the findings were also supported by the use of two reviewers at the analysis stage of the SR. Finally, the inclusion of grey literature within this review reduced the risk of publication bias and increased robustness of findings (Haddaway et al., 2015).

### *Limitations and Challenges*

It is acknowledged that the participants included across studies were not a homogenous group and that this may have impacted on the findings reported within this study. Some participants, particularly from the older studies, had no experience of support from mental health services (Garley & Johnson, 1994) and therefore may have had a different experience to those participants who had been involved in family-based treatment (Fjermestad et al., 2019). In addition to this, the type and severity of the ED experienced by affected siblings differed across studies. A small number of participants has a sibling who experienced severe and enduring AN which may have led to different experiences for the healthy sibling. Furthermore, as discussed in the results section, five participants within this SR had a sibling diagnosed with EDNOS and five were diagnosed as ED only. Additional information on the five participants categorised as ED only was sought but not available. These differences across participants may have led to different experiences for healthy

siblings which may have influenced the results. Although the quality of the studies within this review was good, many of the participants within studies were self-selected and as previously discussed many had experience of being involved with their siblings treatment, meaning that the results of this study may not be generalisable to the general population of healthy siblings.

## Conclusion

There is a growing interest in the importance and impact of the sibling relationship across the lifespan. Within the context of one sibling becoming ill, research suggests that the healthy siblings' world is greatly affected and that they experience major changes within their own life. This systematic review focused on the experience of healthy siblings in the context of EDs and found that their lives are impacted in many ways including through changes to their normal daily lives and routines, conflict within the family system, experiencing difficult emotions and changes to their self-perception including their eating and their body image.

## References

Amaresha, A. C., Venkatasubramanian, G., & Muralidhar, D. (2014). Needs of siblings of persons with psychosis: A systematic descriptive review. *Clinical Psychopharmacology and Neuroscience*, *12*(2), 111.

Angell, M. E., Meadan, H., & Stoner, J. B. (2012). Experiences of siblings of individuals with autism spectrum disorders. *Autism Research and Treatment*, *2012*.

Arcelus, J., Mitchell, A. J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders: a meta-analysis of 36 studies. *Archives of General Psychiatry*, *68*(7), 724-731.

Areemit, R. S., Katzman, D. K., Pinhas, L., & Kaufman, M. E. (2010). The experience of siblings of adolescents with eating disorders. *Journal of Adolescent Health*, *46*(6), 569-576.

Atkins, S., Lewin, S., Smith, H., Engel, M., Fretheim, A., & Volmink, J. (2008). Conducting a meta-ethnography of qualitative literature: lessons learnt. *BMC Medical Research Methodology*, *8*(1), 21.

Bank, L., Burraston, B., & Snyder, J. (2004). Sibling conflict and ineffective parenting as predictors of adolescent boys' antisocial behavior and peer difficulties: Additive and interactional effects. *Journal of Research on Adolescence*, *14*(1), 99-125.

Brennan, P., & Silman, A. (1992). Statistical methods for assessing observer variability in clinical measures. *BMJ: British Medical Journal*, *304*(6840), 1491.

Campbell, R., Pound, P., Morgan, M., Daker-White, G., Britten, N., Pill, R., ... & Donovan, J. (2012). Evaluating meta ethnography: systematic analysis and synthesis of qualitative research.

CASP, U. (2014). Critical Appraisal Skills Programme (CASP) 2014.

Callio, C., & Gustafsson, S. A. (2016). Living with a sibling who suffers from an eating disorder: a pilot interview study. *Journal of Multidisciplinary Healthcare*, *9*, 615.

Chenail, R. J. (2011). Learning to Appraise the Quality of Qualitative Research Articles: A Contextualized Learning Object for Constructing Knowledge. *Qualitative Report*, *16*(1), 236-248.

Dimitropoulos, G., Klopfer, K., Lazar, L., & Schacter, R. (2009). Caring for a sibling with anorexia nervosa: A qualitative study. *European Eating Disorders Review: The Professional Journal of the Eating Disorders Association*, *17*(5), 350-365.

Dodge, E. (2016). Forty years of eating disorder-focused family therapy–the legacy of 'psychosomatic families'. *Advances in Eating Disorders*, *4*(2), 219-227.

East, P. L. (2009). Adolescents' relationships with siblings. *Handbook of Adolescent Psychology*, *2*, 43-73.

Eisler, I. (2005). The empirical and theoretical base of family therapy and multiple family day therapy for adolescent anorexia nervosa. *Journal of Family therapy*, *27*(2), 104-131.

Eisler, I., Simic, M., Blessitt, E., & Dodge, L. & Team. (2016). Maudsley service manual for child and adolescent eating disorders (Revised). London: Child and Adolescent Eating Disorders Service, South London and Maudsley NHS Foundation Trust. Available at: http://www.national.slam.nhs.uk/services/camhs/camhs-eatingdisorders/resources

Feinberg, M. E., Solmeyer, A. R., & McHale, S. M. (2012). The third rail of family systems: Sibling relationships, mental and behavioral health, and preventive intervention in childhood and adolescence. *Clinical Child and Family Psychology Review*, *15*(1), 43-57.

Fjermestad, K. W., Rø, A. E., Espeland, K. E., Halvorsen, M. S., & Halvorsen, I. M. (2019). "Do I exist in this world, really, or is it just her?" Youths' perspectives of living with a sibling with anorexia nervosa. *Eating Disorders*, 1-16.

Fox, J. R., Dean, M., & Whittlesea, A. (2015). The experience of caring for or living with an individual with an eating disorder: A meta-synthesis of qualitative studies. *Clinical Psychology & Psychotherapy*, *24*(1), 103-125.

Friedrich, R. M., Lively, S., & Rubenstein, L. M. (2008). Siblings' coping strategies and mental health services: a national study of siblings of persons with schizophrenia. *Psychiatric Services*, *59*(3), 261-267.

Garley, D., & Johnson, B. (1994). Siblings and eating disorders: A phenomenological perspective. *Journal of Psychiatric and Mental Health Nursing*, *1*(3), 157-164.

Garside, R. (2014). Should we appraise the quality of qualitative research reports for systematic reviews, and if so, how?. *Innovation: The European Journal of Social Science Research*, *27*(1), 67-79.

Haddaway, N. R., Collins, A. M., Coughlin, D., & Kirk, S. (2015). The role of Google Scholar in evidence reviews and its applicability to grey literature searching. *PloS one*, *10*(9), e0138237.

Harrison, K. (2000). The body electric: Thin-ideal media and eating disorders in adolescents. *Journal of Communication*, *50*(3), 119-143.

Hay, P., & Touyz, S. (2015). Treatment of patients with severe and enduring eating disorders. *Current Opinion in Psychiatry*, *28*(6), 473-477

Health Service Executive (2018) *Eating disorder services HSE model of care for Ireland* Available at: https://www.hse.ie/eng/about/who/cspd/ncps/mental-health/eating-disorders/ [Accessed 06 December 2019]

Honey, A., & Halse, C. (2006). The specifics of coping: parents of daughters with anorexia nervosa. *Qualitative Health Research*, *16*(5), 611-629.

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: The Professional Journal of the Eating Disorders Association, 14*(5), 315-322.

Jungbauer, J., Heibach, J., & Urban, K. (2016). Experiences, burdens, and support needs in siblings of girls and women with anorexia nervosa: Results from a qualitative interview study. *Clinical Social Work Journal*, *44*(1), 78-86.

Lamorey, S. (1999). Parentification of Siblings of Children with Disability or Chronic Disease. *Burdened Children: Theory, Research, and Treatment of Parentification*, 75.

Lock, J., & Le Grange, D. (2013). *Treatment manual for anorexia nervosa: A family-based approach*. Guilford Publications.

Latzer, Y., Ben-Ari, A., & Galimidi, N. (2002). Anorexia nervosa and the family: Effects on younger sisters to anorexia nervosa patients. *International Journal of Adolescent Medicine and Health*, *14*(4), 275-282.

Mascha, K., & Boucher, J. (2006). Preliminary investigation of a qualitative method of examining siblings' experiences of living with a child with ASD. *The British Journal of Development Disabilities, 52*(102), 19-28.

Mascolo, M. (2017, November 27). Hope for individuals with Severe and Enduring Eating Disorders. Retrieved from https://www.eatingdisorderhope.com/blog/severe-enduring-eds-seed

McHale, S. M., Kim, J.-Y., & Whiteman, S. D. (2006). Sibling Relationships in Childhood and Adolescence. In P. Noller & J. A. Feeney (Eds.), *Close relationships: Functions, forms and processes* (p. 127–149). Psychology Press/Taylor & Francis (UK).

Moses, D. (2013). *Exploring the Experiences of Siblings of Young People Diagnosed with an 'eating Disorder'* (Doctoral dissertation, University of East London).

Nolbris, M., Enskär, K., & Hellström, A. L. (2007). Experience of siblings of children treated for cancer. *European Journal of Oncology Nursing*, *11*(2), 106-112.

O'Brien, I., Duffy, A., & Nicholl, H. (2009). Impact of childhood chronic illnesses on siblings: a literature review. *British Journal of Nursing*, *18*(22), 1358-1365.

Ortlipp, M. (2008). Keeping and using reflective journals in the qualitative research process. *The qualitative report*, *13*(4), 695-705.

Pakenham, K. I. (2010). 13 Benefit-Finding and Sense-Making in Chronic Illness. *The Oxford handbook of stress, health, and coping*, 242.

Ross, K., & Handy, J. A. (1997). Family perceptions of anorexia nervosa: A qualitative study of two families' histories. *Looking back and moving forward*, *50*, 232-239.

Rossiter, L., & Sharpe, D. (2001). The siblings of individuals with mental retardation: A quantitative integration of the literature. *Journal of Child and Family Studies*, *10*(1), 65-84.

Sanders, A., & Szymanski, K. (2013). Siblings of people diagnosed with a mental disorder and posttraumatic growth. *Community Mental Health Journal*, *49*(5), 554-559.

Sharpe, D., & Rossiter, L. (2002). Siblings of children with a chronic illness: A meta-analysis. *Journal of Pediatric Psychology*, *27*(8), 699-710.

Strober, M., Morrell, W., Burroughs, J., Salkin, B., & Jacobs, C. (1986). A controlled family study of anorexia nervosa. In *Anorexia Nervosa and Bulimic Disorders* (pp. 239-246). Pergamon.

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*(1), 45.

Vandereycken, W. (2002). Families of patients with eating disorders. *Eating disorders and obesity: A comprehensive handbook*, 215-220.

Vandereycken, W., & Van Vreckem, E. (1992). Siblings of patients with an eating disorder. *International Journal of Eating Disorders*, *12*(3), 273-280.

Waldinger, R. J., Vaillant, G. E., & Orav, E. J. (2007). Childhood sibling relationships as a predictor of major depression in adulthood: A 30-year prospective study. *American Journal of Psychiatry*, *164*(6), 949-954.

Walsh, D., & Downe, S. (2006). Appraising the quality of qualitative research. *Midwifery*, *22*(2), 108-119.

Wilkins, K. L., & Woodgate, R. L. (2005). A review of qualitative research on the childhood cancer experience from the perspective of siblings: a need to give them a voice. *Journal of Pediatric Oncology Nursing*, *22*(6), 305-319.

Withers, A., Mullan, B., Madden, S., Kohn, M., Clarke, S., Thornton, C., ... & Touyz, S. (2013). Anorexia nervosa in the family: a sibling's perspective. *Advances in Eating Disorders: Theory, Research and Practice*, *2*(1), 53-64.

Woodgate, R. L. (2006). Siblings' experiences with childhood cancer: a different way of being in the family. *Cancer nursing*, *29*(5), 406-414.

Yang, H. C., Mu, P. F., Sheng, C. C., Chen, Y. W., & Hung, G. Y. (2016). A systematic review of the experiences of siblings of children with cancer. *Cancer Nursing*, *39*(3), E12-E21.

# Chapter Four

## Empirical Study

**Title:** Mental Health Clinicians' Perspectives on Implementing Externalisation in Family-Based Treatment

Prepared in accordance with submission guidelines of the European Eating Disorder Review (Appendix 5)*

**Word count:** 7, 298 (excluding abstract, tables and references)

*Although figures and tables are usually included as separate files for the journal, they are inserted in the text for ease of examination

**Mental Health Clinicians' Perspectives on Implementing Externalisation in Family-Based Treatment**

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*"Then all of a sudden, the parent and child are able to talk about the ED, you know, it's not such a hidden, internal, psychological process that's very sensitive…all of a sudden it's given this name." (Clinician 04)*

**Mental Health Clinicians' Perspectives on Implementing Externalisation in Family-Based Treatment**

Objective: Family-Based Treatment (FBT) is a first line intervention for the treatment of adolescent eating disorders (EDs). FBT consists of a number of phases and interventions, including the use of externalisation, a therapeutic technique which aims to separate the person from the problem through the use of language and metaphor. There is a paucity of scientific research on this technique and consequently, little is known about how clinicians understand, conceptualise and support families to externalise the ED in the context of FBT. This research aimed to gain a deeper understanding of how clinicians employ this technique in the context of FBT. Method: Using thematic analysis, eight semi-structured interviews were conducted with FBT trained clinicians working in child and adolescent mental health services. Results: Three major themes emerged which related to how clinicians use externalisation, the impact it has on family functioning, and the barriers which make externalisation difficult to implement with families. Conclusion: Externalisation is a therapeutic technique which can support a family and young person's (YP's) recovery from an ED when used in conjunction with other therapeutic skills. Clinicians should be aware of potential barriers to the implementation of externalisation such as the YP's problem awareness, age, and duration of ED symptomatology.

*Keywords: Externalisation; Family-Based Treatment; Anorexia Nervosa; Eating Disorder; Clinician Research*

Highlights:

- Externalisation is an important therapeutic technique within the FBT model. Clinicians should invest time learning how to use this technique effectively with families.

- Family functioning can be supported through the successful use of this technique including improving family communication and reducing conflict within relationships.
- ED unawareness can present as a major barrier to externalisation for a YP. There is potential to consider a pre-therapy stage which focuses on a YP's insight, and ambivalence towards change prior to implementing FBT to support the YP's ability to engage with the recovery process.

**Introduction**

Eating Disorders (EDs) such as anorexia nervosa (AN) and bulimia nervosa (BN) are serious mental health conditions which can cause significant physical and psychological distress for a young person (YP) and their family (Smink, Hoeken & Hoek, 2012; Swanson, Crow, LeGrange, Swendsen & Merikangas, 2011). The onset of an ED is often before adulthood and early intervention has been shown to result in better outcomes, including lower rates of relapse and hospitalisation (Hay, 2015). Family-based treatment (FBT), a manualized therapy which sees parents take responsibility for refeeding their child, has demonstrated positive treatment outcomes for adolescents presenting with EDs (Le Grange & Lock, 2009; Lock & LeGrange, 2013). FBT consists of three phases of treatment which include encouraging parents to take control of their child's eating; return of control and responsibility to the adolescent in an age appropriate way; and re-establishing healthy independence for the YP (Lock & Le Grange, 2013). Underlying these phases of treatment, FBT outlines several core principles. This includes an agnostic view of the ED; a focus on the symptoms of the ED in the initial phase of treatment; a non-authoritarian clinical stance; and externalising the ED as an illness or external force impacting on the family (Lock & Le Grange, 2013)

The "Reorganisation of the Family Model" (Eisler, 2005) underpins FBT. This theory views the family as maintaining the ED through reorganisation around the illness (Eisler,

2005, Lock & Le Grange, 2013). This reorganisation results in the ED becoming a central part of family life, with family interactions becoming based on eating, weight and food. This leads to a narrowing of focus on the present, with families becoming overwhelmed by every-day failure experiences which can lead to difficulties in family functioning. Patterns of daily life become rigid and inflexible within the family and a dominant feeling of helplessness can exist (Eisler, 2005; Lock & Le Grange, 2013; Simic & Eisler, 2018).

Research on FBT effectiveness has identified better outcomes for younger adolescents, those who have a shorter period of illness, those who respond early to treatment through rapid weight gain and those who do not have a comorbid psychiatric condition. Furthermore, high levels of parental confidence in initial sessions is indicative of positive treatment outcomes (Darcy et al., 2013; Dimitropoulos et al., 2017; Lock, Couturier, Agras, 2006; Lock, Couturier, Bryson & Agras, 2006). When compared to individual therapy, FBT has been shown to be superior at both one- and five-year follow-up (Eisler et al., 1997; Russell, Szmukler, Dare, Eisler, 1987). While FBT is now argued to be the "gold standard" treatment approach for adolescents with AN, more than half of those undergoing this treatment do not recover to the ideal body weight (IBW) of 95%, the measure of remission in AN (Agras et al., 2014; Le Grange et al., 2016). Moreover, dropout rates of 20% have been reported (Dejong, Broadbent, Schmidt, 2012; Lock et al., 2010).

While much research has focused on the efficacy of the FBT model, less has focused on the core principles and interventions that constitute the model (Wufong et al., 2019). This lack of specific research is interesting when viewed in the context of clinician fidelity, which has been reported to be 60% in manualized FBT (Kosmerly, Waller & Robinson, 2015). While this figure is slightly above other manualised therapies for EDs (e.g. CBT for EDs is <50% fidelity; Waller, Stringer, Meyer, 2012) it suggests "noteworthy gaps" between how FBT implementation is recommended and how it is practiced (Kosmerly et al., 2015 p. 2).

Research on FBT with transition aged youths (TAY; 18-21) may help to contextualise this fidelity rate. Findings from clinicians working with TAY suggest that clinicians may apply the model in different ways when working with different age groups to account for developmental differences. For example, when using externalisation with TAY, some clinicians reported using insight orientated externalisations rather than visual representations of the externalised ED as is used with younger people (Dimitropoulos et al., 2015).

Externalisation is one of the core principles in FBT and is a technique that originated in projective psychology (Bellak, 1954) and gestalt therapy (Perls, 1951), but has been most well developed within narrative therapy with the work of White and Epston (1990). For many individuals diagnosed with an ED, the process of being diagnosed and the labels that become attached to them (i.e. “anorexic” or “bulimic”) lead the person to “fully adopt the identity” of the ED (Weber, Davis & McPhie, 2006, p. 393). This position of adopting the identity of the ED can lead to feelings of shame, blame and guilt (White, 2000). Within FBT, the objective of externalisation is to create a separation between the YP and the ED (Eisler et al., 2016; Lock & Le Grange, 2013). This is primarily achieved using language, metaphor and visuals. For example, a clinician will initiate conversations with the family which linguistically separates the YP (with their achievements, hopes and goals in life) from the ED (Weber et al., 2006). Viewing the ED as an illness is the most prominent strategy used to externalise in FBT and involves shifting a family’s perspective to view the ED as a disease which has taken control of the YP (Lock & Le Grange, 2013). Parents are encouraged to view their child’s ED behaviours, emotions and thoughts as resulting from the impact of starvation on the body and as out of the young person’s control; while YP are supported to view their ED as separate to themselves, and to reflect on the impact of the ED on their lives from this position of separation (Eisler et al., 2016; Lock & Le Grange, 2013). The rationale for externalising the ED is to support the family to view the ED as a “quasi-external force”, rather than an intrinsic

part of the young person (Eisler et al., 2016 p. 32). This therapeutic shift supports the family to find new meaning in the physical, psychological and behavioural aspects of the ED and contributes to parental empowerment, an area identified as essential to recovery by clinicians (Dimitropoulos et al., 2015; Dimitropoulos et al., 2017; Eisler et al., 2016; Lock et al., 2013).

While no research has focused solely on the technique of externalisation within FBT, a number of studies have focused on the experience of those who engage in FBT, and within this research externalisation has been highlighted as being an important technique (Fox, Dean & Whittlesea, 2015; Lock & Le Grange, 2013; Medway & Rhodes, 2016; Williams, Wood & Plath, 2020; Wufong et al., 2019). YP have reported that externalising the ED as an illness within FBT facilitates an increase in parental understanding and empathy and leads to improved family relationships. Furthermore, they report that externalisation can lead to increased insight into the impact of the ED on their lives (Medway & Rhodes, 2016). Parents have reported that externalisation of the ED gives them a space to express the emotions they experience without placing blame on their child, and supports them to view the ED as something outside of their child's control (Wufong et al., 2019). Siblings have reported that externalising the illness supports their understanding of the ED and in turn functions to maintain the relationship between them and their affected brother or sister (Withers et al., 2013).

Although much of this research points to the positive impact of externalisation, the negative effects of this technique have also been reported (Dimitropoulos et al., 2015; Eisler et al., 2016; Wufong et al., 2019). One study which focused on the experiences of families where the YP did not recover with FBT intervention found that externalisation can lead to the YP feeling dismissed, being excluded from therapy and "losing their voice" (Eisler, 2016; Wufong et al., 2019 p. 9). White (2011) argued that the use of dualistic metaphors, such as those of the ED as an illness or an enemy, can lead to distress in families, particularly if the

family do not manage to overcome the ED. This view was further developed by parents of those who did not recover through FBT intervention in Wufong et al's. (2019) study. For these parents, the use of the illness metaphor led to the development of a hostile relationship with the ED and failure to recover being experienced as defeat.

A strong theoretical basis for externalisation is evident within the literature (Knight et al., 2003). Additionally, research focusing more broadly on FBT has improved our understanding of the benefits and challenges of externalisation to some extent. However, there is a paucity of scientific research within the field of FBT, or outside of it, which has focused exclusively on this technique (Ramey, Tarulli, Frijters & Fisher, 2009). Consequently, little is known about how clinicians conceptualise or use externalisation in therapy with families where one child has an ED. This study aims to begin the process of understanding this influential and important technique. To gain a deeper understanding of externalisation, it was proposed that the perspectives and views of those using this technique i.e. clinicians, would be a strong starting point. The current study is an in-depth analysis of eight clinicians' views and experiences of using externalisation in the context of FBT. A deeper understanding of clinicians perspectives, how they conceptualise the technique of externalisation, how they support families to use this technique, and how they manage challenges in its implementation could help improve training in the model, support clinicians using the technique, and help to close the gap between those who recover after an FBT intervention and those who do not.

## Method

### *Data Sample and Procedure*

This study received ethical approval in February 2019 (Appendix 9). Clinicians met the inclusion criteria if they (a) had received training in the FBT model (both formal training

and self-directed training plus supervision were deemed appropriate levels of training); (b) had worked with a minimum of one family using the FBT model; (c) were working in CAMHS; and (d) attended regular supervision (either FBT specific or individual supervision). Eligible clinicians were sent an invitation letter by email which outlined the aims of the research, the voluntary nature of participation and contact details for the main researcher should a person want to opt in (Appendix 6). A total of eight clinicians volunteered to be involved and were subsequently interviewed at a time and location suitable to them. The process of informed consent included participants reading an information sheet developed specifically for the study (Appendix 7), asking any outstanding questions, and completing a consent form (Appendix 7). Thereafter, participants completed a demographic questionnaire (Appendix 8) and a semi-structured interview. Interviews lasted between 50 to 80-minutes and were audio-recorded. An interview guide was developed and followed throughout the interview (table 1). The semi-structured nature of the interview allowed for flexibility to explore ideas that emerged throughout.

**Table 1:** *Semi-structured interview guide*

| Question | Objective |
|---|---|
| 1. Can you tell me a little bit about your experience of using externalisation with adolescents and their families coming to you for Family-based treatment? | *Gain an initial understanding of clinicians' perspective and experience of using the technique* |
| 2. Could you tell me about an experience when externalisation seemed to help a family? | *To further explore clinicians' use of the technique, particularly when they view it as being supportive to a family* |
| 3. Could you tell me about an experience where externalisation seemed to hinder treatment? | *To further explore clinicians' use of the technique, particularly when they view it as being unhelpful to a family* |
| 4. Have you ever had an experience where the family were able to externalise the eating disorder, but the adolescent could not? Or the adolescent refused to? | |
| 5. What strategies/techniques do you use when working with families to help them to externalise the ED? | *To understand how clinicians implement externalisation with families* |

| | |
|---|---|
| 6. Is there a typical progression that happens when working with families? | *To discover whether clinicians view externalisation as developing over a certain timeframe* |
| 7. What are the differences (if any) of using externalisation with an adolescent who has AN versus BN or another type of ED? | *To understand clinicians perspective on the use of externalisation across ED subtypes* |
| 8. Is there anything you struggle with when externalising the ED with families now or in the past? | |
| 9. How does externalising the illness (separating the person from the problem) fit with your existing beliefs on how to view eating disorders? | *Question 9 – 11: Discover clinicians perspectives on externalisation as a technique and whether it fits with their therapeutic stance* |
| 10. Do you integrate externalisation into any of your practice outside of FBT? | |
| 11. Are there any struggles between internalising practices of MDT team versus externalising practices of FBT clinicians? | |

***Data Analysis***

Braun and Clarke's (2006) guidelines on thematic analysis (TA) were followed. An inductive approach to coding was used i.e. the data was used as the starting point for the development of codes and the research analysed the data using a "bottom-up" approach (Terry, Hayfield, Clarke & Braun, 2017). Furthermore, analysis was informed by research relating to ensuring quality in qualitative research (Norwell, Norris, White & Moules, 2017). Data analysis was carried out over six phases. The data analysis process was iterative and recursive with the researcher moving between phases throughout (Braun & Clarke, 2006). The phases included: familiarisation with the data through interviewing participants, listening to audio-recordings and transcribing the data; making initial notes of patterns throughout the data and beginning to create codes which related to specific data extracts for each transcript (Appendix 13); analysing codes and relating them back to the whole data set, merging and discarding of codes, identifying emerging themes and making visual representations of codes

and themes (Appendix 10, 11, 12); reviewing themes against whole data set and reviewing the fit between themes, codes and data extracts; defining and naming themes; and reporting on themes and codes.

### *Researcher as an Instrument*

An assumption of this research paradigm is that data analysis is influenced by the researcher's subjective interpretation of the data (Braun & Clark, 2006). Due to the position of the researcher as an instrument, they must consider the potential influence of their own personal and professional experiences, knowledge, and views, and how these may present as a lens for understanding the data. Throughout the research process, a reflective research journal was used to document the researcher's thoughts, feelings and experiences (Ortlipp, 2008). If biases emerged for the researcher these were explored and teased out in research supervision. For transparency, the researcher is a thirty-year-old female psychologist in clinical training. She had not worked on a CAMHS team previous to completion of this research and therefore did not have any direct experience with the FBT model.

## Results

### *Participants Characteristics*

The sample of participants in this study consisted of eight clinicians working across six different CAMHS services in Ireland: six woman and two men. Participants' professions included nursing, social work, and clinical psychology. Of note, five of the participants had family therapy training and had worked using externalisation in this context prior to using the FBT model. Furthermore, all clinicians had training in therapeutic models outside of FBT. Half of the clinicians had worked with ten or more families using the FBT model. A summary of participant characteristics is shown in table 2.

**Table 2:** Participant characteristics

| | *N* | *Range* |
|---|---|---|
| **Total** | 8 | |
| **Gender** | | |
| Male | 2 | |
| Female | 6 | |
| Age | | 35 – 59 |
| **Professional discipline** | | |
| Nursing | 1 | |
| Social work | 4 | |
| Clinical psychology | 3 | |
| **Total caseload of FBT cases** | | |
| 1 to 5 families | 3 | |
| 5 to 10 families | 1 | |
| 10 + families | 4 | |
| **Presentations using FBT** | | |
| AN | 8 | |
| BN | 2 | |
| Other | 2 | |
| **Additional training** | | |
| CBT | 3 | |
| DBT | 3 | |
| Family Therapy | 5 | |
| Counselling course | 4 | |
| Other | 2 | |

**Table 3:** Overview of Themes and Subthemes

| Theme | Subtheme |
|---|---|
| Clinician Factors | The Importance of Therapeutic Skills |
| | Techniques used to Externalise |
| | Philosophical Struggle |
| Family Functioning | A shared Language |
| | Family Conflict |
| Barriers for the Young Person | Eating Disorder Awareness |
| | Age and Duration of Eating Disorder |

## Key Themes

### *Clinician' Perspectives on Externalisation in FBT*

Three key themes relating to clinicians' perspectives on externalisation were found through analysis: *clinician factors; family functioning* and *barriers for the YP* (table 3). Each theme consists of several subthemes and will be discussed below.

### *Clinician Factors*

When discussing the use of externalisation in FBT, clinicians described therapeutic factors that related to the effective use of this intervention. This included the importance of externalisation being used in the context of other clinical skills, the techniques they used to support families to externalise the ED and the struggles that related to viewing the ED as an illness in FBT.

#### *The Importance of Therapeutic Skills*

All clinicians reported valuing externalisation as a therapeutic tool in FBT, with clinician 1 noting that it was a "central technique" that supported the clinician to get to the "key issues" a family was experiencing. While clinicians valued this therapeutic tool, many

identified the importance of it being used within the context of other therapeutic skills. Clinicians, both implicitly and explicitly, described relying on therapeutic skills such as listening, rapport building, knowing how to time interventions, and the ability to engage with a family and understand the dynamics within the relationships as important factors when trying to implement externalisation.

*It sounds on paper like it's quite an easy thing to engage in but you'd have to also listen and see well how are the family and the YP experiencing it and why is it maybe jarring with them in a way, so when you kind of get an understanding of that you can maybe re-work it in or re-think about how we talk about these things (Clinician 5)*

Furthermore, three participants identified that it takes time and experience to build up this skill and use it effectively with families. Two participants went on to report that to fully understand and utilise the skill of externalisation, it was important for a clinician to read more widely than the FBT manual alone.

*Techniques used to Externalise*

Participants identified several techniques that they used with families to support them to externalise the ED including education, language and metaphors, and sculpting exercises. Four clinicians spoke about the importance of providing information and statistics relating to the effect of starvation on the YP's physical and mental health to the family through education in the initial stages of therapy. This process supports parents to begin to view the ED as an illness that has control over their child's decision-making skills, ability to self-regulate, eating pattern and behaviour. Participants also spoke about the importance of their use of language in sessions with families. They described changing their language to reflect a more externalised version of the problem. This included shifting the focus of their questioning from one which viewed the ED as an internal process within the child to

questions asking about *"the ED"*.

*Instead of saying "what made you vulnerable to the problem…", saying "when do you notice the problem the most and what kind of things are happening when the problem is there" (Clinician 5)*

All clinicians discussed the role of metaphor in externalising the ED. Most clinicians felt that the illness metaphor was the most effective place to start externalising with the family. However, they also reported using bespoke metaphors that suited the families' interests or areas of knowledge throughout therapy.

*…trying to use, even like a sporty kind of analogy for some kids like if the goalie is asleep for 30 seconds that's going to cause trouble you know you have to try and stay awake or stay alert to signs of the ED maybe getting in again… (Clinician 8)*

A noteworthy finding related to the use of sculpting in sessions. Three clinicians, all of whom were trained as family therapists, discussing the use of sculpting as a technique to support externalisation. These clinicians reported engaging families in sculpting exercises, where the externalised ED would be represented by a person or an object within the room and the family would then visually explore their relationship with the ED. The clinicians who had used this technique reported that sculpting can give the family a felt sense of the impact of their difficulties and can support families who are struggling to externalise the ED.

*Philosophical Struggle*

Implicitly and explicitly reflected throughout interviews were the struggles which can present for clinicians when shifting from viewing an ED with a bio-psycho-social lens, to viewing it as a biologically based illness within the FBT model. Participants differed in the

views they held on shifting between these perspectives. For one clinician, while externalising a problem fit strongly with their views on mental health, viewing an ED as an illness did not.

*The whole kind of illness model…I don't subscribe to. But certainly, externalising a problem, taking it away from the person, that I totally believe in…but where it comes to like, a disease model, that's the part that I don't (Clinician 6)*.

Two of the clinicians identified that while they support the families they work with to view the ED as an illness within sessions, the psychosocial view of the ED, which relates to systemic factors and psychological processes, remains at the forefront of their mind throughout their work with families.

*…that was probably his first day where he had a day free of "the ED"… from a clinicians perspective I'm going okay so that's a day where his internal narrative or his cognitive biases or thoughts, his cognitions around food… weren't bothering him (Clinician 4)*

Contrasting this, two clinicians discussed a process of immersing themselves in the externalised view of the ED and engaging with the biological view of the ED as the impact of starvation on the body. These clinicians felt that the process of engaging fully with the externalised view of the ED as an illness supported their ability to empathise with the family and improved their use of the externalising technique. Implicitly, throughout the interviews this position of moving between perspectives was evident. Participants tended to oscillate between discussing the ED as an external entity which existed outside the YP and their family while also formulating about the underlying psychological traits of the YP or systemic factors influencing the family.

### *Family Functioning*

Many of the clinicians interviewed discussed the impact externalisation had on family functioning through supporting communication and reducing conflict between family members.

#### *A Shared Language*

Participants consistently reported that externalisation in the context of an ED gives families a new way of communicating with one another inside and outside of therapy sessions. They reported a key advantage of externalisation is that it situates the ED outside of the person experiencing it. This shift in perspective for a family creates space to discuss the ED. It facilitates conversations which focus on how "the problem" impacts on their lives individually and at a family-wide level.

*So, it's not just about being able to talk to the child with the ED, it's being able to talk to everyone else about "the problem" (Clinician 1)*

Clinician 1 went on to suggest that these conversations begin to pull family members together to fight a common enemy. Four clinicians identified ED behaviours (e.g. the YP restricting food; body checking) as leading to heightened emotion within families. They reported that the introduction of the externalised view of the ED during these times can support family communication and make it easier for parents to effectively intervene with ED behaviours by linking them to the ED rather than seeing them as under the YP's control.

*For instance, if a YP is in front of a mirror…pushing at body parts…they may become distressed. The parent can then go "oh, there's the bully again" or "there's Mr or Ms ED again" so they are able to name it then and that really helps in the recovery process for the young person and the family as well (Clinician 4).*

Clinicians also reported that externalisation supported family subsystems; giving parents a language to communicate between themselves and enabling siblings to find a way to talk about the impact of the ED on their lives.

*Family Conflict*

All clinicians identified the emergence of difficult emotional responses and interactions in families where one child has an ED. They reported that these experiences can lead to family conflict and that externalisation can play a role in its resolution. Most of the participants discussed clinical experiences where parents had placed the responsibility for the ED on the YP.

*…or the family may say it's them [the person with the ED], if they just would eat, we wouldn't have a problem and we wouldn't be here (Clinician 05).*

They reported that parental fear, confusion and lack of information about the ED can lead them to hold a belief that the behaviours they observe in their child (e.g. refusing or hiding food, changes in mood, YP being argumentative) relate to internal psychological processes. This internalised view of the ED can lead parents to blame their child for their ED behaviour and conflict can arise. In these circumstances, clinicians reported that externalising the ED can support parents to view the ED behaviours as out of the child's control, reducing the blame placed on the YP and leading to more harmonious relational interactions.

*I think when you externalise the illness what it does is the parents are less critical and less hostile because…they are able to step back and go "my young child…is not eating because they have this illness" (Clinician 2)*

Two clinicians reflected on this experience from the perspective of the YP reporting that the use of externalisation supports them to feel “personally less blamed and attacked” by their parents.

### *Barriers for the YP*

Clinicians reported that for many of the YP who engage in FBT, externalisation is an important part of therapy that supports them to communicate with their families and treating team, and to reflect on the impact of the ED on their lives. Nevertheless, clinicians reported that certain individual factors relating to the YP can make externalisation more difficult. This included the YP’s awareness of the ED, their age and the duration of time they had been living with the ED.

#### *ED Awareness*

Five out of eight clinicians described working with YP who held a belief that they did not have a problem when beginning therapy and for some, throughout. Clinicians differed in how they described this idea. Some clinicians reported that the YP can be so consumed by the ED that they lack awareness of having a problem. Other clinicians felt that the ED was important to the YP and that they valued aspects of it and therefore did not wish to change their relationship with it.

*It is a part of them, a part they value even though it's a difficult part and they've had, there's a success with losing weight that they are happy with so they don't want to lose it (Clinician 8).*

Participants agreed that when working with a YP who lacks awareness of the ED, or who does not wish to change their relationship with the ED, externalisation can become a difficult task. Externalising the ED in these situations can cause the YP to resist the

externalisation, "kick back" at the process, become frustrated or even "rage against" it. Clinicians demonstrated understanding and empathy for the YP they worked with and acknowledged how difficult it is for a YP to separate from an ED that feels like part of their identity. Of note, one participant reported that for people who experience a chronic, lifelong ED, externalisation may not be helpful when engaging with the person. The clinician felt for a small number of people an ED can become a lifelong, chronic condition where recovery is unlikely. For these clients, their belief that the ED is part of who they are will not lessen over time and the use of externalisation in these cases can reduce the likelihood of engaging therapeutically with the person.

*I suppose, you never move from that pre-contemplative stage to kind of a recovery orientated model, yeah and … I think… if you want to build a relationship with that person, you need to stay with what they're saying about it (Clinician 5).*

*Age and duration of the ED*

Several clinicians reflected on the impact of age and duration of the ED on a YP's ability to engage with externalisation. Across interviews, five clinicians indicated that younger children engage better with externalisation than adolescents, with two clinician's specifying that children under the age of twelve engage best with the process. Participants reported that externalising the ED for a younger child fits with their developmental level through accessing their imagination and defining a somewhat abstract concept (i.e. the ED) in concrete terms. Furthermore, participants felt that a younger child's dependence on their parents, and lack of autonomy further facilitated the process of externalising the ED.

*…under twelves, they are amazing. That language just fits with exactly where their imagination and their brain is situated, they can kind of imagine everything being something that they can manipulate or that is outside their thinking and that makes sense to them (Clinician 5)*

Participants further stated that a younger child is likely to have a shorter duration of time with the ED leading to them being less consumed by the ED and more open to changing their relationship with it. Not all clinicians felt that the YP's age had an impact on their ability to externalise, with one reporting that YP across the age range enjoyed engaging with the externalisation process and that it offered relief from the usual focus of talk therapies on an individual's thoughts, feelings and behaviours. One interesting finding, discussed by four participants, related to using externalisation with YP who have autism spectrum disorder (ASD). Participants reported that if working with a YP with ASD in the context of an ED they would reconsider the use of externalisation. For the two clinicians who had previous experience of working within this context, both reported that the YP struggled to understand the concept of externalisation.

## Discussion

The current research set out to explore the perspectives and views of clinicians using externalisation as a therapeutic technique in FBT. Improvement in our understanding of how clinicians conceptualise and use externalisation, as well as the barriers to same may help to improve current training and supervision in this model of therapy.

### *Clinicians perspectives of, and engagement with, externalisation*

In line with research within the area, the findings in this study suggest that clinicians value externalisation as a therapeutic tool (Dimitropoulos et al., 2017; Ramey et al., 2009). However, they were unanimous in their view that externalisation requires clinical skill to be used effectively and is a tool that clinicians should try to engage with, understand and practice. Previous research focusing on externalisation in narrative therapy suggested that because the initial stages of externalisation (i.e. naming the problem as external to the person, characterising the problem) can feel intuitive to the clinician it can lead to it being "ignored

or downplayed" (Ramey et al., 2009 p. 264). Clinicians in the current research reported the use of listening skills, tuning in to the emotional tone of families in order to know how to time the interventions, and judging when a family may not benefit from the use of externalisation when using this technique.

When approaching FBT as a new therapist, the need to read more widely than the FBT manual in order to fully grasp the concept of the technique and how it is utilised was identified. In line with the interventions outlined in manualised FBT, education about the impact of starvation on the body, and the use of metaphor, particularly the ED as an illness metaphor were used most often with families to support them to externalise (Lock & Le Grange, 2013). In addition to this, some clinicians incorporated sculpting into sessions, particularly with families who struggled to externalise. While not referenced in the manualised version of FBT, the use of sculpting has been reported in other forms of family therapy for EDs (e.g. multifamily therapy and the Maudsley Family therapy; Eisler, 2005).

Participants views and engagement with the "ED as an illness" externalisation metaphor were not homogenous. For some clinicians, viewing the ED as an illness did not fit with their view of mental health or EDs. Others described supporting families to shift their perspectives to this view, while internally translating what they observed in sessions into psycho-social models of understandings. Others reported a process of trying to genuinely engage with the "ED as an illness" metaphor through focusing on the impact of starvation on the physical and mental health of the YP. Professionals across mental health teams can be trained in FBT including those with a background in psychiatry, nursing, social work, family therapy or psychology (Eisler et al., 2016; Lock & Le Grange, 2013). A clinician's foundational training, years of experience working in mental health and possibly life experiences may mean that the way they approach and engage with the "ED as an illness" metaphor differ. Moreover, the majority of clinicians in this study had a mixed caseload and

worked with clients presenting with a range of mental health difficulties with whom a bio-psycho-social view of mental health was used. Potentially, it may be easier for clinicians to immerse themselves in the FBT model and the "ED as an illness" metaphor if they work solely with this model and client group.

***Barriers to Externalisation***

Findings in this study also related to the obstacles to externalisation within the context of FBT. These obstacles mainly related to factors associated with the YP. Although clinicians reported that many YP were supported by the introduction of the externalised view of the ED, they reported that factors such as the YP's ED awareness, age, and duration of the ED impacted on their engagement with this technique. Clinicians reported that often when working with families, the YP does not wish to engage in therapy and a parent will have persuaded the YP to attend. Referred to as working with "involuntary clients" within the literature, research suggests that problem awareness, motivation to change and therapeutic alliance can present as challenges in this work (Sotero, Major, Escudero & Paula Relvas, 2016, p. 37). A lack of ED awareness was described by many of the clinicians. They reported that YP often do not recognise the ED as a problem or can value aspects of the ED and the influence it has had on their lives. Anorexia Nervosa has been cited within the literature relating to EDs as ego-syntonic i.e. people with AN often highly value their ED and view it as a positive, admirable and desirable aspect of their identity (Griffiths, Mond, Murray & Touyz, 2015). Research has highlighted how individuals presenting with AN will credit their illness with helping them to achieve structure and control over their daily lives through following rigorous food and exercise regimes; helping them to avoid difficult emotions by expending all energy focusing on their physical body; and helping them to gain mastery over their body through continued weight loss (Gregertsen, Mandy & Serpell, 2017). Within these

circumstances, externalisation can lead to negative interactions between the YP, their family and the clinician.

Much research in the field of EDs has highlighted the "major hurdle" of problem awareness and readiness to change in recovery from EDs, particularly in AN (Halmi, 2013; Macdonald, Hibbs, Corfield & Treasure, 2012, p. 1; Touyz, Thornton, Rieger, George & Beumont, 2003). Working to overcome this challenge, the stages of change model has been employed in inpatient and outpatient ED settings (Prochaska & DiClemente, 1982; Touyz et al., 2003). The stages of change model consists of six stages, ranging from precontemplation to termination of a behaviour, and can be clinically useful when working with individuals where motivation to change is a barrier to engagement and recovery (Zimmerman, Olsen & Bosworth, 2000). The inclusion of the precontemplation stage which recognises that an individual may be unaware of their problem or not yet ready to change has been reported as particularly useful when working with clients with EDs. In these settings, importance is put on targeting the intervention to the stage of change a person is positioned in, as research suggests that a mismatch between these elements can lead to therapy resistance (Touyz et al., 2003).

Consideration could be given to adding a pre-contemplative stage to FBT for those presenting involuntarily to therapy and lacking problem awareness. Measures have been created to identify the stage of change that individuals presenting with EDs are positioned in (Gusella, Butler, Nichols & Bird, 2003; Rieger, Touyz, & Beumont, 2002). If a YP presents as pre-contemplative, possible brief intervention could target this stage, working with the ambivalence and lack of insight into the ED. Interventions in inpatient and outpatient ED services have previously described the importance of working with a person from their own position towards change (Truyz et al., 2003). Additionally, other behavioural models such as

Dialectical Behavioural Therapy (DBT) use a similar "pre-commitment" stage in order to engage people in therapy in the initial stages (Linehan, 2014).

While not directly identified by clinicians within this study, research has shown that these factors (i.e. involuntary attendance at therapy and a lack of problem awareness) can result in challenges within the therapeutic alliance between the clinician and the YP (Sotero et al., 2016). The therapeutic alliance plays an importance role in most forms of psychotherapy. Within the field of family therapy, a clinician has the added challenge of multiple therapeutic relationships (Johnson & Wright, 2002). Clinicians within this study identified experiences where families engaged with the externalisation technique in different ways (e.g. parents engage with the idea while the YP refused to engage). When these circumstances arise for clinicians, it may be important to consider the impact on the therapeutic relationship across the family system.

Clinicians in this study also identified that the YP's age and duration of time since the onset of the ED as barriers to externalising the ED. The majority of clinicians felt that younger children engaged better with externalisation. A number of factors might influence a YP's ability to engage with the technique of externalisation including developmental factors such as their stage of mental development (Piaget, 1976) or theory of mind (Baron-Cohen, Campbell, Karmiloff-Smith, Grant & Walker, 1995). These areas may be useful to explore in future research relating to externalisation. Clinicians also reported that the timeframe for which a YP had been experiencing an ED may also impact their ability to externalise, with a longer timeframe leading to a greater level of internalisation or identification with the ED, a finding which has been reported in other studies (Dimitropoulos et al., 2015). These findings fit with the broader literature relating to FBT which suggests that treatment is more effective for younger children with a shorter duration of illness (Darcy et al., 2013; Le Grange et al., 2012; Lock et al., 2006; Lock, et al, 2006). Moreover, similar findings have been suggested

by clinicians in relation to parental empowerment in FBT with results suggesting that a YP's age and illness duration negatively impact on parental empowerment (Dimitropoulos et al., 2015; Dimitropoulos et al., 2017).

Previous studies in this area have suggested that when working with adolescents, some adaptions to interventions can support their engagement (Dimitropoulos et al., 2015). Adolescents presenting for FBT may have better insight into the thoughts, feelings, perceptions and behaviours related to their ED and may be able to use externalisation in a way that facilitates further understanding of the impact of the ED on areas of their lives. White (2011) identified how the experience of AN is different for every individual and therefore how a person wishes to externalise and relate to their ED will also differ. Insight-orientated externalisation which externalise aspects of the ED such as perfectionism, expectations or anxiety may be more appropriate and hold more meaning for adolescents attending for FBT. Externalisation can then be used to support the adolescent to focus on the consequences of these aspects of their ED and the impact that they have on the relationships in their lives (Eisler et al., 2016; White, 2011).

Finally, clinicians identified that when working with a YP who presented with ASD and an ED they would not use externalisation. No recommendations for adaptions for this cohort are available within the literature relating to FBT. However, interest in the relationship that exists between EDs and ASD is growing and the literature suggests than when these conditions present comorbidly, interventions can be tailored to support clients' needs (Westwood & Tchanturia, 2017). Support for the use of externalisation with YP who present with ASD and comorbid anxiety has been reported in the literature (McGuinty, Armstrong, Nelson, Sheeler, 2012). Of note, the authors report that externalisation may support YP presenting with high functioning autism.

### *Clinician applications and future directions*

This study found that clinicians value externalisation as an intervention in FBT. The ED as an illness metaphor is used frequently throughout therapy, but clinicians also report nuanced and bespoke use of this technique. Findings from this study suggest that clinicians using FBT could benefit from discrete training on externalisation, with a particular focus on how to externalise with YP who are in their adolescent years, lack problem awareness or have a longer ED history. Specific focus should be given to externalisation in FBT supervision to support clinicians to overcome barriers to externalisation and reflect on the impact of a YP's refusal of externalisation on the therapeutic alliance. Future studies on the role of problem unawareness on the therapeutic alliance are needed. For adolescents, use of insight-orientated externalisation may be more fruitful, making use of their ability to engage with their experience of the thoughts, feelings and behaviours associated with the ED.

Clinicians working in FBT may also consider the relevance of a YP's readiness to change when approaching FBT with a family. As previously discussed, an individual's stage of change and readiness to recover will impact on their ability to engage in therapy. The findings of this research show that a subgroup of YP presenting with an ED might be in the pre-contemplative stage of change. Clinical judgement and a measure of readiness to change (e.g. Anorexia Nervosa Stages of Change Questionnaire; Rieger, Touyz, & Beumont, 2002) could be used to gain more information on a YP's readiness for therapy. For those in the pre-contemplative stage of change, where awareness of the ED and readiness to recover are limited, clinicians should consider carrying out a brief intervention, engaging with the YP's unawareness and/or ambivalence (Touyz et al., 2003). Future research in this area could focus on motivation and readiness to change in YP presenting with EDs for FBT. Greater understanding of the rates of YP presenting in the pre-contemplative stage would support intervention development.

***Limitations***

To the authors knowledge, this study was the first to explore the views and perspectives of clinicians using externalisation in the context of FBT. Clinicians interviewed for this piece of research were self-selected and therefore they may differ characteristically to those who did not participate in the research. Furthermore, the research interviewed a small number of participants who were working in similar, publicly funded health care settings. Therefore, when applying these findings to different contexts, researchers should use caution. Five of the clinicians who partook in the research had previous training and experience in family therapy, meaning they had previous knowledge and experience of the externalisation technique outside of FBT. Consequently, these clinicians may have had additional methods of externalising and may not have relied as heavily on those set out by the FBT model i.e. the "ED as an illness" metaphor. It is possible that clinicians who had no previous experience with externalisation may have different perspectives on externalisation in FBT that were not captured by this research. Future research may also consider the time since the clinician has completed training in FBT and how this may relate to fidelity to the model and the impact on externalisation e.g. does time since training lead to lower rates of fidelity to the model. As this was not the focus of the present study, these data are not available for same.

Another limitation of this study related to the semi-structured interview. One limitation of semi-structured interviews are that they can contain bias due to the questions being developed and shaped by the researcher (Galletta, 2013). While the majority of questions included in the semi-structured interview for this research were open and exploratory to generate discussion, in retrospect, question five and question eleven contain some issues. Question five broached an essential element of externalisation that was important to explore. However, on reflection this question related strongly to the theme "techniques used to externalise" within the results for this study. While this is a limitation of

this study, clinicians spoke at length throughout the interview and in response to other questions posed throughout the interview about how they externalised the ED for families they worked with. It is very likely that had this question not been asked, this theme would have still presented within the data. Furthermore, underlying question eleven was an assumption that MDT teams use an internalising framework for understanding mental health. While this question does pose some issues in terms of bias, it was the final question asked and therefore unlikely to have had a major influence on the areas that clinicians explored throughout the interview. Furthermore, clinicians had often broached this subject prior to the final question in the interview and had explored their views on the practices of the team versus the FBT therapist independently.

### *Conclusion*

This research has highlighted that externalisation as a technique is viewed as valuable to clinicians, regardless of their training or approach to the technique. Furthermore, the clinicians in this study used a diverse range of metaphors (in conjunction with the "ED as an illness" metaphor) with their clients to support them to externalise, often creatively zoning in on areas of interest or knowledge with families to facilitate family engagement**.** Barriers to externalisation included the YP's ED awareness, age, and the duration of illness. For the subgroup of YP who present to therapy but are not yet ready to change their relationship with their ED, clinicians could consider a pre-contemplative stage which could be carried out prior to FBT. This stage would focus on the YP's problem unawareness and ambivalence and may enable a YP to engage more fully with FBT and externalisation at a later stage.

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**References**

Agras, W. S., Lock, J., Brandt, H., Bryson, S. W., Dodge, E., Halmi, K. A., ... & Woodside, B. (2014). Comparison of 2 family therapies for adolescent anorexia nervosa: a randomized parallel trial. *JAMA Psychiatry*, *71*(11), 1279-1286.Byrne, C. E., Accurso, E. C., Arnow, K. D., Lock, J., & Le

Baron-Cohen, S., Campbell, R., Karmiloff-Smith, A., Grant, J., & Walker, J. (1995). Are children with autism blind to the mentalistic significance of the eyes?. *British Journal of Developmental Psychology*, *13*(4), 379-398.

Bellak, L. (1954). A study of limitations and "failures": toward an ego psychology of projective techniques. *Journal of Projective Techniques, 18*(3), 279-293.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101.

Darcy, A. M., Bryson, S. W., Agras, W. S., Fitzpatrick, K. K., Le Grange, D., & Lock, J. (2013). Do in-vivo behaviors predict early response in family-based treatment for anorexia nervosa?. *Behaviour Research and Therapy*, *51*(11), 762-766.

DeJong, H., Broadbent, H., & Schmidt, U. (2012). A systematic review of dropout from treatment in outpatients with anorexia nervosa. *International Journal of Eating Disorders*, *45*(5), 635-647.

Dimitropoulos, G., Freeman, V. E., Allemang, B., Couturier, J., McVey, G., Lock, J., & Le Grange, D. (2015). Family-based treatment with transition age youth with

anorexia nervosa: a qualitative summary of application in clinical practice. *Journal of Eating Disorders, 3*(1), 1.

Dimitropoulos, G., Freeman, V. E., Lock, J., & Le Grange, D. (2017). Clinician perspective on parental empowerment in family-based treatment for adolescent anorexia nervosa. *Journal of Family Therapy, 39*(4), 537-562.

Eisler, I. (2005). The empirical and theoretical base of family therapy and multiple family day therapy for adolescent anorexia nervosa. *Journal of Family therapy, 27*(2), 104-131.

Eisler, I., Dare, C., Russell, G. F., Szmukler, G., le Grange, D., & Dodge, E. (1997). Family and individual therapy in anorexia nervosa: A 5-year follow-up. *Archives of General Psychiatry, 54*(11), 1025-1030.

Eisler, I., Simic, M., Blessitt, E., & Dodge, L. & Team. (2016). Maudsley service manual for child and adolescent eating disorders (Revised). London: Child and Adolescent Eating Disorders Service, South London and Maudsley NHS Foundation Trust. Available at: http://www.national.slam.nhs.uk/services/camhs/camhs-eatingdisorders/resources

Flick, U. (2007). Qualitative research designs. *Designing qualitative research,* 109-114.

Fox, J. R., Dean, M., & Whittlesea, A. (2015). The experience of caring for or living with an individual with an eating disorder: A meta-synthesis of qualitative studies. *Clinical Psychology & Psychotherapy, 24*(1), 103-125.

Galletta, A. (2013). *Mastering the semi-structured interview and beyond: From research design to analysis and publication* (Vol. 18). NYU press.

Gregertsen, E. C., Mandy, W., & Serpell, L. (2017). The egosyntonic nature of anorexia: an impediment to recovery in anorexia nervosa treatment. *Frontiers in Psychology*, *8*, 2273.

Griffiths, S., Mond, J. M., Murray, S. B., & Touyz, S. (2015). Positive beliefs about anorexia nervosa and muscle dysmorphia are associated with eating disorder symptomatology. *Australian & New Zealand Journal of Psychiatry*, *49*(9), 812-820.

Gusella, J., Butler, G., Nichols, L., & Bird, D. (2003). A brief questionnaire to assess readiness to change in adolescents with eating disorders: Its applications to group therapy. *European Eating Disorders Review: The Professional Journal of the Eating Disorders Association*, *11*(1), 58-71.

Halmi, K. A. (2013). Perplexities of treatment resistence in eating disorders. *BMC Psychiatry*, *13*(1), 292.

Hay, P. (2015). Course and outcome of eating disorders. In T. Wade (Ed), *Encyclopedia of Feeding and Eating Disorders*. Singapore: Springer Singapore.

Johnson, L. N., & Wright, D. W. (2002). Revisiting Bordin's theory on the therapeutic alliance: Implications for family therapy. *Contemporary Family Therapy*, *24*(2), 257-269.

Knight, K. M., Bundy, C., Morris, R., Higgs, J. F., Jameson, R. A., Unsworth, P., & Jayson, D. (2003). The effects of group motivational interviewing and externalizing conversations for adolescents with Type-1 diabetes. *Psychology, Health & Medicine*, *8*(2), 149-157.

Kosmerly, S., Waller, G., & Robinson, A. L. (2015). Clinician adherence to guidelines in the delivery of family-based therapy for eating disorders. *International Journal of Eating Disorders*, *48*(2), 223-229.

Linehan, M. (2014). *DBT? Skills training manual*. Guilford Publications.

Le Grange, D., & Chen, E. (2007). Family-based treatment for young adults with anorexia nervosa. *Unpublished Manual. Chicago: Univ Chicago*.

Le Grange, D., Hughes, E. K., Court, A., Yeo, M., Crosby, R. D., & Sawyer, S. M. (2016). Randomized clinical trial of parent-focused treatment and family-based treatment for adolescent anorexia nervosa. *Journal of the American Academy of Child & Adolescent Psychiatry*, *55*(8), 683-692.

Le Grange, D., & Lock, J. (2009). *Treating bulimia in adolescents: A family-based approach*. Guilford Press.

Le Grange, D., Lock, J., Agras, W. S., Moye, A., Bryson, S. W., Jo, B., & Kraemer, H. C. (2012). Moderators and mediators of remission in family-based treatment and adolescent focused therapy for anorexia nervosa. *Behaviour Research and Therapy*, *50*(2), 85-92.

Le Grange, D., Lock, J., Loeb, K., & Nicholls, D. (2010). Academy for eating disorders position paper: The role of the family in eating disorders. *International Journal of Eating Disorders*, *43*(1), 1.

Lock, J., Couturier, J., & Agras, W. S. (2006). Comparison of long-term outcomes in adolescents with anorexia nervosa treated with family therapy. *Journal of the American Academy of Child & Adolescent Psychiatry*, *45*(6), 666-672.

Lock, J., Couturier, J., Bryson, S., & Agras, S. (2006). Predictors of dropout and remission in family therapy for adolescent anorexia nervosa in a randomized clinical trial. *International Journal of Eating Disorders, 39*(8), 639-647.

Lock, J., & Le Grange, D. (2013). *Treatment manual for anorexia nervosa: A family-based approach*. Guilford Publications.

Lock, J., Le Grange, D., Agras, W. S., Moye, A., Bryson, S. W., & Jo, B. (2010). Randomized clinical trial comparing family-based treatment with adolescent-focused individual therapy for adolescents with anorexia nervosa. *Archives of General Psychiatry, 67*(10), 1025-1032.

Macdonald, P., Hibbs, R., Corfield, F., & Treasure, J. (2012). The use of motivational interviewing in eating disorders: a systematic review. *Psychiatry Research, 200*(1), 1-11.

McGuinty, E., Armstrong, D., Nelson, J., & Sheeler, S. (2012). Externalizing metaphors: Anxiety and high-functioning autism. *Journal of Child and Adolescent Psychiatric Nursing, 25*(1), 9-16.

Medway, M., & Rhodes, P. (2016). Young people's experience of family therapy for anorexia nervosa: a qualitative meta-synthesis. *Advances in Eating Disorders, 4*(2), 189-207.

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods, 16*(1), 1609406917733847.

Ortlipp, M. (2008). Keeping and using reflective journals in the qualitative research process. *The qualitative report*, *13*(4), 695-705.

Perls, F., Hefferline, G., & Goodman, P. (1951). Gestalt therapy. *New York*, *64*(7), 19-313.

Piaget, J. (1976). Piaget's theory. In *Piaget and his school* (pp. 11-23). Springer, Berlin, Heidelberg.

Prochaska, J. O., & DiClemente, C. C. (1982). Transtheoretical therapy: toward a more integrative model of change. *Psychotherapy: Theory, Research & Practice*, *19*(3), 276.

Ramey, H. L., Tarulli, D., Frijters, J. C., & Fisher, L. (2009). A sequential analysis of externalizing in narrative therapy with children. *Contemporary Family Therapy*, *31*(4), 262-279.

Rieger, E., Touyz, S. W., & Beumont, P. J. (2002). The Anorexia Nervosa Stages of Change Questionnaire (ANSOCQ): information regarding its psychometric properties. *International Journal of Eating Disorders*, *32*(1), 24-38.

Russell, G. F., Szmukler, G. I., Dare, C., & Eisler, I. (1987). An evaluation of family therapy in anorexia nervosa and bulimia nervosa. *Archives of General Psychiatry*, *44*(12), 1047-1056.

Simic, M., & Eisler, I. (2018). Maudsley Family Therapy for Eating Disorders. In *Encyclopedia of Couple and Family Therapy* (pp. 1-9). Springer, Cham.

Smink, F. R., Van Hoeken, D., & Hoek, H. W. (2012). Epidemiology of eating disorders: incidence, prevalence and mortality rates. *Current Psychiatry Reports*, *14*(4), 406-414.

Sotero, L., Major, S., Escudero, V., & Relvas, A. P. (2016). The therapeutic alliance with involuntary clients: how does it work?. *Journal of Family Therapy*, *38*(1), 36-58.

Swanson, S. A., Crow, S. J., Le Grange, D., Swendsen, J., & Merikangas, K. R. (2011). Prevalence and correlates of eating disorders in adolescents: Results from the national comorbidity survey replication adolescent supplement. *Archives of General Psychiatry*, *68*(7), 714-723.

Terry, G., Hayfield, N., Clarke, V., & Braun, V. (2017). Thematic analysis. *The Sage handbook of qualitative research in psychology*, 17-37.

Touyz, S., Thornton, C., Rieger, E., George, L., & Beumont, P. (2003). The incorporation of the stage of change model in the day hospital treatment of patients with anorexia nervosa. *European Child & Adolescent Psychiatry*, *12*(1), i65-i71.

Waller, G., Stringer, H., & Meyer, C. (2012). What cognitive behavioral techniques do therapists report using when delivering cognitive behavioral therapy for the eating disorders?. *Journal of Consulting and Clinical Psychology*, *80*(1), 171.

Weber, M., Davis, K., & McPhie, L. (2006). Narrative therapy, eating disorders and groups: Enhancing outcomes in rural NSW. *Australian Social Work*, *59*(4), 391-405.

Westwood, H., & Tchanturia, K. (2017). Autism spectrum disorder in anorexia nervosa: an updated literature review. *Current Psychiatry Reports*, *19*(7), 41.

White M., & Epston D. (1990). Narrative means to therapeutic ends. New York and London: W.W. Norton and Company.

White, M. K. (2000). *Reflections on narrative practice: Essays and interviews*. Dulwich Centre Publications.

White, M. (2011). *Narrative practice: Continuing the conversations*. WW Norton & Company.

Williams, L. T., Wood, C., & Plath, D. (2020). Parents' Experiences of Family Therapy for Adolescent Anorexia Nervosa. *Australian Social Work*, 1-12.

Wufong, E., Rhodes, P., & Conti, J. (2019). "We don't really know what else we can do": Parent experiences when adolescent distress persists after the Maudsley and family-based therapies for anorexia ne

Withers, A., Mullan, B., Madden, S., Kohn, M., Clarke, S., Thornton, C., ... & Touyz, S. (2013). Anorexia nervosa in the family: a sibling's perspective. *Advances in Eating Disorders: Theory, Research and Practice*, *2*(1), 53-64.

rvosa. *Journal of Eating Disorders, 7*(1), 5.

Zimmerman, G. L., Olsen, C. G., & Bosworth, M. F. (2000). A 'stages of change' approach to helping patients change behavior. *American family physician*, *61*(5), 1409-1416.

# Chapter Five

## Discussion and Conclusion

This research portfolio had two main aims: (i) it set out to gain a better understanding of the experience of healthy siblings in the context of EDs through systematic review of the current literature base and (ii) to explore the perspective of clinicians using externalisation in FBT through an empirical research study. This final chapter will include a brief discussion of the main findings throughout the portfolio including ideas which could not be expressed within the research papers due to word limit restrictions.

This research adds to the field by further identifying and exploring the system-wide impact of EDs on families. The SR identified the major effect which EDs have on the lives of healthy siblings. The findings which emerged suggested that both the intrapersonal and interpersonal lives of siblings were impacted, with changes to family life, disruption within relationships, and an increase in difficult emotions evident. These findings are similar to what is known in the field about individuals who grow up with an unwell sibling e.g. children who have a sibling with cancer or a chronic illness (Friedrich, Lively & Rubenstein, 2008; O'Brien, Duffy, & Nicholl, 2009; Rossiter & Sharpe, 2001). The SR also added some unique findings to the field relating to the experience of healthy siblings who grow up in the context of an ED specifically. One of the most specific themes for this group related to healthy siblings' relationships with their own bodies. Siblings reported becoming more aware of their own body shape and eating habits and that of those around them. Furthermore, they reported comparing these factors with their affected sibling. Qualitative research is lacking in this area (Fjermestad, Espeland, Halvorsen & Halvorsen, 2019) and future studies should consider qualitatively exploring weight, food choices and body image with siblings of those with EDs. Siblings almost unanimously reported needing more support from services and the clinical implications set out in the SR should be considered by mental health teams working with

families within the context of an ED. Of the participants within the studies who experienced family therapy, many found it helpful. Moreover, externalisation within FBT was reported as a technique which supported and maintained the sibling relationship. For clinicians working with families where siblings attend FBT they should consider supporting this subgroup through providing information which relates to the specific experiences of their family; facilitating one to one sessions outside of family therapy sessions; and helping them to shift their perspective of the ED through externalisation.

The MRP further highlighted the negative impact which an ED can have on a family, with clinicians reporting that problems with family functioning are often evident when families present for therapy, including problems in communication and increased conflict. These findings fit with much of the research which exists on the family experience of EDs (Dodge, 2016; Eisler, 2005; Fox, Dean& Whittlesea, 2015; Mathews,Lenz, Peugh, Copps, Peterson, 2018). The findings of this study suggested that the difficulties experienced within families could often be supported with FBT, and specifically with the therapeutic technique of externalisation. Clinicians identified how the introduction of an externalised view of the ED can support families by giving them a language to discuss their difficulties, while also reducing parental blame towards the child and feelings of shame within parents.

As outlined in the introductory chapter of this portfolio, one of the ways of understanding the impact of an ED on a family is through the “Family Reorganisation Maintenance Model” (Eisler, 2005). Eisler’s explanatory model suggested that the ED becomes the central focus of the family and that families become hyper-focused on the here-and-now, with mealtimes in particular becoming a time of overwhelm leading to difficulties in family functioning (Eisler, 2005; Lock & Le Grange, 2013; Simic & Eisler, 2018). This theoretical model views the family as playing a maintaining rather than a causal role in the ED. However, this model has lacked development or extensive testing (Pennesi & Wade,

2016). Many of the findings across both the SR and MRP contained in this portfolio support the reorganisation of the family model (Eisler, 2005; Lock & Le Grange, 2013). Themes which emerged in the SR suggested that the central role of the ED, and the reorganisation of the family around it, were a cause of distress for siblings. Siblings struggles with the inflexibility of family life which was caused by the ED and the disruption this had on their lives as a result. Furthermore, the MRP highlighted how externalisation (within FBT) may intervene with some of the maintaining family processes (such as increasing communication and reducing conflict), reported by Eisler (2005).

In conclusion, the current research explored two important aspects of EDs for which little prior research had been conducted. This research can contribute to the evidence-base in the field of EDs and family therapy. It also offers unique insights into the impact of EDs on the family system as a whole and may be useful to the future development or adaption of family interventions.

**References**

Dodge, E. (2016). Forty years of eating disorder-focused family therapy–the legacy of 'psychosomatic families'. *Advances in Eating Disorders*, *4*(2), 219-227.

Eisler, I. (2005). The empirical and theoretical base of family therapy and multiple family day therapy for adolescent anorexia nervosa. *Journal of Family Therapy*, *27*(2), 104-131

Eisler, I., Simic, M., Blessitt, E., & Dodge, L. & Team. (2016). Maudsley service manual for child and adolescent eating disorders (Revised). London: Child and Adolescent Eating Disorders Service, South London and Maudsley NHS Foundation Trust. Available at: http://www.national.slam.nhs.uk/services/camhs/camhs-eatingdisorders/resources

Fjermestad, K. W., Rø, A. E., Espeland, K. E., Halvorsen, M. S., & Halvorsen, I. M. (2019). "Do I exist in this world, really, or is it just her?" Youths' perspectives of living with a sibling with anorexia nervosa. *Eating Disorders*, 1-16.

Fox, J. R., Dean, M., & Whittlesea, A. (2015). The experience of caring for or living with an individual with an eating disorder: A meta-synthesis of qualitative studies. *Clinical Psychology & Psychotherapy*, *24*(1), 103-125.

Friedrich, R. M., Lively, S., & Rubenstein, L. M. (2008). Siblings' coping strategies and mental health services: a national study of siblings of persons with schizophrenia. *Psychiatric Services*, *59*(3), 261-267.

Lock, J., & Le Grange, D. (2013). *Treatment manual for anorexia nervosa: A family-based approach*. Guilford Publications.

Matthews, A., Lenz, K. R., Peugh, J., Copps, E. C., & Peterson, C. M. (2018). Caregiver burden and illness perceptions in caregivers of medically hospitalized youth with anorexia nervosa. *Eating behaviors*, *29*, 14-18.

O'Brien, I., Duffy, A., & Nicholl, H. (2009). Impact of childhood chronic illnesses on siblings: a literature review. *British Journal of Nursing*, *18*(22), 1358-1365.

Pennesi, J. L., & Wade, T. D. (2016). A systematic review of the existing models of disordered eating: Do they inform the development of effective interventions?. *Clinical Psychology Review*, *43*, 175-192.

Rossiter, L., & Sharpe, D. (2001). The siblings of individuals with mental retardation: A quantitative integration of the literature. *Journal of Child and Family Studies*, *10*(1), 65-84.

Simic, M., & Eisler, I. (2018). Maudsley Family Therapy for Eating Disorders. In *Encyclopedia of Couple and Family Therapy* (pp. 1-9). Springer, Cham.

Appendix 1

Journal guidelines (SR): International Journal of Eating Disorders

**Reviews**

These articles critically review the status of a given research area and propose new directions for research and/or practice. Both systematic and meta-analytic review papers are welcomed if they review a literature that is advanced and/or developed to the point of warranting a review and synthesis of existing studies. Reviews of topics with a limited number of studies are unlikely to be deemed as substantive enough for a Review paper. The journal does not accept papers that merely describe or compile a list of previous studies without a critical synthesis of the literature that moves the field the forward.

- Word Limit: 7,500 (excluding abstract, references, tables or figures).
- Abstract: 250 words.
- References: 100.
- Figures/Tables: no maximum but should be appropriate to the material covered.

All Review articles must follow the PRISMA Guidelines ( **www.prisma-statement.org** ), summarized in a 2009 *J. Clin. Epidemiol.* article by Moher et al. entitled *"Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement"* (DOI: **10.1016/j.jclinepi.2009.06.005**), freely available for download in both English and Spanish.

**Parts of the Manuscript**

The submission should be uploaded in separate files: 1) **manuscript file**; 2) **figures**; 3) **Supporting Information file(s)**.

***1. Manuscript File***

The text file should contain all of the manuscript text, including the tables and figure legends. The text should be presented in the following order, with items i-v appearing on the **Title Page**:

1. Title
2. A short running title of less than 40 characters
3. The full names of all authors
4. The authors' institutional affiliations where the work was conducted, with a footnote for an author's present address if different to where the work was carried out
5. Word counts (abstract and main text, excl. tables and references)
6. Acknowledgements
7. Abstract and Keywords
8. Main text
9. References
10. Tables (each table complete with title and footnotes)
11. Figure legends

**Title Page**

On the title page, authors should list the **title**, the short running title, the full names of all **authors**, and their affiliations. Authors should also state the **number of words** contained in the abstract and the number of words of the manuscript (excluding tables and references).

**Title**

The title should be short and informative, containing major keywords related to the content. The title should not contain abbreviations (see **Wiley's best practice SEO tips**).

**Authorship**

For details on eligibility for author listing, please refer to the journal's **Authorship policy** outlined in Section 5 of these Author Guidelines.

**Acknowledgments**

Contributions from individuals who do not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

**Conflict of Interest Statement**

Authors will be asked to provide a conflict of interest statement during the submission process. See the journal's policy on **Conflict of Interest** outlined in Section 5 of these Author Guidelines. Authors should ensure they liaise with all co-authors to confirm agreement with the final statement.

**Abstract**

The word maximum and abstract format varies by contribution type (see above). When an abstract is required, the abstract should be typed as a single paragraph. The journal requires **structured abstracts** with three exceptions: the journal will continue to use unstructured abstracts for Clinical Case Reports, Commentaries and "An Idea Worth Researching".

Structured abstracts should be organized as follows: **Objective**: briefly indicate the primary purpose of the article, or major question addressed in the study. **Method**: indicate the sources of data, give brief overview of methodology, or, if review article, how the literature was searched and articles selected for discussion. For research based articles, this section should briefly note study design, how participants were selected, and major study measures. **Results**: summarize the key findings. **Discussion**: indicate main clinical, theoretical, or research applications/implications.

**Keywords**

Please provide five to seven keywords. Keywords should be taken from those recommended by the US National Library of Medicine's Medical Subject Headings (MeSH) browser list at **www.nlm.nih.gov/mesh**.

**Main Text**

- Authors should refrain from using terms that are stigmatizing or terms that are ambiguous. For further explanation and examples, see the 2016 IJED article by Weissman et al. entitled "*Speaking of that: Terms to avoid or reconsider in the eating disorders field*" (DOI: 10.1002/eat.22528.)
- The text should be divided as outlined in Section 3 "Manuscript Categories and Requirements".
- Manuscripts reporting original research should follow the **IMRaD guidelines** (***I***ntroduction, (***M***ethods, ***R***esults, ***a***nd ***D***iscussion), which are

recommended by the International Committee of Medical Journal Editors (ICMJE) (J. Pharmacol. Pharmacother. 2010, 1, 42–58).

- To facilitate evaluation by the Editors and Reviewers, each manuscript page should be numbered; the text should be double-spaced; and line numbers should be applied (restarting from 1 on each page). Instructions on how to implement this feature in Microsoft Word are given here.
- The journal uses US spelling. Authors may submit using any form of English as the spelling of accepted papers is converted to US English during the production process.
- Footnotes to the text are not allowed and any such material should be incorporated into the text as parenthetical matter.
- It is the primary responsibility of the authors to proofread thoroughly and ensure correct spelling and punctuation, completeness and accuracy of references, clarity of expression, thoughtful construction of sentences, and legible appearance prior to the manuscript's submission.
- Authors for whom English is not their first language are encouraged to seek assistance from a native or fluent English speaker to proof read the manuscript prior to submission. Wiley offers a paid service that provides expert help in English language editing—further details are given below.
- Articles reporting data taken from or deposited elsewhere should refer to the journal policy on Data Storage and Documentation in Section 5 (below).

**References**

References in all manuscripts should follow the style of the American Psychological Association (6th edition), except in regards to spelling.

**Tables**

Each table must be numbered in order of appearance in the text with Arabic numerals and be cited at an appropriate point in the text. Tables should be self-contained and complement, not duplicate, information contained in the text. They should be editable (i.e., created in Microsoft Word or similar), not pasted as images. Legends should be concise but comprehensive—the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as standard deviation (SD) or standard error of the mean (SEM) should be identified in the headings. The journal's **Editorial Policy on Sample Size and Statistics** is given in Section 5.

**Figure Legends/Captions**

Each figure caption should have a brief title that describes the entire figure without citing specific panels, followed by a description of each panel. Captions should be concise but comprehensive—the figure and its caption must be understandable without reference to the text. Be sure to explain abbreviations in figures even if they have already been explained in-text. Axes for figures must be labeled with appropriate units of measurement and description. Include definitions of any symbols used and units of measurement.

***2. Figures***

Although authors are encouraged to send the highest quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted. **Click here** for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

Helvetica typeface is preferred for lettering within figures. All letters, numbers and symbols must be at least 2 mm in height. Courier typeface should be used for sequence figures. Figures should be numbered consecutively with Arabic numerals, and they should be numbered in the order in which they appear in the text.

Figures should be submitted as electronic images to fit either one (55 mm, 2 3/16", 13 picas), two (115 mm, 4 1/2", 27 picas), or three (175 mm, 6 7/8", 41 picas) columns. The length of an illustration cannot exceed 227 mm (9"). Journal quality reproduction requires grey scale and color files at resolutions of 300 dpi. Bitmapped line art should be submitted at resolutions of 600–1200 dpi.

Figures submitted in color will be reproduced in color online free of charge. Authors wishing to have figures printed in color in hard copies of the journal will be charged a fee by the Publisher; further details are given **elsewhere** in these Author Guidelines. Authors should note however, that it is preferable that line figures (e.g., graphs) are supplied in black and white so that they are legible if printed by a reader in black and white.

**Graphical Table of Contents**

*International Journal of Eating Disorders* incorporates graphics and a small piece of text from journal articles into the online table of contents (which are distributed to readers who have signed up to Table of Contents (ToC) alerts). The extra graphic and text, in addition to being eye-catching, gives the reader a much more immediate impression of what each article will cover.

If you would like a graphic to accompany your article in the Table of Contents, please specify one of your figures. You will be given the option to specify a figure during the submission process at the file upload stage.

***3. Supporting Information Files(s)***

Supporting Information is information that is supplementary and not essential to the article, but provides greater depth and background. Examples of such information include more detailed descriptions of therapeutic protocols, results related to exploratory or post-hoc analyses, and elements otherwise not suitable for inclusion in the main article, such as video clips, large sections of tabular data, program code, or large graphical files. It is *not* appropriate to include, in the Supporting Information, text that would normally go into a discussion section; all discussion-related material should be presented in the main article.

Because the Supporting Information is separate from the paper and supplementary in nature, the main article should be able to be read as a stand-alone document by readers. Reference to the Supporting Information should be made in the text of the main article to provide context for the reader and highlight where and how the supplemental material contributes to the article.

Should authors wish to provide supplementary file(s) along with their article, these materials *must* be included upon submission to the journal. If such materials are added to the submission as a result of peer review, i.e., during a revision, then the authors should bring this to the attention of the editor in their response letter. If accepted for publication, Supporting Information is hosted online together with the article and appears without editing or typesetting.

**Wiley's FAQs on Supporting Information** are available on the Wiley Author Services site: **www.wileyauthors.com**.

Note: Authors are encouraged to utilize publicly available data repository for data, scripts, or other artefacts used to generate the analyses presented in the paper; in such cases, authors should include a reference to the location of the material within their paper.

**General Style Points**

The following points provide general advice on formatting and style.

- **Terminology**: Terms such as “anorexics” or “bulimics” as personal pronouns, referring to groups of individuals by their common diagnosis, should be avoided. Terms like “individuals with anorexia nervosa”, “people with bulimia nervosa”, or “participants with eating disorders” should be used instead. Note, “participants” should be used in place of “subjects”.
- **Abbreviations**: In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.
- **Units of measurement**: Measurements should be given in SI or SI-derived units. Visit the Bureau International des Poids et Mesures (BIPM) website at www.bipm.fr for more information about SI units.
- **Numbers** under 10 should be spelt out, except for: measurements with a unit (8 mmol/L); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).
- **The word “data”** is plural; therefore, text should follow accordingly (for example, “The data show…the data are … the data were…”).
- **Sex/Gender & Age**: When referring to sex/gender, “males" and “females” should be used only in cases where the study samples include both children (below age 18) and adults and only if word limit precludes using terms such as “male participants/female participants,” “female patients/male patients”; when the participants comprise adults only, the terms “men” and “women” should be used. In articles that refer to children, “boys” and “girls” should be used.
- **Trade Names**: Chemical substances should be referred to by the generic name only. Trade names should not be used. Drugs should be referred to by their generic names. If proprietary drugs have been used in the study, refer to these by their generic name, mentioning the proprietary name and the name and location of the manufacturer in parentheses.
- **Statistics**: Authors should adhere to the journal’s policy on Sample Size and Statistics when reporting studies. For information on how to present p values and other standard measurements see IJED Statistical Formatting Requirements.

Appendix 2

Search strategy by database

| Database | Search Terms |
|---|---|
| Medline | (MH "Feeding and Eating Disorders" OR MH "Anorexia Nervosa" OR MH "Feeding and Eating Disorders of Childhood" OR eating disorder* OR anorex*) AND (MH "Siblings" OR MH "Nuclear Family" OR MH "Family" OR MH "Adult Children" OR brother* OR sister*) |
| PsychINFO | (DE "Eating Disorders" OR DE "Eating Behavior" OR DE "Nutritional Deficiencies" OR DE "Underweight" OR DE "Anorexia Nervosa" OR DE "Eating Disorders" OR DE "Underweight" OR DE "Body Image Disturbances" OR DE "Nutritional Deficiencies" OR anorexi*) AND ((DE "Family Members" OR DE "Family" OR DE "Adopted Children" OR DE "Adult Offspring" OR DE "Biological Family" OR DE "Foster Children" OR DE "Siblings" OR DE "Family of Origin" OR sibling* OR sister* OR brother*) |
| PsycARTICLES | (DE "Eating Disorders" OR DE "Eating Behavior" OR DE "Nutritional Deficiencies" OR DE "Underweight" OR DE "Anorexia Nervosa" OR DE "Eating Disorders" OR DE "Underweight" OR DE "Body Image Disturbances" OR DE "Nutritional Deficiencies" OR anorexi*) AND (DE "Family Members" OR DE "Family" OR DE "Adopted Children" OR DE "Adult Offspring" OR DE "Biological Family" OR DE "Foster Children" OR DE "Siblings" OR DE "Family of Origin" OR Sibling* OR sister* OR brother*) |
| Psychology and Behavioural Science Collection | (DE "EATING disorders" OR DE "EATING disorders in adolescence" OR DE "EATING disorders in children" OR DE "EATING disorders in literature" OR DE "EATING disorders in men" OR DE "EATING disorders in women") AND ( Family* OR siblings* OR DE "SIBLINGS" OR DE "BROTHERS" OR DE "SIBLING attachment" OR DE "SIBLING rivalry" OR DE "SISTERS" OR DE "TWINS" OR DE "SIBLINGS in literature" OR DE "CHILDREN" OR DE "FAMILIES of the mentally ill" OR DE "FAMILY communication" OR DE "FAMILY roles" OR DE "MENTALLY ill -- Family relationships" OR DE "NUCLEAR families" OR DE "ONLY child" OR DE "PARENTS" OR DE "PATIENT-family relations" OR DE "PATIENTS' families" OR DE "PROBLEM children -- Family relationships" OR DE "SIBLINGS" OR DE "SONS" OR DE "CAREGIVER attitudes" OR DE "FAMILY health") |
| CINAHL | ((MH "Eating Disorders") OR (MH "Anorexia") OR (MH "Anorexia Nervosa") OR (MH "Binge Eating Disorder") OR (MH "Bulimia") OR (MH "Bulimia Nervosa") OR (MH "Pica") OR (MH "Night Eating Syndrome") OR anorexi* OR eating disorder) AND ((family* OR sibling* OR sister* OR brother* (MH "Family") OR ((MH "Sibling Relations") OR (MH "Siblings")) |

| | |
|---|---|
| Social Sciences Full Text (H.W Wilson) | ((DE "Eating disorders" OR DE "Anorexia nervosa -- Social aspects" OR anorexi* OR eating disorder) AND ( DE "Sibling attachment" OR DE "Sibling communication" OR DE "Siblings" OR DE "Sick -- Family relationships" OR sister* OR brother* OR sibling* OR DE "Families" OR DE "Children" OR DE "Daughters" OR DE "Extended families" OR DE "Families of the terminally ill" OR DE "Family communication" OR DE "Family roles" OR DE "Mentally ill -- Family relationships" OR DE "Nuclear families" OR DE "Problem children -- Family relationships" OR DE "Siblings" OR DE "Sons") |
| SocINDEX with Full Text | ((DE "EATING disorders") OR (DE "ANOREXIA nervosa -- Social aspects") OR eating disorder* OR anorexi*) AND (DE "Sibling attachment" OR DE "Sibling communication" OR DE "Siblings" OR DE "Sick -- Family relationships" OR sister* OR brother* OR sibling* OR DE "Families" OR DE "Children" OR DE "Daughters" OR DE "Extended families" OR DE "Families of the terminally ill" OR DE "Family communication" OR DE "Family roles" OR DE "Mentally ill -- Family relationships" OR DE "Nuclear families" OR DE "Problem children -- Family relationships" OR DE "Siblings") |

Appendix 3

Example of SR theme (including participant and author quotes) and related analysis

| **Theme: Food and Eating Behaviour** | |
|---|---|
| ***Subtheme 1: Greater awareness of body and eating behaviour*** | |
| Quotations from participants: | |
| • I definitely notice the way people eat. how many bites they take and if they swallow their food really quickly or chew it really slowly (quotation 3; Areemit et al., 2010). | *Awareness of others eating; detailed account of others eating* |
| • I noticed that she ate very little in school … and she didn't eat when she came home either … so I told mum (Anna, 16; Callio et al., 2016). | *Awareness of siblings eating, healthy sibling watching and monitoring siblings food intake in school* |
| • I think it was mum who told me that she vomited in the shower, that is she went to the shower to vomit there, I think that was how it started. (Erik, 15; Callio et al., 2016) | *Greater awareness of social talk of weight and size x2*<br>*Awareness of peoples attitudes towards food, weight* |
| • I hear [people saying] 'I'm fat' a lot more than I used to and I hear 'I need to go on a diet' a lot more (quotation 4; Areemit et al., 2010). | *Surrounded, peer groups engaged in diet behaviour* |
| • (…) 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; Moses, 2013). | *Awareness of own eating* |
| • 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; Moses, 2013). | *Awareness of impact of food on ability importance of food to gain energy food habits more regular.*<br>*Eating behaviour in self* |
| • Mealtimes are more regular now […], because they were a bit haphazard before […] I can do more at school now, I used to be constantly tired at school, but I have become more alert. (Erik, 15; Callio et al., 2016) | *Fear of ED returning ever present, monitoring of sibling* |
| • It is like every time she is going to work out or eats a bit less than usual or she skips a meal, then of course I think: What if she still is sick? (Fjermestad et al., 2019). | *ED impacted on healthy siblings' perspective of food and engagement with it?*<br>*More sensitized to social talk of diets and food intake.* |
| • 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; Moses, 2013). | |
| Interpretation from author: | |
| • The siblings were acutely aware of eating behaviours in themselves, the AED, and in others (Areemit et al., 2010). | |
| • In addition, they were acutely aware of the AEDs' food choices, eating mechanics, and weight reduction behaviours. In some cases, they were aware of this before the ED was diagnosed (Areemit et al., 2010). | |
| • Sometimes, the sibling was the first to notice these changes, after which she/he told the parents, while in other cases it was the parents who informed the sibling (Callio et al., 2016) | |

| | |
|---|---|
| • The siblings were sensitized to general statements about body shape and size. They felt angry when people used words like ‘‘fat’’ and ‘‘diet’’ (Areemit et al., 2010).<br>• Three of the adolescents stated that their sister’s illness had led to “greater awareness of the significance of food” as well as the importance of food for gaining sufficient energy to do things (Callio et al., 2016)<br>• Two adolescents revealed that the family’s eating habits had improved and become more regular due to their sister’s illness, resulting in being able to do more at school (Callio et al., 2016).<br>• Participants said they became more aware of other people’s eating habits (Fjermestad et al., 2019).<br>• Most participants said they became more aware of the eating and exercise habits of others, e.g., paying attention to whether friends were eating less as they were worried friends should start to diet. Many explained they paid attention to the eating habits of their sibling with AN, even after (s)he had recovered, due to fears that she would become ill again (Fjermestad et al., 2019).<br>• Some expressed greater frustration at this increased awareness, which seemed outside of their control and unhelpful in their own lifestyle (Moses, 2013). | |
| ***Subtheme 2: Comparing body shape and size and eating behaviour with sibling***<br>Quotations from participants: | *Initiated by affected sibling* |
| • I never lend her any of my clothes anymore because she’ll say, ‘I couldn’t wear the clothes because it was too big for me, it was just too big for me’. I’ll be like, okay, ‘You don’t need to tell me that three times. Yes, I’m bigger than you’ (quotation 5; Areemit et al., 2010). | *Healthy sibling feeling judged by same* |
| • Of course I was aware that she had become thinner and when walking beside her I appeared a bit fat but it doesn’t affect me because I like myself too much. (Eva, 16; Callio et al., 2016). | *Initiated by healthy sibling at times, Food choice and size often compared* |
| • It’s like she’s a mouse compared to me, like if I stand in the mirror next to her I feel like I’m two of her….I just feel big compared to her…really bulky, and dirty sort of you know, like fat and ughh (Garley & Johnson, 1994). | *Living with sibling intensified this comparison* |
| • I’ve had like cake and everything. . . and she won’t even touch cake. She goes, ‘I just don’t feel like it,’ and everyone must feel like something every now and then you know, but she always says she doesn’t. Sometimes I’d like to be like that (Garley & Johnson, 1994) | *Negative comparisons* |
| • 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; Moses, 2013). | *While they compare, it does not impact **their** body image.* |
| • (…) 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 | *Some experimented with eating behaviours of affected sibling* |

| | |
|---|---|
| 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; Moses, 2013).<br>• It didn't influence me personally, but definitely my younger sister. She is eight years old and has always been a bit pudgy. For a time she also began to orient herself on my ill sister, for example eating less and working out at night. We were all quite shocked because we were afraid that another child would be consumed by anorexia. (Jungbauer et al., 2016) | |
| Interpretation from author:<br>• While participants acknowledged [their thoughts and attitudes] 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 (Moses, 2013).<br>• One participant, who was of normal weight, was conscious of continually comparing herself with her ill sister in terms of willpower, appetite, and body image (Garley & Johnson, 1994).<br>• Siblings frequently compared themselves negatively with their ill sisters in terms of body image and eating patterns. Several participants noted that their sister's illness had made them more aware of their own eating habits (Garley & Johnson, 1994).<br>• None of the siblings perceived that their sister's illness had affected their "own body image." Two of the brothers who participated did not consider that their sister's illness had influenced their perception of their own body, while the other three adolescents stated that their body image was not affected, although admitting that they compared themselves with their sister (Callio et al., 2016)<br>• Siblings, however, denied that living with an AED had any effect on their own eating attitudes, eating behaviours, and body image. Yet, some siblings admitted to experimenting with the eating behaviours of the AED. Others questioned their own eating attitudes, eating behaviours, and body shape and size. Siblings described feeling judged by the AED with respect to food choices, eating habits, and body shape (Areemit et al., 2010).<br>• One study participant reported that, under her sister's influence, she also developed symptoms of anorexia (Jungbauer et al., 2016).<br>• In another case, a participant reported how a younger sibling saw her older anorexic sister as a role model for a time (Jungbauer et al., 2019).<br>• When we were still living with our parents we were very close, perhaps too close. In any case, around that time my sister's anorexia somehow rubbed off on me. I thought I was too fat and lost 13 kilograms in a short period of time. Luckily things got back to normal pretty quickly after I moved out. (23-year-old older sister, age difference 1 year; Jungbauer et al., 2016). | *Some participants reported that their sibs ED led them to be less preoccupied with food and body shape and that the ED did not impact on their attitudes towards others*<br><br>*Discussed having a fear that disorder would inevitably be picked up by her.* |

Appendix 4

ENTREQ Checklist

| No | Item | Guide and description |
|---|---|---|
| **1** | Aim | State the research question the synthesis addresses. |
| **2** | Synthesis methodology | Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology *(e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).* |
| **3** | Approach to searching | Indicate whether the search was pre-planned (*comprehensive search strategies to seek all available studies)* or iterative (*to seek all available concepts until they theoretical saturation is achieved)*. |
| **4** | Inclusion criteria | Specify the inclusion/exclusion criteria *(e.g. in terms of population, language, year limits, type of publication, study type).* |
| **5** | Data sources | Describe the information sources used (e.g. *electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists)* and when the searches conducted; provide the rationale for using the data sources. |
| **6** | Electronic Search strategy | Describe the literature search *(e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits)*. |
| **7** | Study screening methods | Describe the process of study screening and sifting *(e.g. title, abstract and full text review, number of independent reviewers who screened studies).* |

| No | Item | Guide and description |
|---|---|---|
| **8** | Study characteristics | Present the characteristics of the included studies *(e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).* |
| **9** | Study selection results | Identify the number of studies screened and provide reasons for study exclusion *(e,g, for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications t the research question and/or contribution to theory development).* |
| **10** | Rationale for appraisal | Describe the rationale and approach used to appraise the included studies or selected findings *(e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).* |
| **11** | Appraisal items | State the tools, frameworks and criteria used to appraise the studies or selected findings *(e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope* [25]*; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).* |
| **12** | Appraisal process | Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required. |
| **13** | Appraisal results | Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale. |
| **14** | Data extraction | Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? *(e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software).* |
| **15** | Software | State the computer software used, if any. |
| **16** | Number of reviewers | Identify who was involved in coding and analysis. |

| No | Item | Guide and description |
|---|---|---|
| **17** | Coding | Describe the process for coding of data *(e.g. line by line coding to search for concepts).* |
| **18** | Study comparison | Describe how were comparisons made within and across studies *(e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).* |
| **19** | Derivation of themes | Explain whether the process of deriving the themes or constructs was inductive or deductive. |
| **20** | Quotations | Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation. |
| **21** | Synthesis output | Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. *new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).* |

Appendix 5

Journal guidelines (MRP): European Eating Disorders Review

**Research articles** reporting new research of relevance as set out in the aims and scope should not normally exceed 6000 words (excluding abstract, references, tables or figures), with no more than five tables or illustrations. They should conform to the conventional layout: title page, Abstract, Introduction and Aims, Method, Results, Discussion, Acknowledgements and References. Each of these elements should start on a new page.

**Word Limit:** 6,000 (excluding abstract, references, tables or figures).
**Abstract:** 200 words.
**References:** up to 60.

**Main Text File**

As papers are double-blind peer reviewed, the main text file should not include any information that might identify the authors.

The main text file should be presented in the following order:

i. Title, abstract, highlights and key words;
ii. Main text;
iii. References;
iv. Tables (each table complete with title and footnotes);
v. Figure legends;
vi. Appendices (if relevant).

Figures and supporting information should be supplied as separate files.

***Abstract***

All manuscripts should contain an abstract of up to 200 words. An **abstract** is a concise summary of the whole paper, not just the conclusions, and is understandable without reference to the rest of the paper. It should contain no citation to other published work. It must be structured, under the sub-headings: Objective; Method; Results; Conclusions.

***Highlights***

Highlights are mandatory for European Eating Disorders Review. These should appear as three bullet points that convey the core findings of the article.

***Keywords***

Include up to five **keywords** that describe your paper for indexing purposes.

***References***

References should be prepared according to the Publication Manual of the American Psychological Association (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper. A sample of the most common entries in reference lists appears below. Please note that a DOI should be provided for all references where available. For more information about APA referencing style, please refer to the **APA FAQ**. Please note that for journal articles, issue numbers are not included unless each issue in the volume begins with page one.

### *Tables*

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

### *Figure Legends*

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

### *Figures*

Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted. **Click here** for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

## Additional Files

### *Appendices*

Appendices will be published after the references. For submission they should be supplied as separate files but referred to in the text.

### *Supporting Information*

Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc. **Click here** for Wiley's FAQs on supporting information.

Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

If a manuscript describes a new approach and/or technological approach, authors are encouraged to include a small demo video – no more than 60 seconds long.

**General Style Points**

The following points provide general advice on formatting and style:

- **Language:** The language of the journal is English.
- **Abbreviations:** In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only. Distinction should be made between capital and lower case letters, between the letter O and zero, between the letter I and number one and prime, between k and kappa.
- **Units of measurement:** Measurements should be given in SI or SI-derived units. Visit the Bureau International des Poids et Mesures (BIPM) website at www.bipm.fr for more information about SI units.
- **Numbers:** numbers under 10 are spelt out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).
- **Trade Names:** Chemical substances should be referred to by the generic name only. Trade names should not be used. Drugs should be referred to by their generic names. If proprietary drugs have been used in the study, refer to these by their generic name, mentioning the proprietary name and the name and location of the manufacturer in parentheses.

Appendix 6

MRP letter of invitation




***Letter of Invitation***

Dear Clinician,

*Purpose of the study*

You are being invited to take part in a piece of research which aims to explore the experience of clinicians using externalisation, a core principle in Family-Based treatment (FBT), with patients experiencing eating disorders. Research suggests that externalisation is an important part of FBT and predicts outcome for the patient, however, little is known about the experience of clinicians using this technique within the context of eating disorders. The research aims to explore what clinicians find useful and what they struggle with when using externalisation; the clinician's impression of the impact of externalisation on the patient and his or her family and whether there is an impact on the clinician. This research hopes to further understand, develop and improve current practices in externalisation and Family-Based Treatment.

Please note that this is ***NOT*** a study of fidelity to a model. It is not evaluating how closely clinicians keep to the FBT model of treatment. It is an exploration of clinician's personal experiences of using externalisation, both challenges and successes in using externalisation and the clinician's own feelings about it. There are no right or wrong answers.

*What will it involve?*

To participate in this research, you must have worked with one or more families using Family-Based Treatment, you must be attending regular supervision (personal supervision or specific FBT supervision; minimum of once per month) and you must be working in a Child and Adolescent Mental Health Service (CAMHS). If you choose to participate in this research, you will be interviewed by the main researcher at a time and place that is suitable for you e.g. your workplace. The interview is expected to take between 45 to 90 minutes. The data collected from this interview will be used in a Doctorate Dissertation which is to be submitted through Cork University College in May 2020. The data collected may be published in scholarly journals and presented locally and nationally but no individual participation will be identified.

*Voluntary Participation and confidentiality*

Participation in this study is **completely voluntary**. There is no obligation to participate and whether you chose to participate **will not be known by anyone** on the research team apart from the main researcher (Katie Lonergan).

This research has received full ethical approval from the Clinical Psychology Research Ethics Committee in the Department of Psychology, University College Cork.

*Contact details*

If you would just like to find out more about the project before deciding whether to participate, please feel free to contact Katie on the below number or email address.

Your involvement in this research would be greatly appreciated. If you wish to participate, please **email Katie Lonergan directly** including **your name, email address and phone contact details**. Katie will then contact you to arrange a suitable day, time and place to carry out the interview.

| | |
|---|---|
| Katie Lonergan email: | Katie.Lonergan1@hse.ie |
| Katie Lonergan mobile: | 086 066 1875 |
| Dr. Christian Ryan (research supervisor) email: | Christian.ryan@ucc.ie |

Thank you,

Katie Lonergan

Psychologist in clinical training

Appendix 7

MRP Information Sheet and consent form



ucc
Coláiste na hOllscoile Corcaigh, Éire
University College Cork, Ireland

## INFORMATION SHEET

Thank you for considering participating in this research project. The purpose of this document is to explain to you what the work is about and what your participation would involve, so as to enable you to make an informed choice.

### PURPOSE OF THIS RESEARCH STUDY

You are being invited to take part in a piece of research which aims to explore the experience of clinicians using externalisation, a core principle in Family-Based treatment (FBT), with patients experiencing eating disorders. Research suggests that externalisation is an important part of FBT and predicts outcome for the patient, however, little is known about the experience of clinicians using this technique within the context of eating disorders. The research aims to explore what clinicians find useful and what they struggle with when using externalization; the clinician's impression of the impact of externalisation on the patient and his or her family and whether there is an impact on the clinician. This research hopes to further understand, develop and improve current practices in externalisation and Family-Based Treatment.

Please note that this is ***NOT*** a study of fidelity to a model. It is not evaluating how closely clinicians keep to the FBT model of treatment. It is an exploration of clinician's personal experiences of using externalisation, both challenges and success in using externalisation and your own feelings about it. There are no right or wrong answers.

Should you choose to participate, you will be asked to take part in a one-to-one interview with Katie Lonergan. This interview will be audio-recorded and is expected to take 45 - 90 minutes to complete. You will also be asked to complete a brief demographic questionnaire.

### VOLUNTARY PARTICIPATION

Participation in this study is completely voluntary. There is no obligation to participate, and should you choose to do so you can refuse to answer specific questions, or decide to withdraw from the interview. Once the interview has been concluded, you can withdraw your details at any time in the subsequent two weeks.

## CONFIDENTIALITY AND ANONYMITY

All of the information you provide will be kept confidential and anonymous and will be available only to the research team. The only exception is where information is disclosed which indicates that there is a serious risk to you or to others.

## DATA STORAGE

Once the interview is completed, the recording will immediately be transferred to an encrypted laptop and wiped from the recording device. The interview will then be transcribed by the researcher, and all identifying information will be removed. Once this is done, the audio-recording will also be deleted and only the anonymized transcript will remain. These data will be stored on the University College Cork OneDrive system and subsequently on the UCC server. The data will be stored for a minimum of ten years. Information gathered through this research will contribute to a major research project thesis and may also be used in research publications and/or conference presentations.

We do not anticipate any negative outcomes from participating in this study. At the end of the procedure, I will discuss with you how you found the experience and how you are feeling. You may stop the interview at any point if you feel any distress regarding the research. If any clinical issues arise due to the research, we would advise that these are discussed in your on-going supervision or in FBT supervision. If any research issues arise the contact details for the research supervisor, Dr Christian Ryan, are provided below.

## CONTACT DETAILS

This study has obtained ethical approval from the UCC Clinical Psychology Research Ethics Committee. If you have any queries about this research, you can contact me at 117221953@umail.ucc.ie or Dr. Christian Ryan (research supervisor) at Christian.ryan@ucc.ie

**If you agree to take part in this study you will be asked to sign a consent form agreeing to the above on the day of the interview.**

### Consent Form

I……agree to participate in Katie Lonergan's research study.

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

I give permission for my interview with Katie to be audio-recorded.

I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that disguised extracts from my interview may be quoted in the thesis and any subsequent publications if I give permission below:

(Please tick one box:)

I agree to quotation/publication of extracts from my interview ☐

I do not agree to quotation/publication of extracts from my interview ☐

Signed: ……. Date: ……..

PRINT NAME: …….

Appendix 8
MRP demographic questionnaire




1. What is your age?

   _____

2. What is your profession? (Please tick)
   Nurse

   Social Worker

   Psychologist

   Other (Please specify)

   _____

3. How many years have you been working with Adolescents with Eating Disorders (EDs)? (Please tick)
   **0 – 1** years

   **1-3** years

   **3+** years (If possible, please specify)

   _____

4. How many years have you been using family-based treatment (FBT) with families? (Please tick)
   **0-1** years

   **1-3** years
   **3+** years

   _____

5. What training in FBT did you complete? (Please tick)
   Formal FBT 2 day training with Dr. James Lock

   Independent learning from FBT manual and supervision

   Other (Please specify)

   _____

6. How many families are you working with currently using FBT? (Please tick)
   1 – 3 families

   3 – 6 families

   6 + families

7. How many families have you previously worked with using FBT (case now closed)? (please tick)

   0 – 5 families

   5 – 10 families

   10 + families (please estimate if above 10)

8. When working with families using FBT, do you work alone or alongside another clinician during the FBT session? (Please tick)

   Alone
   With another clinician

9. Which other members of your team are actively working the case? (Please tick any answer that is relevant)
10.

    Consultant Psychiatrist

    Dietician

    Other clinician (please specify)

11. What type of ED presentations have you worked with using the FBT model? (Please tick)

    Anorexia Nervosa

    Bulimia Nervosa

    Other (Please specify)

12. Do you have additional therapeutic training? (Please tick)
13.

| | |
|---|---|
| DBT | Family Therapy |
| CBT | Counselling course |
| Other (please specify) | |

14. Do you currently work with any clients other than those with ED's?
    If yes, please describe the ***setting*** and the ***therapeutic model(s)*** used

---

15. Do you attend supervision? (Please tick)

    FBT supervision

    Other (e.g. personal supervision)

---

*Thank you for taking the time to complete this questionnaire.*

Appendix 9

MRP ethical approval (original and confirmatory)

6th December 2018

Coláiste na hOllscoile Corcaigh, Éire
University College Cork, Ireland

Dear Katie,

**Clinical Psychology Research and Ethics Meeting 23.11.18**

**Exploring the Experience of Clinicians using Externalisation as part of Family-Based Treatment with Young People Experiencing Eating Disorders – Katie Lonergan**

Thank you for presenting the above research proposal to the Research and Ethics panel. Based on your written proposal and further clarification and discussion during the meeting, the decision of the panel was:

- **Pass, conditional on required revisions**

In formulating a revised submission please attend to the following issues raised by reviewers on the current proposal:

- Could the three research questions be merged into one?
- It might not be desirable to conduct the interviews in the workplace – perhaps an alternative might also be offered.
- More time might be required for both interviews and transcribing
- It might be an idea to gather the demographic information in a questionnaire before the interview begins

You may re-submit your revised proposal to n.hennessy@ucc.ie at any time but NO LATER THAN Friday 7 January 2019. Please also include a cover letter indicating how and where you have responded to these revisions.

Every best wish with making these revisions.

Yours sincerely,



**Dr Mike Murphy**
Chair Clinical Psychology Research and Ethics Panel

**Hennessy, Nora** <NHennessy@ucc.ie> Tue, Feb 5, 2019, 10:28 AM

to me, Christian

Dear Katie,
Many thanks for you updated form and cover letter.
This has been approved.

Kind Regards,
Nora
Nora Hennessy | Programme Administrator, DCLIN Psychology| School of Applied Psychology| Distillery House, North Mall Campus |UCC ||Ph: (021) 490 4512/ 490 4552

Appendix 10

Code Framework

| | |
|---|---|
| Acknowledgment of uncertain nature of ED | Externalisation used with many psychological issues |
| Adaption of model | Family problem with communication |
| Agency of ED | Family respond well |
| Child as pathway to externalisation | Parents respond well |
| Child's original concept of ED | Family need to take responsibility for problems |
| Different professionals have different framework | FBT and psychosocial framework |
| ED as restricting parental authority | Historical view of ED |
| ED initially internalised part of child to parents | Individual therapy for client |
| Behaviours as internalised | Internalised ED as sensitive to family |
| ED as internalised part of family environment | *Lack of externalisation leads to negative emotions* |
| Externalising makes external the internal ED | MDT uses diagnosis label for ease of communication |
| Increased internalising when parents cannot externalise | *Negotiating externalisation* |
| Internalisation of mental versus physical health | *Externalisation supports parents' positive emotion toward child* |
| Negative attributes of child | Parental emotion becomes focused on the externalised ED |
| Parents acknowledgment of keeping up externalisation | *Externalisation separates behaviour from child* |
| ED journey as difficult | Parents as starting point for externalising |
| ED Venn diagram metaphor | Multiple externalisations |
| Explaining the concept of externalisation to families | Using externalisation to explore other relationships |
| Externalisation as circumnavigating avoidance | Externalising as central technique in FBT |
| Externalisation as coping mechanism | Family members can use externalisation differently |
| Externalisation as reducing parental blame | Focus is behavioural not therapeutic |
| Externalisation as facilitating family communication | Just one tool |
| Externalisation as pathway to refeeding | YP and parents have to connect with externalisation |
| Externalisation as reducing focus of emotion on one person | Parents blame self |
| Externalisation as useful to parents | Parent blame as issue in therapy |
| Externalisation encourages parents to find solution | Parental guilt |

| | |
|---|---|
| Externalisation as communication between clinician, parents and YP | Parents do not notice use of externalisation |
| Externalisation as creating distanced between problem and person | Parents experience relief through externalisation |
| Externalisation as giving space and options | Parent have poor understanding of ED |
| Externalisation reduces blame | Parents who do not take on externalisation |
| Externalisation supports YP to communicate | Not an issue if parents don't take it on |
| Externalisation supports YP's self esteem | Parental sense of mastery leads to recovery |
| **Internalisation and externalisation on continuum** | Parents acknowledge usefulness of externalisation |
| Internalised ED as block to therapy | Parents belief in technique |
| Externalisation gives language to parents | Parents struggle to battle ED |
| Externalisation as psychological language | Parents struggle with different view of ED |
| Parents latch on to externalising language | Political issues in mental health |
| Parents as driver of new language | Psychiatry as main model in service |
| Externalisation gives family a language | Psychiatry versus family therapy externalisation |
| Child as driver of new language | Psychological conceptualisation as too complex for YP |
| Externalising language as shift in therapist position | Reflexive use of externalisation |
| Externalising reduces towards the end of therapy | Reframing back to internalised psychological position |
| Externalisation helps parents in initial stages | Sculpting as externalising technique |
| High usage of Externalisation in initial stages | ED personified |
| Initial stages of externalising are hard | Education as externalising |
| Externalisation at second stage of FBT | Education as separating ED from YP |
| Beginning externalising early | Externalisation can change with deeper characterisation |
| Timing is important | Externalising parts of YP |
| Psychological mindedness | Externalising technique as getting physical |
| Therapist position | Other families as externalising technique |
| Clinician appraisal of research | Parents model therapists |
| Clinician moves between externalised and internalised framework | Techniques work for families who do well |
| Clinician values externalising technique | Stress levels can influence engagement |
| Externalisation not a hindrance | Families are happy with service |
| ED as medical and psychological | Initial reaction to externalisation can be negative |
| ED as part of systemic dysfunction | Positive outcomes can support engagement |
| Embodying position | Therapist negative view of disease metaphor |
| Externalisation as building therapeutic relationships | Acknowledges more than one metaphor |
| Failing therapy increases therapist and blame | Contest metaphor |
| Influence of family therapy training | Diagnosis as externalising |
| Mental health difficulties as normalised | FBT as illness metaphor |

| | |
|---|---|
| Recognition that orientation will impact on delivery | FBT model as illness focussed |
| Skills need to be learned more broadly than FBT | Maudsley position |
| Skill of externalisation | Therapist passion for therapy |
| Acknowledgment of therapist experience reducing self-blame | Useful construct for younger children |
| Systemic impact of ED | Externalisation works with YP way of communicating and understanding |
| Therapist difficulties with externalising | Metaphor as useful construct for any problem |
| Clinician feelings towards externalising in the context of the medical model | Older adolescent harder to manage for parents |
| Natural tension of different perspectives | Younger children have reduced cognitions related to ED |
| Clinician found language difficult initially | YP on the ASD spectrum |
| Clinician moulding self to beliefs | YP emerges from ED |
| Clinician neutrality | YP sees recovery as possible |
| Clinician recognition of natural use of externalising language | YP views ED as part rather than whole |
| Clinician reflexivity | |
| Therapy skills | |

Appendix 11

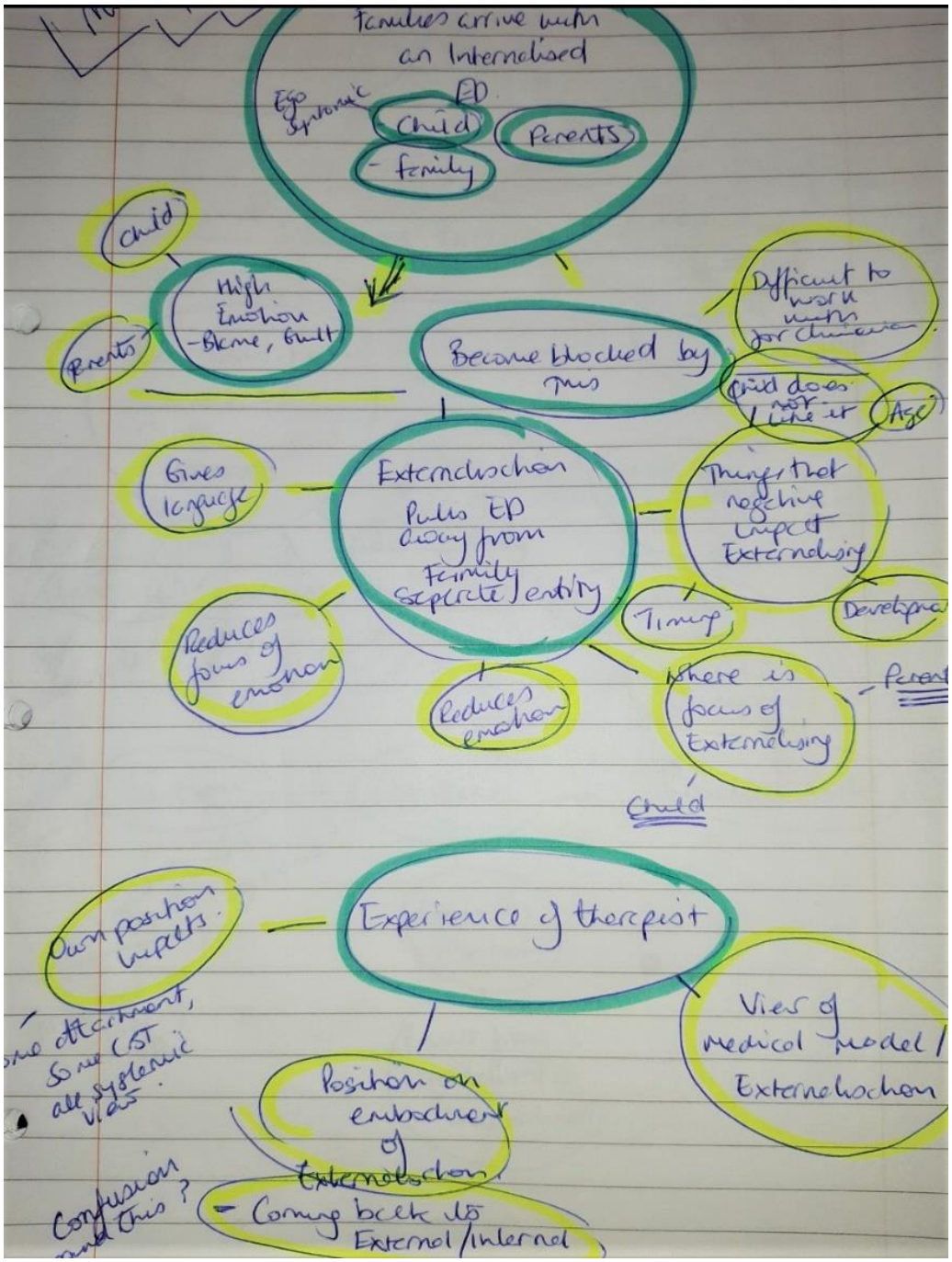
List of Provisional Themes at the end of Phase 4

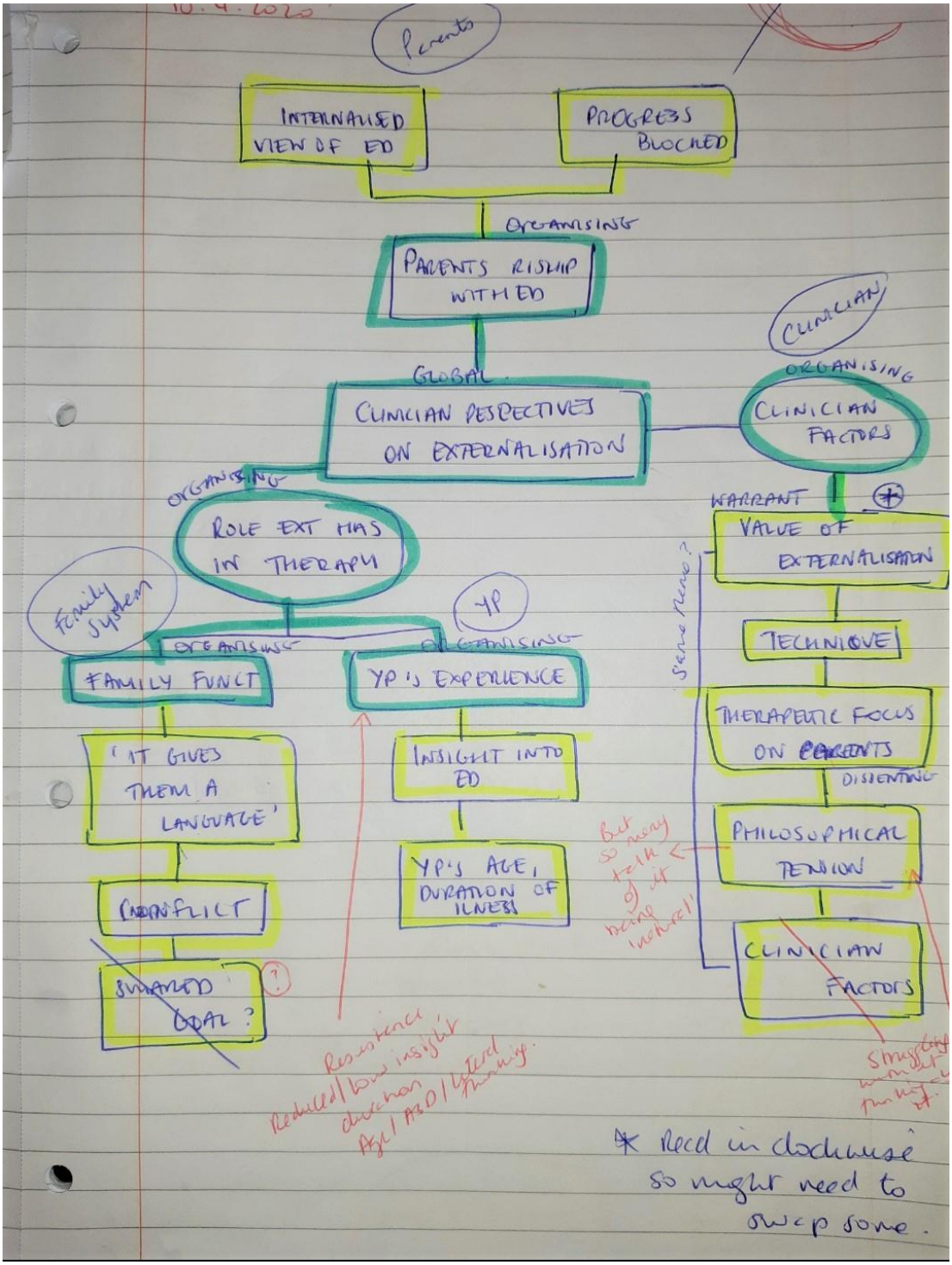
**Thematic Analysis: List of Provisional Themes**

1. Barriers to externalisation
2. Clinician experience
3. ED as difficult
4. Externalisation process throughout therapy
5. Impact of externalisation
6. ED as internalised
7. Parents belief in engagement with externalisation
8. Responsibility
9. Technique
10. YP’s engagement with externalisation

Appendix 12

Examples of initial visual representations of themes and subthemes




Parents
INTERNALISED VIEW OF ED
PROGRESS BLOCKED
ORGANISING
PARENTS RISHIP WITH ED
CLINICIAN
GLOBAL
CLINICIAN PERSPECTIVES ON EXTERNALISATION
ORGANISING
CLINICIAN FACTORS
ORGANISING
ROLE EXT HAS IN THERAPY
WARRANT
VALUE OF EXTERNALISATION
Family system
YP
ORGANISING
ORGANISING
FAMILY FUNCT
YP's EXPERIENCE
TECHNIQUE
THERAPEUTIC FOCUS ON
'IT GIVES THEM A LANGUAGE'
INSIGHT INTO ED
DISENTING
PHILOSOPHICAL TENSION
YP's AGE, DURATION OF ILNESS
CLINICIAN FACTORS
Resistance
Reduced/low insight
duration
Age/ARFID/Lgbtq+ thing.
* Need in discussion so might need to swap some.

Appendix 13

Example of analysis of codes from theme ‘A shared language’

| | |
|---|---|
| A) **It gives them a language/facilitates communication**<br>**Clinician 01:** So why is it important, and I will change it to useful, it’s useful because you can then start to talk about the problem and not be so paralysed by the really really horrible sticky heavy resentful bitter angry emotions which tend to characterise either hostility or paralysis.<br>**Clinician 01:** So, it’s not just about being able to talk to the child with the ED, it’s being able to talk to everyone else about ‘the problem’<br>**Clinician 01:** start to talk about the impact upon relationships but do it in such a way like ‘oh we have a problem, this thing has come into our family and this thing is causing us to, you know, now why don’t we talk about how we can fight back against this thing. This thing being ‘the problem’. As opposed to ‘well how the hell are we going to control our monster of a daughter’.<br>**Clinician 01:** So, we kind of applied externalising and that offered some help, it allowed us to have the conversation in session that this is not her daughter, here’s her daughter, her daughter is ambitious and beautiful etc.<br>**Clinician 01:** Mum was, we were able to, it was useful because we were able to have the conversation in the session, it would be very difficult to have that conversation without externalising. Mum was showing some capacity to follow through.<br>**Clinician 01**: So, when we talk about, we’ll call her Nora, we call her Nora, when we are talking about the ED we call it ‘Ed’. So, when I’m talking about Nora, I’m not talking about Ed. When I’m talking about Ed, I’m not talking about Nora. Just to be able to have the conversation, to separate this stuff.<br>**Clinician 03:** So, it does offer a way to normalise and talk about people’s experiences <which is> really really useful. | *Externalisation leads to family communication about this ‘problem’ that is not only impacting on the YP with the ED but is impacting at a family wide level*<br><br>*It gives them a way to speak to each other and communicate with each other about an issue that is impacting them all without placing the focus of the problem on the YP. These conversations can begin to pull family members together to fight a common enemy and work towards solutions together*<br><br>*Externalising the ED facilitates conversation in therapy sessions. So it gives a common language to the parents, the YP and the clinician and it is through this language and communication that the clinician can support the parent(s) to begin to separate their internalised view of the their child and the ED from the externalised view of the ED as an illness*<br><br>*Gives family a way to talk in context of FBT sessions; gives clinician a way to communicate with family*<br>*Clinician makes use of this language in session to help different family members gain perspective on how the ED influences and affects their* |

| | |
|---|---|
| **Clinician 02:** And, it evolved into something really helpful because this particular kind of bunch of sessions I remember there was a lot of talk about the control it had over this young person and what 'It' was telling this young person to do. So the young person would have talked about her compulsion to exercise through 'It' was telling me. She would have talked about her, that she couldn't eat certain foods because 'It' was telling her to.<br>**Clinician 02:** Em, I think it gave them a shared language or shared metaphor to talk about the ED<br>**Clinician 04:** it also provides a common ground in terms of then it gives a language for the child and therefore because it gives a language to the child talking about their externalised ED it therefore gives a language to the parent.<br>**Clinician 04:** And I'm just thinking off the cuff here but then because I suppose it gives a language, this externalising of the ED it gives it a language or a shape or a size or colour whatever**.** Then all of a sudden, the parent and child are able to talk about the ED, you know, it's not such a hidden, internal, psychological process that's very sensitive, or if you go near it will cause trouble. All of a sudden, it's given this name.<br>**Clinician 04:** So for instance if a young person is in front of a mirror what can happen is, say body length mirrors can be difficult for young people and they might start pushing at body parts or pushing in at body parts or they may become distressed the parent can then go 'oh, there's the bully again or there's Mr or Ms ED again' so they are able to name it then and that really helps in the recovery process for the young person and the family as well.<br>**Clinician 04:** That you know, the child wants low fat butter or low fat milk or doesn't want sweets and the parent goes along with it because it may be very innocent at the beginning but after a while they realise that it may not be something that may be so benign it's actually something that's quite complex and entrenched in the child so I think that externalisation opens up the avenues of communication between the parent and the child and something that's been kind of pushed under and not talked about is then given a language and given attention and able to deal. | *lives. One clinician reported that these conversations could not be facilitated without the use of the externalising technique*<br><br>*Clinician reports that YP is more easily able to communicate the control the ED has over her when communicating it through an externalised form*<br><br>*Clinician feels like the externalised form of the ED allows the child and parent to have a common language to discuss the ED, whereas when the ED is internalised as part of the child it is something that can cause distress when it is focused on*<br>*When the ED is internalised part of child it may be avoided, 'pushed under and not talked about' because parents do not know how to approach it*<br><br>*It gives parents a way to intervene when the YP displays ED behaviours which they may not have previously known how to approach. Being able to intervene with these ED behaviours e.g. refusing food, pinching body parts, supports the YP towards recovery. Ways to communicate through these behaviours.* |

| | |
|---|---|
| **Clinician 04:** equally you know when there's good communication they can see what days Mr ED or the ED is around, how frequently it's around<br>**Clinician 04:** I think it gives the parents language as well in terms of what's going on and they're communicating with their child because you know they come in here for their one hour session on a weekly or possibly more than weekly session on the basis of it's a high priority but ultimately they have to do all the work outside of that so it's the parents that really have to do all the refeeding.<br>**Clinician 04:** so far it's been a very useful tool to externalise the ED for the young person and the family because as I said it gives them the language, it gives them a common ground to talk between parent and child and between clinician and child and between clinician and parent you can use that symbolism or metaphor so I haven't had any difficulties, it's actually made my job easier.<br>**Clinician 05:** so when you start using language that talks about 'the ED' or 'the depression' and take it out of them and you look at it as a separate entity and name it and look at the behaviours that it has the young person doing and the way it influences other members of the family it's easier to talk about it and it feels less personal to the person.<br>**Clinician 06:** So, it's really helpful initially, just to talk a lot about the ED and it gives them language then to separate from their child<br>**Clinician 06:** so, I think it's useful for parents and I think they often will say that that, and they will often latch on to the language<br>**<u>Clinician 06:</u>** So at least you provide them (family including siblings) with a means to talk about this thing and just talking about stuff helps. | *The externalisation leads to communication between the parents and the child in relation to when the ED is most active and least active*<br><br>*Clinicians acknowledgement of the importance of parents having this language as they are at the wheel of recovery. They are the people responsible for feeding the YP*<br><br>*Again, acknowledgement that the language is of benefit to the family but also to the clinician who can now engage with the family in a neutral way where there is no blame placed on any individual*<br><br>*Externalisation makes it easier to talk about the impact of the ED on the family without any one member feeling it is personal to them*<br><br>*Language is the separation, separation not possible without the language*<br><br>*Siblings also find a way to talk about the ED* |

Appendix 14

Quality Checklist for TA (Braun et al., 2006)

| Process | No | Criteria |
|---|---|---|
| Transcription | 1 | The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'. |
| Coding | 2 | Each data item has been given equal attention in the coding process. |
| | 3 | Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive. |
| | 4 | All relevant extracts for all each theme have been collated. |
| | 5 | Themes have been checked against each other and back to the original data set. |
| | 6 | Themes are internally coherent, consistent, and distinctive. |
| Analysis | 7 | Data have been analysed/ interpreted, made sense of/ rather than just paraphrased or described. |
| | 8 | Analysis and data match each other/ the extracts illustrate the analytic claims. |
| | 9 | Analysis tells a convincing and well-organized story about the data and topic. |
| | 10 | A good balance between analytic narrative and illustrative extracts is provided. |
| Overall | 11 | Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly. |
| Written report | 12 | The assumptions about, and specific approach to, thematic analysis are clearly explicated. |
| | 13 | There is a good fit between what you claim you do, and what you show you have done/ i.e., described method and reported analysis are consistent. |
| | 14 | The language and concepts used in the report are consistent with the epistemological position of the analysis. |
| | 15 | The researcher is positioned as active in the research process; themes do not just 'emerge'. |