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REVIEW

The experiences of having a sibling with an eating disorder: A systematic review of the literature

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Abstract

Objective: Research on carers in the context of eating disorders (EDs) has predominantly focused on parents and offspring, overlooking the adverse effects EDs have on the lives of siblings. This study aims to shift the paradigm by reviewing the literature in this area. To the authors' knowledge, this is the first review of the literature that broadly captured the lived experiences of siblings without being limited by specific search terms such as coping strategies and levels of psychopathology.

Method: Six databases (ERIC, MEDLINE, PsycInfo, Pubmed, Scopus, and Web of Science) were searched using predetermined search strings. Quantitative, qualitative, and mixed methods studies were included as long as they were focused on siblings' experiences of having a brother or sister with an ED. No publication date restrictions were applied, and thorough quality assessments were initially carried out before a qualitative analysis of the data was conducted.

Results: Twenty-one studies were eligible for inclusion, thematic synthesis yielded six core themes, and 17 subthemes related to the inter- and intra-personal impacts of the ED on siblings' lives. These themes and sub-themes include fragmentation in family relationships, parentification, and competition and jealousy.

Conclusion: It is of utmost importance to gain a better understanding of siblings' experiences and needs in relation to EDs. The findings are discussed in relation to the existing literature and theoretical and clinical implications, for example, tailored approaches accounting for siblings' experiences.

KEYWORDS

brother, eating disorders, perceived experiences, siblings, sister, systematic review

Highlights

- Eating disorders (EDs) impact many areas of siblings' lives causing immense, inescapable disruption leading siblings to feel less important than their sibling with the ED. This can be due to receiving less attention from

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their parents, other people continuously asking about their SED and not them, and significant life events being overshadowed by the ED and their SED.

- The lacking professional support is in direct contrast to their wish to receive more help from professionals.
- It is essential for professionals to take a proactive approach to identify siblings' needs and offer them more tailored support.

1 | INTRODUCTION

Eating disorders are characterised by a disturbance of eating or eating-related behaviours resulting in altered food consumption and absorption (Diagnostic and Statistical Manual of Mental Disorders-Fifth [DSM-5] edition; American Psychiatric Association, 2013). These serious mental illnesses (Friederich et al., 2013) are persistent in nature with potentially significant and life-threatening consequences (DSM-5, 2013) with an increased mortality risk (Iwajomo et al., 2020), and damage to many organ systems (The Royal College of Psychiatry, 2023). Eating disorders are associated with a high prevalence of comorbid psychiatric conditions, including, mood and anxiety disorders, substance use disorders, and personality disorders (Treasure et al., 2020).

Caring for an individual with an ED can be isolating and extremely distressing (Havard, 2019). Family members experience devastating consequences, on family functioning, work, leisure, and finances (Highet et al., 2005). Due to the age of onset of EDs, caring responsibilities often fall on family members (Fox et al., 2017). A previous meta-synthesis related to caring for an individual with an ED highlighted that caregivers experience high levels of distress, burden, and expressed emotion due to the pervasive impact of the ED (Fox et al., 2017). The authors suggest that interventions for individuals with an ED should also acknowledge carers and close family members as the ED affects their relationships, sense of identity, and physical, emotional, and mental health (Fox et al., 2017). Carers' own needs are often neglected in order to meet the needs of the person they are caring for (Fox et al., 2017).

Similarly, a systematic review of family caregiving in EDs demonstrated that most research has focused on mothers, with the impact on other family members less studied (Anastasiadou et al., 2014). Caregiving experiences are problematic with higher levels of burden associated with a longer illness duration (Anastasiadou et al., 2014). The review found high levels of expressed emotion, psychological distress, anxiety, stress, and

depression in carers of individuals with an ED (Anastasiadou et al., 2014).

The National Institute for Health and Care Excellence (2020) guidelines for EDs highlight that family members who take on the role of caregiving, including siblings of people with an ED, need tailored support and education. However, siblings have been neglected in research studies and clinical practice so it is imperative to gain more insight into their needs and experiences (Maon et al., 2020). A previous systematic review regarding siblings' personal experiences, ways of coping, and levels of psychopathology found that EDs have significant effects on siblings, leading to poorer emotional well-being, and social isolation (Maon et al., 2020). However, only two databases were searched, and the focus was not solely on siblings' experiences. The current review searched seven databases and focused specifically on the siblings' experiences of having a brother or sister with any form of an ED.

As this systematic review is exploratory it does not follow a specific theoretical framework.

2 | METHOD

2.1 | Search strategy

The systematic review followed the "Preferred Reporting Items for Systematic Reviews and Meta-Analyses" (PRISMA) protocol guidelines. The protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO; <https://www.crd.york.ac.uk/prospero> Registration Number: CRD42021253750) on 17 May 2021.

Systematic searches were carried out across six databases: ERIC, MEDLINE, PsycInfo, PubMed, Scopus, and Web of Science, between the 18th and 21st of July 2023. No publication date restrictions were set but restrictions were applied to texts not published in English due to a lack of resources to translate the text. Qualitative, quantitative, and mixed-methods studies were included in the review.

Table 1 details the criteria for study selection.

2.2 | Search terms

The search terms used were:

Eating disorder OR anorexia OR bulimia OR binge
ED
AND
Sibling or brother or sister

2.3 | Study selection and data extraction

Search results were collated, and duplicates were removed, the remaining articles underwent title and abstract screening (by AH and IM). AH and IM conducted the full-text screening and in cases of disagreement or uncertainty, eligibility was assessed by ML and discussions were held to resolve any issues. Figure 1 details the quantity of articles and reasons for exclusion and Table 2 summarises the main findings of each article. Additional records from other sources came from checking reference lists of articles and 'cited by'. Data extraction was conducted by AH using a pre-formatted data extraction spreadsheet on Microsoft Excel, recording study characteristics reported in Table 3.

2.4 | Quality assessment

Quality assessments were conducted independently by AH and IM using Hawker et al.'s (2002) tool for evaluating mixed-methods research before meeting to discuss the scores and resolve any incongruence. The tool

consists of nine questions to be answered by the reviewer on a scale of 1 (very poor) to 4 (good), with total scores ranging from 9 to 36. Due to the paucity of literature in this area, the decision was made not to exclude articles based on the quality assessment scores.

2.5 | Thematic synthesis

Thomas and Harden's (2008) thematic synthesis was conducted by AH. The text was coded and descriptive themes were developed before analytical themes were generated (Thomas & Harden, 2008). Initial themes were revised and refined with the other authors. Thematic synthesis was chosen for this review as it is ideal for the synthesis of both qualitative and quantitative research outcomes, especially when there is heterogeneity in outcome measures and variables (Ryan et al., 2018).

3 | RESULTS

Twenty-one studies (published between 1994 and 2022) met the inclusion criteria, 16 were classified as high quality and the remaining 5 were medium quality. The themes and sub-themes are presented in Figure 2 and described below.

3.1 | The socio-cognitive emotional effects of having a sibling with an eating disorder (SED)

"You have one child with an ED; but then you have another child who is going through the experience of their sibling having an ED, which is also a very traumatic

TABLE 1 Table of inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Those with a sibling with ED symptoms and eating problems based on either self-report measures or a clinical diagnosis.	Articles about obesity or body image that do not directly relate to the clinical diagnosis of an ED
Primary studies reporting original qualitative, quantitative, or mixed methods research.	Articles that are duplicated or do not report primary peer-reviewed research (e.g., reviews)
Peer-reviewed and unpublished, grey literature.	Articles that mention familial experiences of living with someone with an ED but do not specifically mention sibling experiences.
Data was collected directly from individuals who have a brother or sister with an ED.	Articles that mention siblings and EDs but do not focus on the siblings' experiences of having a brother or sister with an ED.
Articles that mention family experiences with other family members provided they have a subsection that focuses on siblings' experiences.	
Research from any date due to the very limited research on siblings' personal experiences of having a brother or sister with an ED (Maon et al., 2020), and the review aims to be inclusive of all suitable research.	

Abbreviation: ED, Eating disorder.

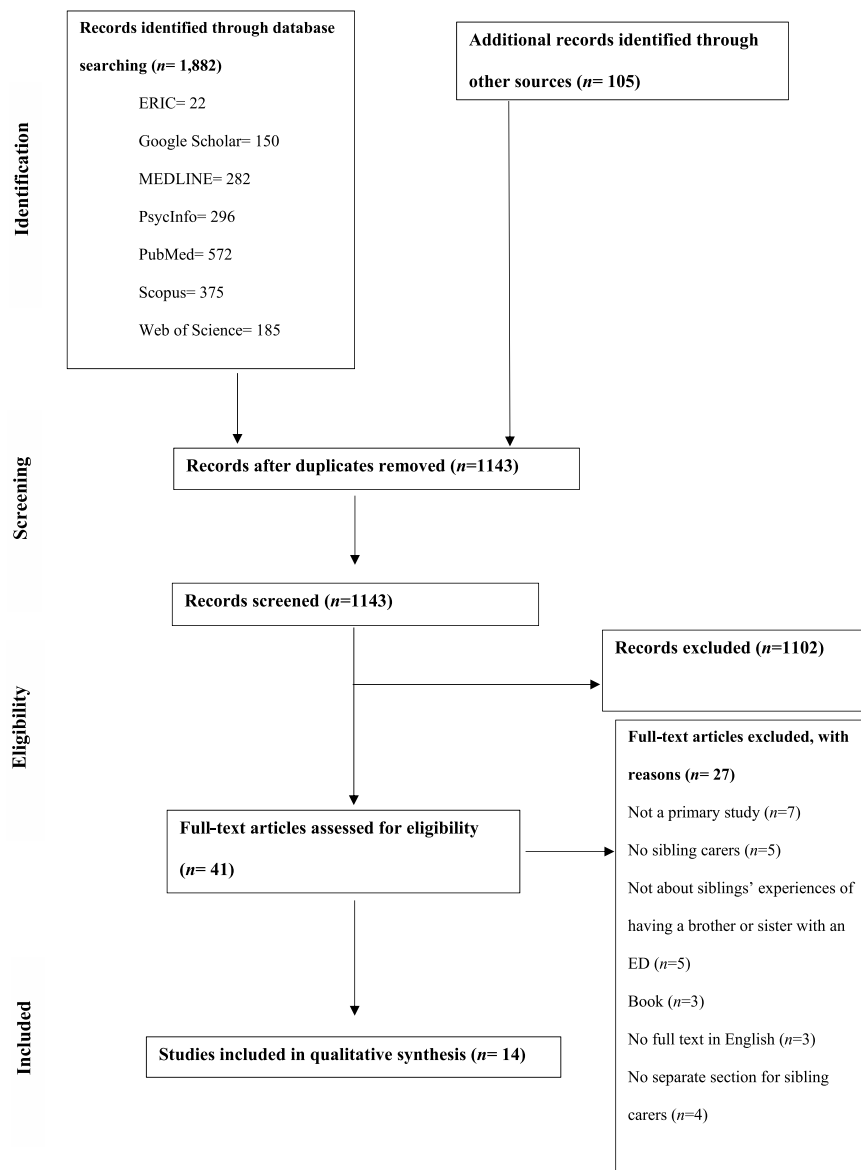


FIGURE 1 PRISMA flow diagram outlining the searching and screening strategy.

experience” (Renfrew Frigon, 2021, p. 60) sums up the siblings’ experience in the context of EDs. The review found that the ED impacts on siblings how they view themselves (Garley & Johnson, 1994) and the world around them (Areemit et al., 2010), with disruption and intrusion onto daily living (Garley & Johnson, 1994) and schoolwork (Latzer et al., 2002). Significantly higher levels of depression were found in siblings with a SED compared to a control group (Latzer et al., 2015), and siblings’ quality of life is adversely impacted by the ED (Areemit et al., 2010). Maladaptive ways of coping were correlated with higher anxiety and depression in siblings (Janik, 2021). Siblings report that the effect of the ED on their lives is inescapable (Areemit et al., 2010), disrupting critical phases of identity formation, and important life events (Grunwald, 2014).

Transitions for example, leaving home to start university or sitting exams may be overshadowed by the ED (Moses, 2013). Siblings report that daily life is taken over by the ED and no time or space is left for the important parts of their lives (Moses, 2013). Siblings are left feeling “sidelined” as they receive less time and attention than their SED (Janik, 2021, p. 55, p. 55)

3.1.1 | Emotional communication in the family

Siblings liken the ED to a destructive force (Jungbauer et al., 2016) and what is broken has to be stuck back together (Grunwald, 2014). Words used to describe the ED are those usually associated with natural disasters,

TABLE 2 Main findings of the studies included in the review taken directly from the articles.

Authors	Quantitative or qualitative	Main findings
(Areemit et al., 2010)	Both	<p>Quantitative results: siblings' average quality of life (QoL), measured by the PedsQL, was above the cut-off point for risk of impaired QoL in all domains and total summary scores. Six siblings scored below the cut-off in various domains (including emotional, social, and school functioning). One sibling scored ≥ 20 on the EAT-26, and female and male participant scores ranged from 0 to 39 and 0–3 respectively (p. 571).</p> <p>Qualitative results: “Struggling to understand the ED” (p. 571); “Acute awareness of ED behaviours and thoughts” (p. 571); “Challenges in understanding non-eating related obsessive behaviours” (p. 571); “increase in family conflicts and arguments” (p. 571); “Compassion and concern for the adolescent with an ED (AED)” (p. 572); “Feelings of loss and sacrifice” (p. 572); “Overwhelming sense of responsibility for the AED” (p. 572); “Pervasiveness of the ED in all aspects of the siblings' life” (p. 572). Duality was interwoven throughout the key themes (p. 571–573).</p>
(Callio & Gustafsson, 2016)	Qualitative	<p>“The adolescent's feelings towards the ill sibling” – <i>“Worry”; “Feelings of anger and irritation”; “Sorrow related to the ill sibling as well as oneself”; “Feelings of shame”; “Joy at being closer”; “The adolescent's perception that the ill sibling had changed since the onset of the ED”</i> – <i>“Changes directly linked to the ED symptoms”; “Mental changes”; “Impact on one's own body image and eating habits”</i> – <i>“Own body image”; “Greater awareness of the significance of food”; “Taking care of oneself”</i> – <i>“Having friends to talk to”; “Maintaining one's everyday life is important but difficult”; “Consequences for the family”</i> – <i>“Everyday life is dominated by mealtimes”; “Experiencing arguments and conflicts”; “Helping out at home”; “Feeling excluded”; “Being involved and not being involved in the ill sibling's treatment”</i> – <i>“Not wishing to be involved”; “Wishing to be involved and informed”</i> (p. 617)</p>
(Dimitropoulos et al., 2009)	Qualitative	<p>“Mediator and protector”; “Familial factors that influence and reinforce the sibling role” – <i>“Denial of the illness”; “Inconsistent familial response to the illness”; “Accommodation and enabling of the ED”; “Parents elicit assistance from non-affected siblings”; “A sense of loyalty and compassion for parents”; “Consequences and benefits of ED to sibling”; “Coping strategies”; “Current and future intentions of caregiving”; “Professional and informal support”</i> (p. 353)</p>
(Fjermestad et al., 2019)	Qualitative	<p>“Anorexia is hard to understand” – <i>“Incomprehensible to begin with”; “Is it the anorexia or my sibling?”; “Lack of information”; “Uncertainty”; “Anorexia evokes difficult emotions”</i> – <i>“Fear”; “frustration”; “Sadness”; “Anorexia affects family dynamics and relations”</i> – <i>“Conflicts and disruptions at home”; “limited and divided family life”; “less attention”; “changed dynamics among children in the family”; “Altered reactions to food”</i> – <i>“Attention to other people's eating habits”; “balanced view on food”; “Conflictual meals”; “Negative experiences as a road to growth”</i> – <i>“Increased knowledge”; “Personal development”; “Ambivalence concerning in-patient treatment”</i> (p. 25)</p>

(Continues)

TABLE 2 (Continued)

Authors	Quantitative or qualitative	Main findings
(Garley & Johnson, 1994)	Qualitative	"Pervasiveness of the illness"; "Intense and conflicted emotions"; "Perspectives of the illness"; "Disruption"; "Role strain"; "Special status"; "Coping with the illness" (p. 159)
(Grunwald, 2014)	Qualitative	"Being affected by the ED; it's everywhere" (p. 136); "Making sense" (p.137) – "Observing" (p. 137); "Accessing information" (p. 138); "It's not her fault: Multifactorial causation" (p. 139); "Being myself" (p. 139)– "I or we?: Finding a role in the family" (p. 139); "I'm less important now" (p. 140); "I can't be me" P. 141); "I'm different" (p. 142); "The perception of others" (p. 142); "I've changed" (p. 142); "Looking after myself" (p. 143); "Avoiding the ED at all costs" (p. 143); "Optimism V Acceptance" (p. 144); "Who can help me?" (p. 144)
(Havard, 2019)	Mixed methods – Qualitative then quantitative	"Inner world": "Making sense of the ED" – "Being 'hit' by the seriousness of the ED"; "The ED as confusing"; "ways to increase understanding"; "Difficult emotions" - "Feeling frustrated"; "Worrying"; "False hope"; "Ways of coping" – "Bottling things up"; "Distraction and escape"; "Staying positive"; "Home and family life": "Changes at home" – "A different and tense environment"; "New rules about what you can say"; "A different person"; "Witnessing distress"; "Being a sibling" – "A unique position"; "Getting all sides of the story"; "Not the priority"; "The sibling relationship"; "Outer world": "Filtering information for 'outsiders'" – "Experiences of telling"; "Reasons not to tell"; "Experiences of treatment" – "Positive experiences"; "less positive experiences" (p. 58). Q-sort task (p. 66): Highest ranking 'most important' themes – "A different and tense environment"; "Witnessing distress"; "Bottling things up"; "Staying positive"; "Distraction and escape"; Highest ranking 'neutral' themes – "Positive experiences of treatment"; "Reasons not to tell"; "Ways of increasing understanding of the ED"; Highest ranking 'least important' themes – "Less positive experiences of treatment"; "New rules about what you can and can't say"; "Not the priority".
(Hutchison et al., 2022)	Qualitative	"Changes as a result of anorexia nervosa" – "Changes in family members"; "Changes in family life"; "Changes in relationships"; "Siblings' role following the development of anorexia nervosa" – "Helping"; "Not troubling others"; "Coping"; "Their needs above yours" – "In the family"; "In services"; "Support for sibling from siblings" (p. 3)
(Janik, 2021)	Both	Quantitative results: At the less than 0.01 level the following variables were significantly related to adaptive coping styles: Self-efficacy, resilience, substance use. At the less than 0.05 level the following variables were significantly related to adaptive coping styles: Anxiety, depression, extraversion. At the less than 0.01 level the following variables were significantly related to maladaptive coping styles: Perseverance, anxiety, depression, resilience, substance use, and conscientiousness (p. 21). At the less than 0.05 level self-efficacy was the only variable significantly related to maladaptive coping styles (p. 22). Qualitative results: "Familial role"; "Support"; "Coping strategies"; "Personal impact"; "Involvement"; "Forgotten siblings"; "Love"; "Responsibility"; "Professional treatment" (p. 25)

TABLE 2 (Continued)

Authors	Quantitative or qualitative	Main findings
(Jungbauer et al., 2016)	Qualitative	“Relationship to the affected sister” (p. 81); “Burdens due to the ED” (p. 81); “Impact on the siblings’ body image” (p. 82); “The effects on family life” (p. 82); “Positive aspects, learning experiences and meaningfulness” (p. 83); “Support needs and experiences with helping professionals” (p. 83).
(Karlstad et al., 2021)	Qualitative	“Put your own oxygen mask on first” (p. 4); “Taking a new role” (p. 4); “Distancing” (p. 5); “Adapting care” (p. 5).
(Latzner et al., 2002)	Qualitative	“Structural processes” (p. 277); “Family dynamic processes” (p. 277); “Emotional processes” (p. 277); “Change in life functions” (p. 279); “Body image” (p. 279); “Narrative of the illness” (p. 279).
(Latzner et al., 2015)	Quantitative	Significantly higher levels of depression and negative relationships among participants with a sister with an ED (study group) than in the control group. No significant difference between the two groups in levels of psychological distress, sense of coherence, or positive relationships. In the study group a negative correlation was found between the positive and negative sibling relationships, this was not found for the control group. Also, negative sibling relationships were more correlated with psychological distress and depression for the study group than for the control group. Negative sibling relationships were negatively correlated with psychological distress and depression for the control group but not the study group. There was a negative correlation between sense of coherence, psychological distress, and depression in both groups, but this was stronger in the study group than in the control group. The higher the sense of coherence, the lower the sense of psychological distress; and the more negative characteristics in the sibling relationship, the higher the level of psychological distress in both groups. The presence of a sister with an ED predicts higher levels of depression in the sister without an ED. The more negative the sibling relationship the higher the level of depression; and the higher the sense of coherence, the lower the level of depression in both groups. A high level of coherence significantly reduced the influence of the ED on the level of depression in sisters without an ED.
(Moses, 2013)	Qualitative	“Making sense of it all” – “Developing understanding” ; “Getting information” ; “A broader context” ; “Home’s not how I remember” – “The main focus” ; “Impact on parents” ; “Changed relationships” ; “It impacts me too” – “Pervasiveness” ; “New roles and responsibilities” ; “Deep feelings but sometimes contradictory” ; “To talk or not to talk?” – “Hearing and being heard” ; “Difficult talk” ; “Life goes on” – “Separate lives” ; “It’s my life, it’s now or never” (p. 43).
(Persico et al., 2021)	Qualitative	“AN explained by siblings” (p. 5) – “It is like imprisonment” (p. 5); “There is a need to self-harm” (p. 5); “It never gets completely better” (p. 5); “The siblings’ individual emotional experiences” (p. 5) – “We do not understand why” (p. 5); “We are powerless” (p. 5); “We feel angry” (p. 5); “The siblings’ family experiences” (p. 5) – “It is hard for the parents” (p. 5); “We try to help” (p. 6); “We keep our distance” (p. 6); “We have to stay out of it, without leaving them completely in the dark” (p. 6); “Experience inside the “sibling group” (p. 6) – “We are able to express things” (p. 6); “Attending the group sessions enables us to keep our distance and provide help at the same time” (p. 6); “Fear, sadness and difficulty talking, but also happiness” (p. 6); “We want to talk about subjects that we may not have thought about” (p. 6).

(Continues)

TABLE 2 (Continued)

Authors	Quantitative or qualitative	Main findings
(Quish, 2010)	Qualitative	<p>“Discovery of sibling’s illness” (p. 25) – <i>“Changes in eating behaviour”</i> (p. 25); <i>“Physical changes”</i> (p. 26); <i>“Emotional changes”</i> (p. 27); Emotional responses towards sibling’s illness (p. 27)– <i>Initial feelings in response to sibling’s illness</i> (p. 27); <i>“Changes in feelings overtime”</i> (p. 31); <i>“Attitude towards food affected by sibling’s ED”</i> (p. 32); “Behavioural responses to sibling” (p. 34); “Family environment” (p. 35); <i>“Experience living with sibling”</i> (p. 35); <i>“Perception of parental responses to their child’s ED”</i> (p. 36); <i>“Perception of sibling responses”</i> (p. 37); <i>“Coping mechanisms utilised by siblings”</i> (p. 38); “Advice for mental health clinicians” (p. 39).</p>
(Renfrew Frigon, 2021)	Qualitative	<p>“View of the family” – <i>“Exposure to conflict and distress”</i>; <i>“Experiences with anorexia as traumatic”</i>; <i>“well’ versus ‘unwell’ identities”</i>; “Role change among ‘well’ siblings” – <i>“Caregiver role”</i>; <i>“Protector/mediator role”</i>; <i>“Avoider role”</i>; <i>“Role change as adaptive”</i>; “Coping through the illness” – <i>“Healing as a family”</i>; <i>“Access to services and support”</i>; <i>“Needs as ‘well’ siblings”</i> (p. 53)</p>
(Scutt et al., 2022)	Qualitative	<p>“Eating difficulties were influenced by sibling’s AN” – <i>“Emotionally charged mealtimes at home”</i>; <i>“Comparison and competition”</i>; <i>“Increased focus on body image and diet”</i>; “Changing eating patterns to manage difficult emotions” – <i>“Feeling responsible for a sibling with AN”</i>; <i>“Restricting eating to manage emotions”</i>; <i>“Traumatic experiences increasing the need for control”</i>; “Systemic pressure to be thin” – <i>“Family beliefs about diet and body size”</i>; <i>“The thin ideal”</i>; “Finding appropriate support was difficult for participants” – <i>“Being the well sibling”</i>; <i>“Difficulties getting support”</i>; <i>“Types of support that may have helped”</i> (p. 5)</p>
(Twardowski-Deskin, 2022)	Qualitative	<p>“Progression of sister relationship” – <i>“Relationship before diagnosis”</i>; <i>“Relationship directly after diagnosis”</i>; <i>“Relationship now”</i>; “Identity formation” – <i>“View of self”</i>; <i>“Insecurities”</i>; <i>“Confidentiality”</i>; “Family systems” – <i>“Role in family”</i>; <i>“Expectations of family”</i>; <i>“Family dynamics”</i>; “Experience of bulimia nervosa” – <i>“Discovery of bulimia nervosa”</i>; <i>“Impact of bulimia nervosa on participant”</i>; <i>“Experience of bulimia nervosa now”</i>; “Experience of meals” – <i>“Experience of food in family”</i>; <i>“Experience of meals after diagnosis”</i>; “Perception of the treatment process” – <i>“Participant impression of sister undergoing treatment”</i>; <i>“Participant engagement in sisters treatment”</i>; <i>“Discussion of treatment with sister”</i>; <i>“Perception of father’s view of treatment”</i>; <i>“Discussion of mother’s view of treatment”</i>; <i>“Siblings’ view of treatment”</i>; <i>“View of participation in treatment now”</i>; <i>“Sister’s participation in treatment now”</i>; “Participant’s support structures” (p. 131)</p>
(Varnell, 2014)	Qualitative	<p>“Sibling identity” – <i>“Who am I and what is my role?”</i>; <i>“Who do I want to be? Reflection on the impact on ‘self’”</i>; “The vulnerable social ‘self’” – <i>“Experience of disclosure, stigma and evaluation of social relationships”</i>; “Intra- and Inter-personal coping” – <i>“Self-coping”</i>; <i>“The use of ‘others’ as support”</i>; <i>“The use of professional support?”</i> (p. 54)</p>
(Withers et al., 2014)	Qualitative	<p>“The sibling relationship” (p. 56); “Knowledge of AN” (p. 57); “Time-out’ from AN” (p. 57); “Emotional supports” (p. 58); “Involvement in treatment” (p. 59) – <i>“Understanding AN and having a role”</i> (p. 59); <i>“Better communication in the family”</i> (p. 59); <i>“Difficulties with Family Based Therapy (FBT)”</i> (p. 60).</p>

Note: Bolded text indicates main themes and italicised text indicates subthemes taken directly from the articles included in the review as set out in the original papers.

TABLE 3 Characteristics of the studies.

Author(s) (publication year and country)	ED subtype and how defined	Design	Participants (<i>N</i> , age, gender, race, ethnicity, and socioeconomic status, where reported)	SED age and gender	Research Instruments	Quality assessment score	Treatment status of SED
Aremit et al. (2010), Canada	AN (<i>N</i> = 13) EDNOS (<i>N</i> = 4)	Cross-sectional	<i>N</i> = 20 Age: 10–16 30% male, 70% female.	11–17, 11.76% male, 88.24 female	General assessment questionnaire (demographic information, if having a SED affected QoL, relationship with SED and QoL before and after onset of ED. Paediatric quality of life inventory 4.0 generic core scales (PedsQL; [Varni et al., 1979]); Eating Attitude Test-26 (EAT-26; [Garner, 2004]); parents completed a questionnaire describing demographic characteristics of the family and SED; semi- structured focus group interview schedule.	32	Not reported
Callio and Gustafsson (2016), Sweden	Not reported	Cross-sectional, small-scale pilot study	<i>N</i> = 5 Age: 15–20, 3 male, 2 female	Not reported	Interview guide	28	Recruited from a specialist treatment unit
Dimitropoulos et al. (2009), Canada	AN	Cross-sectional	<i>N</i> = 12 Age: <i>M</i> = 25.6, <i>SD</i> = 7.85	Age: <i>M</i> = 25.4, <i>SD</i> = 7.34	Semi-structured interview schedule	32	Recruited from an in- patient ED programme
Fjermestad et al. (2019), Norway	AN	Cross-sectional, retrospective (3–6 years post admission)	<i>N</i> = 13 Age: 12–23, 10 girls, 3 boys from 10 families	At admission: 5–169 females, 1 male	Interview guide	31	SED was an in-patient at a regional specialist inpatient clinic from 2008 to 2014

(Continues)

T A B L E 3 (Continued)

Author(s) (publication year and country)	ED subtype and how defined	Design	Participants (<i>N</i> , age, gender, race, ethnicity, and socioeconomic status, where reported)	SED age and gender	Research Instruments	Quality assessment score	Treatment status of SED
Garley and Johnson (1994), Canada	AN	Cross-sectional	<i>N</i> = 5 Age: 15–18, all female	14–17, all female	N/A	31	SED was attending an ED clinic
Grunwald (2014), United Kingdom	All AN with 1 possibly also BN	Cross-sectional	<i>N</i> = 8 Age: 14–17, 1 male, 7 female, white British <i>N</i> = 3, white <i>N</i> = 1, white Irish <i>N</i> = 1, white Caucasian <i>N</i> = 2, mixed <i>N</i> = 1	N/R for ages, all females	Semi-structured interview schedule	32	Not reported
Havard (2019), England	AN	Sequential exploratory	<i>N</i> = 12 (11 returned for Q- sort task) Age: 11–21, 7 female, 5 male (2 sets of participants had the same unwell sibling, white British <i>N</i> = 12	11–17, 9 female, 1 male	Demographic questionnaire; semi- structured interview schedule; grid for Q-sort task	32	SEDs were receiving treatment from specialist ED teams
Hutchison et al. (2022), England	AN or related restrictive EDs	Cross-sectional	<i>N</i> = 14 Age: 11–19, 6 male, 8 female	13–18, all female	Flexible, semi-structured topic guide	31	Recruited through the Maudsley centre for child and Adolescent eating disorders (MCCAED)

TABLE 3 (Continued)

Author(s) (publication year and country)	ED subtype and how defined	Design	Participants (N, age, gender, race, ethnicity, and socioeconomic status, where reported)	SED age and gender	Research Instruments	Quality assessment score	Treatment status of SED
Janik (2021), America	Not reported	Cross-sectional	<p><u>Survey:</u> N = 95</p> <p>Age: 18–62, 64 male, 31 female, ethnicity: 67.4% white, others identified as Black or African American, Asian, American Indian or Alaska Native or Prefer not to say¹</p> <p>Follow-up interviews: N = 3</p> <p>Age: 18–24, all female, all white</p>	Not reported	Beck anxiety inventory (BAI [Beck, Steer, & Carbin, 1988]); patient health questionnaire – 9 (PHQ-9 [Kroenke et al., 2001]); GRIT-S scale (Duckworth & Quinn, 2009); Generalised Self-efficacy scale (Schwarzer & Jerusalem, 1995); brief resilient coping scale (Sinclair & Wallston, 2004); drug abuse screening test-10 (Skinner, 1982); big five Inventory-10 (BFI-10 [Rammstedt & John, 2007]); brief COPE (Carver, 1997); Semi-structured interview guide.	27	Not reported
Jungbauer et al. (2016), Germany	AN	Explorative, Cross-sectional	<p>N = 16</p> <p>Age: 12–52, 12 sisters, 4 brothers, German Nationals N = 16</p>	15–46, all female	Socio-demographic questionnaire, interview guide	33	Does not specify if SED is still in treatment but recruitment was mainly through institutions and professionals with regular contact with females with AN

(Continues)

TABLE 3 (Continued)

Author(s) (publication year and country)	ED subtype and how defined	Design	Participants (N, age, gender, race, ethnicity, and socioeconomic status, where reported)	SED age and gender	Research Instruments	Quality assessment score	Treatment status of SED
Karlstad et al. (2021)	AN (N = 6), BN (N = 2)	Cross-sectional	N = 10, 3 male, 7 female from 8 families, age: 21- 31	N = 10Age: 20-30	Semi-structured interview schedule	33	All had received in-patient or out-patient treatment at some point, and some were still being treated. Recruited from ED and general psychiatrists' units and user organisations for patients with EDs
Latzer et al. (2002), Israel	AN	Cross-sectional	N = 9 Age: 11–18, all female (younger sister closest in age to SED)	N/R for ages, all females	Semi-structured interview schedule	26	SED was being treated in an ED clinic
Latzer et al. (2015), Israel	AN (N = 10), BN (N = 10); DSM- IV-TR	Cross-sectional	N = 60 Age: 13–31 control group - 30 females who had sisters without EDs (M = 21.67, SD = 4.48). 30 females with sisters with ED (M = 21.70, SD = 3.91), Israeli N = 60	N/R for ages, all females	Beck depression inventory (BDI; [Beck et al., 1961, 1988]); brief symptom inventory (BSI; [(Derogatis & Melisaratos, 1983)]; sibling relationship questionnaire (Furman & Buhrmester, 1985); the sense of coherence questionnaire (Antonovsky, 1987, 1998)	31	SED had made an initial application for treatment within the previous 2 years to three major ED clinics.
Moses (2013), England	AN (N = 5), EDNOS (N = 1)	Cross-sectional	N = 6 Age: 11–18, all female, white British N = 4, British Pakistani N = 2	11–24, all female	Interview guide	35	Recruited from in-patient and out-patient services

TABLE 3 (Continued)

Author(s) (publication year and country)	ED subtype and how defined	Design	Participants (<i>N</i> , age, gender, race, ethnicity, and socioeconomic status, where reported)	SED age and gender	Research Instruments	Quality assessment score	Treatment status of SED
Persico et al. (2021), France	AN	Exploratory	<i>N</i> = 7 Age: 6–19, 4 males, 3 females	N/R for ages and gender	Socio-demographic data sheet; semi-structured interview guide for focus groups; two ludic group activities - emoji cards and a wish list to help participants clarify and voice their ideas.	31	Currently being treated at a particular hospital
Quish (2010), America	Subtype not reported; DSM- IV	Cross-sectional	<i>N</i> = 10 (2 females from the same family and 2 males from the same family) Age: 20–38, 6 female, 4 male, Caucasian <i>N</i> = 10, Irish <i>N</i> = 3, Scottish decent <i>N</i> = 2, Scandinavian <i>N</i> = 2, German descent <i>N</i> = 1, Jewish <i>N</i> = 1	17–45, all female	Semi-structured interview schedule	32	Eight participants had a SED who were actively suffering from an ED, two participants had a SED in recovery
Renfrew Frigon (2021), Canada	AN	Retrospective, exploratory	<i>N</i> = 5, 4 female, 1 non- binary/female Age: 21–64 (at time of interviews) Ethnicity: All white	<i>N</i> = 5, gender not reported Age: 24–67 (at time of interviews)	Semi-structured interview guide	34	Not reported
Scutt et al. (2022), England	AN	Reflexive thematic analysis methodology	<i>N</i> = 11, 2 male, 9 female Age: 21–33 Ethnicity: All white Country or residence: <i>N</i> = UK, <i>N</i> = New Zealand, <i>N</i> = South Africa, <i>N</i> = Ireland	<i>N</i> = 11, all female Age: not reported	Semi-structured interview guide	35	Not reported

(Continues)

TABLE 3 (Continued)

Author(s) (publication year and country)	ED subtype and how defined	Design	Participants (N, age, gender, race, ethnicity, and socioeconomic status, where reported)	SED age and gender	Research Instruments	Quality assessment score	Treatment status of SED
Twardowski- Deskin (2022), America	BN	Case studies	N = 2, all female Age: 24 and 63, both Caucasian	N = 2, all female Age: 22 and 55 (approximately at the time of the interviews)	Semi-structured interview guide; sentence completion series-adult	28	Not reported
Varnell (2014), England	BN (N = 2), EDNOS (N = 6)	Cross-sectional	N = 8 Age: 12–19, 4 male, 4 female	12–18, 1 male, 7 female	Semi-structured interview schedule	35	SED was accessing child and adolescent mental health services
Withers et al. (2014), Australia	AN	Cross-sectional	N = 20 Age: 12–18, 5 male, 15 female	14–24 gender unknown	Semi-structured interview schedule	29	SED currently receiving treatment

such as, “devastation”, chaos, and stress (Quish, 2010, p. 35). Siblings spoke of the “warzone” the ED causes, likening it to extreme conflict and ruin (Varnell, 2014, p. 66). The home environment becomes less happy (Havard, 2019) but siblings may not share their distress as they are concerned about adding more strain on their parents (Fjermestad et al., 2019).

Communication between siblings and their SED becomes more limited and restricted (Areemit et al., 2010). Siblings become cautious about what topics can be spoken about (Persico et al., 2021) in order to reduce conflict (Karlstad et al., 2021) as some topics become off limits (Grunwald, 2014). Siblings may be more sensitive to language related to body shape and size and feel angry when people use words like “fat” and “diet” (Areemit et al., 2010, p. 571).

3.1.2 | Attitudes towards food and body image.

The presence of an ED within a family changes the way all members view food (Fjermestad et al., 2019), and impacts siblings' food choices (Areemit et al., 2010; Scutt et al., 2022), and eating behaviours (Areemit et al., 2010; Garley & Johnson, 1994). There is a greater emphasis on food (Fjermestad et al., 2019) and siblings are more aware of their food and diet choices which extends to how this would affect their SED (Quish, 2010).

Female siblings experienced feelings of being watched and judged by their SED (Hutchison et al., 2022). Some siblings reported being made to eat to set a good example for their SED to the extent of over-eating (Scutt et al., 2022), and developing disordered eating behaviours themselves (Quish, 2010). Others reported mirroring their SEDs' behaviours to maintain a close connection (Quish, 2010). One participant shared that their SED actively encouraged them to engage in disordered eating behaviours (Twardowski-Deskin, 2022). Other siblings made moral judgements about food as good or bad and something you earn, treat, or reward yourself with prompting them to be careful about their relationship with food and body image (Fjermestad et al., 2019).

3.2 | Difficulty expressing emotions

Siblings struggled to voice their experiences and communicate their feelings (Moses, 2013; Persico et al., 2021). Siblings fear sharing their experiences with others as it is often perceived negatively by the family unit, including their SED (Moses, 2013).

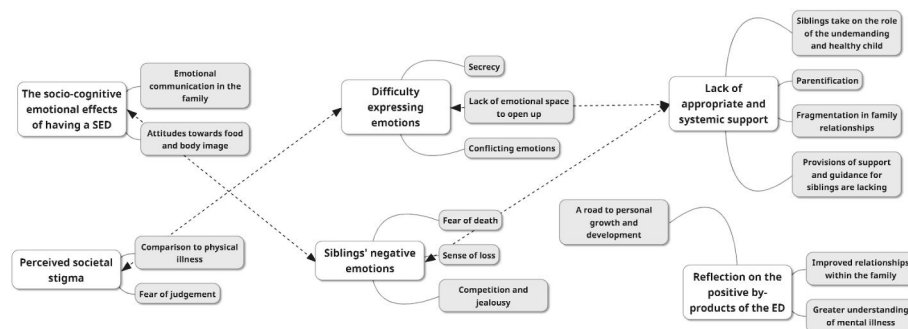


FIGURE 2 Thematic Map of themes and sub-themes. The thematic map illustrates the themes and sub-themes yielded from the thematic synthesis. Dashed arrows show the links between themes.

3.2.1 | Secrecy

In some families, their SED's ED was conceptualised as a secret to be hidden (Varnell, 2014). Some siblings explained that this was because their SED was ashamed (Withers et al., 2014). However, others expressed that their situation was scary and they did not want to talk about it (Withers et al., 2014). Many siblings explained that their parents were reluctant to ask for help or to discuss the ED outside of the family, wanting to pretend that everything was okay (Quish, 2010). This secrecy limited their friendships and inhibited their social growth (Areemit et al., 2010; Havard, 2019; Varnell, 2014).

3.2.2 | Lack of emotional space to open up

Siblings have concerns about the ED on other family members (Dimitropoulos et al., 2009). Siblings reported being grateful to be given the opportunity to speak openly and share their worries (Varnell, 2014).

3.2.3 | Conflicting emotions

Siblings experience conflicting feelings about their SED's ED (Havard, 2019; Latzer et al., 2002; Persico et al., 2021; Quish, 2010; Varnell, 2014); on the one hand, they feel love and compassion for their SED but also anger and frustration (Areemit et al., 2010). They fluctuate between the belief that their SED is behaving this way on purpose, and using the ED for attention, but they may also recognise that their sibling is powerless to change their behaviours (Areemit et al., 2010). Conflicting emotions are a key part of the siblings' experiences.

3.3 | Lack of appropriate and systemic support

Unfortunately, the impact of the ED on siblings is often neglected (Varnell, 2014), and siblings feel less important than their SED (Havard, 2019), as though everything is happening around them rather than with them (Grunwald, 2014). Within and outside the family all the time and attention were dedicated to the SED (Callio & Gustafsson, 2016; Fjermestad et al., 2019; Hutchison et al., 2022; Jungbauer et al., 2016; Karlstad et al., 2021; Moses, 2013; Quish, 2010; Renfrew Frigon, 2021) leaving siblings feeling neglected and overshadowed by their SED (Grunwald, 2014; Jungbauer et al., 2016; Moses, 2013). Talk about their homework, social life, and exams was minimised in contrast to what their SED was going through (Grunwald, 2014; Hutchison et al., 2022). Participants expressed a need for parenting (Grunwald, 2014). Many noted that important moments in their lives go unnoticed as though their parents do not care about them (Moses, 2013). One participant expressed "... as a young person, you don't have the resources to get through something like that. How do you survive it? I don't know" (Renfrew Frigon, 2021, p. 68).

3.3.1 | Siblings take on the role of the undemanding and healthy child

Three studies noted that they minimise their distress in order to alleviate their parents' worry and concern for them (Garley & Johnson, 1994; Grunwald, 2014; Havard, 2019; Janik, 2021; Karlstad et al., 2021; Twardowski-Deskin, 2022). Often they suffer in silence so as not to burden others; they do not see themselves as needing support but rather as the caregiver and healthy sibling (Renfrew Frigon, 2021). Siblings frequently make

sacrifices on behalf of their SED (Renfrew Frigon, 2021), such as restricting their social activities and not seeing their friends to please their sibling (Callio & Gustafsson, 2016). Notably, one sibling explained that they may be physically healthier than their SED but not necessarily healthier in terms of their mental health as they were also living through and witnessing trauma (Renfrew Frigon, 2021).

3.3.2 | Parentification

Siblings are often expected to be mature, independent, and take on more responsibilities than is normally expected at that age (Jungbauer et al., 2016). Siblings express feelings of duty and obligation often with a reversal of roles within the family whereby younger siblings take on the role of the older sibling (Jungbauer et al., 2016). Siblings are often conflicted in their loyalties to their SED and parents (Areemit et al., 2010) this may include gathering information and reporting back to parents, which was compared to acting as a spy and gathering intel (Varnell, 2014).

3.3.3 | Fragmentation of family relationships

In some families, siblings considered themselves as the only source of support for their SED (Dimitropoulos et al., 2009; Scutt et al., 2022) because their parents minimised or denied the ED (Dimitropoulos et al., 2009). Concerns about what they perceived as neglect (Quish, 2010) led them to serve as a protector for their SED (Dimitropoulos et al., 2009).

3.3.4 | Provisions of professional support and guidance for siblings are lacking

Many siblings reported dissatisfaction with professional support (Jungbauer et al., 2016). Some reported feeling forced into engaging with services that they did not want to be in contact with (Grunwald, 2014) whereas others were not included in treatment or family therapy or well informed about the ED (Jungbauer et al., 2016). Some expressed a wish to be given practical tips about providing support and more information about the illness and guidance so they can be more confident in helping their SED (Jungbauer et al., 2016). Siblings may seek reassurance that they are doing their best and there is nothing more they can do, they are not to blame for the ED and are not responsible for their SEDs' recovery (Dimitropoulos et al., 2009).

3.4 | Perceived societal stigma

Siblings are aware of the stigma surrounding EDs with many people blaming the family for the ED (Grunwald, 2014), which becomes a barrier to disclosure. Siblings experience judgement, negative attitudes, and shame and embarrassment at disclosure (Varnell, 2014). Many in society assume that recovery is easy and just a question of eating more (Moses, 2013). Siblings expressed a need for society to understand what it is truly like to have a family member with an ED (Renfrew Frigon, 2021).

3.4.1 | Comparison to physical illness

Siblings reported on a lack of understanding about mental health (Varnell, 2014) and considered that people would be more supportive if it was a physical or visible illness with effective and proven treatment (Moses, 2013).

3.4.2 | Fear of judgement

Siblings expressed concerns about how other people would react. Fear of judgement or feeling as though they are contaminated by the ED prevents them from relying on their friends as confidants (Varnell, 2014).

3.5 | Siblings' negative emotions

Siblings described an increase in negative emotions, such as tension (Latzner et al., 2002) and turmoil stemming from the ED (Persico et al., 2021). Compulsive behaviours evoke many difficult feelings, such as embarrassment, weariness, and sadness (Areemit et al., 2010) but siblings question their right to feel angry at their situation (Garley & Johnson, 1994) and specific features of the illness such as rigid behaviours and obsessions (Fjermestad et al., 2019), and often downplay their negative emotions when relaying their experiences (Havard, 2019).

3.5.1 | Fear of death

Many siblings report that their lives are plagued with worry and concern about the life-threatening weight loss and the risk of suicide (Jungbauer et al., 2016). They describe themselves as witnessing a gradual death with their SED slowly wasting away in front of them (Quish, 2010; Scutt et al., 2022) and experiencing a profound sense of loss.

3.5.2 | Sense of loss

Siblings experience loss and abandonment in many areas of life due to the ED, they feel that they have lost their SED as a sibling (Fjermestad et al., 2019; Renfrew Frigon, 2021) and friend (Fjermestad et al., 2019; Garley & Johnson, 1994; Varnell, 2014). They report a loss of contact (Jungbauer et al., 2016) and closeness with their SED (Areemit et al., 2010). Accordingly, siblings report a lack of normality (Varnell, 2014) and a loss of identity (Areemit et al., 2010; Garley & Johnson, 1994; Grunwald, 2014), they are only seen as a sibling of (Areemit et al., 2010; Garley & Johnson, 1994), and in relation to, their SED yet they still want to be seen and treated as themselves (Grunwald, 2014). Siblings endure grief and a loss of joviality, happiness, and closeness within the family (Jungbauer et al., 2016). They mourn their childhood (Areemit et al., 2010; Varnell, 2014), their role as a child in the family, and being looked after by their parents (Varnell, 2014) as they face a loss of parental attention (Jungbauer et al., 2016). Siblings also report a loss of time spent as a family doing nice things together and going away as the ED and their SED's food concerns restrict activities as a family (Callio & Gustafsson, 2016).

3.5.3 | Competition and jealousy

Some siblings reported feeling a sense of competition and jealousy over their SEDs' weight loss (Quish, 2010), which may exacerbate siblings' own struggles with weight (Quish, 2010). They constantly compare themselves with their SED and struggle to see themselves positively (Areemit et al., 2010).

3.6 | Reflection on the positive by-products of the eating disorder

Some siblings were able to reframe the illness and to note opportunities for learning and post-traumatic growth.

3.6.1 | A road to personal growth and development

Many siblings described personal growth and development resulting from the experience (Areemit et al., 2010; Dimitropoulos et al., 2009; Fjermestad et al., 2019; Garley & Johnson, 1994; Grunwald, 2014; Havard, 2019; Jungbauer et al., 2016; Karlstad et al., 2021; Varnell, 2014) with an increase in positive attributes (Fjermestad et al., 2019; Varnell, 2014). Some siblings noted that they

were better able to reprioritise their values (Fjermestad et al., 2019; Jungbauer et al., 2016) and see the importance of family, experiencing more respect for and connection with their family members (Fjermestad et al., 2019). Others saw the ability to prioritise others over themselves as a positive as they do not always need to be the centre of attention (Jungbauer et al., 2016). The experience has also led to become them more mature (Garley & Johnson, 1994; Grunwald, 2014), empathetic, tolerant (Garley & Johnson, 1994), independent (Karlstad et al., 2021), and understanding of others (Fjermestad et al., 2019). They also noted an increase in confidence, strength, and resilience (Areemit et al., 2010; Grunwald, 2014; Varnell, 2014). Some also noted that they were better able to set boundaries and prioritise and recognise the importance of their own health and well-being (Jungbauer et al., 2016).

However, one participant did reflect on whether the growth they experienced was due to the ED or due to normal growth and development, and whether this is the person they would have turned out to be even without the ED "...I don't know if that's just the way that I am, like before it happened, if I was destined to be that way, or if it's because of how things were then." (Grunwald, 2014, p. 143).

3.6.2 | Improved relationships within the family

Another positive outcome of the ED is stronger and closer familial relationships (Areemit et al., 2010; Callio & Gustafsson, 2016; Fjermestad et al., 2019; Hutchison et al., 2022; Latzer et al., 2002; Varnell, 2014; Withers et al., 2014). Communication is more open and honest, and the family spends more time together (Fjermestad et al., 2019) and siblings believe that family bonds have now become stronger (Withers et al., 2014). They report a closer relationship with their parents (Areemit et al., 2010; Grunwald, 2014), particularly following their SED's recovery (Grunwald, 2014). Similarly, siblings report a closer sibling relationship with their SED (Callio & Gustafsson, 2016; Havard, 2019; Latzer et al., 2002; Moses, 2013; Scutt et al., 2022) which is also more supportive (Scutt et al., 2022). They spend more time together, take better care of each other (Callio & Gustafsson, 2016), and experience an increase in communication and joviality with their SED as a result of the ED (Havard, 2019). Likewise, siblings tell of a better sibling relationship with their other siblings in the family and the family is a source of support for them (Moses, 2013). However, some express regret and sadness over the reason for and the way in which these relationships were

strengthened (Dimitropoulos et al., 2009) as the family had to live through the ED of a loved one for this to happen.

3.6.3 | Greater understanding of mental illness

Many siblings noted their increased understanding of mental illness (Janik, 2021; Jungbauer et al., 2016) and their sensitivity to triggers so they ensure they listen when someone needs support and act quickly before things escalate (Callio & Gustafsson, 2016; Janik, 2021).

4 | DISCUSSION

This paper aimed to systematically review and synthesise the literature pertaining to siblings' experiences of having a brother or sister with an ED. Twenty-one studies were eligible for inclusion. To the authors' knowledge, this is the first systematic review focused on siblings' experiences without being limited by specific search terms, such as levels of psychopathology and coping strategies (Maon et al., 2020). By searching a larger number of databases, we have expanded upon the most recent systematic review in this area (Maon et al., 2020) and added to our understanding of siblings' experiences of having a brother or sister with an ED.

The analysis of these reports suggested that there needs to be a greater focus on the needs of siblings of people with EDs. Some themes were shared with family members' experiences of having a relative with other chronic illnesses and included a lack of appropriate and systemic support (Batchelor et al., 2022; Cribben et al., 2021; Fletcher et al., 2021; Frierson, 2012; Sanders et al., 2014; Sin et al., 2014), perceived societal stigma (Abrams, 2009; Fletcher et al., 2021; Frierson, 2012), and parentification (Beffel et al., 2023; Boumans & Dorant, 2018; Frierson, 2012; Lukens et al., 2004; McDaniel & Pisani, 2012).

Other themes such as that relating to competition and jealousy appeared to be unique to EDs. They arise from the perception that EDs are viewed as a choice made to obtain perceived benefits because some of the symptoms and the traits that might underpin them are considered desirable and admired (Roehrig & McLean, 2010). Most studies that supported this theme included SEDs with anorexia nervosa (Areemit et al., 2010; Jungbauer et al., 2016; Scutt et al., 2022), one of which also included SEDs with ED not otherwise specified (Areemit

et al., 2010), one did not report the ED subtype (Quish, 2010), and one was focused on bulimia nervosa (Twardowski-Deskin, 2022). As such, it seems that competition and jealousy may be more prominent when the SED has anorexia nervosa, although this could be because most studies only focused on anorexia nervosa so this notion cannot be confirmed. However, this theme was also found in studies focused on ED subtypes other than AN.

At least 16 of the studies were related to anorexia nervosa (some did not report the ED subtype) but there did not appear to be any differences in sibling experiences and the themes based on the ED subtype. The only apparent differences were the ED-related behaviours that were witnessed, for example, restricting in AN, and bingeing or evidence of purging in BN.

4.1 | Limitations

Due to the paucity of quantitative research in this area, a meta-analysis was not possible as there was not enough information to calculate effect sizes (Cheung & Vijayakumar, 2016). Additionally, within the four studies including quantitative data, there was heterogeneity in the measures used, as there is no one standardised measure, highlighting the need for more research, particularly quantitative, in this area, and a standardised measure to assess siblings' experiences.

The review highlights methodological limitations in the extant literature in this area. The scope of sampling in the included studies was very limited regarding the representation of different ED subtypes. Out of the 21 studies included in the review, only seven included siblings of SEDs with an ED other than AN, and five of these also included SEDs with AN in their sample. The lack of studies investigating the effects of other ED categories prevents comparison of the unique effect of each ED subtype on siblings (Maon et al., 2020). Although there is often overlap in clinical features of many EDs, they are distinct disorders, hence are likely to lead to different experiences for siblings caring for their SED (Perkins et al., 2004).

Moreover, nine studies did not report the race and ethnicity of the participants and none reported socioeconomic status; yet EDs can affect individuals of any race, ethnicity, and socioeconomic status (Schaumberg et al., 2017). This lack of detail poses a limitation, inhibiting investigation of any potential salient differences in siblings' experiences across different racial, ethnic, and socioeconomic groups. These limitations

imposed restrictions on the current review as it did not allow comparisons regarding siblings' experiences as a function of siblings' age, gender, or their SED's ED diagnosis to be made.

4.2 | Theoretical and clinical implications

The current review highlights the increased risks siblings possess, and this knowledge can be used to aid in early detection and prevention of symptoms in siblings. Professionals must be proactive in identifying siblings' needs and offering support (Maon et al., 2020; Varnell, 2014). Additionally, caregivers and parents should be educated about siblings' needs so they can help and support siblings and increase their involvement in treatment. Although clinical guidelines and standards now recognise the need to provide information and support for carers, these findings suggest that this may need to be tailored to the specific needs of sibling caregivers. Future work should use co-production to empower siblings and voice their experiences, ensuring these interventions are appropriate and well-suited to their intended audience.

Siblings stress the importance of professionals recognising the ED's disruptive and stressful impact (Quish, 2010). The findings could be used to help transform and inform more inclusive ED intervention models that accommodate siblings' needs. One-size-fits-all approaches have not been successful in education (Weis et al., 2016) and medicine (Schee genannt Halfmann et al., 2017) as they do not fit all needs, for example, siblings will have diverse needs based on the ED subtype of their SED. As such, it is of utmost importance to consider and promote the individual characteristics of everyone that can be affected by a range of clinical (e.g., diagnosis) and social (e.g., socioeconomic) factors. Such approaches have been successfully implemented in other ED clinical work such as within care for young people with EDs (Babb et al., 2021; Mitrofan et al., 2019; Robinson et al., 2020).

4.3 | Conclusions

This systematic review has illustrated the various ways that siblings are impacted when a co-sibling develops an ED. Their lives are affected in many ways including attitudes towards food and body image, parentification, and fragmentation in family relationships. Moreover, the secrecy, stigma shame, and fear of contagion associated with an ED limit access to social support. It is hoped that this review will highlight the needs and experiences of siblings and direct future research into navigating their specific needs.

For example, there is limited research on the experiences of siblings with a SED who has BN or BED.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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ENDNOTE

¹ No exact percentages were reported for ethnicities other than white and could not clearly be ascertained from the chart provided.

REFERENCES

- Abrams, M. S. (2009). The well sibling: Challenges and Possibilities. *American Journal of Psychotherapy*, 63(4), 305–317. <https://doi.org/10.1176/appi.psychotherapy.2009.63.4.305>
- American Psychiatric Association, A. P. (2013). *Diagnostic and Statistical Manual of mental disorders (DSM-5®)*. American Psychiatric Publishing.
- Anastasiadou, D., Medina-Pradas, C., Sepulveda, A. R., & Treasure, J. (2014). A systematic review of family caregiving in eating disorders. *Eating Behaviors*, 15(3), 464–477. <https://doi.org/10.1016/j.eatbeh.2014.06.001>
- Antonovsky, A. (1987). *Unraveling the mystery of health: How people manage stress and stay well* (p. 218). Jossey-Bass.
- Antonovsky, A. (1998). The sense of coherence: A historical and future perspective. In *Stress, coping, and health in families: Sense of coherence and resiliency* (pp. 3–20). Sage Publications, Inc.
- 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. <https://doi.org/10.1016/j.jadohealth.2009.12.011>
- Babb, C., Brede, J., Jones, C. R. G., Elliott, M., Zanker, C., Tchanturia, K., Serpell, L., Mandy, W., & Fox, J. R. E. (2021). 'It's not that they don't want to access the support...it's the impact of the autism': The experience of eating disorder services from the perspective of autistic women, parents and healthcare professionals. *Autism*, 25(5), 1409–1421. <https://doi.org/10.1177/1362361321991257>
- Batchelor, R., Cribben, H., Macdonald, P., Treasure, J., Cini, E., Nicholls, D., & Kan, C. (2022). The experiential perspectives of siblings and partners caring for a loved one with an eating disorder in the UK. *BJPsych Open*, 8(2), e76. <https://doi.org/10.1192/bjo.2022.43>
- Beck, A. T., Epstein, N., Brown, G., & Steer, R. A. (1988). An inventory for measuring clinical anxiety: Psychometric properties. *Journal of Consulting and Clinical Psychology*, 56(6), 893–897. <https://doi.org/10.1037/0022-006X.56.6.893>
- Beck, A. T., Steer, R. A., & Carbin, M. G. (1988). Psychometric properties of the Beck depression inventory: Twenty-five years of evaluation. *Clinical Psychology Review*, 8(1), 77–100. [https://doi.org/10.1016/0272-7358\(88\)90050-5](https://doi.org/10.1016/0272-7358(88)90050-5)

- Beck, A. T., Ward, C. H., Mendleson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry*, 4(6), 561–571. <https://doi.org/10.1001/archpsyc.1961.01710120031004>
- Beffel, J. H., Nuttall, A. K., Vallotton, C. D., Peterson, C. A., & Decker, K. B. (2023). Influences of sibling disability and childhood caregiving experiences on interest in a disability-specific helping profession. *Children and Youth Services Review*, 146, 106817. <https://doi.org/10.1016/j.childyouth.2023.106817>
- Boumans, N. P. G., & Dorant, E. (2018). A cross-sectional study on experiences of young adult carers compared to young adult noncarers: Parentification, coping and resilience. *Scandinavian Journal of Caring Sciences*, 32(4), 1409–1417. <https://doi.org/10.1111/scs.12586>
- 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, 615–622. <https://doi.org/10.2147/JMDH.S115934>
- Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the brief COPE. *International Journal of Behavioral Medicine*, 4(1), 92–100. https://doi.org/10.1207/s15327558ijbm0401_6
- Cheung, M. W.-L., & Vijayakumar, R. (2016). A Guide to conducting a meta-analysis. *Neuropsychology Review*, 26(2), 121–128. <https://doi.org/10.1007/s11065-016-9319-z>
- Cribben, H., Macdonald, P., Treasure, J., Cini, E., Nicholls, D., Batchelor, R., & Kan, C. (2021). The experiential perspectives of parents caring for a loved one with a restrictive eating disorder in the UK. *BJPsych Open*, 7(6), e192. <https://doi.org/10.1192/bjpo.2021.1019>
- Derogatis, L. R., & Melisaratos, N. (1983). The brief symptom inventory: An introductory report. *Psychological Medicine*, 13(3), 595–605. <https://doi.org/10.1017/S0033291700048017>
- Dimitropoulos, G., Klopfer, K., Lazar, L., & Schacter, R. (2009). Caring for a sibling with anorexia nervosa: A qualitative study. *European Eating Disorders Review*, 17(5), 350–365. <https://doi.org/10.1002/erv.937>
- Duckworth, A. L., & Quinn, P. D. (2009). Development and Validation of the short Grit scale (Grit-S). *Journal of Personality Assessment*, 91(2), 166–174. <https://doi.org/10.1080/00223890802634290>
- 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: The Journal of Treatment & Prevention*, 28(1), 80–95. <https://doi.org/10.1080/10640266.2019.1573046>
- Fletcher, L., Trip, H., Lawson, R., Wilson, N., & Jordan, J. (2021). Life is different now – impacts of eating disorders on carers in New Zealand: A qualitative study. *Journal of Eating Disorders*, 9(1), 91. <https://doi.org/10.1186/s40337-021-00447-z>
- Fox, J. R., Dean, M., & Whittlesea, A. (2017). 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. <https://doi.org/10.1002/cpp.1984>
- Friederich, H.-C., Wu, M., Simon, J. J., & Herzog, W. (2013). Neurocircuit function in eating disorders. *International Journal of Eating Disorders*, 46(5), 425–432. <https://doi.org/10.1002/eat.22099>
- Frierson, L. (2012). The impact of sibling mental illness on the well sibling. Theses, Dissertations, and Projects. Retrieved from <https://scholarworks.smith.edu/theses/910>
- Furman, W., & Buhrmester, D. (1985). Children's perceptions of the Qualities of sibling relationships. *Child Development*, 56(2), 448–461. <https://doi.org/10.2307/1129733>
- Garley, D., & Johnson, B. (1994). Siblings and eating disorders: A phenomenological perspective. *Journal of Psychiatric and Mental Health Nursing*, 1(3), 157–164. <https://doi.org/10.1111/j.1365-2850.1994.tb00039.x>
- Garner, D. (2004). Eating disorder inventory-3 (EDI-3) professional Manual. Lutz, FL: Psychological assessment resources. *International Journal of Eating Disorders*, 35, 479.
- Grunwald, J. (2014). *A Portfolio of Academic, Therapeutic practice and research work: Including an investigation of siblings and eating disorders: Recognition, experience and stigma*. University of Surrey [University of Surrey]. Retrieved from <https://openresearch.surrey.ac.uk/esploro/outputs/doctoral/A-Portfolio-of-Academic-Therapeutic-Practice/99513263902346>
- Havard, L. (2019). Living with a young person with an eating disorder: The sibling experience. [Thesis, University of Leicester]. <https://doi.org/10.25392/leicester.data.10305323.v1>
- Hawker, S., Payne, S., Kerr, C., Hardey, M., & Powell, J. (2002). Appraising the evidence: Reviewing Disparate data systematically. *Qualitative Health Research*, 12(9), 1284–1299. <https://doi.org/10.1177/1049732302238251>
- Hight, N., Thompson, M., & King, R. (2005). The experience of living with a person with an eating disorder: The impact on the carers. *Eating Disorders*, 13(4), 327–344. <https://doi.org/10.1080/10640260591005227>
- Hutchison, S., House, J., McDermott, B., Simic, M., Baudinet, J., & Eisler, I. (2022). Silent witnesses: The experience of having a sibling with anorexia nervosa. *Journal of Eating Disorders*, 10(1), 134. <https://doi.org/10.1186/s40337-022-00655-1>
- Iwajomo, T., Bondy, S. J., Oliveira, C. de, Colton, P., Trottier, K., & Kurdyak, P. (2020). Excess mortality associated with eating disorders: Population-based cohort study. *The British Journal of Psychiatry*, 1–7. <https://doi.org/10.1192/bjp.2020.197>
- Janik, E. (2021). “Forgotten Children”: Siblings of Adolescents with eating disorders.
- 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. <https://doi.org/10.1007/s10615-015-0569-7>
- Karlstad, J., Moe, C. F., Wattum, M., Adelsten Stokland, R., & Brinchmann, B. S. (2021). “Putting your own oxygen mask on first”: A qualitative study of siblings of adults with anorexia or bulimia. *Journal of Eating Disorders*, 9(1), 83. <https://doi.org/10.1186/s40337-021-00440-6>
- Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9. *Journal of General Internal Medicine*, 16(9), 606–613. <https://doi.org/10.1046/j.1525-1497.2001.016009606.x>
- Latzer, Y., Ben-Ari, A., & Galimidi, N. (2002). Anorexia nervosa and the family: The effects of younger sisters to anorexia nervosa patients. *International Journal of Adolescent Medicine and*

- Health*, 14(4), 275–281. <https://doi.org/10.1515/IJAMH.2002.14.4.275>
- Latzer, Y., Katz, R., & Berger, K. (2015). Psychological distress Among sisters of young Females with eating disorders: The role of negative sibling relationships and sense of coherence. *Journal of Family Issues*, 36(5), 626–646. <https://doi.org/10.1177/0192513X13487672>
- Lukens, E. P., Thorning, H., & Lohrer, S. (2004). Sibling perspectives on severe mental illness: Reflections on self and family. *American Journal of Orthopsychiatry*, 74(4), 489–501. <https://doi.org/10.1037/0002-9432.74.4.489>
- Maon, I., Horesh, D., & Gvion, Y. (2020). Siblings of individuals with eating disorders: A review of the literature. *Frontiers in Psychiatry*, 11. <https://doi.org/10.3389/fpsyt.2020.00604>
- McDaniel, S., & Pisani, A. (2012). Family Dynamics and caregiving for people with Disabilities (pp. 11–28). https://doi.org/10.1007/978-1-4614-3384-2_2
- Mitrofan, O., Petkova, H., Janssens, A., Kelly, J., Edwards, E., Nicholls, D., McNicholas, F., Simic, M., Eisler, I., Ford, T., & Byford, S. (2019). Care experiences of young people with eating disorders and their parents: Qualitative study. *BJPsych Open*, 5(1), e6. <https://doi.org/10.1192/bjo.2018.78>
- Moses, D. (2013). Exploring the experiences of siblings of young people diagnosed with an ‘eating disorder’. [Pro_doc, University of East London]. <https://doi.org/10.15123/PUB.3446>
- National Institute for Health & Care Excellence. (2020). *Eating disorders: Recognition and treatment* (pp. 1–45). NICE Guideline NG69.
- Perkins, S., Winn, S., Murray, J., Murphy, R., & Schmidt, U. (2004). A qualitative study of the experience of caring for a person with bulimia nervosa. Part 1: The emotional impact of caring. *International Journal of Eating Disorders*, 36(3), 256–268. <https://doi.org/10.1002/eat.20067>
- Persico, A., Grandclerc, S., Giraud, C., Moro, M. R., & Blanchet, C. (2021). “We Thought We were Alone”: The Subjective experience of the siblings of anorexic Adolescent patients. *Frontiers in Psychiatry*, 12, 664517. <https://doi.org/10.3389/fpsyt.2021.664517>
- Quish, S. (2010). Siblings’ perspectives: The impacts of having a sibling who suffers from an eating disorder: A project based upon an independent investigation. Theses, Dissertations, and Projects. Retrieved from <https://scholarworks.smith.edu/theses/514>
- Rammstedt, B., & John, O. P. (2007). Measuring personality in one minute or less: A 10-item short version of the Big five inventory in English and German. *Journal of Research in Personality*, 41(1), 203–212. <https://doi.org/10.1016/j.jrp.2006.02.001>
- Renfrew Frigon, J. (2021). “Hugely traumatic things happened”: ‘well’ siblings’ retrospective insights alongside anorexia. University of British Columbia. <https://doi.org/10.14288/1.0401115>
- Robinson, I., Stoyel, H., & Robinson, P. (2020). “If she had broken her leg she would not have waited in agony for 9 months”: Caregiver’s experiences of eating disorder treatment. *European Eating Disorders Review*, 28(6), 750–765. <https://doi.org/10.1002/erv.2780>
- Roehrig, J. P., & McLean, C. P. (2010). A comparison of stigma toward eating disorders versus depression. *International Journal of Eating Disorders*, 43(7), 671–674. <https://doi.org/10.1002/eat.20760>
- Ryan, C., Hesselgreaves, H., Wu, O., Paul, J., Dixon-Hughes, J., & Moss, J. G. (2018). Protocol for a systematic review and thematic synthesis of patient experiences of central venous access devices in anti-cancer treatment. *Systematic Reviews*, 7(1), 61. <https://doi.org/10.1186/s13643-018-0721-x>
- Sanders, A., Szymanski, K., & Fiori, K. (2014). The family roles of siblings of people diagnosed with a mental disorder: Heroes and lost children. *International Journal of Psychology*, 49(4), 257–262. <https://doi.org/10.1002/ijop.12020>
- Schaumberg, K., Welch, E., Breithaupt, L., Hübel, C., Baker, J. H., Munn-Chernoff, M. A., Yilmaz, Z., Ehrlich, S., Mustelin, L., Ghaderi, A., Hardaway, A. J., Bulik-Sullivan, E. C., Hedman, A. M., Jangmo, A., Nilsson, I. A. K., Wiklund, C., Yao, S., Seidel, M., & Bulik, C. M. (2017). The Science behind the Academy for eating disorders’ nine Truths about eating disorders. *European Eating Disorders Review: The Journal of the Eating Disorders Association*, 25(6), 432–450. <https://doi.org/10.1002/erv.2553>
- Schee genannt Halfmann, S., Evangelatos, N., Schröder-Bäck, P., & Brand, A. (2017). European healthcare systems readiness to shift from ‘one-size fits all’ to personalized medicine. *Personalized Medicine*, 14(1), 63–74. <https://doi.org/10.2217/pme-2016-0061>
- Schwarzer, R., & Jerusalem, M. (1995). Generalized self-Efficacy scale. In S. Wright, M. Johnston, & J. Weinman, *Measures in health psychology: A user’s portfolio. Casual and control beliefs* (pp. 35–37). NFER-NELSON. Retrieved from <https://psycnet.apa.org/doiLanding?doi=10.1037%2F00393-000>
- Scutt, E., Langdon-Daly, J., & Smithson, J. (2022). Experiences of eating difficulties in siblings of people with anorexia nervosa: A reflexive thematic analysis. *Journal of Eating Disorders*, 10(1), 123. <https://doi.org/10.1186/s40337-022-00646-2>
- Sin, J., Spain, D., Jordan, C., & Griffiths, A. C. (2014). Siblings of individuals with severe mental illness. *The Journal of Mental Health Training, Education and Practice*, 9(4), 215–221. <https://doi.org/10.1108/JMHTEP-04-2014-0006>
- Sinclair, V. G., & Wallston, K. A. (2004). The development and psychometric evaluation of the brief resilient coping scale. *Assessment*, 11(1), 94–101. <https://doi.org/10.1177/1073191103258144>
- Skinner, H. A. (1982). The drug abuse screening test. *Addictive Behaviors*, 7(4), 363–371. [https://doi.org/10.1016/0306-4603\(82\)90005-3](https://doi.org/10.1016/0306-4603(82)90005-3)
- The Royal College of Psychiatry (2023). Medical emergencies in eating disorders (MEED): Guidance on recognition and management (CR233) (CR233). Retrieved from <https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2022-college-reports/cr233>
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1), 45. <https://doi.org/10.1186/1471-2288-8-45>
- Treasure, J., Duarte, T. A., & Schmidt, U. (2020). Eating disorders. *The Lancet*, 395(10227), 899–911. [https://doi.org/10.1016/S0140-6736\(20\)30059-3](https://doi.org/10.1016/S0140-6736(20)30059-3)

- Twardowski-Deskin, J. (2022). *Exploring the lived experience of sisters of women diagnosed with bulimia nervosa: A qualitative case study*. Adler University, Clinical Psychology - Chicago.
- Varnell, C. J. (2014). Siblings' experiences of having a brother or sister with an eating disorder: A qualitative exploration. Retrieved from <https://era.ed.ac.uk/handle/1842/14222>
- Varni, J. W., Lovaas, O. I., Koegel, R. L., & Everett, N. L. (1979). An analysis of observational learning in autistic and normal children. *Journal of Abnormal Child Psychology*, 7(1), 31–43. <https://doi.org/10.1007/BF00924508>
- Weis, R., Dean, E. L., & Osborne, K. J. (2016). Accommodation decision making for Postsecondary Students with learning Disabilities: Individually tailored or one size fits all? *Journal of Learning Disabilities*, 49(5), 484–498. <https://doi.org/10.1177/0022219414559648>
- Withers, A., Mullan, B., Madden, S., Kohn, M., Clarke, S., Thornton, C., Rhodes, P., & Touyz, S. (2014). Anorexia nervosa in the family: A sibling's perspective. *Advances in Eating Disorders*, 2(1), 53–64. <https://doi.org/10.1080/21662630.2013.839187>

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