MAYA KUHL BSc Hons

EXPLORING EXPERIENCES OF EXTERNALISING AND THE ANOREXIC VOICE

Section A: How do clients, carers and clinicians experience therapeutic externalisation of anorexia nervosa?

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Section B: Exploring Carers' Perceptions of the Anorexic Voice: A Reflexive Thematic Analysis

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Summary of MRP Portfolio

Part A

This review synthesised literature exploring people with anorexia nervosa’s (PwAN's), carers' and clinicians' experiences of therapeutic externalisation. Relevant literature was discovered using a systematic search of online databases which found 18 papers that met inclusion criteria. Meta-ethnography was used to synthesise the literature. Findings highlighted stakeholders' contradictory views on the impact of externalisation on PwAN's relationships and sense of identity, indicating that this technique has the potential to help or harm PwAN's recovery. Ways of understanding these contradictory views and the need for clinicians to adapt externalising techniques were emphasised. Review limitations, clinical implications and future research needs are outlined.

Part B

This qualitative study explored carers’ perceptions of the anorexic voice (ANV). Thirteen participants were interviewed, and their transcripts interpreted using Reflexive Thematic Analysis. Findings revealed that the ANV holds many meanings, and the construct attracted advocates and critics among carers. Advocates recognised the ANV as a powerful bully and found they could bring positive changes by altering their relationship with it. Carers outlined benefits, shortcomings and criticisms of the ANV, which under scrutiny, revealed significant overlap with perspectives on externalising. These findings are outlined in the context of existing literature, and the limitations, clinical implications and future directions are illustrated.

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Major Research Project

Part A: Literature Review

How do clients, carers and clinicians experience therapeutic externalisation of anorexia nervosa?

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Background and aims: Many people with anorexia nervosa (PwAN) experience it as a key part of their identity, which can impact motivation for recovery. Externalisation has gained traction in the treatment of AN for its ability to create separation between an individual and problems which have become internalised and identified with. Preliminary review of research which explored PwAN's, carers' and clinicians' experiences of externalisation highlighted some conflicting views. This review therefore aimed to systematically review available literature on stakeholders' experiences of externalising AN. **Method:** Literature was systematically searched and synthesized using the meta-ethnographical approach. **Results:** 18 studies met inclusion criteria. Analysis highlighted that stakeholders held contradictory views about the impact of externalisation on PwAN's relationships and identity. Explanations for contradictions were provided. The need for clinicians to adapt techniques and challenges of researching externalisation were emphasised. **Conclusions:** Externalisation has the potential to help or harm PwAN's journey to recovery. Clinicians using externalisation must be sensitive to its impact and able to adapt their approaches. Using externalisation to help PwAN author their own relationship to AN, rather than imposing prescribed perspectives, may enhance benefits and reduce harm. However, more research is needed to understand how externalisation can be used most effectively.

Introduction

Anorexia nervosa (AN) can devastate the lives of individuals and their loved ones, this is perhaps most poignantly captured by the stark finding that AN has one of the highest mortality rates amongst psychiatric disorders at nearly six times higher than the general population (Schmidt et al., 2016). Furthermore, AN impacts an individual's physical, psychological and social wellbeing (Chidiac, 2019) and has a substantial burden on caregivers (Viana et al., 2013).

NICE (2017) recommends psychological intervention for AN treatment. However, many people struggle to fully recover (Bulik et al., 2007), and high drop-out rates from treatment are notable (Wallier et al., 2009). Part of the challenge is that people with AN (PwAN) often have low motivation for recovery (Abbate-Daga et al., 2013). Given these challenges, unsurprisingly, staff find it challenging to work with PwAN (Davey et al., 2014), and carers often feel dissatisfied with treatment (Fox et al., 2017). These shortcomings have been met with calls for advances in psychological treatment (Oldershaw et al., 2019; Solmi et al., 2021).

A phenomenon that provides insight into sufferer's ambivalence towards recovery is the commonly reported experience of an anorexic identity, sometimes described as a voice (Noordenbos & Van Geest, 2017) or personified as a separate or part self (e.g. Williams & Reid, 2012). Qualitative research exploring PwAN's experiences of recovery has revealed that some view attempts to overcome AN as akin to 'killing your best friend' (Tierney & Fox, 2010, p.249), and is feared by others as tantamount to partial or total loss of identity (e.g. Duncan et al., 2015; Jenkins & Ogden, 2012; Tan et al., 2003).

In addition to PwAN, carers and clinicians have also reported noticing the development of an anorectic identity that seems to 'take on a life of its own' (Treasure et al., 2020; p.2) and increasingly dominate over the individual's former identity (Tan et al., 2003). One mother's description of AN captures a rather graphic depiction of this as a "parasite that attempts to consume ... [and] obliterate the true gentle nature of its host." (Claude-Pierre, 1997; p.39).

Various theories have been put forward that help us understand the experience of AN as akin to identity. Treasure et al. (2020) highlight the extensive impact of AN on an individual's life, noting behavioural, interpersonal and even neurological changes (Barona et al., 2019), which, taken together, could account for the dramatic changes in identity. Koskina and Schmidt (2019) have argued that AN identity may arise since it typically develops during teenage years, a life stage often marked with identity exploration and development (Dunkel, 2000; Erikson, 1968).

Oldershaw and colleagues (2019) theorise that the stark identity changes observed in PwAN may be explained by the loss of their emotional self. Literature is synthesised to emphasise how anorectic behaviours may develop to help individuals avoid experiencing overwhelming emotions. Since our ability to process emotions is fundamental to our identity (Bosma & Kunnen, 2001) and guides our understanding of our needs, PwAN become increasingly unattuned to their actual needs leaving them progressively more reliant upon external cues, such as weight goals, to guide their behaviour. Through this perpetuating cycle, it is possible to see how an anorexic identity can grow while the individual's former self diminishes, even in the face of grave danger such as starvation.

Other theories suggest that PwAN may develop divided inner selves to preserve a socially conforming external self and direct unacceptable aspects of identity inward (Maji & Dixit, 2019). This theory is supported by evidence which indicates that women who conform to socially prescribed gender norms, such as suppressing anger (Hambrook et al., 2011), are more prone to eating behaviour problems (Frank & Thomas, 2003).

Given the common experience of AN as akin to an identity, experienced as a voice, part-self or external force which 'possess' the individual (Svenaeus, 2013; p.85), a therapeutic technique which fits with the treatment of AN is externalisation. Externalisation is most clearly explained within narrative therapy (NT; White & Epston, 1990) and aims to help people objectify and personify problems they are experiencing to create space between them and the problem, enabling an individual to recognise that 'this is of me, however it isn't the total of me' (Bird, 2004, p.43). With this distance from the problem, the hope is that it gives an individual an opportunity to explore their relationship to the problem from a different perspective and reduce feelings of guilt and blame (Madigan & Goldner, 1998). Specifically, externalising conversations are designed to help individuals reflect on beliefs that fuel the problem, the influence of wider-societal narratives, and their impact on their lives. Finally, individuals are invited to take a stance on how they would wish to move forwards in their relationship with the problem, referred to as re-authoring their story (Freedman & Combs, 1996).

In NT for AN, externalising conversations can lead to clients being invited to write a letter, poem or drawing (or whatever the client chooses) to the externalised AN (White & Epston, 1990). Together these documents form part of the Anti-Anorexia Archive of Resistance, made available to all PwAN to challenge AN (Epston & Maisel, 2010).

Of note in the treatment of AN is the adoption of externalisation into family-based therapy (FBT), which is NICE recommended (2017) and considered by some as the gold standard of treatment for adolescent AN (Murray et al., 2012). Manualised versions of FBT, such as the Maudsley family therapy model (MFT; Lock & Le Grange, 2013), are most commonly offered due to its evidence base (Fisher et al., 2019).

Similarly to NT, within FBT, externalisation aims to create separation between the PwAN and AN through language, metaphor and imagery (Weber et al., 2006). A key difference, however, is that within FBT, families are encouraged to view AN as an illness that has taken over the PwAN (Lock et al., 2001). For example, families are invited to see PwAN's behaviours, thoughts and emotions as due to starvation and, therefore, out of their control (Lock et al., 2001). The goal of externalisation in this context is to align families together in the "fight" against "the anorexia" by shifting familial blame and criticism to an externalised entity (Lock & Le Grange, 2013; p.80).

As outlined above, externalisation is a technique embedded within broader therapeutic models. A consequence is that there is very little research directly exploring externalisation, its efficacy, or clients', clinicians' or family members' perspectives of it (Ono et al., 2003; Lonergan et al., 2022). However, some insights into externalisation have been gained through qualitative research into NT, FBT and other forms of AN treatment. For example, Heywood and colleagues (2022) conducted a narrative synthesis of NT literature on eating disorders (ED). They found externalisation was the most frequently cited technique in supporting clients to unpack dominant narratives that were maintaining their difficulties and recognising the impact of the problem on their lives.

Within FBT literature, externalisation has been highlighted as an important technique (Lock & Le Grange, 2013; Williams et al., 2020). For example, PwAN have highlighted externalisation's role in increasing familial empathy and understanding (Medway & Rhodes, 2016). Furthermore, Wufong and colleagues (2019) found that parents valued externalisation since it enabled them to see AN as beyond their child's control which reduced blame. In a meta-synthesis exploring clinicians' experiences of FBT, the family's ability to externalise was seen as a critical facilitator of change (Byrne, 2019).

However, some research into FBT has raised the possibility that externalisation could have harmful consequences (Dimitropoulos et al., 2015; Eisler et al., 2016). For example, PwAN believed externalisation led their views to be dismissed as belonging to AN, leaving them feeling excluded from therapy (Wufong et al., 2019).

Reflecting similar patterns to those shown in FBT literature, research exploring PwAN's experiences of treatment settings and recovery have uncovered positive and negative appraisals of externalisation. For example, in a meta-synthesis of qualitative studies exploring PwAN's recovery experiences, externalisation of AN was identified as a key component in reclaiming one's identity (Stockford et al., 2019). Furthermore, Dawson et al. (2014) reported that PwAN viewed their ability to externalise AN as a tipping point within their recovery journey. In contrast, women who experienced inpatient treatment recounted how experiences of externalisation led them to feel like a "walking eating disorder" (Holmes et al., 2021., p.50) and as though their genuine opinions were dismissed.

Given the potential promise of externalisation as a valuable therapeutic tool in the treatment of AN, yet also the identification of negative experiences, there has been a call for more research into externalisation (Lonergan et al., 2022; Voswinkel et al., 2021). To inform the direction of such research, capturing and synthesising available literature exploring externalisation experiences could prove useful and will form the basis of this review. Given that the vast majority of existing research in this topic area is qualitative, a meta-ethnographic approach seems appropriate since it would facilitate synthesis of literature which explores perspectives of externalisation while also enabling the development of new insights (Noblit & Hare, 1988). PwAN, carers and clinicians (herein referred to as stakeholders) play a crucial role in recovery from AN (Stockford et al., 2019). For this review to have greater depth and impact (Obeid et al., 2020), it seems imperative to include research which explores all of these stakeholders' views.

This review, therefore, aims to develop a rich understanding of stakeholders' experiences of externalisation as a therapeutic technique. In line with the ethos of qualitative research, an inductive rather than hypothesis-testing approach will be taken to explore this experience. The following research questions provide prompts to consider varied aspects of stakeholder's experience:

1. What stands out about stakeholders' descriptions/ experiences of externalisation?
2. What help or harm can externalisation bring in terms of recovery from AN?
3. What helps stakeholders to use externalisation effectively?
4. What barriers or challenges do stakeholders face when using externalisation?
5. Can stakeholders help us understand potentially conflicting views on externalisation?
6. Are there any differences between:
    1. Stakeholders' perspectives and experiences of these processes?
    2. Externalisation when used in different therapeutic models and settings?

Method

Search Strategy

A systematic search of bibliographic databases was conducted on 21st October 2022. Four databases were used for the following reasons; PsychInfo due to a large number of records it holds across behavioural, social science and mental health fields; Web of Science due to its rich data spanning a range of academic fields; CINAHL for its inclusion of nursing and allied health literature; and PubMed for its global reach of biomedicine and health records.

Table 1 shows the literature search terms used to meet the review aims outlined above. Endeavouring to capture all relevant literature pertaining to externalisation, experts in the field were consulted on appropriate search terms. In addition, a hand search of reference lists of articles captured by the initial search was also conducted.

Table 1

Search Terms used to Systematically Search for Literature

Search terms	Where in text
“anorexic voice” OR “anorexic self” OR “anorectic voice” OR “or “anorectic self” OR externalis* or externaliz* or personif*	All text
therap* or intervention* or treat*	Abstract
anorexi* or “eating disorder”	Abstract
qualitative or perspect or experien* or percep*	Abstract

Inclusion & Exclusion Criteria

Inclusion and exclusion criteria are shown in Table 2 below. To capture PwAN's, carers' and clinicians' experiences of externalising AN, a wide range of qualitative studies were included with no date limitation. Case studies were included, given their potential to gain an in-depth, holistic view of a research problem (Baškarada, 2014). Additionally, including unpublished articles such as doctoral theses seemed appropriate since a quality assessment would be conducted to exclude low-quality research from subsequent review. This review focused on stakeholders' experiences and perspectives of externalisation in the context of AN and excluded papers with mixed samples from other eating disorders. Translation of literature fell outside this project's scope, thereby excluding papers not written in English. Titles, abstracts and parts of the papers produced by the search were reviewed against these parameters. Only papers that met the inclusion criteria were read in full and assessed for quality.

Table 2

Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
Empirical research including peer-reviewed journal articles, case studies and doctoral theses	Book chapters, review articles, opinion pieces
Qualitative techniques were used to explore subjective experiences of externalisation, either alone or as part of mixed methodology	Quantitative research
Research which explores a range of stakeholders' (PwAN's/ carers'/ clinicians') experiences and perspectives of therapeutic externalisation used in the treatment of AN	Research which explores experiences or perspectives of externalised forms of AN rather than the process of externalisation
Experiences of externalisation must be in the context of treatment for AN	Research which explores externalisation of disorders that are not AN, including other eating disorders such as Bulimia Nervosa or Binge Eating Disorder
Research published in the English language	Research not published in the English language
Research determined to have reasonable quality (see quality assessment method section for details)	Research that is determined to be methodologically 'fatally flawed' based on the CASP quality assessment tool

Quality Assessment Method

Qualitative methods vary and are based on a range of theoretical, ontological and epistemological paradigms. These paradigms hold different positions regarding “the nature of knowledge, the goal of inquiry, the role of values, the role of theory, the way in which the voice is represented, the researcher role, and the criteria used to judge the legitimacy of the research” (Sparkes & Smith, 2013; p.10) making it difficult to assess the quality of such diverse qualitative literature (Osbeck, 2014). Adding further complexity to this task, some advocates of meta-synthesis reviews have argued that it may be unhelpful to exclude research based on minor methodological flaws as the findings may still add value to the research area (Bondas & Hall, 2007; Sattar et al., 2021). As such, many researchers utilising the meta-synthesis approach use tools to identify and exclude ‘fatally flawed’ studies but retain studies with mild or moderate methodological flaws (e.g. Fox et al., 2015). Given that research on stakeholders’ experience of externalisation was known to be limited from the outset of this review (Voswinkel et al., 2021), it felt appropriate to adopt this process to maximise the capture of literature.

To determine studies that were ‘fatally flawed’ and structure critical reflection on the methodological quality of literature, the Critical Appraisal Skills Programme (CASP) was used (Singh, 2013). The CASP framework has received some criticism; for example, Long and colleagues (2020) argue that the CASP fails to adequately evaluate the congruence between the research paradigm and design. However, despite its imperfections, it seemed an appropriate tool for this meta-synthesis as it applies to a range of paradigms underpinning qualitative research and enables novice researchers to effectively report on study quality (Dixon-Woods et al., 2007; Hoffmann, et al., 2013). Furthermore, the checklist provides numerical scoring, which provides a system to determine research which is ‘fatally flawed’.

Table 3 shows the quality classification system using the CASP checklist adopted from Fox et al.'s (2015) meta-synthesis for this review.

Table 3

Quality Classification System

Score	Quality Classification	Included/ Excluded in Meta-synthesis
> 8.5	High quality and deemed to have a low likelihood of methodological flaws	Included
Between 5-8	Medium quality and deemed to have a moderate likelihood of methodological flaws	Included
< 5	Low quality and deemed to have a high likelihood of methodological flaws	Excluded

Method of Synthesis

Many methods may be used to synthesise qualitative literature (Finfgeld-Connett, 2018). However, meta-ethnography (Noblit & Hare, 1988) was chosen in this study for its capacity to give voice to: experts by experience through the inclusion of direct data such as participant quotes; researchers through the inclusion of data interpreted through their eyes; the present author through an invitation of their novel interpretations that have arisen through an iterative process of synthesis and reflection on all of the data (Espindola & Blay, 2009). These perspectives are referred to as first, second and third-order constructs, respectively in the meta-ethnographical approach. Furthermore, the meta-ethnographical approach was chosen since it is underpinned by the interpretivist paradigm (Soundy & Henneghan, 2022), which sits well with the author's epistemological view of the world that most closely aligns with social constructivism (Amineh & Asl, 2015). The approach adopted was the 7-step meta-ethnography method outlined in Sattar and colleagues' (2021) guide and is summarised in Table 4.

Table 4

Overview of Meta-Ethnography Methodology

Stage	Overview	Description/ Correlating Section of Review
1)	Identifying an area of interest	Outlined in the Introduction section
2a)	Defining the focus	Outlined in the Review Aims in the Introduction section
2b)	Locating the relevant studies	Outlined in the Search Strategy section
2c)	Deciding which studies to include	Outlined in Inclusion and Exclusion Criteria section
2d)	Quality appraisal	Outlined in Methods: Quality Assessment and Quality Assessment Results sections
3)	Reading the studies	The papers were read in full. A summary of the papers is outlined in Characteristics of Studies table
4)	Determining how the studies are related	First order and second order extracts of papers relevant to the review aims were transferred onto NVivo (Version 12 Pro) and key concepts were coded accordingly. The coded extracts were then reviewed to determine relationships between papers that were relevant to the review aims
5)	Translating the studies into one another	Studies were 'translated' into one another by exploring themes and meanings that arose from the different papers and developing overarching categories to capture these concepts. Contradictions were explored for 'refutational synthesis'
6)	Synthesising the translations	This 'translated' data was then reviewed, reflected upon and synthesised to create novel interpretations, or third order constructs, that represented the themes and meanings presented by the first and second order constructs
7)	Expressing the synthesis	Outlined in Results and Discussion sections

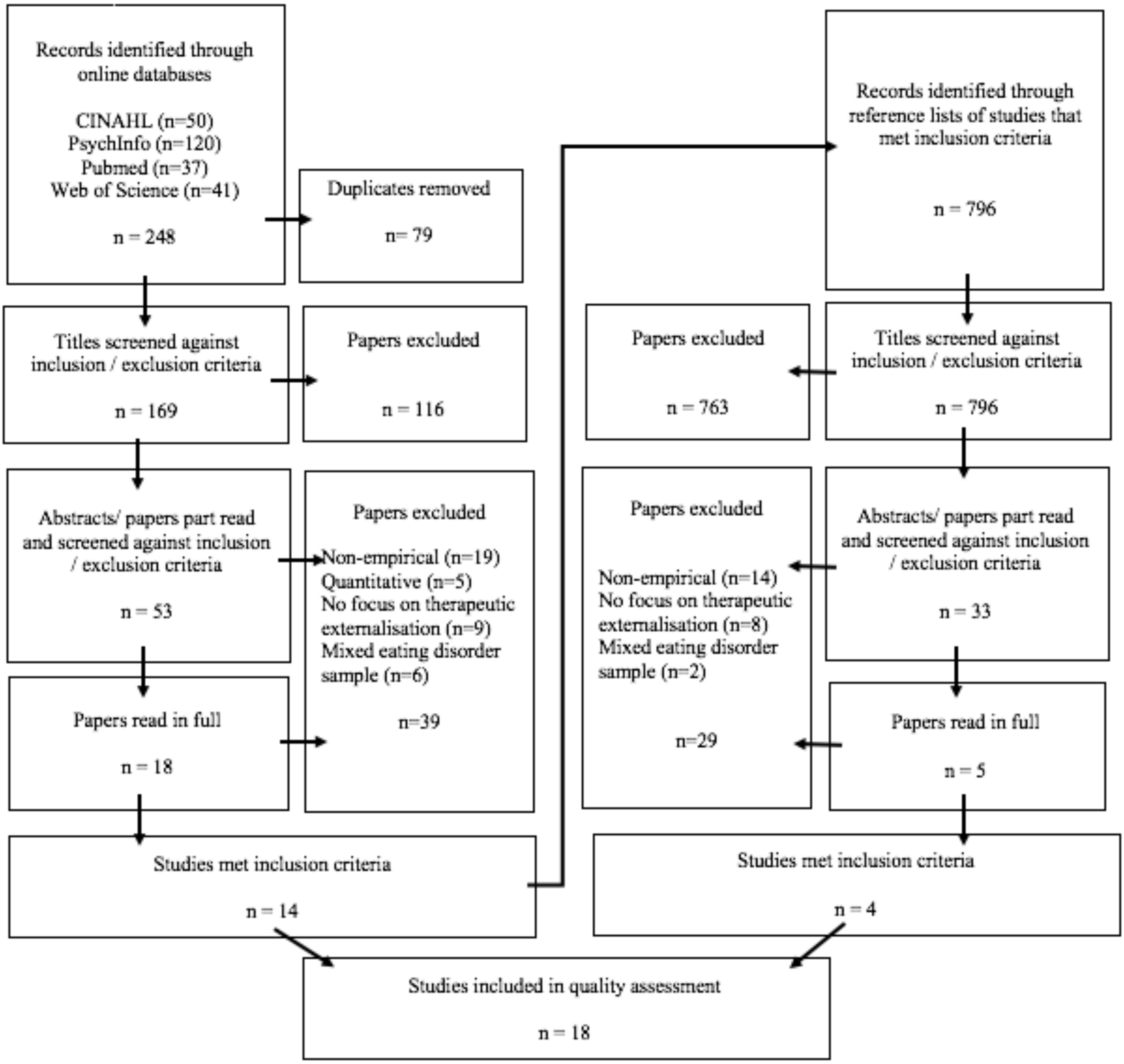
Integrating the author's social constructivist standpoint into the meta-ethnography approach, care was taken to be aware of potential assumptions implicit in knowledge shared from their own, participants' and researchers' views by reflecting on the social, historical and cultural context in which views have been shared (Burr, 2015). To aid this process, reactions and reflections on the data were captured through annotations of the data in NVivo. In addition, broader reflections on the process were captured in a journal kept throughout the process and, where relevant, discussed in supervision.

Results

Following the search methodology, and applying inclusion and exclusion criteria previously outlined, the literature search results are shown in Figure 1.

Figure 1

Prisma Diagram of Literature Search Results



Identified Studies

Eighteen studies met inclusion criteria, key characteristics are summarised in Table 5.

PwAN Study Characteristics

Eight studies explored PwAN's perspective with a total of 71 participants. Studies mostly recruited adult participants (n=6), though adolescent PwAN were also represented (n=2). Most studies recruited exclusively female participants (n=7) while one study had a mixed male and female sample, though only one male participated. PwAN had been invited to share their experiences of FBT (n=3), inpatient care (n=2), recovery (n=1), a group based on NT (n=1) and a day care centre (n=1). One study only included participants who identified as recovered from AN, while five explored past experiences of treatment regardless of recovery status and two of current treatment.

Carer Study Characteristics

Six studies explored carers' perspectives, with a total of 80 participants. Studies most commonly recruited parents (n=4), however one study included a family (parents, sibling and PwAN) and another study had a mixed sample including parents, siblings and partners. All studies included mixed male and female participants, though the number of female participants was higher at 49 compared to 31 male participants. Participants were most likely to be carers of children/ adolescents with AN (n=5), though one study included carers of adults with AN. Carers were sharing their experiences of either FBT (n=3) or skills training workshops (n=3).

Clinician Study Characteristics

Six studies explored clinicians' perspectives, with a total of 72 participants. Studies most often included those trained in FBT (n=4), the remaining two studies included participants from a wide range of healthcare professions including nurses, dieticians and psychologists. Half of the studies represented mixed male-female samples (n=3). Across the studies, 67 females participated compared to five males.

Finally, the studies were conducted in four parts of the Western world: UK (n=8), Australia (n=6), Scandinavia (n=2) and Canada (n=2). There was insufficient data to report on ethnicity of participants.

Table 5

Characteristics of Studies

Reference and journal publication/ thesis	Location of study	Study aims	Participant characteristics and number	Data collection and analysis method	Key findings
1.Bryne (2019) Thesis, University of Glasgow	West Scotland, UK	To explore clinicians' experiences and views of practising FBT with adolescent clients	Clinicians who are trained in and actively using FBT to treat adolescent AN N= 8 Gender: Female Data on ethnicity not included	1:1 semi-structured interview Thematic analysis	Client hope, clinician experience and a family's ability to separate young person from AN were perceived to facilitate treatment success. Parental and co-morbid mental health difficulties and appropriate resources were perceived barriers to FBT treatment success.
2.Conti et al. (2021) Research Square Journal	Sydney, Australia	To explore adolescent clients' experience of FBT for AN	Clients who had previously received FBT for adolescent AN N= 14 Gender: Female Data on ethnicity not included	1:1 semi-structured interview Inductive thematic analysis	Working as a family was viewed as the key to recovery. Young people needed support to navigate their identity and have a voice in treatment.
3.Conti et al. (2017) Australian and New Zealand Journal of Family Therapy	Sydney, Australia	To explore the lived experience of a family who engaged with FBT for adolescent AN	A family who had experienced FBT for one member's adolescent AN N=4 Gender: Mixed male (n=1) and female (n=3) Data on ethnicity not included	1:1 Semi-structured interview Critical discursive analysis	The family found initially FBT offered them a sense of responsibility which was containing. In later stages, the family experienced FBT as blaming and the young person with AN felt her views were externalised along with her AN.
4. Dawson et al. (2014) Qualitative Health Research	Sydney, Australia	To explore the process of recovery from chronic AN	Clients who had experienced chronic AN (>7 years) and were now fully recovered N=8 Gender: Female Data on ethnicity not included	1:1 semi-structured interview Narrative inquiry	Recovery was experienced as a long and complex process that included four phases: • feeling unable or unready to change • finding motivation increased and changed • PwAN felt able to take action against the AN • rehabilitation and reflection

5. Dimitropoulos et al. (2015) Journal of Eating Disorders	Ontario, Canada	To identify how clinicians employ the FBT model when working with 'transition age youth' (16–21) with AN.	Clinicians who are trained in and practise FBT for adolescent AN N= 30 Data on gender or ethnicity not included	1:1 semi-structured interview and focus groups Directed content analysis	Participants modified FBT when working with 16-21-year olds by: • working more collaboratively with the client • providing greater opportunities for independent eating • introducing relapse prevention in the latter phase of the treatment.
6. Dimitropoulos et al. (2017) Journal of Family Therapy	Ontario, Canada	To explore which principles of FBT are perceived to be most valuable by clinicians	Clinicians who worked in paediatric teams offering FBT to treat adolescent AN N= 34 Gender: Mixed male (n=2) and female (n=32) Data on ethnicity not included	Focus groups Thematic analysis	Parental empowerment (PE) was viewed as the most salient principle of FBT. Factors such as emotional dysregulation within families and long-standing eating disorder symptoms were thought to impede PE. Interventions such as externalisation and psychoeducation were viewed as key components of enhancing PE.
7. Goddard et al. (2010) European Eating Disorders Review	UK	To explore clients' experiences of their carers taking part in a Collaborative Care skills training	Adult clients accessing inpatient care whose carers had attended a skills workshop N=10 Gender: Mixed male (n=1) and female (n=9) Data on ethnicity not included	1:1 semi-structured interview Interpretative Phenomenological analysis (IPA)	Clients held positive attitudes towards involving carers in their care. Skills training approaches can have positive effects for adult inpatients with AN, for example by reducing expressed emotion and creating a calmer atmosphere at home.
8. Goodier et al. (2014) International Journal of Eating Disorders	Western Australia	To explore carers' experiences of a skills-based training intervention	Parent carers of children with AN who attended a skills-based training workshop N=11 Gender: Mixed male (n=4) and female (n=7) Data on ethnicity not included	1:1 semi-structured interview Inductive thematic analysis	Parents found skills-training workshops improved knowledge and care-giving experiences, increasing effective management of their child's illness, communication and family dynamics. Opportunities to talk and learn from other families was experienced as supportive.
9. Graham et al. (2019) Thesis, Cardiff University	UK	To explore the perceptions of the anorexic voice amongst clinicians	Clinicians from a range of disciplines who worked in adult ED services N=15 Gender: Mixed male (n=1) and female (n=14) Data on ethnicity not included	1:1 semi-structured interview Thematic analysis	Clinicians saw externalising the anorexic voice as a key therapeutic technique to increase compassion, while recognising that it does not resonate with all clients.

10. Holmes et al. (2021) Feminism and Psychology	UK	To understand how experiences of trust featured in AN treatment settings	Adult clients with experience of inpatient treatment for AN N=14 Gender: Female Data on ethnicity not included	1:1 semi-structured interview Thematic analysis using a discourse-analytic framework	Participants experienced a lack of trust from clinicians influenced by systems in place in in-patient settings. In particular, participants experienced a disqualification of their views which led to low self-esteem, reduced motivation, treatment termination and re-traumatisation.
11. Ibrahim & Tchanturia (2018) International Journal of Group Psychotherapy	London, UK	To evaluate a pilot group using the Tree of Life model for adults with AN	Adult clients who attended a Tree of Life group at a specialist day centre N=4 Gender: Female Data on ethnicity not included	Focus group Thematic analysis	Participants felt the group provided them with: • creativity • new perspectives • hope • a sense of community
12. Lonergan et al. (2022) Journal of Family Therapy	Ireland	To further understanding of clinician's experiences of using externalisation	Clinicians with FBT training and experience who work with children and adolescents with AN N=8 Gender: Mixed male (n=2) and female (n=6) Data on ethnicity not included	1:1 semi-structured interview Thematic analysis	Externalisation can support a young person's recovery from AN when used in conjunction with other therapeutic skills. Clinicians should be aware of potential barriers to the implementation of externalisation, such as problem awareness, age and duration of illness.
13. Toubøl et al. (2019) Scandinavian Journal of Caring Science	Denmark	To examine carer's perception of skills acquired during training	Parent carers of children with AN who attended an outpatient skills-training course inspired by the New Maudsley Method N=21 Gender: Mixed male (n=9) and female (n=12) Data on ethnicity not included	Focus groups Deductive dominant content analysis	Parents found the training helped them to: • separate their children from the illness • better understand their child's inner life • find new ways of parenting which involved more communication
14. Voswinkel et al. (2021) Research Square	Netherlands	To investigate client's perspectives and experiences of externalisation	Adult clients who had received FBT or the Maudsley Model for Anorexia Nervosa Treatment for Adults (MANTRA) N= 14 Gender: Mixed male (n=2) and female (n=6) Data on ethnicity not included	1:1 semi-structured interview Inductive thematic analysis	Client's perceptions on the relationship between AN and their identity varies greatly; some experience AN as part of who they are, others experience it as completely alien to them. Externalisation is sometimes experienced as helpful. However, others believed externalisation led to their views being labelled as 'AN' and not trusted.

15. Whitney et al. (2011) European Eating Disorders Review	UK	To compare outcomes in individual family versus multi-family workshops	Carers (parents, partners and siblings) of adults with AN who took part in individual family or multi-family workshops N= 23 Gender: Mixed male (n=10) and female (n=13) Data on ethnicity not included	1:1 semi-structured interview IPA	Carers benefitted from working with other families. Carers felt there was a lack of structure in individual family therapy. Most carers felt the interventions helped them communicate, understand the illness and gain personal and familial insight. Although there was lack of consensus on the most helpful techniques.
16. Williams et al. (2020) Australian Social Work Journal	New South Wales, Australia	To explore parents' experiences of family-based interventions for AN	Parent carers of adolescents with AN who had taken part in either manualised FBT or non-manualised systemic interventions N=9 Gender: Mixed male (n=3) and female (n=6) Data on ethnicity not included	1:1 semi-structured interview IPA	Findings highlight: • the impact of AN on the whole family • the gatekeeping role of health professionals in providing access to support and treatment • the value of externalisation • the prime importance of the therapeutic alliance between parents and clinicians the importance of tailoring treatment to the unique circumstances, values, and culture of each family
17. Wright & Hacking (2011) Journal of Psychiatric and Mental Health Nursing	UK	To explore the impact of therapeutic relationships between clinicians and PwAN	Adult clients in an AN day care service N= 6 Gender: female Ethnicity: White British Multidisciplinary clinicians in an AN day care service N=7 Gender: female Ethnicity: White British	1:1 semi-structured interview IPA	People with AN valued authentic relationships in their care staff. Feeling cared for and nurtured fostered a sense of safety, hope and optimism. Externalising AN had positive and negative consequences
18. Wufong et al. (2019) Journal of Eating Disorders	Sydney, Australia	To explore parents' experiences of ineffective Multi-Family Therapy (MFT) /FBT	Parent carers of children with AN who had attended FBT or Multi-Family Therapy N=13 Gender: Mixed male (n=4) and female (n=9) Data on ethnicity not included	1:1 semi-structured interview Critical discursive analysis	Parents perceived MFT/FBT to: • provide a map for therapy which reduced anxiety and improved family functioning • inadequately address parental guilt and blame through externalisation of AN • perpetuated guilt by raising anxiety • when ceased, left parents struggling with an uncertain future, and fears for the wellbeing of their children.

Quality Assessment

The quality of studies was assessed using the methodology outlined above. Assessment ratings using the CASP framework are shown in Table 6. All 18 studies that met inclusion criteria were found to have sufficient methodological quality and were retained for analysis. A strength of literature included in this meta-synthesis was rigorous data analysis; studies commonly reported using processes such as second author and respondent validation of analysis to ensure it adequately represented the data. Furthermore, all 18 studies provided a clear statement of findings. Regarding weaknesses, overall studies rarely reported the relationship between researchers and participants. When they did, the impact of the relationship on the findings was even less frequently considered.

Table 6

Quality Evaluation Assessment using CASP Framework

	Evaluation criteria as outlined by CASP											
Study	Statement of aims	Method	Design	Recruitment strategy	Data collection	Researcher ppt relationship	Ethical issues	Data analysis	Statement of findings	Value of research	**Total score**	**Overall rating**
1.Bryne (2019)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9	High
2.Conti et al. (2021)	Y	Y	Y	IP	Y	N	Y	Y	Y	Y	8.5	High
3.Conti et al. (2017)	IP	Y	IP	Y	IP	IP	Y	IP	Y	Y	7.5	Medium
4. Dawson et al. (2014)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9	High
5. Dimitropoulos et al. (2015)	Y	Y	IP	Y	Y	IP	Y	Y	Y	Y	9	High
6. Dimitropoulos et al. (2017)	Y	Y	Y	IP	Y	N	IP	Y	Y	Y	8	Medium
7. Goddard et al. (2011)	Y	Y	Y	IP	Y	N	Y	Y	Y	IP	7.5	Medium
8. Goodier et al. (2014)	Y	IP	IP	IP	IP	Y	Y	Y	Y	IP	7.5	Medium
9. Graham et al. (2019)	Y	Y	IP	IP	Y	N	N	Y	Y	IP	7	Medium
10. Holmes et al. (2021)	IP	Y	IP	IP	IP	Y	Y	Y	Y	IP	7.5	Medium
11. Ibrahim & Tchanturia (2018)	Y	IP	IP	Y	IP	Y	IP	Y	Y	Y	8	Medium
12. Lonergan et al. (2022)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9	High
13. Toubøl et al. (2019)	Y	Y	Y	IP	Y	Y	Y	Y	Y	Y	9.5	High
14. Voswinkel et al. (2021)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10	High
15. Whitney et al. (2011)	Y	Y	Y	Y	IP	IP	Y	Y	Y	Y	9	High
16. Williams et al. (2020)	Y	Y	Y	IP	Y	Y	Y	Y	Y	Y	9.5	High
17. Wright & Hacking (2012)	Y	Y	Y	IP	Y	N	IP	Y	Y	Y	8	Medium
18. Wufong et al. (2019)	Y	Y	Y	Y	Y	IP	Y	IP	Y	Y	9	High

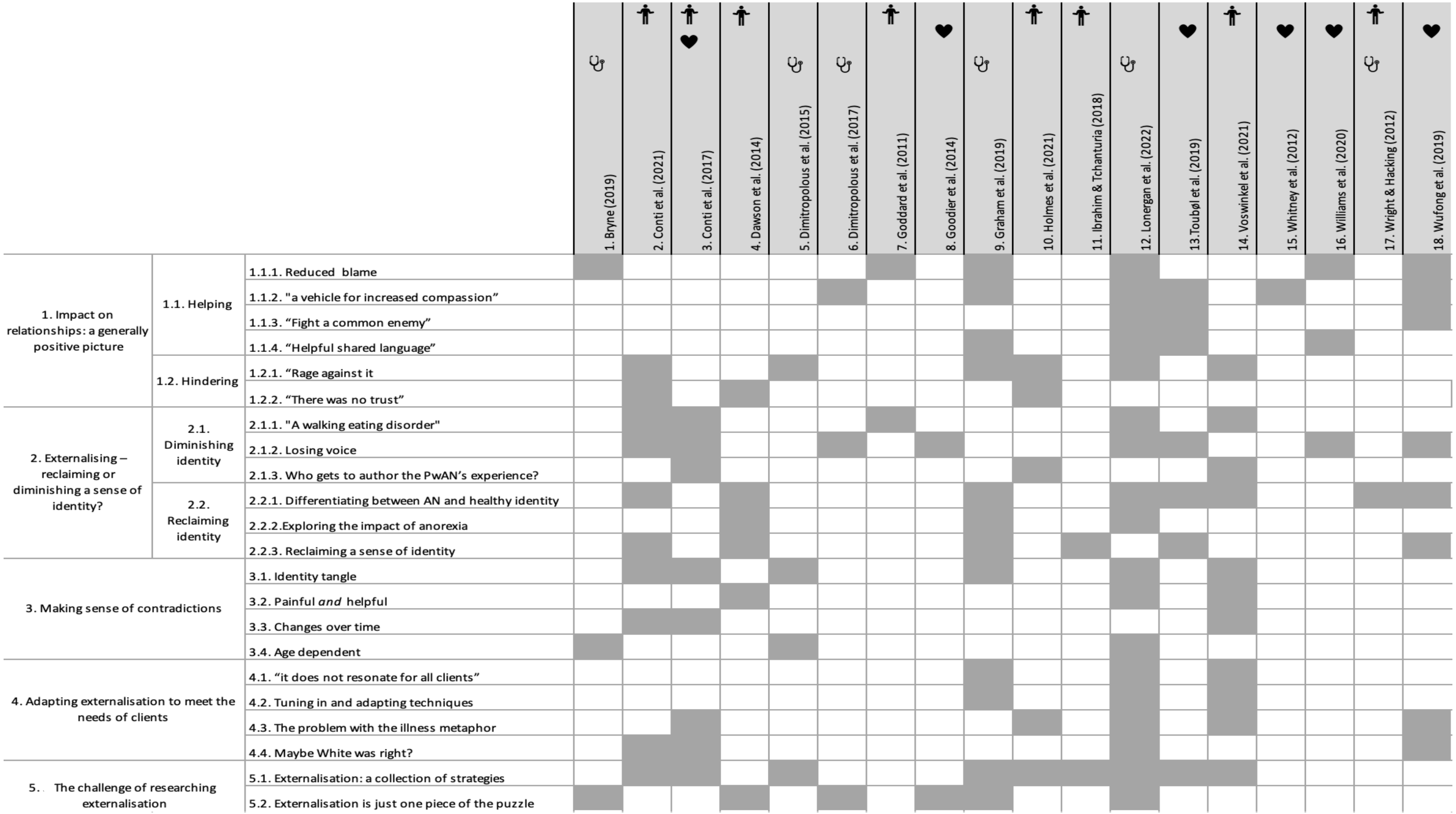
Note. Y= yes, N= no, IP= in part, ppts refers to participants. A study was awarded 1 point if it met the criteria in full, 0.5 points if it met it in part and 0 points if it did not meet the criteria.

Meta-Ethnography Results

Through the meta-ethnographic approach, five main concepts were developed, capturing 21 sub-concepts shown in Figure 2 and discussed below. The first main concept captured divided opinions on the impact of externalisation on relationships. A similar pattern emerged in the second main concept, which highlighted how stakeholders had differing views on the role of externalisation in PwAN's sense of identity. The third main concept synthesised first and second-order explanations and shed light on the contradictions highlighted by the first two concepts. The fourth integrated perspectives on the need to adapt externalisation to meet clients' needs. Finally, the fifth concept outlined some of the challenges of researching externalisation. The studies will now be referred to using the correlating numbers outlined in Tables 5-6.

Figure 2

Outline of Meta-Ethnography Results



			🩺 1. Bryne (2019)	🧍 2. Conti et al. (2021)	🧍 ♥ 3. Conti et al. (2017)	🧍 4. Dawson et al. (2014)	🩺 5. Dimitropolous et al. (2015)	🩺 6. Dimitropolous et al. (2017)	🧍 7. Goddard et al. (2011)	♥ 8. Goodier et al. (2014)	🩺 9. Graham et al. (2019)	🧍 10. Holmes et al. (2021)	🧍 11. Ibrahim & Tchanturia (2018)	🩺 12. Lonergan et al. (2022)	♥ 13.Toubøl et al. (2019)	🧍 14. Voswinkel et al. (2021)	♥ 15. Whitney et al. (2012)	♥ 16. Williams et al. (2020)	🧍 🩺 17. Wright & Hacking (2012)	♥ 18. Wufong et al. (2019)
1. Impact on relationships: a generally positive picture	1.1. Helping	1.1.1. Reduced blame	▨						▨		▨			▨				▨		▨
		1.1.2. "a vehicle for increased compassion"						▨			▨			▨	▨		▨			▨
		1.1.3. "Fight a common enemy"												▨	▨					▨
		1.1.4. "Helpful shared language"									▨			▨	▨			▨		
	1.2. Hindering	1.2.1. "Rage against it		▨			▨				▨	▨		▨		▨				
		1.2.2. "There was no trust"		▨		▨						▨								
2. Externalising – reclaiming or diminishing a sense of identity?	2.1. Diminishing identity	2.1.1. "A walking eating disorder"		▨	▨				▨					▨		▨				
		2.1.2. Losing voice		▨	▨			▨		▨				▨	▨			▨		▨
		2.1.3. Who gets to author the PwAN's experience?			▨							▨				▨				
	2.2. Reclaiming identity	2.2.1. Differentiating between AN and healthy identity		▨		▨					▨			▨	▨	▨			▨	▨
		2.2.2.Exploring the impact of anorexia				▨					▨			▨						
		2.2.3. Reclaiming a sense of identity		▨		▨					▨		▨		▨					▨
3. Making sense of contradictions		3.1. Identity tangle		▨	▨		▨				▨			▨		▨				
		3.2. Painful *and* helpful				▨								▨		▨				
		3.3. Changes over time		▨	▨											▨				
		3.4. Age dependent	▨				▨							▨						
4. Adapting externalisation to meet the needs of clients		4.1. "it does not resonate for all clients"									▨			▨		▨				
		4.2. Tuning in and adapting techniques									▨			▨		▨				
		4.3. The problem with the illness metaphor			▨							▨		▨		▨				▨
		4.4. Maybe White was right?		▨	▨									▨						▨
5. The challenge of researching externalisation		5.1. Externalisation: a collection of strategies		▨	▨		▨				▨	▨	▨	▨	▨	▨				
		5.2. Externalisation is just one piece of the puzzle	▨			▨		▨		▨	▨			▨						

Note. The following symbols were used to depict the sample of participants included in the study: PwAN = 🧍 carers = ♥ clinicians = 🩺

1. Impact on Relationships: A Generally Positive Picture

Across the studies, there was a sense that externalisation could improve stakeholder relationships by redirecting difficult feelings away from PwAN and towards AN. This paved the way for more empathy and understanding, a shift welcomed by stakeholders and perceived to influence recovery. In contrast, although seemingly less evident, was the perspective that externalisation could increase frustration and conflict between PwAN and those around them. Notably, contributions which strengthened the view that externalisation helped relationships tended to draw on the perspectives of clinicians and carers. Whereas experiences of the frustration externalisation can elicit were generally in relation to PwAN.

1.1. Helping Relationships

1.1.1. Reduced Blame

Clinicians (studies 1, 9, 12), carers (studies 16, 18) and PwAN (study 7) emphasised how externalisation enabled carers and clinicians to reduce blame towards PwAN, by redirecting difficult feelings away from PwAN and towards AN. Stakeholders welcomed this shift and acknowledged its positive impact on their relationships.

> "This [increased empathy] was facilitated in some cases by externalising the illness and directing frustration towards the illness not the individual: "She recognises that I have AN, it's not just my personality...and it's the AN she hates [not me]. She says she hates it for what it does to me and she hates the illness and sees how horrible it is...I like that she sees it as separate in one way because it makes me know that she doesn't hate me" (Researcher with PwAN quote, study 7).

1.1.2. Externalising Anorexia "A Vehicle For Increased Compassion" (Clinician, Study 9)

Redirecting difficult feelings such as blame and frustration away from the PwAN and towards anorexia paved the way for increased compassion and empathy (studies 6, 9, 12, 13, 15, 18).

> "It was evident that the externalisation technique supported parents in their experiences of battling a foe, and within this maintaining a separate space to love and care for their child" (Researcher, study 16).

1.1.3. "Fighting a Common Enemy" (Researcher, 12)

According to clinicians (study 12) and carers (studies 13, 18), externalisation helped relational interactions by uniting families against AN as a common enemy.

> "we were a joint force. I think if you can work together really quickly it helps because an eating disorder can get around one of you, but if it knows that dad's there backing up everything that mum says and vice-versa, I think that helps" (Carer, study 16).

1.1.4. "Helpful Shared Language" (Clinician, Study 9)

Carers (studies 13, 16) and clinicians (studies 9, 12) believed externalisation brought stakeholders closer by providing a shared language and aiding conversations about AN that deepened understanding of one another's perspectives.

> "Externalisation... [gave] parents a language to communicate between themselves and [enabled] siblings to find a way to talk about the impact of the ED on their lives" (Researcher, study 12).

1.2. Hindering Relationships

1.2.1. "Rage Against it [Externalisation]" (Clinician, Study 12)

In contrast to stakeholders' perspectives that externalisation could improve relational interactions, some recognised how externalisation could increase their frustration and conflict (studies 2, 5, 9, 10, 12, 14).

> "My parents were taught at the clinic to distinguish the child from the eating disorder... So, quite often, if I did something stupid or behaved badly, my parents would say "Oh, just let her talk, it is the eating disorder speaking". It would infuriate me, I'd think: 'Do you really not take me serious anymore?" (PwAN, study 14).

1.2.2. "There Was No Trust" (Pwan, Study 10)

Additionally, PwAN disclosed that this process made them feel untrusted by their carers and clinicians (studies 2, 10, 14), which often made them feel demotivated.

> "Another view towards an externalising approach reported by some of the participants was that they sometimes felt as if HCP's, or family-members, referred to behaviour as part of AN when in their own opinion this was not the case; it could result … in a feeling of not being trusted or believed" (Researcher, study 14).

2. Externalising – Reclaiming or Diminishing a Sense of Identity?

As per the first overarching concept, the second highlights how the impact of externalisation on PwAN's sense of identity attracted contradictory perspectives. Some felt that externalisation diminished PwAN's identity by attributing their views to an illness to justify excluding it. In contrast, others felt it supported PwAN to get distance from AN, enabling them to regain their true identity and life outside of the illness. This concept captured complex dilemmas raised by externalisation, such as who decides what belongs to an 'anorexic self' versus an 'authentic self'.

2.1. Diminishing Identity

2.1.1. "A Walking Eating Disorder" (Pwan, Study 10)

There was recognition amongst stakeholders (studies 2, 3, 7, 12, 14) that externalisation could lead to PwAN's opinions and behaviours being attributed to the externalised AN. This made PwAN feel like they were losing their identity to the 'disordered' entity.

> "If I chose something, it was always assumed that the eating disorder chose it . . . I was tired of being viewed through this lens of the eating disorder behaviour . . . Even if I said "I miss my family, I want to go home" they'd just say "that's your eating disorder talking"" (PwAN, study 10).

2.1.2. Losing Voice

A consequence of PwAN's views being attributed to AN was that they were then discounted, leading many to feel they lost their voice (studies 2, 3, 6, 8, 12, 13, 16, 18). Furthermore, this exclusion led to frustration amongst PwAN linked with the sub-concept "Rage against it".

> "the whole person of Hayley the Maudsley [method] had somewhat ignored that from the very start…we talk in these beautiful terms of "it was the eating disorder and not Hayley in the room" and all those euphemisms but effectively Hayley was still in the room but she was treated as though she wasn't. And it was actually really, I'm getting goose bumps talking about it because that was probably the most unnerving thing that the person who I believe has been the key to recovery… was deliberately excluded from the process" (Carer, study 3).

2.1.3. Who Gets to Author a PwAN's Experience?

In study 3, second-order constructs raised important questions about who decides whether we can or should separate out different parts of people's identities and who has the authority to decide which behaviours or opinions belong to which identity. Further insights were synthesised to highlight ethical issues with automatically mistrusting PwAN's perspectives and privileging those of carers or clinicians (studies 3, 10, 14).

> "Upon what criteria is it decided that a person's voice is theirs or the voice of the eating disorder? And who decides? And at what point does the totalisation of an adolescent's actions …as 'the eating disorder' risk their identity being externalised and further lost to 'the eating disorder?'" (Researcher, study 3).

> "One of the most significant issues to emerge in this study is the denial of patient "voice". The construction of "anorexic" voices as being "outside of the true"… these pathologising discourses should not be underestimated… as they can also "strip people of their civil liberties" (Researcher, study 10).

2.2. Reclaiming Identity

2.2.1. Differentiating Between AN and Healthy Identity

Unsurprisingly given the aims of externalisation, stakeholders across studies recognised the ability of this technique to create distance between their authentic identity and AN and found this was a key process in recovery (studies 2, 4, 9, 12, 13, 14, 17, 18).

> "I started to wonder that maybe a disease was controlling me and that, perhaps, I wasn't to blame for it… If it was a disease, then I didn't have to have it. Having the strength to realise that I could get out enabled me to break out" (PwAN, study 4).

2.2.2. Exploring the Impact of Anorexia

A perceived benefit of having space from AN was that it enabled new perspectives on how it impacted PwAN's lives (studies 4, 9, 12).

> "Being able to start externalising it and get distance on it may mean that [PwAN] might be able to be a bit more judgemental of it, or critical of the critical voice" (Clinician, study 9).

2.2.3. Reclaiming a Sense of Identity

This distance gave PwAN opportunities to reclaim a sense of identity outside of AN which was frequently linked with recovery (studies 2, 4, 9, 11, 13, 18).

> "By externalising the disorder, parents could keep it at arm's length, regard it as a phenomenon apart from the child and distinguish the healthy from the sick. In that way,

> the daughter's healthy identity could be preserved and amplified … which made it possible to gradually regain power over the symptoms" (Researcher, study 11).

3. Making Sense of the Contradictions

Throughout the studies, stakeholders and researchers offered insights that shed light on some contradictions within stakeholders' perspectives on externalisation.

3.1. Identity Tangle

First-and-second-order constructs converged to hypothesise that the more AN had been internalised as a PwAN's identity, the greater the likelihood that an individual may feel excluded or diminished by attempts to externalise AN (studies 2, 3, 5, 9, 12, 14). This finding goes some way to explain the conflicting perspectives highlighted in the 'Externalising – reclaiming or diminishing a sense of identity?' sub-concept.

> "I've never really used that separation terminology until probably now, (...) my eating disorder was me, (...) That was my talent, that was what I was good at, that's what I excelled in because I'd lost a lot of my identity, so I felt that that was my identity" (PwAN, study 2).

3.2.Painful *and* Helpful

As highlighted in 'Identity tangle', separating from a part of one's identity could be experienced as a painful process. Studies 4, 12 and 14 highlighted how this process could be experienced as both painful and helpful, providing further explanation for the variety of stakeholders' perspectives on externalisation.

> "Participants described it as being difficult in the short run, but they would also perceive it as necessary for recovery in the long run, since it could help them recognise which behaviour and which thoughts were evoked by AN" (Researcher, study 12).

3.3. Changes Over Time

Extracts from the literature indicated that PwAN's perspectives on externalisation often fluctuated over time (studies 2, 3, 14).

> "Nevertheless, the effects of externalisation of the eating disorder were evident when Hayley reconstructed her narrative about a turning point during the four months post MFT/FBT (…) Hayley: "I think I had enough to convince myself that the eating disorder is lying to me and that like up there was just that sort of spark of hope and determination which really helped me to imagine life without it"" (Researcher with PwAN quote, study 3).

3.4. Age Dependent

Providing further explanation for the varying opinions on externalisation, clinicians felt externalising techniques were better received by younger PwAN who may more readily take on the views of carers and clinicians (studies 1, 5, 12).

> "I find [16-21-year olds] don't like it, they get mad...your job as a teenager at that point is to figure out identity, self-concept, and someone's kind of telling you that it's an eating disorder that's part of you. I think that's an insult to some kids" (Clinician, study 5).

4. Adapting Externalisation to Meet the Needs of Clients

A key concept that arose from stakeholders' experiences was adapting externalisation to meet clients' needs. This overarching concept explores the context in which externalisation was experienced and synthesises second-order interpretations that offer ideas about flexibly using externalisation.

4.1. "It Does Not Resonate for All Clients" (Clinician, Study 9)

Capturing the contradictions highlighted in overarching concepts 1 and 2, some clinicians and researchers explicitly named that externalisation was not an effective strategy for everyone (studies 9, 12, 14). Researchers named issues such as PwAN's variable relationship with their AN identity (12) and overuse of the technique leading to client loss of voice (14) as reasons for some PwAN disregarding externalisation. Clinicians cited reasons such as PwAN having a long-standing AN diagnosis (12), a co-occurring diagnosis of Autism Spectrum Disorder (12) or more generally not resonating with the idea of AN representing a separate or defined part of them (9) as reasons for disregarding externalisation.

> "Many HCPs stated that while the [anorexic voice] resonated with some PwANs, others did not relate to it: "She went through therapy and they were talking about the anorexic voice and she came home really upset saying, "I don't think I've got anorexia because I don't have the anorexic voice" (Researcher with clinician and PwAN quote, study 9).

4.2. Tuning in and Adapting Techniques

First and second-order insights were offered to manage the challenge that externalisation does not resonate with everyone. Key concepts were tuning into how families respond to externalisation and adapting the approach accordingly (9, 12, 14).

> "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 young person 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, study 12).

4.3. The Problem with the Illness Metaphor

Second-order interpretations from studies 3, 10, 12, 14, and 18 emphasised that externalising AN using the prescribed illness metaphor imposed a narrow perspective of AN as 'bad'. This was seen to run the risk of alienating PwAN, who feel synonymous with or value AN.

> "When externalisation is confined to a dualistic biomedical discourse, an adolescent's experience is constructed as an illness/disease that is totalised as bad, with recovery—as the antithesis of illness/disease—constructed as entirely good. Michael White has argued that dualistic conceptions of AN set up the task of therapy as adversarial and risk leading to a sense of exhaustion when this does not eventuate" (Researcher, study 18).

4.4. Maybe White was Right?

Throughout the literature, there was an encouragement to move away from the illness metaphor and adopt externalisation techniques outlined by NT (studies 2, 3, 12, 18). Researchers argued it would overcome some of the issues raised and empower PwAN to author their own stories related to AN.

> "Within narrative therapy, this practice [externalisation] is intertwined with inviting the experiencing person to map the effects of the problem (White, 2007; White & Epston, 1990) and from this standpoint, the problem is named on their own experience-near terms that can handle the contingencies of their complex social reality" (Researcher, study 3).

5. The Challenge of Researching Externalisation

A reflection by the present author was the challenge of understanding the impact of externalisation because it is practised in various ways and often embedded into wider therapeutic practises as captured by two sub-concepts below.

5.1. Externalisation: A Collection of Strategies

Various methods of externalisation were described throughout the studies, including using the illness metaphor (studies 2, 5, 12, 14); using bespoke metaphors (studies 9, 11, 13); sculpting exercises in which AN is represented by a person or object (study 10); personifying AN (studies 12, 14); inviting carers to view AN as separate (study 16); using Venn diagrams to illustrate differences between PwAN and their AN identity (study 2); interviewing PwAN from the position of their AN self (studies 2, 9); creating visual depictions of AN (study 5).

5.2. Externalisation: Just One Piece of the Puzzle

Furthermore, clinicians and researchers in studies 1, 4, 6, 8, 9, and 12 highlighted how externalisation is a therapeutic technique embedded within a broader therapy model or setting, further complicating our ability to draw firm inferences about its impact.

> "Eight factors emerged that clinicians believed could facilitate successful FBT treatment in children and adolescents with an eating disorder; early intervention, younger age of child, alignment, adhering to the model, supervision, clinician experience working with ED, externalising anorexia" (Researcher, study 1)

> "We educate about eating disorders, we lift blame, we raise anxiety, we externalise the illness" (Clinician, study 6).

Discussion

PwAN’s relationship to their AN identity seems crucial to understanding their experience of the disorder and motivation for recovery (e.g. Conti et al., 2020; Duncan et al., 2015). For example, PwAN commonly report experiencing a critical inner voice (Noordenbos & Van Geest, 2017) often referred to as an anorexic voice (ANV) that is either part of, or separate to, the individual (Tierney & Fox, 2010; Williams & Reid, 2012). The ANV has been implicated in the development, maintenance and ambivalence PwAN can hold about recovery. Namely, a typical feature of the ANV is its criticisms around shape and weight and its encouragement for individuals to engage in AN behaviours (Pugh, 2016; Tierney & Fox, 2011). Furthermore, this critical inner voice commonly attacks PwAN’s self-worth, leading many to feel increasingly powerless to refuse its demands and lacking confidence to stand up to it (Aya et al., 2019; Burnett-Stuart, 2021). This type of relationship that PwAN can have with their ANV has led some to liken it to an abusive partner and connect it to the perpetuation of AN and a barrier to recovery (Burnett-Stuart, 2021; Tierney & Fox, 2011).

Perhaps because of the capacity for externalisation to create distance between an individual and internalised aspects of their identity (White, 1990), it has gained traction as a therapeutic intervention for AN (Lock et al., 2001). While research focussing on externalisation is limited (Lonergan et al., 2022), this technique has gained some attention in research exploring stakeholder’s experiences of various therapeutic models and settings for AN (e.g. Heywood et al., 2022; Medway & Rhodes, 2016). A preliminary review of this research highlighted that externalisation offered benefits such as an opportunity for PwAN to reclaim their identity and recover from AN (Stockford et al., 2019). However, other research highlighted the potential for externalisation to impede recovery, for example, by alienating and excluding PwAN from therapy (Wufong et al., 2019). Therefore, this review set out to synthesise existing literature exploring the experiences and perspectives of PwAN, carers and clinicians on externalisation and aimed to provide stakeholder-led insights into if and how externalisation may be used effectively in treating AN and to shed light on potentially conflicting views.

A central concept that emerged in this review was stakeholders' experience of externalisation impacting their relationships with one another. Generally, stakeholders believed externalisation fostered healthy relationships between PwAN and those supporting them in several ways. Since supportive relationships are 'pivotal in the recovery process' (Peskett et al., 2022, p.43); this review indicated that externalisation may indirectly support recovery by improving interactions between family members.

By providing an outlet for stakeholders' anger and frustration, externalisation removed barriers to supportive relationships by reducing blame and conflict with PwAN (Hutchinson & Rapee, 2007). In addition, this outlet made space for compassion and empathy, both hallmarks of healthy relationships (Lathren et al., 2021) and facilitative to recovery from AN (Espíndola & Blay, 2009). Furthermore, externalisation seemed to unite families by providing a shared language about AN and bought them together to fight against a common enemy. In further support that externalisation may indirectly foster recovery by improving relationships, wider research has highlighted that having a shared language between stakeholders about AN is crucial to recovery (e.g. Dawson et al., 2014; Yorke et al., 2021).

In contrast to the picture that externalisation improved relationships was the view that it could cause frustration for PwAN and conflict between stakeholders. In many cases, this stemmed from PwAN feeling as though *their* views were attributed to AN and consequently discounted, leaving them feeling excluded or mistrusted. Demonstrating how these experiences could impede recovery, PwAN often cite a lack of trust as a key reason for disengaging from treatment (Holmes et al., 2021; Vandereycken & Devidt, 2010). Furthermore, conflict and highly expressed emotions between family members have been found to negatively impact treatment outcomes (Rienecke et al., 2016).

This review highlighted that many of the perceived benefits of externalisation related to carers and many adverse effects were felt by PwAN, emphasising a contrast between these stakeholders regarding how they experienced and evaluated externalisation. While PwAN's perspectives must play a vital role in developing our understanding of effective AN treatment, carers too can play a crucial role but are often overlooked (Fox et al., 2017; Treasure et al., 2021). Supporting PwAN can have a heavy toll on carer’s lives; Fox and colleagues (2017) highlight that caring for a PwAN can bring up a host of challenging feelings such as anger, guilt, worry, shame and blame which can be tough to grapple with and a barrier to their caring role. This review emphasised that externalisation went some way to helping carers manage these feelings. Given the impact this could have on carers' wellbeing and ability to offer ongoing care (Anastasiadou et al., 2014), these benefits should not be readily discounted. In addition, externalisation was found to facilitate indirect support to PwAN, for example, by enhancing carer compassion. However, PwAN may not link such benefits with externalisation, which could lead them to offer a less favourable view of the technique than it deserves.

Stakeholders’ views on the impact of externalisation on PwAN’s identity attracted further divided opinions. For example, numerous studies highlighted the potential for externalisation to diminish PwAN’s sense of identity by dismissing their views as belonging to AN, making them feel excluded and frustrated. Such feelings of disempowerment may have vital implications for PwAN and could lead them to hold more tightly onto AN, which offers them both a sense of identity and power (Williams & Reid, 2007), which may explain why failing to include PwAN in treatment decisions meaningfully has been found to reduce motivation and adherence (Holmes et al., 2021).

In contrast, this review also captured the stakeholder belief that externalisation created distance between PwAN's authentic and AN identity, enabling new perspectives such as the impact of AN on their lives. Some saw this as a crucial process in supporting PwAN to reclaim their authentic identity, an evidenced core component of effective treatment across therapeutic models (Conti et al., 2020).

Helpfully, some insights were put forward from stakeholders and researchers alike to shed light on these contradictory views. Firstly, literature converged to imply that the more closely PwAN's sense of identity was linked with AN, the more likely they were to appraise externalisation negatively. This finding corresponds with previous meta-synthetic research highlighting that PwAN often struggle to engage with psychological change when they experience their identity as synonymous with AN (Gregertsen et al., 2017).

Secondly, the relationship that PwAN have with their AN identity may help us understand why their perspectives on externalisation change over time. PwAN's relationship to their AN identity can fluctuate significantly and be described as anywhere between "angel or devil" and "part of me or taking over me" at different points in time (Burnett-Stuart, 2021; p.10). Given that people's relationship to their AN identity influences their experience of externalisation, this fluctuating relationship further explains why perspectives on externalisation appear changeable and, at times, polarised.

Thirdly, this review brought together literature to illustrate how some PwAN experience externalisation as simultaneously unpleasant and helpful for their recovery, shedding further light on the contradictory views. This picture fits with previous research which exposed PwAN's experience of giving up their AN identity as both a painful and necessary part of recovery (Conti et al., 2020).

Finally, half of the studies exploring clinician's views determined that externalisation may work better for younger people than older adolescents with AN since they may be accustomed to being guided by their parent's way of viewing the world and, therefore, may more readily adopt the metaphor of AN as an illness. The same pattern has been found in research exploring FBT outcomes more broadly (Lock et al., 2006), which is perhaps unsurprising given that the adolescent stage is usually marked by greater independence from parents while FBT promotes parental responsibility over key PwAN behaviours (Dimitropoulos et al., 2015).

This meta-synthesis highlighted concerns about using the illness metaphor to externalise AN, as is instructed in manualised FBT (Lock et al., 2001). In a handful of studies, researchers argued that utilising externalisation as a tool to dismiss a PwAN's views on the basis that they belong to an illness can lead to a fight for a monopoly of the truth between stakeholders. Voswinkel and colleagues (2021) refer to this as 'testimonial injustice' (p.12) and highlight the ethical slippery slope stakeholders could find themselves on if one's mental health status is viewed as a valid determinant of authority over the truth.

Conti and colleagues (2017) asked the pertinent question of 'who decides?', meaning who has authority over the truth. The issue of whose truth we buy into has important clinical implications. Tan and colleagues (2003) outline a dilemma this raises; if we assume AN is an illness impacting someone's capacity to make decisions about their true self, we are justified in discounting those views since it is in the person's best interest. However, if someone's AN identity is understood to be their true identity, then assuming the person has capacity, we surely have a duty to respect and honour any wishes they express regardless of how much those views differ from our own or risky the consequences may be. This dilemma touches upon a broader ethical debate within the mental health field in which families and professionals can find tension between protecting individuals from harm and wishing to respect and empower their choices (Braye et al., 2017). This dilemma is perhaps more keenly felt in the AN arena due to the ego-syntonic nature between peoples' identities and traits recognised as AN (Gregertsen et al., 2017).

This meta-synthesis bought forth ideas that could resolve the dilemma. Some researchers argued that by using externalising techniques outlined by NT, whereby PwAN are invited to author their own unique and nuanced relationship with AN (White & Epston, 1990), it might be possible to both empower PwAN and give them the best chance of ‘re-covering their life and identity from AN’ (Wufong et al., 2019; p.14).

Limitations

A limitation of this study is that it included research exploring experiences of externalisation in several different contexts. The diversity of the methods of externalisation experienced by stakeholders across the studies is captured by the sub-concept 'Externalisation: A collection of strategies'. An implication is that evaluations of externalising synthesised in this study may conflate perspectives on rather diverse externalising techniques making it difficult to understand how evaluations link with various methodologies.

Furthermore, externalisation is embedded into broader therapeutic practices with limited research into it as a standalone technique; of the 18 studies included in this review, only two papers focussed directly on stakeholder's experiences of externalisation (Lonergan et al., 2022; Voswinkel et al., 2021). This limitation made it difficult to determine what impact externalisation alone may have had in AN amelioration or deterioration. Adopting a wider lens for this review, for example, exploring stakeholders' experiences of externalising within the FBT model, may have better contextualised the findings.

A further limitation of this review is that translator costs fell outside of the project scope resulting in the exclusion of research published in languages other than English. Although the included studies were conducted in geographically diverse areas spanning Europe, Australasia and North America, these areas are also Western and predominantly White. Therefore, the language limitation likely excluded stakeholders' perspectives from other ethnicities and cultures, narrowing the perspectives offered. Since people's ethnic background and cultural experiences shape their perception of AN, treatment and recovery (Yu & Perez, 2020), this limitation has implications for the generalisability of the results. A critique of the available literature which has a bearing on this point is the underreporting of the ethnicity of participants noted in this review. Without information about ethnicity, it is impossible to contextualise the results from this perspective or gauge the extent of unmet needs in diversifying recruitment samples.

Recommendations for Future Research

This review identified two specific avenues of future research to address the paucity of research into externalisation and the implications this has. Firstly, researchers argued that it might be possible to enhance the benefits and reduce the harm externalisation can cause by moving away from the illness metaphor and empowering PwAN to author their relationship with AN, as outlined by NT. However, empirical research into the impact of NT on AN is sadly lacking and seemingly absent for individual therapeutic components such as externalisation (Heywood et al., 2022). Therefore, more research into stakeholders' experiences of externalisation in the context of NT would be beneficial to understand if the call for this approach is warranted.

Secondly, this review exposed variability in terms of externalising methods employed by clinicians and acceptability experienced by stakeholders. Lonergan and colleagues (2022) found that clinicians' ability to adapt externalisation techniques to meet clients' needs was essential to their success. However, clinicians often used trial and error before finding effective methods. Therefore, more research into which externalisation techniques are most effective when treating AN could inform future training for clinicians and enhance the utility of externalising.

Implications for Clinical Practice

Implicitly highlighted by the contradictory views about externalisation, and explicitly recognised by some clinicians and researchers, was the view that externalisation "does not resonate for all clients" (Graham et al., 2019; p.2). This review found that some clinicians were sensitive to this and used their therapeutic skills to adapt their techniques accordingly. However, given some of the issues stakeholders raised in this meta-synthesis, it seems externalisation is only sometimes offered sensitively and effectively. This study, therefore, encourages clinicians who use this technique to be aware of the potential harm it can cause, evaluate its acceptability amongst PwAN and be willing to adapt or altogether cease externalising techniques.

This review emphasised challenging tensions between protection and empowerment in clinicians' work with PwAN who may actively resist recovery even when in a life-threatening condition. In addition to future research exploring which methods of externalisation may best achieve both empowerment and recovery, it may be helpful for clinicians to consider techniques that could be used alongside therapeutic modalities which include externalisation to enhance the likelihood that PwAN are able to work towards these, at times, seemingly opposing goals. In their meta-synthesis of experiences of AN recovery, Duncan and colleagues (2015) cite PwAN's genuine motivation for recovery as the key to enabling autonomy and empowerment in PwAN's treatment journeys. Clinicians may consider incorporating motivational interviewing into their work, an approach that can be used adjunct to a wide range of therapeutic models to enhance motivation by exploring ambivalence about change in a person-centred, non-judgemental way (Arkowitz et al., 2015).

Conclusions

This review highlighted stakeholders' contradictory views on the impact of externalisation on PwAN's relationships and sense of identity, indicating that this technique has the potential to help or harm PwAN's journey to recovery. Ways of understanding these contradictory views were offered, and the need for clinicians to adapt and evaluate externalisation in practice was identified as a critical implication. More research focussing on stakeholders' experiences of externalisation within an NT approach or how externalisation can be optimised to promote recovery would benefit the field.

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MAYA KUHL BSc Hons

Major Research Project

Part B: Empirical Study

Exploring Carers' Perceptions of the Anorexic Voice: A Reflexive Thematic Analysis

Word Count: 8,000 (323)

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Abstract

Carers' support is a crucial component of successful treatment for anorexia nervosa (AN), yet research indicates their inclusion in treatment and research needs improvement. The anorexic voice (ANV) is a phenomenon that seems clinically relevant to our understanding of the development, maintenance and amelioration of AN, yet it lacks carers' perspectives. This study addressed this knowledge gap and explored 13 carers' perspectives of the ANV using semi-structured interviews. Transcripts were analysed utilising reflexive thematic analysis. Results revealed that carers held varying definitions of the ANV, and the construct attracted both advocates and opponents. Advocates of the ANV recognised it as a powerful bully and found they could support recovery by altering how they and their loved ones related to the bully. In addition, themes of the ANV both helping and hindering the caring role emerged. These findings are outlined in the context of existing literature and an exploration of the limitations, clinical implications and future directions from this study are illustrated. For example, this study highlighted that carers could play a vital role in supporting their loved ones to develop a healthier relationship with their ANV. However, in-depth research is needed to explore how stakeholders define the ANV.

Introduction

Anorexia Nervosa and the Role of Carers

There is a long-held recognition of the importance of family processes in the development and maintenance of Anorexia Nervosa (AN; Fisher et al., 2019). Early family therapy (FT) approaches attempted to outline models of family processes that increased vulnerability to AN, such as dynamics where conflict was avoided, change was resisted, and parents were highly protective (Rosman et al., 1978). While some empirical evidence supports an association between such family environments and AN (Cerniglia et al., 2017), there is recognition that a range of unique family processes and experiences may be significant in its development (Nilsson et al., 2007).

More recent frameworks for understanding the development and maintenance of AN acknowledge the complex interplay of genetic, psychological and environmental factors (Culbert et al., 2015). Furthermore, research has highlighted the psychological distress and far-reaching impact on the whole family system that caring for a person with AN (PwAN) can have (Fox et al., 2017). An association between particular family dynamics and AN may therefore illustrate the family's re-organisation around the disorder rather than such dynamics driving AN aetiology (Whitney & Eisler, 2005). Acknowledging this, Schmidt and Treasure's (2006) evidence-based model illustrates the cyclical role of carer distress in maintaining AN symptomology, as interactions between family members can lead to conflict or accommodation of symptoms in a bid for harmony. These ways of coping can both in turn exacerbate AN and familial distress.

It follows that interventions which include carers are more likely to be successful; Family-Based Therapy (FBT) is the first recommended treatment for young PwAN in the UK due to its evidence base indicating longer-lasting outcomes (Couturier et al., 2013; NICE, 2017; Smith & Cook-Cottone, 2011). Based on improved outcomes, treatment for adults emphasises the importance of including carers (Hodsoll et al., 2017; Magill et al., 2016). However, there is a recognition that carer inclusion must be at the PwAN's discretion (NICE, 2017). Furthermore, meta-analytic data and service user perspectives indicate that poor inclusion of carers hinders better outcomes in PwAN of all ages (Goddard et al., 2013; Kästner et al., 2021).

In addition to the vital role carers play in ameliorating AN, the impact of the caring role on their wellbeing must not be overlooked. Carers report struggling with feelings of guilt, anger, despair and anxiety (Beale et al., 2005; Cottee-Lane et al., 2004; Treasure et al., 2001) and are at an increased risk of developing mental health conditions, a vulnerability which has increased since the pandemic (Anastasiadou et al., 2014; Richardson et al., 2020). In line with healthcare policy which increasingly emphasises the need for early prevention and intervention (NHS England, 2019), providing carers with appropriate information and support could also play a crucial role in protecting their wellbeing (Hodsoll et al., 2017; Sepulveda et al., 2008).

Meaningful inclusion of carers' perspectives in research is crucial to the development of effective treatment and services (Obeid et al., 2020; Sepulveda et al., 2008). For example, including carers' perspectives in a meta-review exploring key ingredients of successful treatment highlighted an unmet need for more individualised treatments for PwAN and their families (Gustafsson et al., 2021). Although including carers in treatment and research could have widespread benefits (Treasure et al., 2021), research has shown that they often feel excluded and unsupported in their role (Fox et al., 2017).

The Anorexic Voice

A research topic that seems significant in developing our understanding and treatment of AN is the anorexic voice (ANV; Chua et al., 2022; Pugh, 2020). Research suggests that an overwhelming majority of people with an eating disorder (ED) report experiencing a critical inner voice (Noordenbos et al., 2014; Noordenbos & Van Geest, 2017). While there is variability in how the ANV presents, individuals who experience such voices commonly observe criticisms around their shape and weight, encouragement to engage with AN behaviours and it increasing in power (Pugh, 2016; Tierney & Fox, 2011). In support that these subjective experiences correlate to tangible consequences, Pugh and Waller (2016) found that the perceived power and malevolence of the ANV were associated with indicators of more serious AN, such as lower weight. PwAN generally experience the ANV as emanating from them or part of them (Fox & Diab, 2015; Williams & Reid, 2012), which differs from voicing hearing in other contexts in which voices are heard as separate from the self (Longden et al., 2012). As such, reference to the ANV herein refers to this collection of manifestations of the ANV.

Research into the ANV indicates it plays a role in developing, maintaining and impeding recovery from AN. In the early stages of AN, individuals report feeling enticed by the voice as it meets critical needs, such as providing a sense of companionship or identity (De Giacomi, 2019; Williams et al., 2016). However, as the ANV becomes more punitive and critical, hearers have shared experiences of engaging with AN behaviours to appease it (Tierney & Fox, 2011). Shedding light on ambivalence about recovery that is often observed in PwAN (Gregertsen et al., 2017), individuals often report both a desire to escape and connect with the voice (Dawson et al., 2015), as well as a lack of confidence to stand up to it (Tierney & Fox, 2010).

Emerging research indicates that working with the ANV in treatment could prove effective. For example, recovered PwAN reflected on progress within their recovery correlating with changes in their relationship to the ANV (Peskett, 2022). Furthermore, therapeutic techniques which alter PwAN's relationship with the ANV may support recovery. For example, separating oneself from, standing up to and gaining new perspectives on the ANV have been experienced as supporting recovery (De Giacomi, 2019; Jenkins & Ogden, 2012; Lock et al., 2004).

Theories of the ANV

Although a more thorough review of theories applied to make sense of the ANV is beyond this study's scope and available elsewhere (Pugh, 2020) to contextualise existing literature and the current study, it seemed beneficial to explore some here. One theory is that the ANV could be regarded as a version of Stone and Stone's (1993)' inner critic', which is hypothesised to develop to echo the concerns of wider society and those close to us, encouraging us to live in line with their expectations thus protecting us from the shame of criticism or pain of rejection. In support of this theory, PwAN's relationship to their ANV mirrors their relationship style in external relationships (Forsén Mantilla et al., 2018). Additionally, the ANV appears to share characteristics of the voice of abusers or bullies from PwAN's past (Morrison et al., 2022). Furthermore, societal pressures such as body shape ideals are risk factors for developing AN, indicating such messages may have been internalised (Logrieco et al., 2021; Stice et al., 2002).

Dissociation from aspects of the self due to adverse experiences is theorised to be implicated in voice hearing in other contexts (Longden et al., 2012). Applying this theory to AN, Pugh et al. (2018) found an association between the power of the ANV and emotional abuse in childhood mediated by experiences of dissociation. This theory would make sense of the common experience of the ANV as somewhat detached from oneself and beyond the individual's control (Jenkins & Ogden, 2012).

In psychoanalytic terms, the ANV could be viewed as an individual's 'shadow', representing unacceptable or disowned aspects of the person's personality (Jung, 1971). Jung argued that people could become 'possessed by their own shadow' (p.145) if their conscious mind is shocked, confused or overwhelmed. In support of this, AN disproportionately affects females (Van Eeden et al., 2021), who are discouraged from expressing feelings such as anger and encouraged to display more positive emotions (Hambrook et al., 2011; Zeman et al., 2012). In contrast, PwAN commonly describe the ANV as angry, destructive and antithetical to their personality, indicating it may represent unacceptable aspects of their identity (Smethurst & Kuss, 2018). In further support, Fox and colleagues (2013) found that PwAN viewed anger as more unacceptable than healthy controls and expressed anger via disgust for their body which was viewed as acceptable.

Challenges of the ANV

While the ANV may help us better understand AN (Pugh, 2016), it is difficult to ascertain the precise role of the ANV within the life-threatening disorder that so terrifies and confuses carers and clinicians (Fox et al., 2017; Webb et al., 2022). Firstly, for some, the ANV is described as a perceptual experience (Higbed & Fox, 2010; Pugh, 2016), while for others, it represents a metaphor or way of externalising thoughts relating to AN (Graham et al., 2019). Often, these constructions are conflated under the same label, complicating the task of understanding how these different experiences influence AN.

Secondly, there is a significant overlap between factors attributed to the ANV and those attributed to AN more broadly in the development and maintenance of AN. For example, as highlighted above, the sense of identity the ANV provides people is thought to help us understand how AN develops. However, before research on the ANV, the sense of identity AN brings has been mooted as a factor explaining AN development (Stockford et al., 2019). Though no empirical research has explored explanations for these overlapping findings, possible explanations are that the ANV may further add to a sense of identity that AN already offers, or perhaps PwAN experience AN and the ANV synonymously such that perceived benefits would relate to both, or maybe the ANV voices the sense of identity that AN offers.

The Current Study

Our understanding of the ANV and how it can support recovery is growing. However, of 13 studies included in a systematic review (Aya et al., 2019) and 19 in an unpublished meta-ethnography (Burnett-Stuart, 2021), carers' perspectives were not represented, indicating an absence of in-depth research in this area. Given the important insights and perspectives carers may bring to our understanding of AN, investigating how they think about this clinically relevant phenomenon may be beneficial in enhancing treatment approaches for people with AN and better supporting carers in their role. This study, therefore, aims to address this gap and explore carers' perceptions of the ANV. A qualitative approach will be taken to privilege carers' perspectives and allow for a rich exploration of their knowledge and experiences in this unchartered territory.

Specifically, this study sought to explore the following key issues:

1. How do carers understand and relate to the ANV?
2. How do carers' perceptions and experiences compare to carer's understanding of how their loves ones perceive and experience the ANV?
3. What role, if any, do carers see for the ANV in recovery?

Methods

Ethical Considerations

Recognising that caring for a loved one with AN can be challenging (Zabala et al., 2009) and discussing the ANV may be emotive (Tierney & Fox, 2010), the research team ensured the ethical conduct of the study remained a paramount concern throughout and adhered to protocols outlined in the proposal approved by an NHS Research Ethics Committee (Appendix A).

Design

To explore carer's perspectives of the ANV, a qualitative design was used. Semi-structured interviews were employed as carer's perspectives on the ANV have not yet been explored, and this method facilitates sharing of experiences such as; personal meanings, descriptions, and novel perspectives not limited by the interview guide (Guba & Lincoln, 1994; Smith & Sparkes, 2016).

Reflexive thematic analysis (RTA) was used to synthesize data (Braun & Clarke, 2019) as it allows the exploration of data in novel research areas where prior assumptions are not required (Willig, 2013). Furthermore, it enables researchers to capture potentially diverse perspectives and gives participants a voice in research (Trainor & Bundon, 2021).

The lead researcher’s epistemological standpoint aligns most closely with social constructionism. Believing that the construction of knowledge happens in interactions between people and that many valid versions of reality exist (Amineh & Asl, 2015), there was a commitment to shine a light on neglected carers’ perceptions and those ‘most facilitative of recovery and meaning-making’ (Pugh, 2016; p.76). Braun and Clarke (2019) outline how good quality RTA can be achieved with any epistemological underpinning and emphasize the importance of the researcher’s reflective engagement throughout the data analysis.

Service User Involvement

Consultation of experts by experience via a focus group played an influential role in shaping the study design (Appendix B). For example, this process highlighted the emotive nature of discussions regarding the ANV, which informed a protocol to manage distress (Appendix C). In addition, participants emphasised a desire for the study to be recovery-oriented, shaping the overarching research aims.

Participants

To recruit carers of PwAN, a purposive sampling approach was used. The aim had been to recruit participants via NHS and independent organisations. Though an NHS trust consented to advertise the project (Appendix D), delays in facilitation of the carers’ group where the project was planned to be advertised meant all participants were recruited via the New Maudsley Carer’s Network. In line with their organisational protocols, individuals who subscribed to receive research adverts received a copy of the recruitment poster (Appendix E) via their network lead.

Inclusion Criteria

Participants were required to have experience caring for a loved one with AN, be aged 18+ and be able to speak fluent English since translator costs fell outside of the study scope. Thirteen carers participated; eleven were interviewed individually, and one couple participated together. Recruitment was suspended at this point as data collection was deemed to have adequately met the research aims (Braun & Clarke, 2021). Participant information is shown in Table 1.

Table 1

Participant Information

Pseudonym of participant/s	Pseudonym of loved one with AN	Relationship to PwAN	Length of time in caring role	Gender	Ethnicity (as described by participant)
Linda	Lisa	Mother	3 years	Female	White British
Tony	Tina	Father	8 months	Male	White
Alan	Amy	Father	1 year	Male	White Anglo Saxon British
Claire	Chloe	Mother	3 years	Female	White British
Molly	Michael	Mother	2 years	Female	White British
Jackie	Julie	Mother	8 years	Female	White British
Sandra and Simon	Sally	Mother and Father	14 years	Female, Male	Both White British
Nancy	Naomi	Mother	1 year and 6 months	Female	European White
Fiona	Fern	Mother	5 years and 6 months	Female	White British
Dawn	Daisy	Mother	1 year and 9 months	Female	White British
Emma	Ellie	Mother	2 years	Female	European White
Helen	Harriett	Mother	14 years	Female	White Caucasian

Note. Participants and their loved ones were given pseudonyms to protect their identity. Generic pseudonyms of ‘Anna’ or ‘Ed’ replaced personal names given to the ANV throughout the transcripts to further protect participants’ identity.

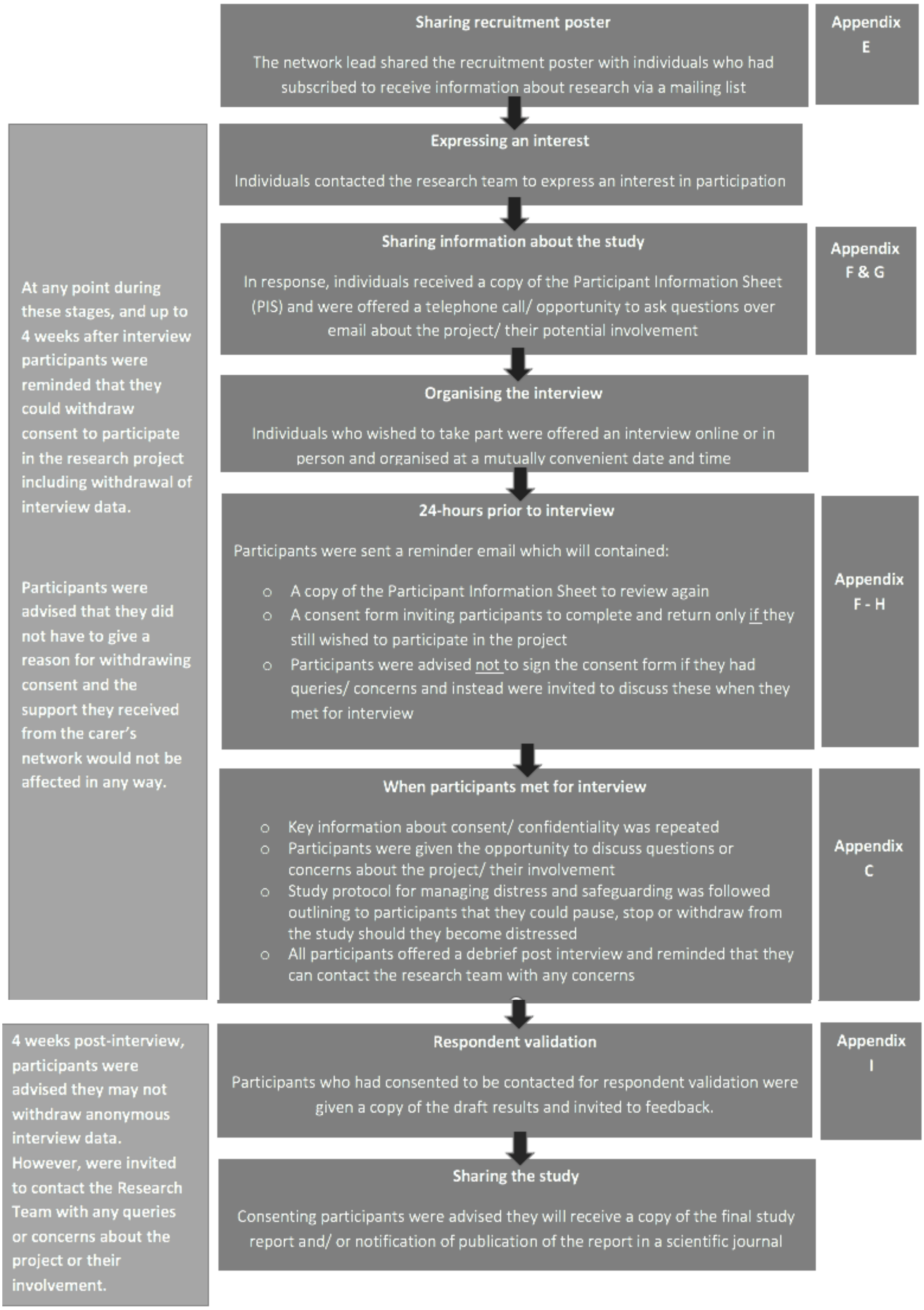
Seventeen carers responded to the recruitment advertisement. Five individuals expressed initial interest in participation but did not make further contact having received study information. To minimise intrusion, these individuals were not asked why they did not pursue participation.

Procedure

Individuals who expressed an interest in taking part were given information (Appendix F) and ethical procedures around consent were carefully followed as outlined in the Participant Journey (Figure 1).

Figure 1

Participant Journey



Sharing recruitment poster

The network lead shared the recruitment poster with individuals who had subscribed to receive information about research via a mailing list

Appendix E

Expressing an interest

Individuals contacted the research team to express an interest in participation

Sharing information about the study

In response, individuals received a copy of the Participant Information Sheet (PIS) and were offered a telephone call/ opportunity to ask questions over email about the project/ their potential involvement

Appendix F & G

Organising the interview

Individuals who wished to take part were offered an interview online or in person and organised at a mutually convenient date and time

24-hours prior to interview

Participants were sent a reminder email which will contained:

- A copy of the Participant Information Sheet to review again
- A consent form inviting participants to complete and return only if they still wished to participate in the project
- Participants were advised not to sign the consent form if they had queries/ concerns and instead were invited to discuss these when they met for interview

Appendix F - H

When participants met for interview

- Key information about consent/ confidentiality was repeated
- Participants were given the opportunity to discuss questions or concerns about the project/ their involvement
- Study protocol for managing distress and safeguarding was followed outlining to participants that they could pause, stop or withdraw from the study should they become distressed
- All participants offered a debrief post interview and reminded that they can contact the research team with any concerns

Appendix C

At any point during these stages, and up to 4 weeks after interview participants were reminded that they could withdraw consent to participate in the research project including withdrawal of interview data.

Participants were advised that they did not have to give a reason for withdrawing consent and the support they received from the carer's network would not be affected in any way.

Respondent validation

Participants who had consented to be contacted for respondent validation were given a copy of the draft results and invited to feedback.

Appendix I

Sharing the study

Consenting participants were advised they will receive a copy of the final study report and/ or notification of publication of the report in a scientific journal

4 weeks post-interview, participants were advised they may not withdraw anonymous interview data. However, were invited to contact the Research Team with any queries or concerns about the project or their involvement.

Data Collection

Experts by experience and the research team who held professional and research experience with AN collaboratively developed the semi-structured interview guide which explored participant's experiences, perspectives of the ANV and its potential role in recovery (Appendix J). Aiming to privilege the value of knowledge constructed by experts by experience, the interviewer remained attentive to topics that seemed meaningful to participants and invited curiosity through open-ended questions (Andrews, 2012). While remaining aligned with the overall research aims, the guide evolved as the interviews occurred. Notably, it was adapted to enable a fuller exploration of perspectives which critiqued the ANV.

All participants opted for their interviews to take part online. Interviews lasted between 31 and 68 minutes, with a mean average of 51 minutes.

Analysis

RTA followed the stages outlined by Clarke and Braun (2016), summarised in Table 2 below. To effectively integrate reflexivity throughout the process, Braun and Clarke (2019, p.93) emphasize the requirement to keep 'bending back on yourself'; being aware of your personal reactions and querying your assumptions throughout analysis. To ensure engagement with the data remained thoughtful and reflective throughout the journey the lead researcher kept a journal for the duration of the study (Appendix K) and accessed supervision regularly (Trainor & Bundon, 2021). To support the various stages of this process software programme NVivo was used.

Table 2

Stages of Reflexive Thematic Analysis Employed

Stage	Process	Description
1	Familiarisation with data	Interviews were transcribed by the lead researcher, checked and then read multiple times
2	Generation of codes	Codes were generated by holding the research aims in mind, systematically reviewing the interview transcripts and applying coding labels to meaningful or significant extracts throughout the transcripts. The codes were then reviewed and revised, rejecting some, combining others and generating new codes
3	Searching for themes	Initial themes were developed by reviewing codes and deciphering overarching themes that connected the codes. Themes were understood to be constructed by the researcher in collaboration with the data
4	Reviewing themes	Themes were reviewed and refined via a systematic process of evaluating: • Consistency: assessing whether the theme is underpinned by a central meaning • Validity: assessing whether the theme reflected the transcript data • Utility: assessing whether the theme connected to the research question and aims and highlighted an experience or perspective that seemed significant within the topic
5	Naming and defining the themes	Defining and naming themes and sub-themes, ensuring each is differentiated, appropriately clustered and named (Terry et al., 2017)
6	Constructing the report	Developing a report which provides a concise, coherent and interesting account of the story and incorporates extracts that both represent and bring the data to life

Quality Assurance

To enhance the quality of the analysis the lead researcher had a bracketing interview prior to commencing interviews to explore their thoughts and initial reactions to the interview guide. This process highlighted biases such as their view that the ANV was a helpful concept and prevalent amongst PwAN. These biases were revisited before interviews and throughout the analysis to ensure alternative views were explored. The lead researcher also revisited the interview guide at key points throughout the process, reflecting on their reactions to the questions. This process exposed an evolving relationship to the concept of the ANV and its utility, influenced by experiences of participants shared during interview and consumption of literature relating to the ANV. For example, the lead researcher's initial bias that the ANV was a helpful concept developed into a more negative view as interviews were underway, before reaching a more balanced perspective of the ANV in the later project stages.

A process of respondent validation was followed to further privilege the perspectives of people with lived experience of caring for PwAN within this project. Participant burden was reduced by enabling participants to opt in or out of this stage. In line with advice from Birt and colleagues (2016) consenting participants received a draft copy of the results in an email inviting their feedback (Appendix I). Six of the 13 participants provided comment on the results and an iterative and discursive process of feedback shaped the final report, captured in Appendix L.

Results

Reflexive thematic analysis resulted in eight main themes and 25 subthemes outlined in Table 3.

Table 3

Summary of Themes and Sub-themes

Main themes	**Sub-themes**
One Label, Many Definitions	***Intrusive Voice*** ***Inner Dialogue*** ***An Externalised Form of AN.***
A spectrum of connection to the ANV	***Advocates*** ***Critics***
The Insidious Invasion of Loved Ones	***The Seducer*** ***The Powerful Bully*** ***The Shadow that Takes Over***
The powerful feelings evoked in carers	***Hate*** ***Grief*** ***Powerlessness***
Relating to the ANV	***A Challenge to Manage*** ***Avoid Conflict*** ***Stand up to the ANV*** ***Ignore the ANV*** ***Embrace the ANV***
A Helping Hand on a Difficult Journey	***Tolerance*** ***Compassion*** ***Hope*** ***Empathy***
Externalising Techniques Should Come with a Warning Sign	***Loved Ones May Reject the ANV*** ***Externalising Could Create Problems*** ***Go Gently*** ***Just for Carers***
Wider systemic issues	***The Impact on the ANV***

One Label, Many Definitions

Participants' varying understanding of what the ANV constituted emerged throughout the process. While there were some commonalities illustrated in the sub-themes below, each participant held a unique understanding of the ANV.

Intrusive Voice.

Four participants described the ANV as a voice which their loved one heard, was intrusive and sounded very different to their own voice. Common amongst these descriptions was PwAN experiencing the voice as loud.

> "That's why she wasn't able to eat because she was doing as she was told by the voice in her head. And it shouts at her… she'll say 'it's too loud, it's too loud!'" (Linda)

Inner Dialogue.

Four participants likened the ANV to one of many inner voices that are often in dialogue with one another. When experienced like this, the ANV tended to be recognised as separate from other inner voices because of its sinister aims to influence AN behaviours, rather than being perceptually distinct.

> "We all have an internal dialogue with ourselves and you know, I know that mine is my own voice…. So, I said, 'well, how can you tell your anorexic voice from your own voice?' and she said the only way she can tell is if it's saying something that she knows is going to harm her" (Claire).

An Externalised Form of AN.

Seven participants described the ANV as a construct which enabled them to separate their loved one from AN, aligned with the therapeutic technique of externalising. For three of these participants, the ANV purely represented a metaphor which supported this process. In contrast, the others spoke about it as a genuine experience for their loved ones, which had the added benefit of enabling them to create separation between the person and AN.

> “All the textbooks talk about the anorexic voice and how… it’s good to separate the anorexic voice from the person” (Tony).

> “her anorexic voice … it’s really loud in her head and it bullies her…. I’ve made sense of it by separating it from my daughter…. it’s like a monster inhabiting her head” (Claire).

A Spectrum of Connection to the ANV

Participants varied in terms of how much the ANV resonated for them. The majority were advocates, but a few opposed the validity and utility of the construction.

Advocates. Ten participants felt the ANV was a useful construct that fit with their loved one’s experiences and helped them as a carer to make sense of the development and maintenance of AN.

> “There is a fundamental, very fundamental change in brain chemistry…That is the reason for the existence of that voice” (Alan).

> “I think the whole of anorexia is based on guilt, actually, …All of the behaviours that they do is to avoid guilt that the voice makes them feel” (Jackie).

Opponents. In contrast, three participants opposed the ANV construct. Two participants believed alternative ways of conceptualising their loved one's AN identity were more fitting.

> "I just wouldn't have used the word anorectic voice. I've certainly had the experience of something other than themselves having a very critical influence on their behaviours … Perhaps it's more like a part of themselves" (Helen).

In contrast, another participant opposed the ANV on the grounds that externalising aspects of individual's personality was invalid and potentially harmful.

> "One thing that triggered me to participate on your research is this title anorexic voice…which to me I didn't agree. I said no, there's no other voice…There's this discussion on social media; try to separate the anorexic part of your child. I cannot … it's their lovely personality if it's a positive… if it's a negative, oh it's another voice…" (Nancy)

The Insidious Invasion of Loved Ones

Advocates of the ANV illustrated how it invaded their loved ones' lives by presenting itself subtly before becoming punitive and cruel. Participants highlighted the contrast between their loved one and the ANV and noticed obvious signs when the ANV took control as if it had 'possessed' them.

The Seducer. Half of the participants described how the ANV enticed their loved ones into a strong bond with it by initially offering value to their lives, such as a sense of friendship or an inner cheerleader before evolving into a punitive, critical voice.

> “At first, it's a friend… saying ‘I'm gonna look after you’ … originally there to support her and help her through a hard time but then … you realize it's taken over and by the time it’s taken over, it's too late. You're in it, and it's got control of you and then you can't control it.” (Fiona).

The Powerful Bully. Nearly all participants depicted the ANV as a powerful, evil force that sought the isolation, misery, destruction and death of their loved one. A few participants believed that the ANV could exercise such power over their loved one because it inhabited their mind leaving them with no escape from its influence. Several participants used the metaphor of bully to describe the ANV but to capture the potency of evilness and power; many used metaphors beyond human qualities illustrated by Figure 2.

Figure 2

A Word Cloud of the Metaphors Used to Describe the Anorexic Voice

Note. The size of word correlates to frequency of use throughout participant transcripts.

> “the cruellest thing about the anorexic voice is that it wants to hide Sally away from everybody she loves……It wants to isolate, wants to rip everybody apart… [It] doesn’t want them to have a life and wants that person to listen to the voice all the time…” (Sandra).

> “The anorexic voice wants her to die. That's what it wants, it wants to take her to a place that she can't come back from. That's its aim!” (Fiona).

The Shadow that Takes Over. Seven participants emphasized the stark contrast between their loved one and the ANV, often highlighting their smiley and happy nature in juxtaposition to the angry hostility of the ANV that seemed to possess them. Four participants noticed how their loved ones were visibly different when the ANV had taken over.

> “She was very much Julie and chatty and smiley and then almost like a switch, you’d see her change … like they’re possessed by it” (Jackie).

> “And so, for Ellie, this Ed, I can see him just like a dark shadow…. I mean, her whole face changes...and it’s as if Ed sucks her out” (Emma).

The Powerful Feelings Evoked in Carers

Carers often became emotional sharing the intense feelings that the ANV stirred up in them. It seemed possible that talking about an externalised form of AN that separated their loved one from it enabled carers to share their strong feelings openly.

Hate. Ten participants shared feelings of hatred towards the ANV for how it had treated their loved one and the traumatic impact it had on their families.

> "I hate it. It's something that that bullies my daughter, and I can't protect her from it…yeah, I really, really loathe it" (Claire).

Grief. Five participants felt a sense of grief at the life the ANV had stolen from their loved one.

> "Grieving for my son because it had come in and taken him out of life, like, you know, he was 4.5 months in the inpatient unit… it took him into a world that ... we never would have imagined he would be a part of" (Molly).

Powerlessness. Five participants felt powerless in response to the strength and influence the ANV had over their loved one.

> "Helpless. Overwhelmingly helpless.… you can't reach them when anorexia sets in it's like talking to a wall" (Emma).

Relating to the ANV

Most participants who bought into the concept of the ANV struggled to manage it in effective ways. However, despite these challenges, reflecting techniques one might use in interpersonal relationships, participants found ways to relate to the ANV which helped their loved one have a healthier relationship with it.

A Challenge to Manage. Most participants felt drawn into predicaments where they needed to stand up to the ANV and assert boundaries about food or exercise but found this elicited extreme, often aggressive reactions. To add to carers' challenge, they often suspected the ANV was trying to fight with them to alienate them from their loved ones.

> "You try and make them eat more food, but the possession [by the voice] is so strong that that's when food goes flying … and then the screaming and shouting and the rages came" (Fiona).

> "What was difficult, very difficult was like bait was being put out to actually … start fighting or start digging the trenches" (Helen).

Avoid Conflict. Seven participants had learnt that, although challenging, it was imperative that they avoided conflict with the ANV.

> "If I had an argument with Ed, he'd be in my son's head going 'Your mum doesn't understand you, she doesn't know what she's doing, she's just trying to make you fat'. So, you know, so it made sense to me that I really had to avoid arguments at all costs" (Molly).

Stand up to the ANV. Five participants found ways to support loved ones to stand up to the voice and refuse its demands. Each participant's unique approach demonstrated the need for carers to work with loved ones to find a strategy that worked for them.

> “She’ll look at something and say ‘Do I have to eat this?’ and we’ll say ‘Yes, you do….’. The reason, she’s doing that is so… she can tell her voice ‘My mum has told me I have to eat so you need to go away’” (Fiona).

Ignore the ANV. Over half of the participants tried to reduce the ANV’s power by ignoring it as much as possible and encouraging loved ones to focus on their identity outside of AN.

> “I was ignoring and turning my back on [the ANV] as much as I could to talk to Daisy” (Dawn).

> “that was me managing the voice…reminding her why she had to do it so that she could do all these things that she wants to do in the future” (Jackie).

Befriend the Bully. Two participants felt it was crucial for them to get to know the ANV; to understand its purpose, tactics and goals so they could support their loved ones to have a different relationship with it.

> “Sometimes you have to befriend that bully…you’ve got to embrace the eating disorder side of somebody’s head, as well as the healthy side of someone’s head to really, really help them.” (Molly)

> “I think it’s very important to work with the anorexic voice… You have to work to keep it in the room.” (Emma)

Furthermore, two participants believed that supporting PwAN to befriend the ANV could enable them to harness its power and work with it rather than against it in recovery.

> “From Mike’s perspective it’s like ‘Ed is so powerful and that is part of me, I have that superpower’…If we can we befriend it…the powerfulness of it, that’s where you can get into post-traumatic growth’” (Molly).

A Helping Hand on a Difficult Journey

In addition to bringing about change by relating to the ANV differently, carers also found the concept of the ANV supported them with several processes which positively impacted their wellbeing and relationships with loved ones. However, a close inspection of these benefits revealed that they were mainly attributed to the process of externalisation, using the ANV as a metaphor.

Tolerance. Four participants felt that separating their loved one from AN made tolerating challenging behaviours more bearable, enabling them to remain caring throughout these incidents.

> “The relationship between her mother and her kind of broke down… You could say she was terrorised by Tina, or you could say she was terrorised by the eating disorder. And it was a lot easier to say she was terrorised by the eating disorder” (Tony).

Compassion. Three participants emphasised how being able to attribute challenges that AN bought to the family to the ANV reduced feelings of blame and helped them retain love and compassion for their loved one.

> “you’re getting to a situation where [AN] is making you hate your child… once we had Anna, we could put our energy against that and it seemed to sort of salvage the love that one had for one’s child” (Simon).

Hope. The concept of the ANV helped three participants hold onto hope that they would be able to recover their loved one’s former identity.

> “To actually recognise that my daughter is still in there and all her good qualities, even though sometimes it’s very, very hard to see… almost impossible to see when you’re on the receiving end of onslaught after onslaught” (Helen).

Additionally, five participants saw PwAN’s ability to differentiate between themselves and the ANV as a step towards recovery leaving them feeling optimistic about the future.

> “One doctor we met said ‘Oh, it’s really good that she’s named that’ because in her view… ‘it’s the beginning of healing’” (Emma).

However, one final crucial benefit that emerged encompassed recognition of the ANV as a distressing experience for their loved one rather than a tool to externalise.

Empathy. Three carers felt the ANV concept helped them recognise the powerful bully their loved one contended with, which generated empathy and enabled them to support their loved one with greater kindness.

> "I had one person from the team trying to encourage me to eat and I had another one in my ear as the voice of anorexia and that was so overwhelmingly hideous… That was like 'Oh my God, that's what my daughter is having to go through.'" (Linda).

Externalising Techniques Should Come with a Warning Sign

Both participants who advocated for and opposed the ANV were keen to convey that, when used to externalise AN, the construct had the potential to cause harm. At the same time, participants recognised the potential benefits it bought and offered insights about how to manage this dilemma.

Loved Ones May Reject the ANV. Seven participants shared experiences where their loved ones had fiercely rejected attempts by them to externalise AN using the ANV construct, most often because their loved one dismissed the notion that the ANV was separate from them.

> "She will still get angry when people think it's some something else, and she'll say, 'it's not… It's just me'" (Linda).

Externalising Could Create Problems. In contrast to the ways externalising was found to support carers, seven participants highlighted problems it could cause and the painful experiences of the conflict and disconnection it could bring.

> “You know, I did some courses and there was stuff about trying to separate out, and she would go ballistic, *ballistic*” (Helen).

> “I just sort of said to her, ‘Look Tina, you know none of this is your fault’ and she goes, ‘Well what do you mean?’ And I went, ‘Well, you want to eat and everything, but the eating disorder won’t let you’. She just said, ‘Well, that’s rubbish, I can eat when I want…get out, get out!’… That was really the last... meaningful conversation we’ve had” (Tony).

Go Gently. Two participants felt it was essential to gently introduce the ANV as a way of helping their loved one make sense of their experience and, if it resonated, remain gentle and curious about whether it fit with their loved one’s experience at that moment in time.

> “I think as a carer, the best thing to do is sew a seed and see whether the seed takes or not…and that seed did…. so I might just say ‘do you think that might be Anna telling you?’” (Sandra).

Just for Carers. Having recognised the potential pitfalls and benefits of externalising AN, four participants suggested it may be a way of thinking about their loved one's difficulties that they kept to themselves.

> "If I start talking about the anorexic voice as if it's distinct from my daughter, she gets absolutely furious…So, I don't do that anymore. I can think it… this is anorexia, but I don't say this is your anorexia talking" (Alan).

Systemic Issues

The majority of participants experienced issues with accessing appropriate support for their loved ones and links were made with how this impacted the ANV.

The Impact on the ANV. Two participants highlighted that failure to access early support enabled the ANV to grow in power. A further participant emphasised that techniques such as externalising require sufficient resources around them in order to work effectively.

> "We went to the doctors and they just weighed her and said she didn't meet [...] the threshold for the BMI, so she couldn't get any treatment […] the eating disorder voice was like, 'right, well…we can amp things up and cut food back even more'" (Dawn).

> "externalising of the anorexia is in the clinical guidelines [….]The problem is if you're... with a service that can't offer anything, it's not meeting face-to-face, it's one appointment a week … It's not really doing a version of the Maudsley family-based treatment as it's meant to be" (Alan).

Discussion

Recognising that the ANV may play an essential role in supporting our understanding and treatment of AN but that research lacked carers' insights; this study was the first to explore carers' perspectives of the ANV. It aimed to explore carers’ understanding of and relationship to the ANV, their perspectives on its potential role in recovery and compare this with the perspectives of other stakeholders captured in existing research.

Mirroring existing research into clinicians’ and PwAN’s perspectives, (Graham et al., 2019), this study revealed that carers held many definitions of the ANV that ranged from understanding it as a perceptual experience, to a metaphor which facilitated externalising. Additionally, amongst the carers that participated, the construct had advocates and opponents of its validity and utility.

Supporting the view that the ANV has an integral role in developing and maintaining AN (Aya et al., 2019; Pugh, 2016), advocates of the ANV in this study illustrated how the concept had helped make sense of their loved ones’ presentation. Encouragingly, this study also revealed striking similarities between carers' and PwANs' descriptions of the ANV. For example, there was agreement in the observed seductive qualities of the ANV able to secure an individual's attachment to it early on by offering something valuable like a sense of friendship or motivation before transforming into a punitive and harmful force (De Giacomi, 2019; Tierney & Fox, 2010; Williams et al., 2016).

Furthermore, carers' descriptions of a bully that attacked self-worth and isolated individuals to gain increasing power over them resonated with several studies that have likened the ANV to an abuser within a close relationship (Aya et al., 2019; Tierney & Fox, 2011). Carers found the conceptualisation of the ANV as an inner bully valuable as it fostered an understanding that dangerous engagement with AN behaviours may be motivated by a desire to appease the voice. Additionally, recognising loved ones as victims of bullying generated empathy.

Likewise, the majority of carers, akin to PwAN in existing literature (Smethurst & Kuss (2018; Tierney & Fox, 2010), described their loved one in polar opposite terms to the ANV; often their loved ones' amiable, kind and happy nature was emphasised in contrast to the destructive, evil force that took over. This finding seemed to lend support to the conceptualisation of the ANV as Jung's (1971) shadow in which undesirable and disavowed aspects of personality can take hold when individuals are distressed and overwhelmed.

However, this study also revealed one significant difference between carers' and PwANs' perceptions of the ANV; carers' descriptions were generally more one dimensional focusing on the negative, evil qualities in comparison to PwAN's, which have often been polarised and dualistic, recognising the ANV as both an 'angel and devil' (Pratt, 2016; p.58) or sometimes frightened and vulnerable (Tierney & Fox, 2011).

Experiences shared by carers in this study supported recent research, which suggests that PwAN can take steps towards recovery by altering their relationship with the ANV (Peskett, 2022). Furthermore, the strategies carers employed, such as helping their loved one to stand up to or ignore the voice, mirrored strategies in the existing literature that have been found to reduce AN behaviours (Peskett, 2022; Pratt, 2016).

Though a minority view offered in this small-scale study, some carers felt that 'befriending the bully' and getting to know the ANV and their loved one's relationship with it would better equip them to bring about change. This idea aligns with therapeutic approaches such as chair work within Emotion Focussed Therapy (EFT) or Voice Dialogue which invite dialogue between different voices or parts of the self to bring about change in the dynamics between them (Elliott et al., 2004; Hibbs et al., 2021; Stone & Stone, 1989). Though more research exploring the impact of such approaches in the treatment of AN is needed, Dolhanty and colleagues (2007) outline how inviting the ANV into the therapy chair can help uncover insights such as its reasons for existing, which can direct subsequent therapeutic focus. Furthermore, in a small-scale study which used chair work to facilitate dialogue between PwAN and their ANV, participants felt able to gain separation from and new insights into their ANV, leaving them feeling 'hopeful' and 'motivated' about recovery but desired greater involvement of family members to 'maximise the benefits of the method' (Chua et al., 2022; p.607).

Overall, this study therefore bolstered evidence indicating that therapeutic strategies enabling PwAN to alter their relationship with the ANV may support recovery and crucially highlighted that carers could play a vital role in supporting their loved ones to achieve these changes. However, it also revealed that carers experienced significant challenges relating effectively to the ANV, leaving some feeling powerless. While there are unlikely prescriptive or easy solutions to effective management of the ANV, this finding adds to evidence highlighting a need to include carers more meaningfully in treatment and better support them in their role (Fox et al., 2017).

This study revealed variability in carer’s perceptions of the ANV which ranged from representing an experience that resonated for their loved ones to a metaphor which aided externalisation of AN and at times holding multiple meanings to participants. The overlap, and at times conflation, between carer’s perceptions of the ANV as a construct and externalisation as a therapeutic tool is perhaps unsurprising given that externalisation is commonly used in family treatment of AN. Family based therapy (FBT) is a first line treatment for children and young PwAN (NICE, 2017) which utilises externalisation to create separation between the person and AN in order to align families together and unite them against the externalised AN (Lock & Le Grange, 2013).

Perhaps a natural consequence of the perceptual overlap between the ANV and externalisation is that carer’s perceptions of the challenges and criticisms of the ANV raised in this study corresponded with evaluations of externalising as a therapeutic technique raised in existing literature. For example, in this study, the ANV was found to enable carers to sever their loved ones from the negative qualities of the ANV, facilitating open expressions of hatred towards the ANV while retaining love and compassion for their loved ones. This finding correlates with existing research into PwAN's (Goddard et al., 2011), clinicians' (Lonergan et al., 2022) and carers' (Toubøl et al., 2019; Whitney et al., 2011) experiences of externalisation which value its ability to generate compassion towards PwAN by redirecting feelings of anger and blame towards AN.

Additionally, carers in this study found that their loved ones often rejected their attempts to externalise certain behaviours or remarks on the grounds that there was no separate ANV influencing their behaviour. This finding mirrors similar findings into research into carers’ experiences of externalising elsewhere (Williams et al., 2020; Wufong et al., 2019). Moreover, like previous research with PwAN, carers in this study found externalising could lead to conflict and disconnection between them and their loved ones (Conti et al., 2021; Voswinkel et al., 2021).

A further critique of externalising using the ANV construct highlighted in this study was its potential to reject parts of a person. Vitousek (2005) advises caution against externalising techniques on similar grounds, arguing that demonising the 'anorexic self' and idealising the 'real self' can lead to exacting standards of an individual's personality, which could lead some to hold onto their anorectic identity as an accepted way of expressing undesirable impulses. The antithetical descriptions of PwAN and the ANV uncovered in this study indicates that carers may have a tendency towards holding such polarised views and be at risk of running into such issues. A possible solution to this could be to avoid offering prescribed negative narratives about the ANV when utilising externalising techniques and instead invite PwAN to author their own narratives about the ANV. Such methods would align most closely with externalising approaches as outlined in narrative therapy (NT) which emphasise the importance of individuals having ownership of the narrative around the problem that is bought to therapy (White & Epston, 1990). A further possibility could be to seek psychological approaches which seek to accept the whole person (Prochaska & Norcross, 2018; Stevens, 1986).

Taking these results together, this study therefore adds to the evidence base which emphasizes some of the benefits and shortcomings of using externalising techniques, and uniquely adds carers’ perspectives of utilising the ANV as a conceptual tool to aid this process. However, given that carers held various definitions of the ANV, ranging from a metaphor to aid externalising, to a perceptual experience for their loved one, it is challenging to disentangle how different conceptualisations of the ANV are linked to the aforementioned benefits, challenges, and criticisms.

Finally, carers in this study reminded us that therapeutic techniques and concepts, however useful, rely on systems around them to function correctly (Wonderlich et al., 2020). Participants shared experiences of themselves and their loved ones encountering challenges accessing appropriate support, particularly in the early stages of AN. Such challenges echo reviews of NHS ED services, indicating that resource issues have meant only 'the most severe cases are treated appropriately' (Scott, 2021), which has worsened in the wake of COVID-19 (Ayton et al., 2021). This is hugely problematic given early detection has the potential to save lives, prevent suffering, and be cost-effective (Austin et al., 2022). Furthermore, this study illustrates the impact this may have on the ANV, as it was seen to grow in power when left unmanaged, adding another dimension to the growing calls for the government to take responsibility for the healthcare crisis (Iacobucci, 2023).

Limitations

A limitation of this study was its lack of depth exploring carers' definition of the ANV. Though this was touched upon within interviews, captured by the 'one label, many definitions' theme, its absence from the interview guide meant it was neglected as a focus. This led to challenges understanding the relative benefits and shortcomings of different conceptualisations of the ANV to carers. In particular, disentangling these from perceptions of externalising more broadly.

Review of the recruitment poster (Appendix E) highlighted a bias towards inclusion of participants with a favourable view of the ANV, which likely influenced the proportion of advocates and opponents who participated. This limitation appears to be pertinent to other research on the ANV (e.g. Tierney & Fox, 2010). The omission of opposing perspectives may mean valid criticisms are missing from our current understanding of the ANV, which could be informative to treatment approaches and guidance that draw upon this concept.

Finally, participants in this study were recruited from a single carer's network. The information or support accessed through this network may influence participants' perspectives, potentially limiting the views offered. Furthermore, all participants identified as White, parents of PwAN and the majority (69%) were female. Advertising in other spaces, particularly where people from diverse ethnic backgrounds or were fathers, partners and siblings of PwAN, could have diversified the views offered. Treatment advances are shaped by the knowledge gleaned in research (Roberts et al., 2020). For AN treatments to meet the needs of the diverse populations they serve, including diverse perspectives in research is crucial (Anastasiadou et al., 2014).

Clinical Implications

Following growing interest in the ANV in recent years (Aya et al., 2019; Pugh, 2016) and taking note of advances in voice hearing in other contexts (Middleton et al., 2022), there is increasing interest in therapeutic approaches which seek to influence changes in the relational dynamics between PwAN and the ANV (e.g. Chua et al., 2022; Hibbs et al., 2021). This study found that such approaches would benefit from the inclusion of carers, who may be able to support their loved ones in implementing changes. Additionally, empowering carers to develop a different relationship to the ANV could also have a positive impact on AN and improve their experiences of the caring role.

This study found that the concept of the ANV offers support to some carers, does not resonate with others and holds different meanings for each individual. To complement these diverse findings it will be helpful for healthcare professionals to invite discussion about the ANV but avoid imposing it, or prescriptive definitions of it, onto individual's experience. Psychological formulation is a flexible tool that would be well-suited to uniquely conceptualise each individual's experiences of AN and, where relevant, the ANV, to inform a treatment plan (Johnstone & Dallos, 2013; Pugh, 2016).

This study found that many carers used the ANV to externalise and separate their loved ones from AN. This separation provided carers with hope, compassion and tolerance for challenging behaviours. However, carers also found it was frequently met with resistance by their loved ones, causing conflict and disconnection. To maximise the possible benefits and reduce the likelihood of harm that such techniques can bring, it feels necessary for professionals encouraging the use of such techniques to be aware of the challenges and take heed of two key pieces of advice offered by carers in this study. Firstly, to offer ideas gently and with curiosity about whether they fit with experience. This advice aligns with a social constructionist view that personal constructions of distress are more empowering than dominant definitions (Lock et al., 2004). Secondly, it may be helpful for carers to externalise certain behaviours and remarks but keep this process private from PwAN. To avoid the possible harm caused by externalising altogether, a third option could be to look to alternative treatment approaches which seek to accept all parts of an individual.

There were similarities between how participants in this study and PwAN in existing literature described the ANV. However, a key difference was that PwAN's descriptions tended to include positive, negative and vulnerable qualities, while carers' descriptions generally converged around negative qualities. This disparity in perspectives may indicate an unmet need for carers to better understand the value their loved ones place on the ANV.

Tools such as the Decisional Balance exercise (Langley et al., 2018) which facilitate conversations between carers and loved ones about valued aspects of AN, could facilitate effective, empathic conversations about PwAN's attachment to the ANV and resistance to change to inform ways forward (Pos & Choi, 2019; Treasure et al., 2003).

Future Directions

Although this was not the first study to highlight that the ANV holds unique meaning for individuals (Graham et al., 2019), current research lacks deep insight into the variety of conceptualisations. Learning lessons from voice hearing in other contexts, attempts to define and delineate such diverse experiences are likely to prove fruitless (Moskowitz et al., 2012). However, future in-depth research exploring various stakeholders' understanding of what the ANV constitutes and how various conceptualisations link with benefits and shortcomings perceived by PwAN, carers and clinicians could be informative to advancing treatment approaches.

Furthermore, to address the potential bias of favourable views towards the ANV in research, future research could invite those who oppose the ANV to understand their criticisms of this construct better. Such research could aid our understanding of the ANV and uncover alternative constructions of PwAN's experiences that may hold utility.

Finally, carers in this study frequently reported their loved one's resistance to externalising techniques and the negative consequences this could bring. It feels important to take notice of this given that externalising is commonly used in treatments for AN such as FBT, a first-line treatment for young PwAN (Lock & Le Grange, 2013; NICE, 2017). Future research that explores the acceptability of or harm-reducing ways of utilising this technique could support the treatment of AN moving forwards. Pugh (2016) argues that conceptualising the ANV as a distinct part of, rather than separate from, oneself may overcome some challenges with externalising. In support of this, in a small-scale study, PwAN found sessions which utilised therapeutic chair work, inviting them to recognise the ANV as a distinct part of themself, as an acceptable and tolerable intervention. However, attrition rates were comparable to other AN treatments, warranting further investigation (Hibbs et al., 2021).

Conclusions

This study revealed that the ANV is defined in many ways and the construct has both advocates and critics amongst carers. Advocates of the ANV recognised it as a powerful bully and found that altering their own and their loved ones' relationship with the ANV could reduce its influence over AN behaviour. An implication of this finding is that treatment advances which seek to alter relational dynamics between PwAN and the ANV would benefit from including carers.

Carers offered insights into the benefits, shortcomings and criticisms of the ANV, which under close scrutiny revealed significant overlap with perspectives on externalising. This highlighted the challenging task of evaluating the utility of a concept which holds variable meanings. Future research would benefit from in-depth exploration of stakeholders' definitions of the ANV and the merits and shortfalls of such conceptualisations.

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Appendix A: Ethical Approval Letter

This has been removed from the electronic copy due to copyright reasons.

Appendix B: Focus Group Discussion Guide

Agenda

Introduction (15 minutes)
- Welcome
- Purpose of the focus group
- Housekeeping
- Introductions
- Key points about the project

Discussion points (1 hour)
- 4 points (so roughly 15 minutes each)

Ending (15 minutes)
- Summary
- 1 take home from everyone
- Next steps
    - Payment
    - Project proposal
    - Hold onto your details to let you know once the project is publicly available?

Welcome

- Thank you
- Recognition of Christmas being a difficult time

Purpose of the group

- We are conducting a research project to understand how carers experience the Anorexic Voice – an inner voice that research suggests is commonly reported in people who suffer with Anorexia.
- Because this topic isn't something that has been researched with carers previously, we want to utilise your experience and expertise as carers to think about how best to go about this project, and challenges that we may have overlooked coming at this as researchers and not people with lived experience as carers.

Housekeeping

- Confidentiality, people may share personal, sensitive stories or views - please respect privacy and different viewpoints
- Discussions from today will inform the project, but wouldn't be reporting anyone's words directly
- Recording. I will rewatch, make notes and then delete, is that ok?
- Anything else that people feel would be helpful to feel comfortable today?
- Mute. If you would like to speak, unmute, use the chat box.
- Easy to go off on slight tangents – the tangents may be on important topics, but may not be particularly relevant to thinking about this research project – so I may need to move us along in the agenda, keep us focussed on thinking about this project
- Payment

Introduce ourselves

- Say our name and why we were interested in this Focus Group. Invite someone else to speak who hasn't introduced themselves yet.

Key points about the project

- This is our provisional plan (although this could change depending on discussions we have today)
    - Interview people with lived experience of caring for someone who suffers with Anorexia about their experience with the ANV.
    - 10-15 people
    - Interviews will last between 30 minutes and hour
    - Semi-structured interview – go into the interview with an idea of topics that it would be helpful to cover, but have the flexibility that if something comes up we hadn't thought about before, that it could be explored.
    - The topics that we cover in interview that's something that I am hoping to shape based on discussions that we have today.
    - Anything else that anyone would like to know about the project plan?

Discussion points:

1. Is the Anorexic Voice something that you have experience of?
    - **a.** If yes, how does this experience get talked about?
    - **b.** If no, is it that it doesn't get talked about? Or is the idea understood in a different way? Or using different language?
2. How might developing an understanding of carers' experiences and perceptions of the Anorexic Voice be helpful or potentially unhelpful?
    - **a.** In your opinion, what might be the benefits of knowing more about how carers perceive the anorexic voice?
    - **b.** Are there possible drawbacks?
3. How can we best support carers in talking about their experiences and perceptions of the Anorexic Voice?
4. Are there any aspects of the Anorexic Voice and/or caring for someone who has this experience (or not) that you feel are most important to ask about or explore with participants in this study?
    - **a.** How can we make this study most useful / relevant to carers and loved ones with an eating disorder?
5. Can you foresee any challenges with the project that it would be helpful for us to think about?

Summary

- Attempt to summarise discussions
- Everyone share one thing that they would really like me to hold in mind as I take this forward
- Next steps – contact everyone re. payment
- Hold onto your details and let you know once the research is published?
- Thank you!

Appendix C: Protocol for Managing Participant Distress and Safeguarding

IRAS ID: 307132
Version: 1

Study protocol for managing participant distress and safeguarding

Protocol for managing distress

1. **Prior to interview:**

Participants will be advised of their right and choices should they become distressed during the interview. This is outlined in the script below, in addition to the Participant Information Sheet.

Script:
The Research Team and I acknowledge that the anorexic voice is an emotional topic for some people, and you may have had difficult or sensitive experiences with the anorexic voice. Your safety and wellbeing is incredibly important to us. So, I want to remind you that if you become distressed during the interview you have many choices. You can:

- *Stop the interview altogether. You can withdraw your data. I would completely understand and there would be no consequences.*
- *You can take some time out, and let me know whether you'd like to resume the interview, or stop the interview.*
- *You can also postpone the interview, so we could arrange another time to meet*
- *You can skip out a question, or questions*

So if it's feeling too much, do you think you could let me know so we can think about how best to manage?

If I'm concerned about your wellbeing, I will bring this up with you. Is there anything that it could be helpful for me to look out for, for example a sign that you are distressed and we might need to take a break?
If you do become distressed, is there anything in particular that it might be helpful for me to know. For example, some people prefer having space to talk about it, others might just need some time on their own.

2. **During interview**

If a participant becomes distressed during interview, the interviewer is a trainee clinical psychologist with over 6 years of experience working in mental health services offering people emotional support. The interviewer would therefore use their therapeutic skill to:

- Validate and normalise the participant's distress

- Incorporate any distress management responses that a participant has requested
- Remind participants of their rights and choices and discuss with them what they would like to do
- Think with the participant about existing support they have in place to support them with their feelings of distress
- Discuss additional resources participants could access for further support (see Resources Handout below)

3. Post interview

All participants, regardless of whether they seemingly became distressed or not will be invited to debrief (see script below). Their rights post interview are also outlined in the Participant Information Sheet. Participants will also be provided with a Resource List (see below).

Script:

- *Do you have any questions or concerns about the project?*
- *Do you have any questions or concerns about your involvement in the project?*
- *I want to remind you that you have up to 4 weeks to withdraw your consent and data.*
- *After 4 weeks, I will have started to do the analysis of the data. This involves me looking for themes that occur for a number of participants. For this reason, it is not possible for you to withdraw your data. However, if you become concerned about the project, or your data please get in touch with me or another member of the research team (details are on the Participant Information Sheet) and we can discuss this.*

If you wish to access further support, here are some resources that you may find helpful. Provide Helpful Resources Sheet (see below)

Helpful resources

If you are in crisis

- Contact **SANE** helpline, by leaving message on **07984 967 708**
  - They can offer emotional support via telephone
  - They can give you guidance on how to access further support
- Ring or text a **friend or family** member.
- Contact **Samaritans** any time on **116 123.** They offer a listening service.
- **SHOUT** offers text support any time, **text SHOUT to 85258**
- Telephone **NHS 111** by dialling 111.
- Find your local **NHS Crisis line** (England only)

Go to your local accident and emergency department if you are feeling suicidal or if you have self-harmed and are concerned about it.

If you already have contact with mental health services:

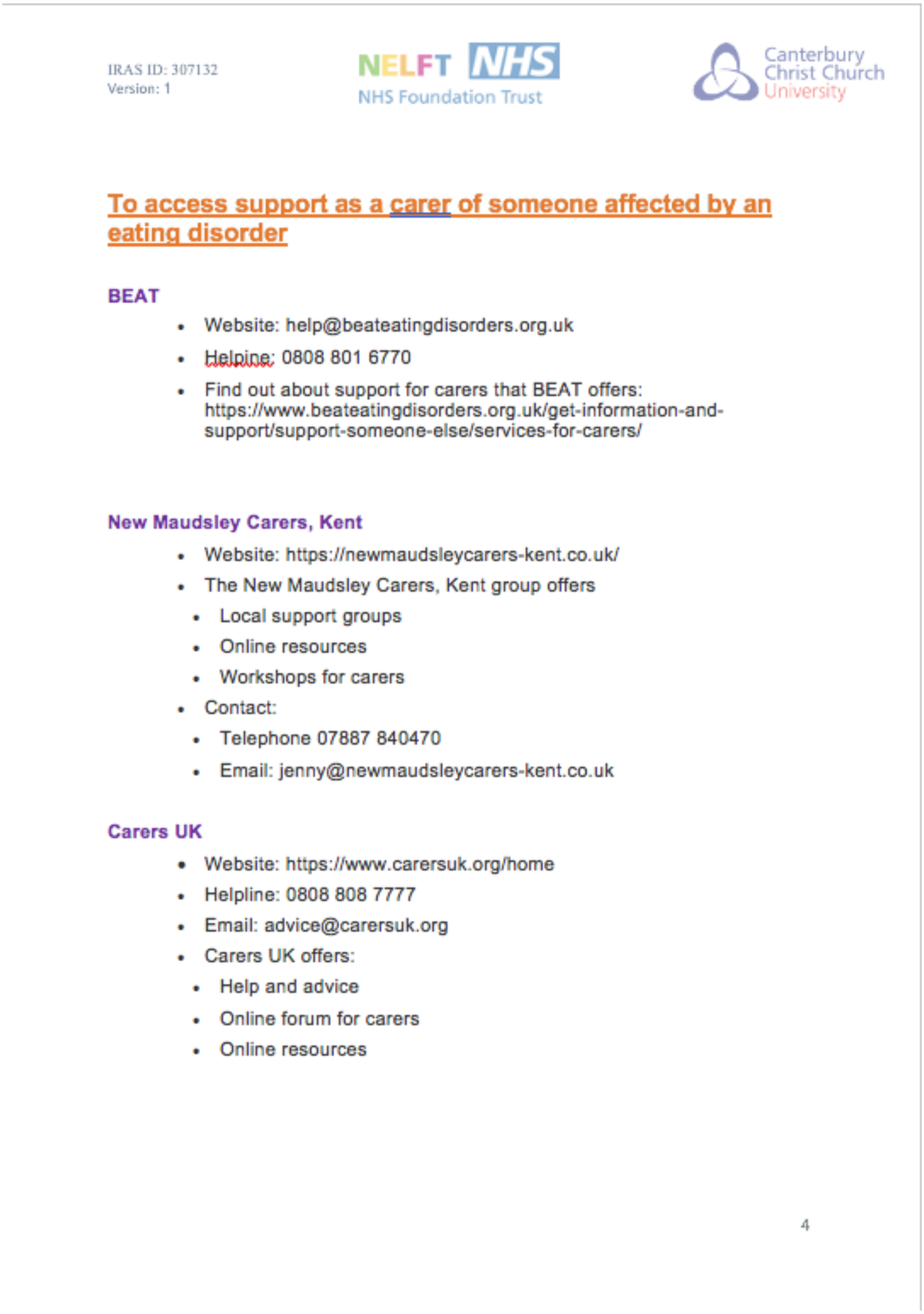
- Contact your **local community mental health team**
- Contact your **crisis team** if you have one.

If you have had no contact with mental health services, for example, it may be the first time you or someone else has been in crisis:

- Contact your **out-of-hours GP service**. Google 'out of hours GP in x' (give your location).

Alternatively, your GP surgery will usually provide an answer phone message advising you of who to contact in an emergency, together with other useful telephone numbers.

Make an appointment with your regular GP, as this is usually the first point of contact for anyone concerned about mental health problems.



To access support as a carer of someone affected by an eating disorder

BEAT

- Website: help@beateatingdisorders.org.uk
- Helpine: 0808 801 6770
- Find out about support for carers that BEAT offers: https://www.beateatingdisorders.org.uk/get-information-and-support/support-someone-else/services-for-carers/

New Maudsley Carers, Kent

- Website: https://newmaudsleycarers-kent.co.uk/
- The New Maudsley Carers, Kent group offers
  - Local support groups
  - Online resources
  - Workshops for carers
- Contact:
  - Telephone 07887 840470
  - Email: jenny@newmaudsleycarers-kent.co.uk

Carers UK

- Website: https://www.carersuk.org/home
- Helpline: 0808 808 7777
- Email: advice@carersuk.org
- Carers UK offers:
  - Help and advice
  - Online forum for carers
  - Online resources

Protocol for managing Safeguarding

1. **Prior to interview:**

The interviewer is the student who is managing the day-to-day activities of the project. The interviewer is a trainee clinical psychologist, and has an employment contract with Surrey and Borders NHS Partnership Trust, contracted until September, 2023. As part of this contract, the interviewer undertakes regular mandatory safeguarding training. They also have the 'NHS Safeguarding Application' downloaded on their work telephone which outlines the types of abuse and neglect to look out for, and guidance on how to raise concerns along with relevant contact numbers across all NHS trusts country-wide. Participants recruited through the New Maudsley Kent Carer's Group are funded by the Charlie Waller Trust, and so safeguarding concerns would go to their safeguarding lead.

When participants agree to take part in the study, they will be asked to provide their full name, contact details and organisation through which they heard about the study. This ensures that the Research Team has such information to share with the relevant agencies should the need to raise a safeguarding occur. Participants will be advised of the limits of confidentiality should they disclose serious risk to themselves or another person. This is outlined in the script below, in addition to the Participant Information Sheet.

Script
What you share with me during interview will be kept confidential. As outlined in the Participant Information Sheet, I will use quotes from the interview in the final report, but all identifiable information will be removed and any names will be changed so that no one would know these quotations came from you.

However, if you were to tell me something that made me think that you, or another person was at serious risk of harm, I will need to break that confidentiality and discuss this with other agencies. In the first instance, this would likely be with my supervisors, the Research Team. If we thought we needed to, we may then share information with the Care Team supporting you and your loved one and possibly alert relevant services. In most cases, I would discuss this with you first, and you would be given the choice to disclose the information yourself, or for me to share the information on your behalf. Are you ok to proceed with the interview on that basis?

2. **Should a safeguarding concern arise during interview or respondent validation phase, the following process would be followed:**

    a) Believe the participant and take the information seriously
    b) Listen, encourage, but avoid asking leading questions
    c) Tell the participant they are concerned about the information that has been shared and will need to talk to someone else and explain the next steps

d) If there is immediate and serious risk of harm, relevant agencies such as the police/ emergency services/ safeguarding leads will be contacted immediately.
e) If there are concerns, but they are not immediate, the student researcher will contact the Research Supervisors (Dr Matthew Pugh/ Dr Anna Oldershaw) to discuss this and determine any next steps that need to be taken.
f) If it is deemed that a safeguarding does need to be raised, the student researcher will share their concerns with the participants and consent will be sought to break confidentiality to disclose this information to the relevant agencies including the service where the participant's loved one is accessing support for their eating disorder, and the participant is accessing support as a carer.
g) Ideally the disclosure would be made to the service or agency by the participant, or together with the researcher. If speaking to the participant about concerns could increase risk of harm to another person or the participant does not consent to the sharing of this information, it will still be necessary to break confidentiality.
h) Disclosures and conversations relating to the process outlined above will be documented, signed and dated and shared with the relevant agencies involved in the process to ensure relevant information is documented on care records appropriately.

Appendix D: Local Trust Capacity and Capability Approval

This has been removed from the electronic copy due to copyright/ confidentiality reasons.

Appendix E: Recruitment Poster

Are you a carer of a loved one with Anorexia Nervosa?

Have you been aware of your loved one experiencing an Anorexic Voice?

Would you like to take part in some research to share your views on the Anorexic Voice?

To find out more, get in touch with Maya Kuhl.

We know that including carers in the treatment of anorexia has been found to show benefits for both them and their loved one [1]. But… research also shows that carers often feel 'shut out of treatment' [2]. We are conducting a research project to understand how carers experience the Anorexic Voice.

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Interested in taking part? Here's what's involved:

What? An interview (30 – 60 minutes) where you will be asked questions about your experience of the Anorexic Voice within your caring role.

Why? By researching carer's views about the Anorexic Voice, we hope to better understand if this is a helpful concept to people caring for loved ones living with the disorder. This could lead to future research or improve treatment interventions involving carers and the Anorexic Voice.

When? Get in touch with Maya to arrange a time for interview that suits you. There are a maximum of 12 spaces and people will be offered interviews on a first come first served basis.

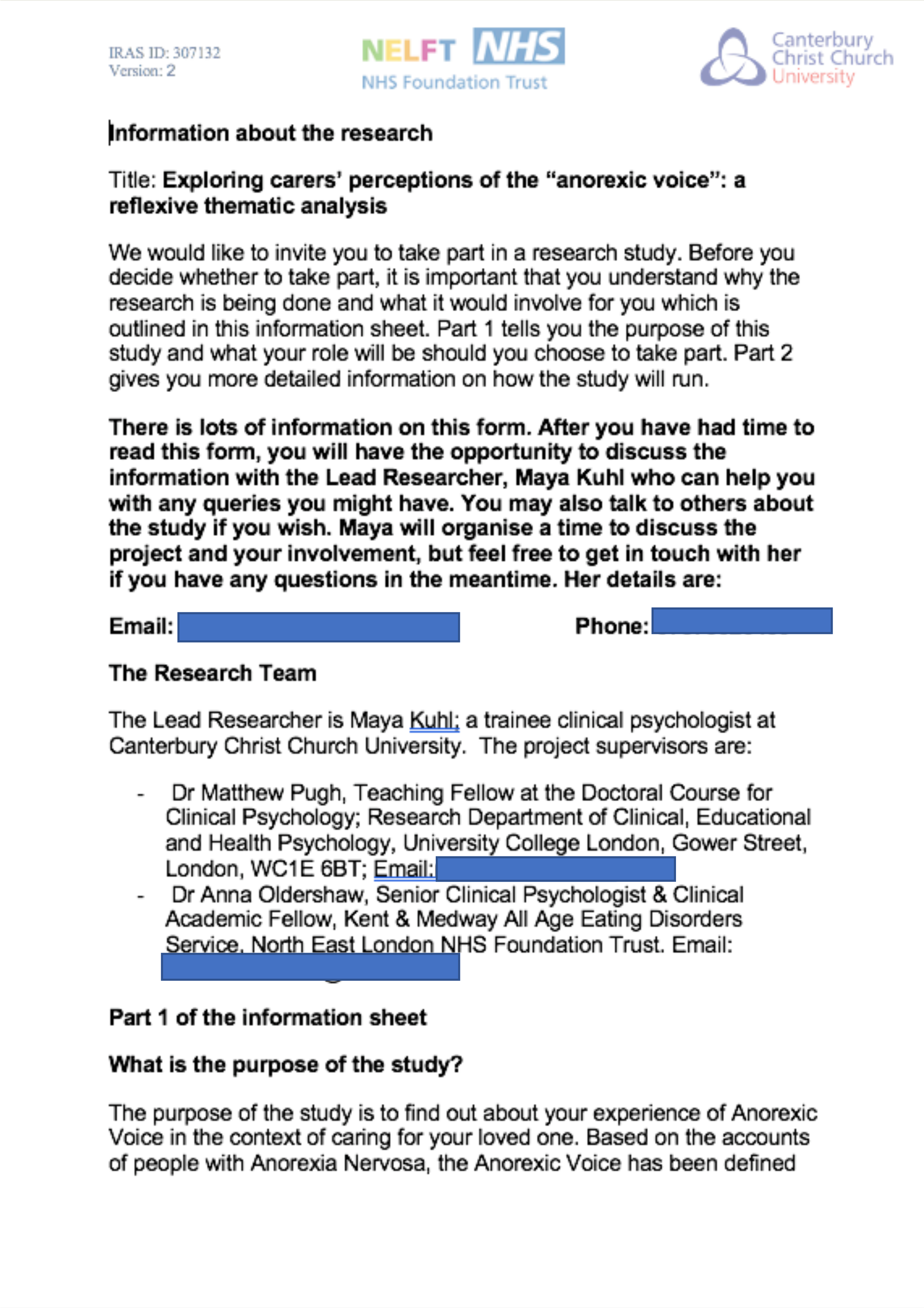
Where? The interview can place via secure video link, or in person at Vincent Square, West London/ The Courtyard, Maidstone, Kent.

Who? This project is being led by Maya Kuhl, a trainee clinical psychologist with Canterbury Christ Church University. The project is supervised by Dr Matt Pugh, and Dr Anna Oldershaw; clinical psychologists experienced in treatment and research of eating disorders.

How? If you're interested in taking part, get in contact with Maya Kuhl to find out more:

☎ [redacted] ✉ [redacted]

Appendix F: Participant Information Sheet



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Information about the research

Title: **Exploring carers' perceptions of the "anorexic voice": a reflexive thematic analysis**

We would like to invite you to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you which is outlined in this information sheet. Part 1 tells you the purpose of this study and what your role will be should you choose to take part. Part 2 gives you more detailed information on how the study will run.

There is lots of information on this form. After you have had time to read this form, you will have the opportunity to discuss the information with the Lead Researcher, Maya Kuhl who can help you with any queries you might have. You may also talk to others about the study if you wish. Maya will organise a time to discuss the project and your involvement, but feel free to get in touch with her if you have any questions in the meantime. Her details are:

Email: [redacted] **Phone:** [redacted]

The Research Team

The Lead Researcher is Maya Kuhl; a trainee clinical psychologist at Canterbury Christ Church University. The project supervisors are:

- Dr Matthew Pugh, Teaching Fellow at the Doctoral Course for Clinical Psychology; Research Department of Clinical, Educational and Health Psychology, University College London, Gower Street, London, WC1E 6BT; Email: [redacted]
- Dr Anna Oldershaw, Senior Clinical Psychologist & Clinical Academic Fellow, Kent & Medway All Age Eating Disorders Service, North East London NHS Foundation Trust. Email: [redacted]

Part 1 of the information sheet

What is the purpose of the study?

The purpose of the study is to find out about your experience of Anorexic Voice in the context of caring for your loved one. Based on the accounts of people with Anorexia Nervosa, the Anorexic Voice has been defined as a non-psychotic inner voice experienced by some people with Anorexia that provides a critical commentary focused on their diet, shape, weight, and personal qualities (Graham et al., 2019).

By hearing your views, this may help to improve our understanding of whether the Anorexic Voice is an important experience for carers and their journey in supporting their loved one in recovery.

Why have I been invited?

We are recruiting people who have experience caring for a loved one with a diagnosis of anorexia nervosa. This is why we have invited people who attend the carers skills workshop at Vincent Square/ SOLACE group/ New Maudsley Carer's Group. We are interested in hearing your experiences of the anorexic voice, whether it is something that you relate to or not and your views about it.

Do I have to take part?

Taking part in the research is entirely voluntary and it is up to you to decide whether to join the study. If you agree to take part, you will be asked to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you or your loved one receives, now or in the future.

What will happen to me if I take part?

If you agree to take part, Maya will organise a time to meet you for interview. The interview, may take up to an hour. If you would prefer to meet for 2 shorter interviews, please let Maya know and this can be arranged.

You can choose whether to have the interview in person or online:

- Online - We would ask that you choose this option if have a space where you and the interviewer can hear one another and you would feel comfortable sharing your experiences and views of the Anorexic Voice.
- Face to face – you can meet Maya for interview at
  - Vincent Square, London (SW10 9NG) **OR**
  - The Courtyard, Maidstone, Kent (ME14 1PA) where your loved one may have accessed support for their diagnosis.

The interview will include questions about whether you relate to the 'Anorexic Voice' in caring for your loved one. You will be invited to share your views on the Anorexic Voice. We are interested in understanding a range of carer's views on this topic, whether you relate to the 'Anorexic Voice' or not, we want to hear your perspective.

The interviews will be audio recorded and anonymously transcribed (typed up) in full by Maya Kuhl (Lead Researcher). Your name and identifying details will be changed so that no one would know these quotations came from you.

Once all of the interviews are completed, the Research Team will complete a 'Thematic Analysis' of the information. This involves reviewing the information shared by all participants during interview (between 10- 20 in total) and reporting themes, or commonalities in participant's experience of the Anorexic Voice.

Approximately 3-6 months after interview, you will be given the opportunity to provide feedback on the results. If you decide to participate in this part of the study, you will receive a summary of the findings and invited to comment on the results (the themes highlighted by the Research Team), in particular to evaluate whether they adequately capture the experiences of the Anorexic Voice that you shared during interview. Providing this feedback is optional.

What are the possible disadvantages and risks of taking part?

We acknowledge that some people may have had difficult experiences with the Anorexic Voice and may become distressed during the interview. Maya Kuhl will interview you, and she has over 6 years of experience working in mental health services and offering people emotional support. If you decide to take part, and become distressed during the interview, you can think with Maya about how best to manage the situation. You may wish to stop the interview altogether and withdraw your data, or possibly pause or postpone the interview for another time.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help us understand carer's perspectives on the 'anorexic voice'. As clinical practice is informed by research, it is possible that the outcomes of this study may in-turn improve carer's experience of and treatment of people with a diagnosis of anorexia nervosa. You may also find it helpful to reflect on and share your own experience of the anorexic voice within the project.

Expenses and payments

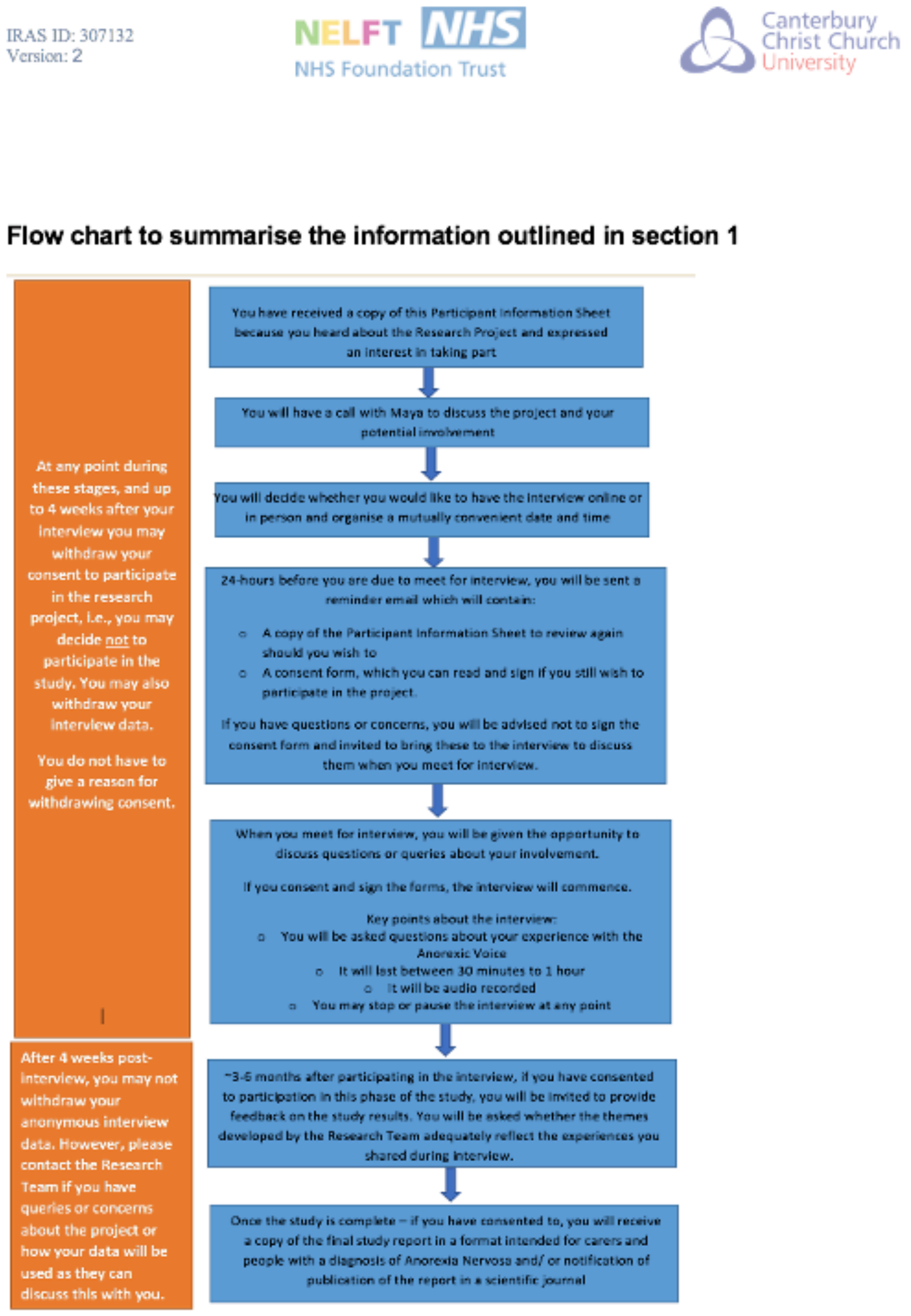
We can provide up to £10 per person in travel expenses. Depending on the number of participants who interview online or in person, it may be possible to reimburse participants for up to £20. Please discuss this with Maya if you are interested in receiving travel expenses.

What if there is a problem?

In the first instance, please discuss any concerns you have with Maya Kuhl or the project supervisors, Dr Matthew Pugh and Dr Anna Oldershaw (details at the top of this information sheet). For information about making complaints, please see Part 2 of this information sheet.

Will information from or about me from taking part in the study be kept confidential?

Yes, all information about you will be handled in confidence in line with legal requirements. There are some rare situations in which information would have to be shared with others. The details of this are included in Part 2.



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Flow chart to summarise the information outlined in section 1

You have received a copy of this Participant Information Sheet because you heard about the Research Project and expressed an interest in taking part

You will have a call with Maya to discuss the project and your potential involvement

You will decide whether you would like to have the interview online or in person and organise a mutually convenient date and time

24-hours before you are due to meet for interview, you will be sent a reminder email which will contain:

- A copy of the Participant Information Sheet to review again should you wish to
- A consent form, which you can read and sign if you still wish to participate in the project.

If you have questions or concerns, you will be advised not to sign the consent form and invited to bring these to the interview to discuss them when you meet for interview.

When you meet for interview, you will be given the opportunity to discuss questions or queries about your involvement.

If you consent and sign the forms, the interview will commence.

Key points about the interview:

- You will be asked questions about your experience with the Anorexic Voice
- It will last between 30 minutes to 1 hour
- It will be audio recorded
- You may stop or pause the interview at any point

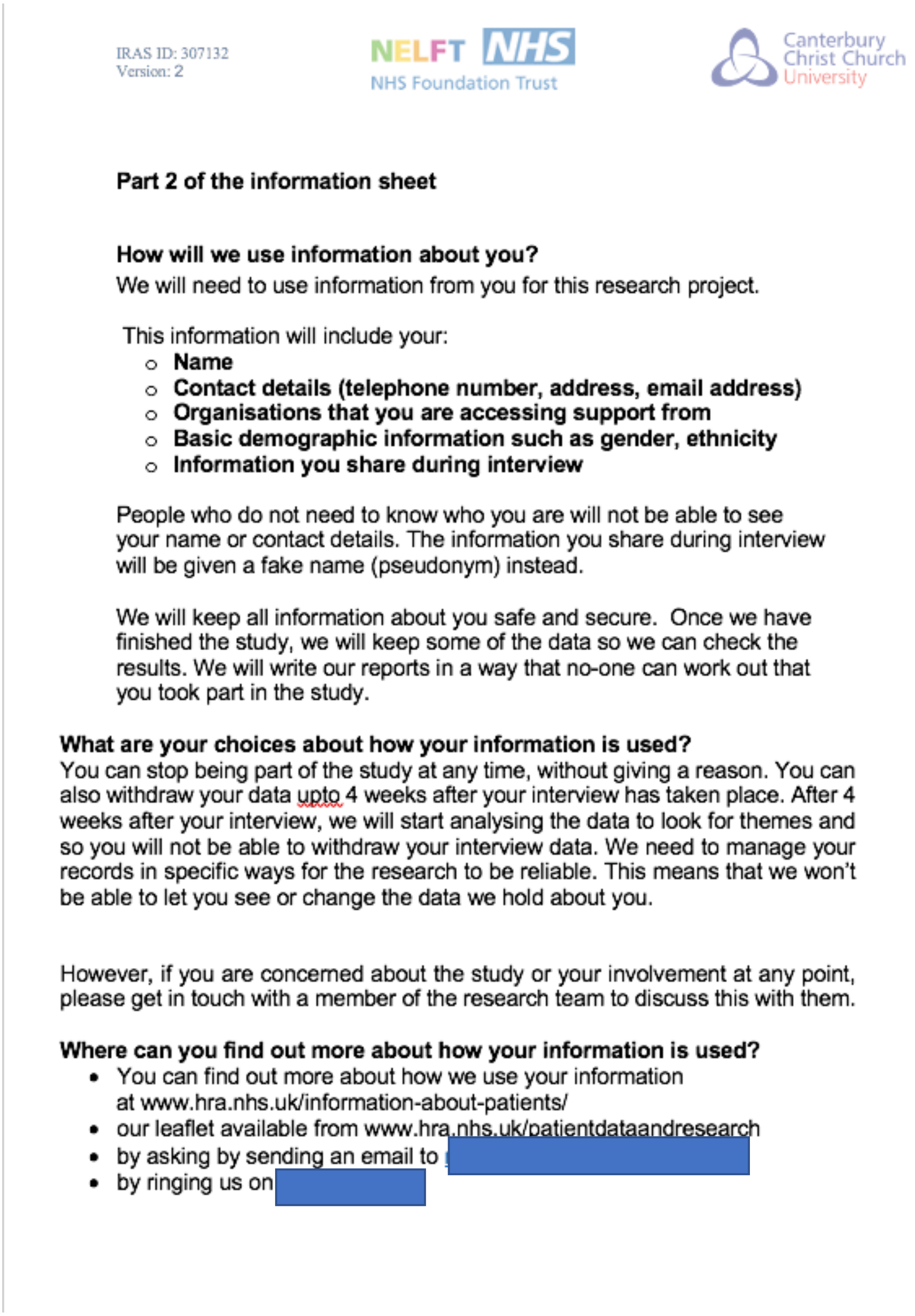
~3-6 months after participating in the interview, if you have consented to participation in this phase of the study, you will be invited to provide feedback on the study results. You will be asked whether the themes developed by the Research Team adequately reflect the experiences you shared during interview.

Once the study is complete – if you have consented to, you will receive a copy of the final study report in a format intended for carers and people with a diagnosis of Anorexia Nervosa and/ or notification of publication of the report in a scientific journal

At any point during these stages, and up to 4 weeks after your interview you may withdraw your consent to participate in the research project, i.e., you may decide not to participate in the study. You may also withdraw your interview data.

You do not have to give a reason for withdrawing consent.

After 4 weeks post-interview, you may not withdraw your anonymous interview data. However, please contact the Research Team if you have queries or concerns about the project or how your data will be used as they can discuss this with you.



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Part 2 of the information sheet

How will we use information about you?
We will need to use information from you for this research project.

This information will include your:

- **Name**
- **Contact details (telephone number, address, email address)**
- **Organisations that you are accessing support from**
- **Basic demographic information such as gender, ethnicity**
- **Information you share during interview**

People who do not need to know who you are will not be able to see your name or contact details. The information you share during interview will be given a fake name (pseudonym) instead.

We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?
You can stop being part of the study at any time, without giving a reason. You can also withdraw your data upto 4 weeks after your interview has taken place. After 4 weeks after your interview, we will start analysing the data to look for themes and so you will not be able to withdraw your interview data. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

However, if you are concerned about the study or your involvement at any point, please get in touch with a member of the research team to discuss this with them.

Where can you find out more about how your information is used?

- You can find out more about how we use your information at www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking by sending an email to [redacted]
- by ringing us on [redacted]

What if I have a question?

- If you have a question or concern about any aspect of this study, you can ask to speak to Maya and she will do her best to address it. You can contact her on the details outlined above.

What if there is a problem?

You can make a complaint about the research study, the way you have been dealt with, or any possible harm suffered by contacting Dr Fergal Jones [redacted] Clinical Psychology Programme Research Director at the Salomons Institute for Applied Psychology. This will be taken seriously and investigated accordingly. Complaints will be handled on an individual basis.

If you would like to speak to someone independent of the research you can contact the Patient and Liaison Service (PALS): https://www.nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service/

Will the interview space be confidential?

It is important that interviews take place in a space that will facilitate confidentiality. You can choose for the interview to take place online via secure video link or at Vincent Square, London (SW10 9NG)/ The Courtyard, Maidstone, Kent (ME14 1PA).

If you choose to have the interview via secure video link, you will be interviewed by Maya Kuhl, the Lead Researcher. Maya has a home office space, which offers privacy and confidentiality.

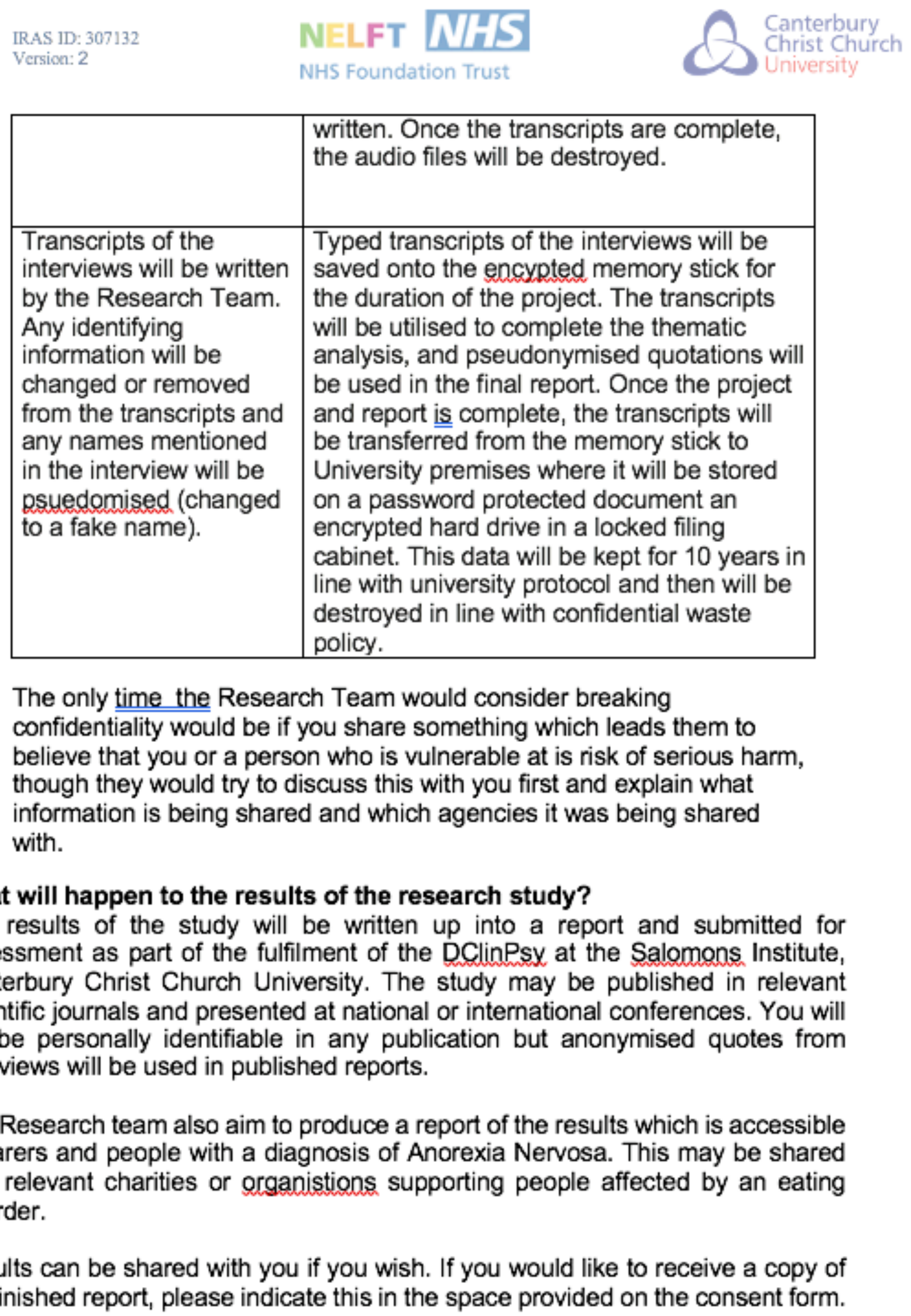
If you choose to meet in person, interviews can take place at Vincent Square, London (SW10 9NG)/ The Courtyard, Maidstone, Kent (ME14 1PA). These buildings are utilised for clinical work and offer a private, quiet and confidential space for the interviews to take place.

Will information from or about me from taking part in the study be kept confidential?

Yes, all of your information will be kept confidential. How the different types of information being managed is detailed below.

Type of information	How it is being managed
Your contact details including telephone	These details will be saved onto a password protected document that only the Research

number, address and email address. We will also ask you about any organisations that you are accessing support from as a carer. Consent forms which will have your first and second name and signature. The consent forms will also include your unique pseudonym (fake name) to securely link this to your interview data. Personal information such as your age, gender, ethnicity, length of time in the role of carer.	Team has access to. This identifiable information will be kept separately to any of the other information outlined below. By linking your name and interview data, this will enable you to withdraw your data – should you wish to, within the 4 week period post interview. Once all the data has been collected, consent forms will remain password protected and be saved to a hard drive and kept in a locked room on University premises. This data is stored securely for 10 years after which point it is destroyed in line with confidential waste policy. Contact will only be made with you in ways that you have consented to. Your contact details will be deleted once the project is complete and relevant information has been shared with you. Personal information will be anonymously processed and reported within the final project report, e.g. '7 Participants described their gender as female, 4 as male and 2 as non-binary'.
Audio files from interviews.	Interviews will be recorded on an electronic voice recorder or recorded securely on the online video platform. Once the interview is complete, the files will be and transferred immediately onto an encrypted and password protected memory stick approved for use in the NHS. Only the Lead Researcher will have access to the recordings. The original recording will be destroyed. The audio files will stored on the memory stick until the transcripts have been



	written. Once the transcripts are complete, the audio files will be destroyed.
Transcripts of the interviews will be written by the Research Team. Any identifying information will be changed or removed from the transcripts and any names mentioned in the interview will be psuedomised (changed to a fake name).	Typed transcripts of the interviews will be saved onto the encypted memory stick for the duration of the project. The transcripts will be utilised to complete the thematic analysis, and pseudonymised quotations will be used in the final report. Once the project and report is complete, the transcripts will be transferred from the memory stick to University premises where it will be stored on a password protected document an encrypted hard drive in a locked filing cabinet. This data will be kept for 10 years in line with university protocol and then will be destroyed in line with confidential waste policy.

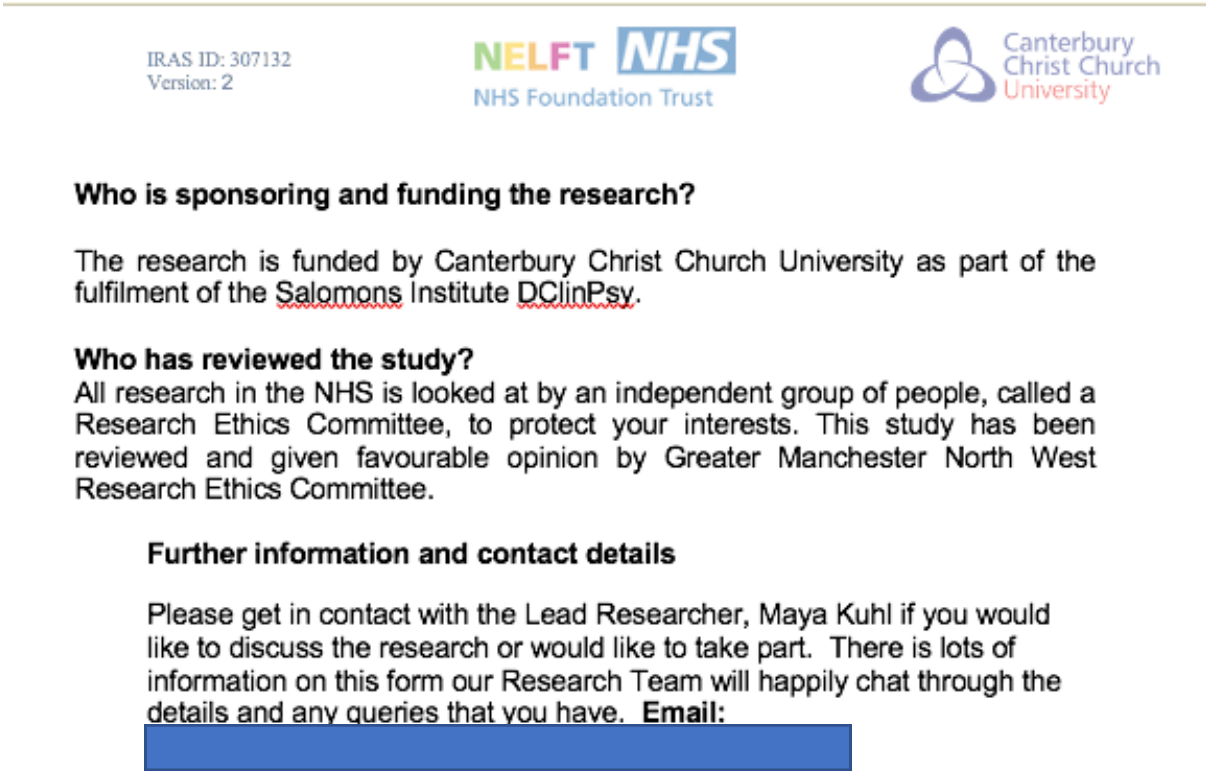
The only time the Research Team would consider breaking confidentiality would be if you share something which leads them to believe that you or a person who is vulnerable at is risk of serious harm, though they would try to discuss this with you first and explain what information is being shared and which agencies it was being shared with.

What will happen to the results of the research study?

The results of the study will be written up into a report and submitted for assessment as part of the fulfilment of the DClinPsy at the Salomons Institute, Canterbury Christ Church University. The study may be published in relevant scientific journals and presented at national or international conferences. You will not be personally identifiable in any publication but anonymised quotes from interviews will be used in published reports.

The Research team also aim to produce a report of the results which is accessible to carers and people with a diagnosis of Anorexia Nervosa. This may be shared with relevant charities or organistions supporting people affected by an eating disorder.

Results can be shared with you if you wish. If you would like to receive a copy of the finished report, please indicate this in the space provided on the consent form.



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Who is sponsoring and funding the research?

The research is funded by Canterbury Christ Church University as part of the fulfilment of the Salomons Institute DClinPsy.

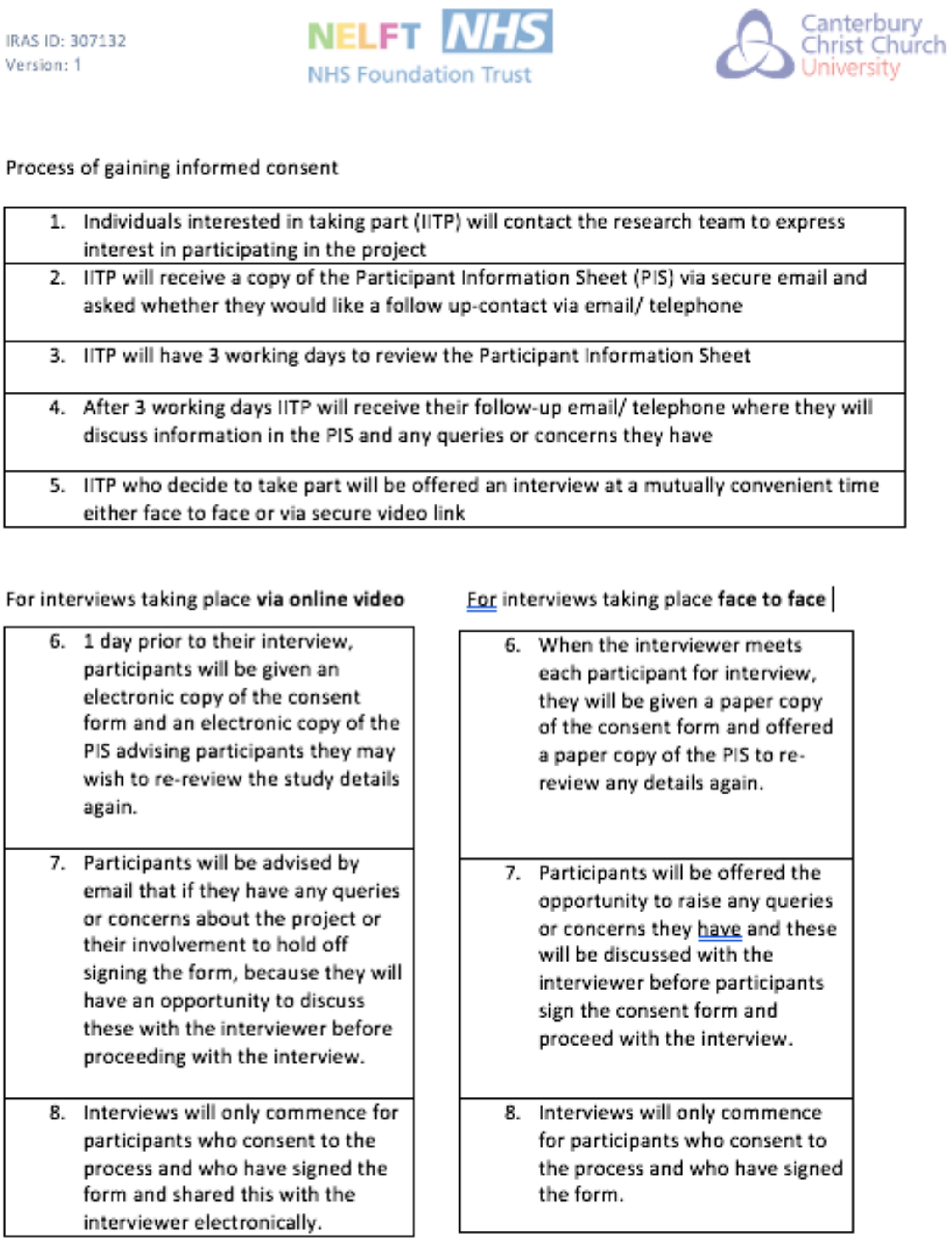
Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Greater Manchester North West Research Ethics Committee.

Further information and contact details

Please get in contact with the Lead Researcher, Maya Kuhl if you would like to discuss the research or would like to take part. There is lots of information on this form our Research Team will happily chat through the details and any queries that you have. **Email:** [redacted]

Appendix G: Consent Form Process



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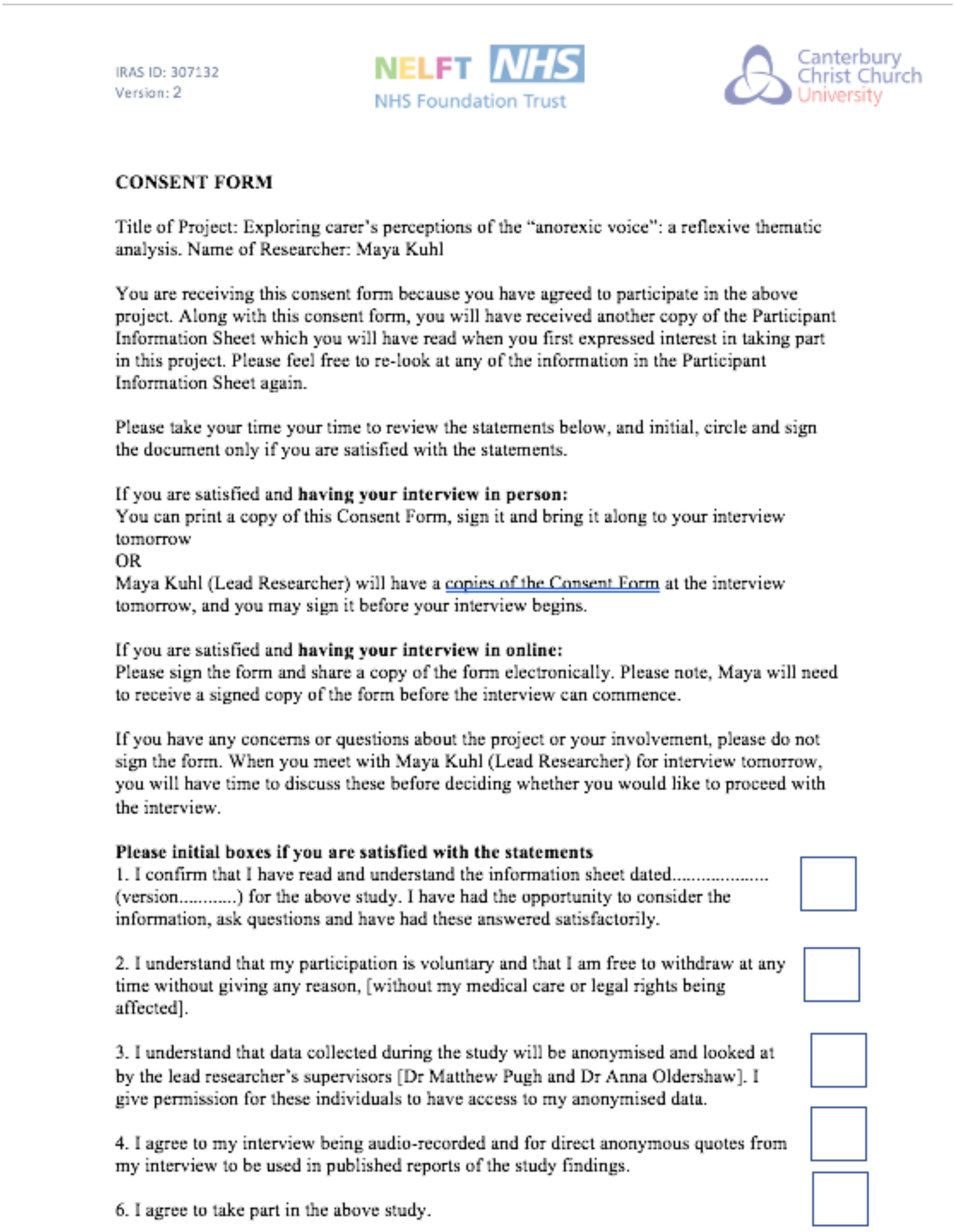
Process of gaining informed consent

1. Individuals interested in taking part (IITP) will contact the research team to express interest in participating in the project
2. IITP will receive a copy of the Participant Information Sheet (PIS) via secure email and asked whether they would like a follow up-contact via email/ telephone
3. IITP will have 3 working days to review the Participant Information Sheet
4. After 3 working days IITP will receive their follow-up email/ telephone where they will discuss information in the PIS and any queries or concerns they have
5. IITP who decide to take part will be offered an interview at a mutually convenient time either face to face or via secure video link

For interviews taking place **via online video**	For interviews taking place **face to face**
6. 1 day prior to their interview, participants will be given an electronic copy of the consent form and an electronic copy of the PIS advising participants they may wish to re-review the study details again.	6. When the interviewer meets each participant for interview, they will be given a paper copy of the consent form and offered a paper copy of the PIS to re-review any details again.
7. Participants will be advised by email that if they have any queries or concerns about the project or their involvement to hold off signing the form, because they will have an opportunity to discuss these with the interviewer before proceeding with the interview.	7. Participants will be offered the opportunity to raise any queries or concerns they have and these will be discussed with the interviewer before participants sign the consent form and proceed with the interview.
8. Interviews will only commence for participants who consent to the process and who have signed the form and shared this with the interviewer electronically.	8. Interviews will only commence for participants who consent to the process and who have signed the form.

Appendix H: Consent Form



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CONSENT FORM

Title of Project: Exploring carer's perceptions of the "anorexic voice": a reflexive thematic analysis. Name of Researcher: Maya Kuhl

You are receiving this consent form because you have agreed to participate in the above project. Along with this consent form, you will have received another copy of the Participant Information Sheet which you will have read when you first expressed interest in taking part in this project. Please feel free to re-look at any of the information in the Participant Information Sheet again.

Please take your time your time to review the statements below, and initial, circle and sign the document only if you are satisfied with the statements.

If you are satisfied and **having your interview in person:**
You can print a copy of this Consent Form, sign it and bring it along to your interview tomorrow
OR
Maya Kuhl (Lead Researcher) will have a copies of the Consent Form at the interview tomorrow, and you may sign it before your interview begins.

If you are satisfied and **having your interview in online:**
Please sign the form and share a copy of the form electronically. Please note, Maya will need to receive a signed copy of the form before the interview can commence.

If you have any concerns or questions about the project or your involvement, please do not sign the form. When you meet with Maya Kuhl (Lead Researcher) for interview tomorrow, you will have time to discuss these before deciding whether you would like to proceed with the interview.

Please initial boxes if you are satisfied with the statements

1. I confirm that I have read and understand the information sheet dated.................... (version............) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, [without my medical care or legal rights being affected]. ☐

3. I understand that data collected during the study will be anonymised and looked at by the lead researcher's supervisors [Dr Matthew Pugh and Dr Anna Oldershaw]. I give permission for these individuals to have access to my anonymised data. ☐

4. I agree to my interview being audio-recorded and for direct anonymous quotes from my interview to be used in published reports of the study findings. ☐

6. I agree to take part in the above study. ☐

Please circle the appropriate response

7. In ~3-6 months **I would like / would not like** to participate in providing feedback on the themes developed by the Research Team which will be based on their review of the experiences shared by all participants during interview

8. In ~18 months **I would like / would not like** to receive a copy of the final research report which will be designed for carers of and people with a diagnosis of Anorexia Nervosa

9. In ~2 years **I would like / would not like** to receive notification if the final research report is published in a scientific journal.

Name of Participant____________________ Date________________

Signature ___________________

Name of Person taking consent __Maya Kuhl___________ __Date____________

Signature ____________________

To be completed by researcher and participant:

Preferred pseudonym (fake name) for study report

____

PLEASE SEE NEXT PAGE TO COMPLETE BASIC INFORMATION

Basic information

Name:	
Contact details	Telephone number: Email address:
This study has recruited participants through carer's support groups and networks. How did you hear about the study?	
How would you describe your ethnicity?	
How would you describe your gender?	
What is your relationship to the person that you care for who has (or has had) Anorexia?	
Length of time in caring role?	

Appendix I: Respondent Validation Email

Title: Carer's perceptions of the anorexic voice_review of results section

Email body:

Dear,

Thank you again for taking part in the ‘Carer’s perceptions of the anorexic voice’ research project. I’m contacting you as you opted to take part in reviewing the results section, a draft of which is attached here in this email.

To develop the results, I have used thematic analysis, which attempts to highlight key themes in participant’s personal experiences shared during interview. Some of the themes may fit with your individual experience, other themes may have been constructed based on other participant’s experience and may not fit with your own.

Individually and as a group you made my job of analysing the data both very rewarding and rather challenging as you offered such rich insights and helpful perspectives that it was impossible to include everything. I therefore tried to take the approach of thinking what would be helpful for other carers, people with anorexia, researchers and service developers to know about the concept of the anorexic voice moving forwards.

With this in mind, if you would like to give feedback, please answer the following questions:

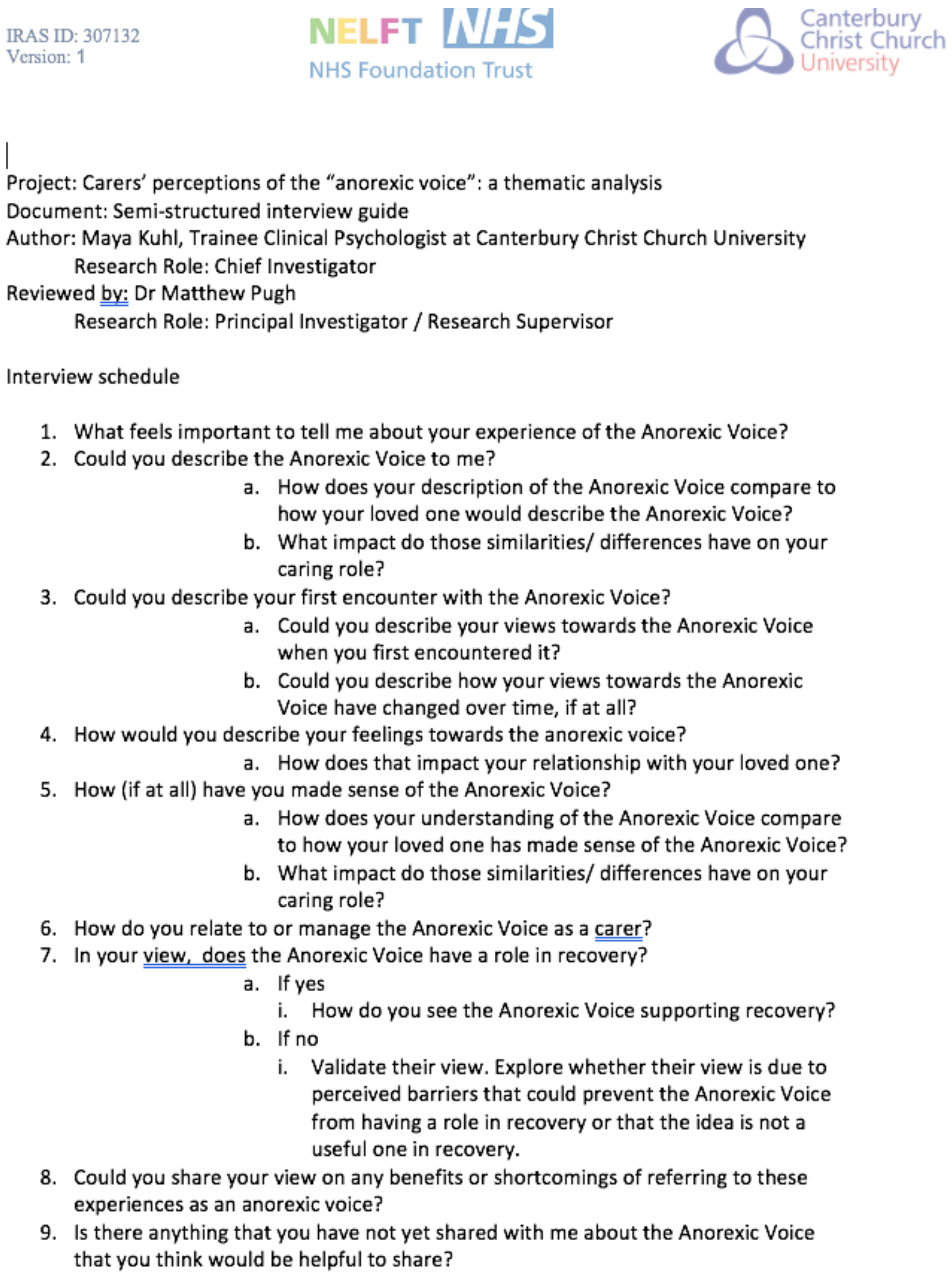
1. Do the results as a whole adequately represent your experience of the Anorexic Voice’
2. Is there anything that you would like to add?
3. Is there anything that you would like to change?

I’m happy for you to email me any feedback you have, or we can discuss it over the phone or on video – I am free any time between 9am – 5pm next Thursday 2nd March. If you do have feedback, please could you share this with me Wednesday 8th of March.

Best wishes,

Maya

Appendix J: Interview Guide



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Canterbury Christ Church University

Project: Carers' perceptions of the "anorexic voice": a thematic analysis
Document: Semi-structured interview guide
Author: Maya Kuhl, Trainee Clinical Psychologist at Canterbury Christ Church University
    Research Role: Chief Investigator
Reviewed by: Dr Matthew Pugh
    Research Role: Principal Investigator / Research Supervisor

Interview schedule

1. What feels important to tell me about your experience of the Anorexic Voice?
2. Could you describe the Anorexic Voice to me?
    a. How does your description of the Anorexic Voice compare to how your loved one would describe the Anorexic Voice?
    b. What impact do those similarities/ differences have on your caring role?
3. Could you describe your first encounter with the Anorexic Voice?
    a. Could you describe your views towards the Anorexic Voice when you first encountered it?
    b. Could you describe how your views towards the Anorexic Voice have changed over time, if at all?
4. How would you describe your feelings towards the anorexic voice?
    a. How does that impact your relationship with your loved one?
5. How (if at all) have you made sense of the Anorexic Voice?
    a. How does your understanding of the Anorexic Voice compare to how your loved one has made sense of the Anorexic Voice?
    b. What impact do those similarities/ differences have on your caring role?
6. How do you relate to or manage the Anorexic Voice as a carer?
7. In your view, does the Anorexic Voice have a role in recovery?
    a. If yes
        i. How do you see the Anorexic Voice supporting recovery?
    b. If no
        i. Validate their view. Explore whether their view is due to perceived barriers that could prevent the Anorexic Voice from having a role in recovery or that the idea is not a useful one in recovery.
8. Could you share your view on any benefits or shortcomings of referring to these experiences as an anorexic voice?
9. Is there anything that you have not yet shared with me about the Anorexic Voice that you think would be helpful to share?

If the idea of the Anorexic Voice does not resonate with individuals:

1. How else are you making sense of these experiences/ what's happening?
2. What concerns or reservations do you have about this as an idea?
3. Why do you think other people are so interested in this idea?

Appendix K: Abridged Research Journal

6th December, 2021
I have had a lot of responses to people wanting to participate in the focus group. This is a really good sign that there is interest in this topic and also makes me feel quite reassured when it comes to recruiting for the study later on down the line. I think I also feel a little apprehensive though, so I think I will put together a bit of a guide for myself to help prepare for it.

17th December, 2021
I held the focus group earlier on today and it was so so so helpful. It actually made me realise that this is an important piece of research. I was totally underestimating how emotional it can get talking about anorexia and the anorexic voice though. It is shocking to realise how devastating this illness can be for families. It was also really helpful to hear that carers really want practical advice and information that might help them to support their loved one to recovery. I really want to hold onto that insight and make sure I weave it in throughout the course of the study.

18th Feb, 2022
My word this IRAS form is longgggggg. I think I am pretty much there now, so I can go ahead and book the review – although I have no idea as to how to go about this process either. I really do think the process needs updating, I really have been put off conducting any more research that requires NHS ethics as it's just so unbelievably cumbersome, confusing and just filled with red tape (if that's the right expression). I genuinely believe they need to change the process to differentiate between big clinical trials and the type of research I'm doing where I'm interviewing 12 people who are reaching out to me and asking to participate.

May 5th 2022
Just had my bracketing interview with ******** I surprised myself with how much I 'knew' about the anorexic voice, which is of course all from literature that I've read. Somewhere in the literature is described like an angel and a devil and that description has stayed with me and I realised that this is how I am imagining participants might describe it this way too, so I will need to make sure I am aware of other ways people might experience it. The '90% of people with anorexia' statistic has really stuck in my mind too, and I realised I have been kind of anticipating that anorexic voice is something that carers connect with or have recognise in their loved one so I will need to watch out for this bias.

I also had quite a strong view that it could be helpful in recovery, along the lines of work I know Matt's been doing around using voice dialogue with the anorexic voice. Again, I will need to pay attention to alternative views in the interviews and analysis.

24th May 2022
I got HRA approval today – which is fantastic news. I now have to get local R&D approval which I have heard is very variable between trusts. Fingers crossed it's straight forward with NOCLOR.

7th June, 2022
So the process of getting local approval is taking a lot longer than expected. After chatting to Matt, it looks like I can go ahead and start recruiting from the New Maudsley Carer's Network as I have HRA approval, just not local approval, and the network lead has said she would be more than happy to advertise the project. At least the process has been really straight forward with them, they seem to really value research.

18th July 2022
First interview later on in the week, I have just re-looked over my notes for the bracketing interview and watched some videos on semi-structured interviews. Really looking forward to getting started and curious as to what I will discover.

I am also feeling a bit apprehensive though, I hope the interview guide works out ok in interviews. I suppose it has got some quite broad and general questions which will help to give space to what's important to participants. I suppose even if the guide is missing something I can evolve it.

20th July 2022
I'm now having to go back to HRA for such minor changes for NOCLOR. Honestly, this whole process is ridiculous and so confusing. It feels like such a shame, because the actual research project feels like a genuinely useful and interesting one, but this side of the process makes me feel really quite stressed and frustrated. I hope I'm able to put that to one side for the interview tomorrow.

29th July
I've done the first 3 interviews now and already uncovering a lot about anorexia and the anorexic voice. It's really heart breaking to think about what these young people and their families go through, it just feels so utterly traumatising. I suppose I'm noticing my shock at the tragedy of this illness.

As for the anorexic voice, for two participants it feels like it's so clearly there. It sounded so scary the way they described it, literally like it possessed their child and was just so cruel to them, like so much beyond what everyone thinks about with anorexia about restricting food, like just the sheer cruelty of the sorts of things it would say. It's unbelievable to think it can take hold so quickly. I can see the links with the research suggesting it's like an abusive relationship and to think that's going on in their mind self to self from such a young age. Just so shocking and I want to hold onto the shock, I want to try and be able to convey it in the report, because I suppose they can get a bit clinical.

29th July
As for the other participant it maybe feels more like it was a tool that he was encouraged to use to separate his daughter from the ANV. It was interesting, he was kind of on the fence about the idea. The other thing I'm noticing is that out of the 3 interviews so far, 2 participants have described how trying to separate their loved one from the ANV caused real problems in their relationship, for the third participant that had led to a complete breakdown in their communication months ago that hasn't been repaired. Of course it's difficult to know how much that was just linked to the ANV, but still it's a strong reaction that warrants thought.

8th August, 2022
Now I’m a few interviews in and it seems to be going well. Everyone I’ve met is so knowledgeable and motivated. To begin with I think I felt a bit intimidated and like I should know more about anorexia, but I’ve actually started to think it could be a real positive of this study, that I’m being guided by experts by experience and don’t have so many experiences and assumptions of my own going into this.

22nd August, 2022
I’ve realised that both participants who were quite critical of the concept of the anorexic voice also expressed some hesitations about whether they could participate because they opposed it. It probably took quite a bit of courage to participate given the Researcher-Participant power imbalance. I feel like I did a reasonable job of reassuring them that their views were welcome and valuable. But I looked back at the recruitment poster and I do think the project has been geared up to invite people to participate if the idea resonates with them. I am kicking myself as other participants who had criticisms of the ANV would have been super valuable. If I had my time again, I would more clearly invite people to participate even if they think the concept isn’t valid or doesn’t fit. But, what I can do now again is look out for alternative views and just try to explore them. Also, I could include this thinking in the discussion for future research.

7th September, 2022
A real theme in the interviews is participants having heart-breaking experiences (and understandably strong views) about resource issues. It’s heart breaking that the NHS is in such a mess but I feel conflicted about how much space to give it in interviews because it’s it feels quite separate from my research topic.

7th September, 2022
On second thoughts, these ideas do not exist in a vacuum, so of course the context of what’s going on at the time of the interviews impacts how people relate to and understand the anorexic voice. It’s also just coming up so much in interviews that it feels important to include it somehow. Perhaps even in the introduction….

10th October, 2022
After all of the hoops I jumped through to get local approval, the next carer’s group that I could attend and advertise to isn’t until next year which is just delaying my project too much. Can’t believe how much time and effort went into the whole NHS ethics process and I could have just gone through university ethics and recruited through independent organisations. Anyway, I will contact the individuals who expressed interest and I said I was out of space and offer the space to them.

14th November, 2022
As I’m doing my Part A and pulling together all this research on externalising it’s really highlighted to me some of the issues that people can experience with being encouraged to externalise parts of them or the idea of anorexia being a voice or separate self/ part of them being imposed on people. It seems to be really fit with what some of the participants shared with me in interview where the idea of the anorexic voice had created real issues within their relationships. It seems to be quite prevalent that its an issue. I wonder if clinicians using the technique recognise this?

28th November, 2022
In doing my part A something that has come up that I'm especially interested in this question of 'who has authority over the truth?', really who does have the authority to say, that's you or that's your anorexia talking. On one hand I can totally see how people would end up there, because their child or teenager might have drastically changed pretty much over night, and the starvation of their brain would cause them to think, feel and behave so differently that I can understand where they are coming from. At the same time, I can only imagine what that would feel like on the receiving end. This Tan and Hope paper is so interesting as well, because it's talking about how if anorexia is part of someone's identity, and (as an adult) they are refusing treatment and have capacity, then we need to respect their wishes. But, if anorexia has taken over their identity, we need to protect them from it to help them recover their former identity. A right conundrum, especially as people's relationship to their identity fluctuates so much. Doing this review has really made me think quite differently about externalising as a technique. I still think it could be helpful, but really do believe it needs to be done with and not to people.

7th December, 2022
Just got my Part A feedback from Anna and have got really minor amends. I am so so so so happy, I really thought I would have more revisions. This means I can focus on Part B, and think I should be able to make the April deadline.

12th December, 2022
Listening back to the transcripts and noticing how emotional it was for participants to share their feelings towards the anorexic voice. Maybe having space to acknowledge those feelings is important. I'm noting this down as sometimes it's hard to capture the feeling of a moment and I wonder whether it might get a bit lost when I get to coding and I'm more distanced from the feeling of the interaction during the interview.

19th Jan, 2023
50 codes and I'm only half way through the transcripts!!! In some ways, I think my job of bringing this altogether will be easy because I have so many rich, interesting and useful insights from participants. But, the (anxious me) thinks it's going to be really tricky because it'll be really hard to cut anything out as it all seems so interesting and relevant. I've got a load of codes that are loosely connected to descriptions of the anorexic voice, and though bully and powerful are coming up a lot there's also metaphors, like tsunami, devil, and Voldemort that only crop up once but seem to really powerfully capture the essence of the ANV. I must remember that I am drawn to metaphors, and so it will be important to try and fairly represent participant's views.

In reflecting on this, I have noticed that I am getting drawn into trying to create themes, so I think I need to pull back and just stick to the process of coding, then once it's done I can move onto reviewing all of the codes and seeing if there are themes that bring the codes together.

23rd January, 2023
Having thought about this some more, I think using the metaphors could be a good way to go because metaphors allow people to make links in their mind with many other descriptions. So I think this would be a really good way to capture the many codes I have about power, evil, destructive etc. Also, I think there's a reason people might have been reaching for metaphors, they sort of conjure up imagery and feelings in a way descriptive words can't. It seems the

ANV is so almighty and awful that it is difficult to capture in words and you kind of need those connections in your mind to really get close to understanding the dread and influence of the ANV.

1st February, 2023
I think I've found a way forward with a set of codes and themes I'd been struggling with. So I did have a theme of 'Validity' then it had lots of subthemes like Valid and Intrusive, Valid and an inner voice, Invalid – a metaphor for externalising, but now I've separated it out to capture the different definitions of the ANV and then have a separate theme around resonance for carers. Because some thought it was a really useful construct, but then how they talked about it suggested they understood it very differently to how I perhaps have in my mind was an ANV is.

14th February, 2023
Finding this all a bit tricky at the moment. So, I have theme developing around how the anorexic voice could help carers, like make the journey more bearable or understanding what it's like for their loved one, but I'm realising that some participants are more referring to externalising than the ANV. For example, I have two participants who didn't really like the idea of the anorexic voice, but when I asked about the benefits or shortcomings of it as a concept, they viewed some really clear benefits of it. Feeling quite unsure how to try and convey this within the themes.

3rd March, 2023
I have had quite a few responses from participants from the respondent validation, which is great, but I am now trying to think about how to squeeze it all in. I definitely take the point that linking the anorexic voice more directly with restrictive eating would be helpful to more closely link the two, but I'm thinking about how I could bring this into the themes….

Having had a think about this, I actually think I could bring this into the introduction or discussion because I can link it to existing research which has an established link between these things. This feels like a good solution, as then I'm not trying to shoe horn it into the results section where it doesn't really fit, but I am also incorporating this insight from a carer.

9th March
More feedback from participants. Really reassuring to hear positive feedback that the results do resonate with their experiences. I had been feeling unsure about how much to include this sub-theme of 'befriending the bully' as there was minimal codes and extracts that led to the development of the theme, so really helpful to hear from one carer that although they can't imagine using the strategy in their situation, that it was interesting to hear. Makes me think of the 'difference that makes a difference' in family therapy and how actually it is helpful to include alternative views, because it might just spark an idea in someone's mind that could lead to change if they're a bit stuck and perhaps things aren't moving forward.

15th March, 2023
Had some feedback from Matt and Anna, and thinking about their point about whether to use quotes as theme and sub-theme labels. It can help bring it to life and give voice to carers, but on the other hand, I was feeling like some of the labels didn't quite capture the theme. I think I was applying it as a system, rather than because it really worked. Writing this down, I am drawn towards re-labelling my sub-themes to better convey the meaning and only retaining the quote if I think it really works.

22nd March, 2023
I’m feeling a bit conflicted about how much to include ideas around moving away from externalising altogether in the discussion, so I thought I’d turn to my journal to work through my motivations.
The reasons I think it could be helpful: Participant ‘Nancy’ explicitly spoke about moving away from externalising altogether. Though she was the only participant, since the study was biased towards those who favour the concept, it is possible that there are others who might think along similar lines, and certainly the research on externalisation does indicate this. Also, the fact that so many carers had issues with externalising with their loved ones, it might could be a good idea to introduce this thought.

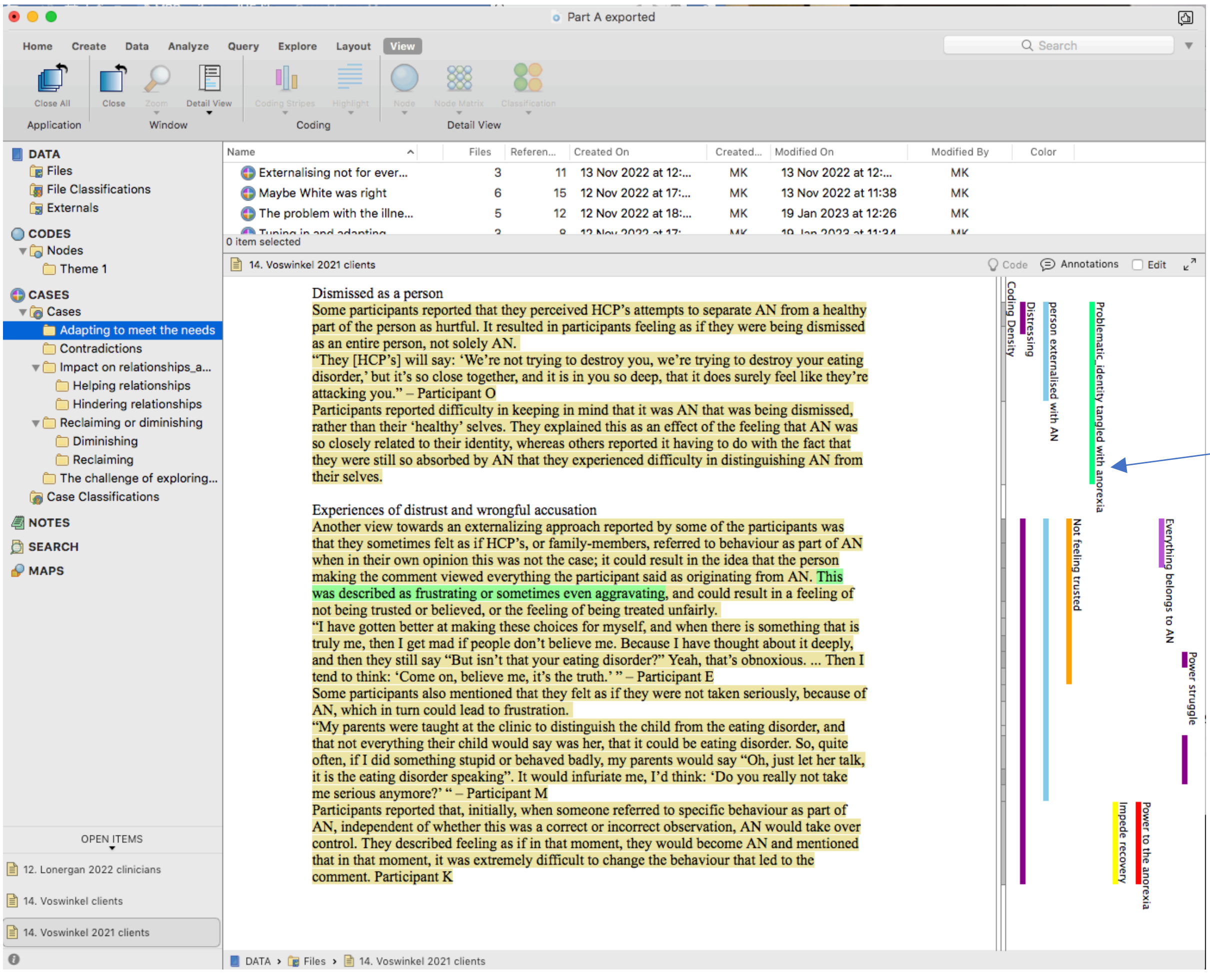
The reasons I’m concerned about including it, is, I wonder as a carer reading it, one might think ‘it’s easy for you to say, but we need to be able to separate/ externalise to cope’.

Wrting this down, I’m thinking as long as the benefits of externalising are clearly outlined, and it’s just mooted as an option, that’s probably a good middle ground.

Appendix L: Respondent Validation Responses

This has been removed from the electronic copy due to confidentiality reasons.

Appendix M: Meta-ethnography Synthesis Process (Part A)



Name	Files	Referen...	Created On	Created...	Modified On	Modified By	Color
Externalising not for ever...	3	11	13 Nov 2022 at 12:...	MK	13 Nov 2022 at 12:...	MK	
Maybe White was right	6	15	12 Nov 2022 at 17:...	MK	13 Nov 2022 at 11:38	MK	
The problem with the illne...	5	12	12 Nov 2022 at 18:...	MK	19 Jan 2023 at 12:26	MK	
Tuning in and adapting	3	9	12 Nov 2022 at 17:	MK	19 Jan 2023 at 11:34	MK	

0 item selected

14. Voswinkel 2021 clients

Dismissed as a person

Some participants reported that they perceived HCP's attempts to separate AN from a healthy part of the person as hurtful. It resulted in participants feeling as if they were being dismissed as an entire person, not solely AN.

"They [HCP's] will say: 'We're not trying to destroy you, we're trying to destroy your eating disorder,' but it's so close together, and it is in you so deep, that it does surely feel like they're attacking you." – Participant O

Participants reported difficulty in keeping in mind that it was AN that was being dismissed, rather than their 'healthy' selves. They explained this as an effect of the feeling that AN was so closely related to their identity, whereas others reported it having to do with the fact that they were still so absorbed by AN that they experienced difficulty in distinguishing AN from their selves.

Experiences of distrust and wrongful accusation

Another view towards an externalizing approach reported by some of the participants was that they sometimes felt as if HCP's, or family-members, referred to behaviour as part of AN when in their own opinion this was not the case; it could result in the idea that the person making the comment viewed everything the participant said as originating from AN. This was described as frustrating or sometimes even aggravating, and could result in a feeling of not being trusted or believed, or the feeling of being treated unfairly.

"I have gotten better at making these choices for myself, and when there is something that is truly me, then I get mad if people don't believe me. Because I have thought about it deeply, and then they still say "But isn't that your eating disorder?" Yeah, that's obnoxious. ... Then I tend to think: 'Come on, believe me, it's the truth.' " – Participant E

Some participants also mentioned that they felt as if they were not taken seriously, because of AN, which in turn could lead to frustration.

"My parents were taught at the clinic to distinguish the child from the eating disorder, and that not everything their child would say was her, that it could be eating disorder. So, quite often, if I did something stupid or behaved badly, my parents would say "Oh, just let her talk, it is the eating disorder speaking". It would infuriate me, I'd think: 'Do you really not take me serious anymore?' " – Participant M

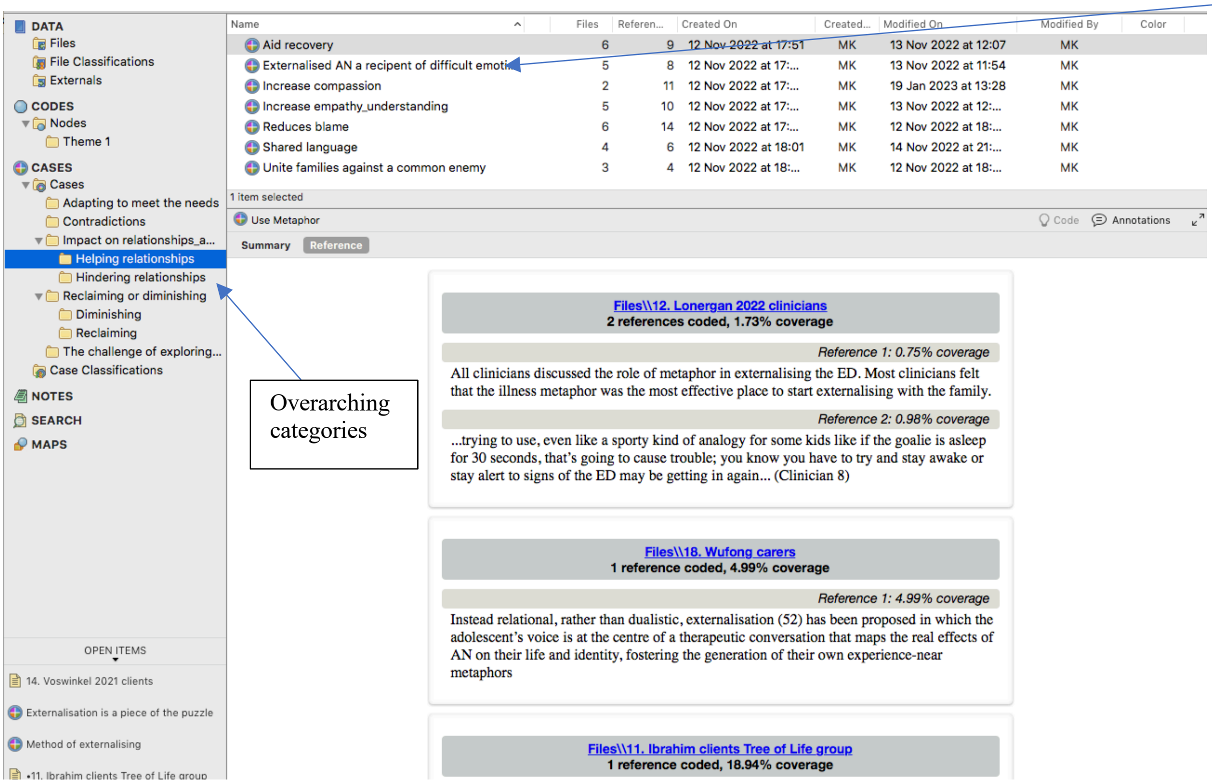
Participants reported that, initially, when someone referred to specific behaviour as part of AN, independent of whether this was a correct or incorrect observation, AN would take over control. They described feeling as if in that moment, they would become AN and mentioned that in that moment, it was extremely difficult to change the behaviour that led to the comment. Participant K

First order and second order extracts of papers relevant to the review aims were transferred onto NVivo and key concepts were coded accordingly.

Coding of concepts

Once this process was complete across all 18 studies, concepts with their extracts were reviewed to determine meaning between studies against the research aims.

Concepts



Name	Files	Referen...	Created On	Created...	Modified On	Modified By	Color
Aid recovery	6	9	12 Nov 2022 at 17:51	MK	13 Nov 2022 at 12:07	MK	
Externalised AN a recipent of difficult emoti...	5	8	12 Nov 2022 at 17:...	MK	13 Nov 2022 at 11:54	MK	
Increase compassion	2	11	12 Nov 2022 at 17:...	MK	19 Jan 2023 at 13:28	MK	
Increase empathy_understanding	5	10	12 Nov 2022 at 17:...	MK	13 Nov 2022 at 12:...	MK	
Reduces blame	6	14	12 Nov 2022 at 17:...	MK	12 Nov 2022 at 18:...	MK	
Shared language	4	6	12 Nov 2022 at 18:01	MK	14 Nov 2022 at 21:...	MK	
Unite families against a common enemy	3	4	12 Nov 2022 at 18:...	MK	12 Nov 2022 at 18:...	MK	

1 item selected

Use Metaphor

Files\\12. Lonergan 2022 clinicians
2 references coded, 1.73% coverage

Reference 1: 0.75% coverage

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.

Reference 2: 0.98% coverage

...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 may be getting in again... (Clinician 8)

Files\\18. Wufong carers
1 reference coded, 4.99% coverage

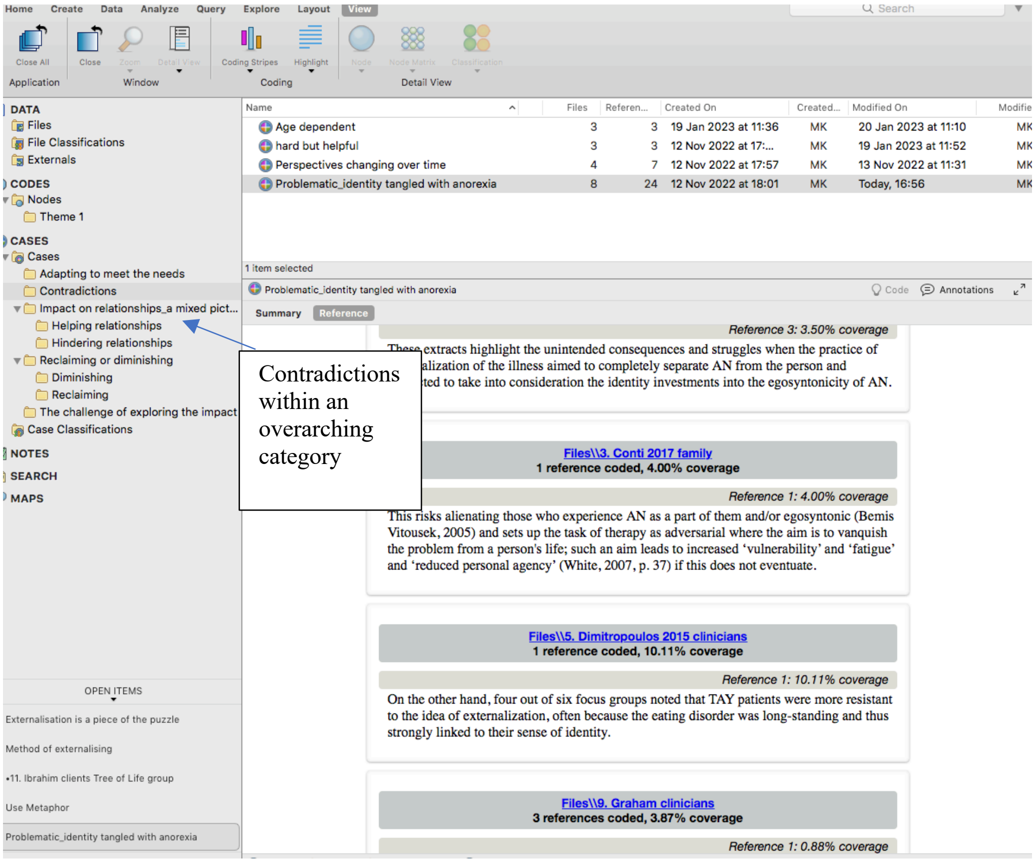
Reference 1: 4.99% coverage

Instead relational, rather than dualistic, externalisation (52) has been proposed in which the adolescent's voice is at the centre of a therapeutic conversation that maps the real effects of AN on their life and identity, fostering the generation of their own experience-near metaphors

Files\\11. Ibrahim clients Tree of Life group
1 reference coded, 18.94% coverage

Overarching categories

Studies were 'translated' into one another by exploring themes and meanings that arose from the different papers. Concepts were organised into folders of overarching categories



Name	Files	Referen...	Created On	Created...	Modified On	Modifie
Age dependent	3	3	19 Jan 2023 at 11:36	MK	20 Jan 2023 at 11:10	MK
hard but helpful	3	3	12 Nov 2022 at 17:...	MK	19 Jan 2023 at 11:52	MK
Perspectives changing over time	4	7	12 Nov 2022 at 17:57	MK	13 Nov 2022 at 11:31	MK
Problematic_identity tangled with anorexia	8	24	12 Nov 2022 at 18:01	MK	Today, 16:56	MK

1 item selected

Problematic_identity tangled with anorexia

Reference 3: 3.50% coverage

These extracts highlight the unintended consequences and struggles when the practice of alization of the illness aimed to completely separate AN from the person and ted to take into consideration the identity investments into the egosyntonicity of AN.

Files\\3. Conti 2017 family
1 reference coded, 4.00% coverage

Reference 1: 4.00% coverage

This risks alienating those who experience AN as a part of them and/or egosyntonic (Bemis Vitousek, 2005) and sets up the task of therapy as adversarial where the aim is to vanquish the problem from a person's life; such an aim leads to increased 'vulnerability' and 'fatigue' and 'reduced personal agency' (White, 2007, p. 37) if this does not eventuate.

Files\\5. Dimitropoulos 2015 clinicians
1 reference coded, 10.11% coverage

Reference 1: 10.11% coverage

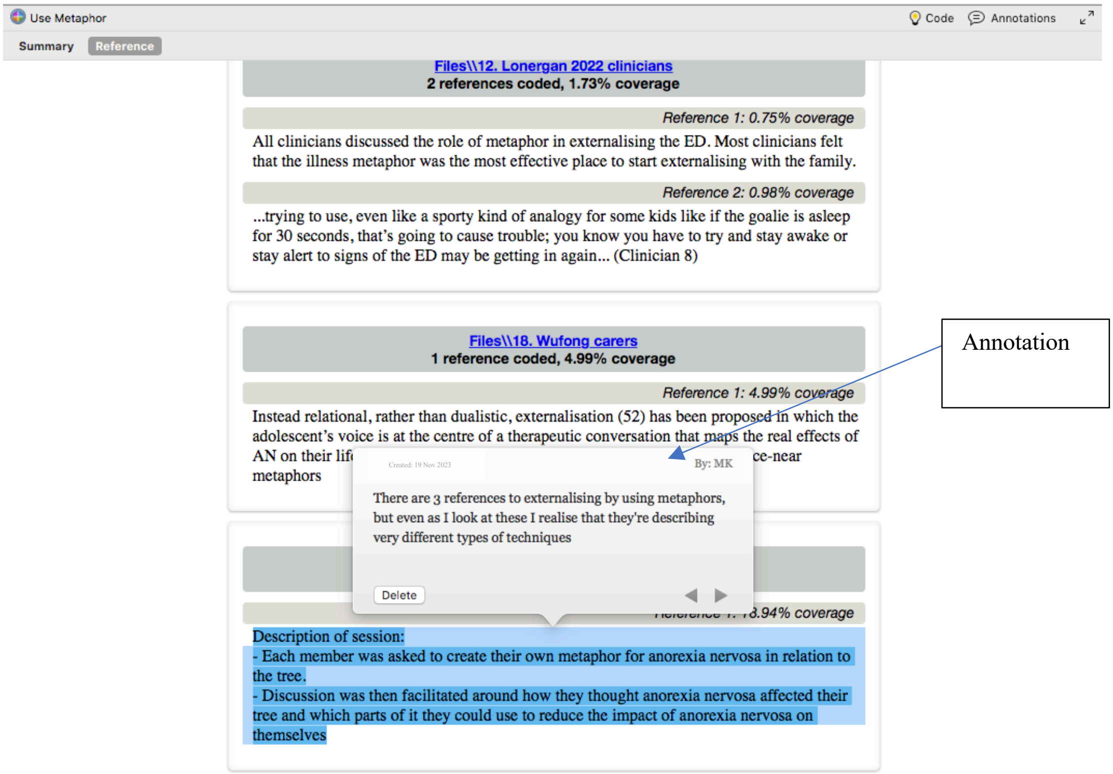
On the other hand, four out of six focus groups noted that TAY patients were more resistant to the idea of externalization, often because the eating disorder was long-standing and thus strongly linked to their sense of identity.

Files\\9. Graham clinicians
3 references coded, 3.87% coverage

Reference 1: 0.88% coverage

Contradictions within an overarching category

Contradictions were explored for 'refutational synthesis'. Some contradictions came to sit in a common overarching category.



Files\\12. Lonergan 2022 clinicians
2 references coded, 1.73% coverage

Reference 1: 0.75% coverage

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.

Reference 2: 0.98% coverage

...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 may be getting in again... (Clinician 8)

Files\\18. Wufong carers
1 reference coded, 4.99% coverage

Reference 1: 4.99% coverage

Instead relational, rather than dualistic, externalisation (52) has been proposed in which the adolescent's voice is at the centre of a therapeutic conversation that maps the real effects of AN on their lif ce-near metaphors

Created: 19 Nov 2023

By: MK

There are 3 references to externalising by using metaphors, but even as I look at these I realise that they're describing very different types of techniques

8.94% coverage

Description of session:
- Each member was asked to create their own metaphor for anorexia nervosa in relation to the tree.
- Discussion was then facilitated around how they thought anorexia nervosa affected their tree and which parts of it they could use to reduce the impact of anorexia nervosa on themselves

Annotation

This 'translated' data was then reviewed, reflected upon and synthesised to create novel interpretations, or third order constructs. Annotations were used to capture reflections when re-reviewing the concepts to aid this process

Appendix N: Theme Development Table (Part B)

Theme	Sub-theme	Codes	Example quotes
One Label, Many Definitions	Intrusive Voice	Loud	“he’d literally sit there with his hands over his ears kind of going ‘la, la, la, la, la.’ And that was because he’d got this voice in his head that was like so noisy” (Molly) “Loud. That's the only word she ever uses. The voice is just really, really loud” (Linda) “sometimes she'll say ‘it's too loud, it's too loud’ what’s going on in her head” (Fiona)
		Voice as separate	“she tells us what her anorexic voice is saying to her” (Claire) “it talks to her at night” (Fiona) “That voice was unbelievably different from her own, it felt like an outside force had just kind of hijacked her when the voice had taken over” (Jackie)
	Inner dialogue	Inner voices in conflict	“So she's got her own voice and the voice of anorexia. So now she's trying to find a way of not listening to the anorexic voice, but listening to her own” (Sandra) “like the way it was with my daughter she, she'd have that voice, but she'd also have another voice that was… knew that there was something wrong and knew and was trying to fight it” (Dawn) “it’s like an argument within herself” (Emma)
		The ANV is like other inner voices	“I mean we have a voice. If you go and go to shop and try a new dress on for wedding or something, and you ‘ ooh do I like it’, ‘maybe I like it, nice colour’, another voice goes ‘hmm… maybe not, your bum doesn't look good in it’, ‘yeah OK I'll try and find another one’” (Emma) “Because we all have an internal dialogue with ourselves and you know, I know that mine is my own voice…” (Claire)
		Discerning the ANV from other inner voices	“But you know the internal conversations we have inside of ourselves, it’s the case when you're anorexic, it's it's it's just so negative everything is so overwhelmingly negative” (Emma)

			"And she said the only way she can tell is if it's saying something that she knows is going to harm her, then she knows it's her anorexic voice and not her voice" (Claire)
	ANV an externalised form of AN	ANV enables separation from PwAN	"At the beginning we didn't know how to separate the person from the illness and yeah, we thought it was just Sally. Now we are so able to differentiate Sally from the anorexic voice" (Sandra) "I think [naming the ANV] is very positive because it gets this evil thing, it separates it from you, I mean it is part of you, but it is separate" (Emma)
		ANV responsible for actions	"I was conscious of this was not her, this was all, all anorexia" (Linda) "it's not them - it's the eating disorder that's doing that" (Jackie)
A Spectrum of Connection to the ANV	Advocates	Linked with brain changes	"It kind of made sense because his brain had become starved; it was like there were two different sides of him" (Molly) "It is the disease and the changes in their brain that is manipulating them" (Claire) "The biological reason for the that being the case, there is a fundamental, very fundamental change in brain chemistry, in brain biology. That is the reason for the existence of that voice" (Alan)
		Influences AN behaviour	"Well, I think that's what happens is that all the power goes to the voice and the sufferer is following that voice" (Claire) "So I think that all of the behaviours that they do is to avoid guilt that the voice makes them feel" (Jackie) "She came back afterwards and said 'I'm sorry it wasn't me, Mummy.' And that's the first time I think I realized the strength of this voice" (Emma)
		AN synonymous with ANV	"This is all the whole thing really of Anorexia is this voice telling you that you… what you can and can't do. That you can't eat basically, because of this controlling bully" (Fiona)

			"the illness to me is a big voice" (Sandra)
	Opponents	ANV does not resonate	"One thing that triggered me to participate on your research is this title anorexic voice. Which to me I didn't agree. I said no, there's no other voice" (Nancy) "I just wouldn't have used the word anorectic voice…. I think the word voice is much too narrow and simplistic of a term to use" (Helen)
		Alternative constructs work better	"So, from that point of view, maybe not so much the voice, but just trying to separate the eating disorder from the person is helpful" (Tony). "Perhaps it's more like a part of themselves" (Helen)
		Opposition to externalising	"There's this discussion on social media; try to separate the anorexic part of your child. I cannot - because my child has always been developing obsessions, so it's her obsessive nature. And if it's healthy obsession, yes, of course it's not another voice it's their… it's their lovely personality if it's a positive… If it's a negative, oh it's another voice…no!" (Nancy)
The Insidious Invasion of Loved Ones	The Seducer	Friend to Bully	"all you want to do is have a friend and then this monster moves in" (Emma) "to start off with the anorexic voice is definitely the patient's friend, then it can become the bully" (Molly)
		In control to being controlled	"it was originally there for her to support her and help her through a hard time but then it, you know, then it takes over and then she realized […]it's too late. You're in it, and it's got control of you and then you can't control it" (Fiona) "So, they are in control. But I think very quickly then being in control becomes them being controlled" (Jackie)
		Cheerleader to critic	"So, I think the eating disorder fed on all the compliments and was saying to her 'look, you

			see everyone's telling you how good you look, you can be more confident', you know, 'follow me and things will be great'. So, the anorexic voice was probably quite gentle in the beginning" (Claire) "She was just being told by the anorexic voice, never to stop - always keep pushing 'Try everything, do everything, you're amazing' kind of thing 'you can do it'. She was never, ever good enough… it … kind of matures within her ... to be punitive. So 'you can't do that because…you are not good enough'" (Sandra).
	The Powerful Bully	Bully	"Probably just call it the bully more than anything else" (Jackie) "It's very bullying" (Claire) "Bully voice in her head" (Tony)
		Powerful	"Realizing what how strong and powerful and how overwhelming the bombardment is" (Linda) "The power that it has… the strength it seems to have over all the element and especially probably the clinicians as well" (Helen) "So just today, the anorexic voice said 'no, you can't'. And that power was more powerful than she could cope with today" (Sandra) "I can't think of a word that is more powerful than powerful but…." (Fiona)
		So powerful it can defy logic	"Anosognosia, means you have no idea what the person is talking about. So, I'd be saying to my son, to start with I'd be arguing with logic, because that's you do. So I'd be saying, 'darling you're a clever boy, you know that you need to eat more and exercise less' and he would have absolutely no idea what I was talking about" (Molly) "I was talking about her when her heart rate was under 40, and they had the limit set on the machine, so different nurses would come and just turn it off… it was like the machine was the problem. so you did have quantitative, numerical evidence. Which you wouldn't have with 'she said this', or 'she ate this much' which is all kind of subjective. And I think that

			like tiptoeing around the anorexic voice” (Helen) “She used to water load at home, so when she was on leave at the weekend, she could show the ward she'd done really well. But she was refusing 2/3rds of her meals at home[….]she was losing weight at home.[....] but the conviction with which she would say this showed that there was…[….]some element of suspension of disbelief that she created within herself” (Alan)
		Evil	“I mean it's just.. just a really wicked, wicked, cruel….vindictive thing” (Jackie). “this evil thing” (Emma) “I think what really is the cruellest thing about the anorexic voice is that it wants to hide Sally away from everybody she loves” (Sandra)
		Metaphors	“like an ailment” (Dawn) “Darth Vader comes to mind” (Emma) “Tsunami” (Emma) “this emerging monster inside” (Emma) “like a monkey on your shoulder occasionally, and then having the monkey there permanently.” (Helen) “it's like a monster inhabiting her head” (Claire) “it was like your child’s been taken over by the devil” (Molly) “Voldemort is the eating disorder” (Jackie) “Like a bramble that finds every flipping crack in the ground to grow up” (Sandra) “it's just it's like the devil, it's like the devil it possesses her” (Fiona)
		Sinister aims	“The anorexic voice wants her to die. That's what it wants, it wants to take her to a place that she can't come back from. That's its aim!” (Fiona).

			“You have this voice that uses, you know, putting you down, trying to destroy you” (Emma) “the anorexic voice, basically just doesn't want them to have a life…the chief goal of getting her back into feeling like she's a nobody” (Sandra)
		Harsh task master	“you can't eat, you must continue to do exercise, you must go through pain in order to be able to see your friend today” (Sandra) “every time she weighed herself the voice would say to her ‘OK, so you've got here today, but tomorrow it needs to be even less’” (Fiona) “She's made a rule for herself that she won't have breakfast on the ward, so that’s that. And that's the anorexic voice” (Alan)
		Attacking self-worth	“And the anorexic voice said, ‘well, you're a stupid person for doing that, you are so useless.” (Sandra) “a voice that makes somebody feel utterly worthless and vile and disgusting” (Jackie) “it just is constantly having a go at her and telling her that she's fat and that she's ugly “(Fiona)
		Appeasing the voice	“she was always trying to placate it. And so she saw it as something that needed to be appeased, and then it would be quieter.” (Claire) “when I think what it must have been like to have people around trying to get the tube down her to feed her. And I think that getting to that stage is because at least at the end of that she could tell her anorexia ‘I did absolutely everything in my power to stop food going into my body’ to lessen that guilt” (Jackie)
		Inescapable	“it's something in your head that's going on every minute of every waking hour” (Claire) “So there’s a really interesting chart that was about a bit of research that was done in terms of how much of your mind is taken up with the anorexic voice, this is when you’re the sufferer, like the different stages of weight loss. So my son got to about 60-65% weight for height, so

			BMI of 12 or 13, and what this chart showed is that 90-100% of your brain power is taken up thinking about eating disorder related stuff, like food, weight and shape" (Molly) "it wants that person to listen to the voice all the time" (Sandra)
	The shadow that takes over	Positive qualities in loved ones	"Tina's our lovely girl who, you know, was really well adjusted and athletic and just really easy to live with, a pleasure to live with before this" (Tony) "she was very much Julie and chatty and smiley" (Jackie) "She was, you know, she was never an angry child… before she was a happy, really happy, easy going, a really easy going child" (Fiona)
		The ANV is not the loved one	"that monster is not my daughter" (Claire) "They're like out of themselves, you know, they bear no resemblance to their… any of their qualities" (Helen) "it was total obsession in her face and she was totally… it was not her" (Fiona)
		Invaded by the ANV	"The voice is more like a for me, it's always seemed like a possession so it feels like the voice has possessed my child" (Fiona) "it was just that that voice had taken over his head completely" (Molly).
		Visible changes	"You can see her eyes move as though she's listening to what's going on in her head and then literally it shuts down her whole body language, well, well, she'll curl in on herself well, it's a very closed in" (Fiona) "And so for Ellie, this Ed, I can see him just like a dark shadow…. I mean, her whole face changes…..and it's as if Ed sucks her out, yeah sucks her out" (Emma)
		Switch	"I would have seen it switch…. especially if it was like something contentious and then she would just flip in an instant and you would get whooaa the whole shebang" (Helen).

			"Then almost like a switch, you'd see her change and what was coming out of her mouth wasn't what she would say" (Jackie)
The powerful feelings evoked in carers	Hate	Hate	"I hate it, I hate it with every fibre of my being and that will make me that makes me really emotional" (Fiona) "I hate the power that it has…. It just makes me feel so mad" (Linda)
		Want it gone	"Well the anorexic voice, I wish that it would just go… I just want it gone. I want the anorexic voice, that thing gone" (Dawn) "I wish I could just bat it away" (Jackie)
		Anger	"absolute fury at times" (Alan) "anger at the life it's stealing away from Sally really" (Sandra)
	Grief	Sense of loss (evoked grief or anger or both)	"it's taken my daughter and it's …it's changed our whole family's idea of growing up and being kids" (Fiona) "how could it have taken over my precious little girl?" (Linda) "As I was watching it, I was going; these dancers aren't any better than she is, yet they're here dancing at the Albert Hall. I could be here watching my daughter. Except for the anorexia that stopped her. So, I will never get that experience of going somewhere really special like the Albert Hall to watch my daughter dance" (Claire)
		Sad/ hurting	"Sadness" (Alan) "I feel hurt by it" (Linda) "I think it makes us very sad when we're going through a bit of a tough day or a tough week or and it, the anorexic voice gets us down even though we can't show it to her, you know, it's very demoralizing" (Sandra)
	Powerless	Powerless	"Helpless. Overwhelmingly helpless. I'm terrified of it….There's nothing… you can't reach them when anorexia sets in it's like talking to a wall" (Emma)

			“We couldn’t do anything to stop it…. completely disempowered” (Molly) “I can't protect her from it” (Claire)
		A relief	“Actually parents are pretty powerless… it's quite liberating in a way to reach the realization, because you've been desperately looking for any solution in any country, any treatment. And you suddenly you reach the realisation that there was realization that I couldn't fix it” (Alan)
		In awe of power	“So the weird one was slightly in awe of it… But this kind of admiration, of like this is so powerful” (Molly)
Relating to the ANV	A challenge to manage	ANV wanted a fight	“what was difficult, very difficult was like bait was being put out to actually engage and start fighting or start digging the trenches” (Helen) “that anorexic voice wants to say ‘no, I want us to engage in this battle’ because all that does is alienate you from each other. And then it’s in power, so…”(Fiona) “We will suddenly say, ‘oh, hang on, Sally, we're being drawn in by Anna’” (Sandra)
		Struggling to find strategies that work	“Sometimes I just break down and go ‘I can't do this” (Emma) “when we tried to back away to not engage, to side-step, step back that wasn’t even possible” (Helen) “I probably I don't always deal with it quite right…. And you might go into ‘Well, the anorexic voice is telling you this, this and this…. Of course, that goes badly! We’ve pretty much gotten rid of that, but it still happens from time to time” (Sandra)
	Avoid conflict	Step away from conflict	“One of the things that I'm having to learn to do is step back from it” (Linda) “I used to say myself ‘step out of the boxing ring, get out, get out, get out!’ when it was trying to hook me in” (Helen) “I have to learn when to back off” (Claire)
		Stay calm	“I try to be calm” (Emma)

			“there are times when he's actually better at just dealing with her in a really quiet and calm way” (Claire) “I keep trying to keep rationalise it, as in, this is an illness induced phenomena” (Linda)
	Ignore the ANV	Wait to speak to loved one	“When she's letting out sort of anorexic rubbish, it's kind of; right, but that's not her and let it calm down and we'll have a reasoned conversation about this where I'll be able to speak to her” (Claire) “I shouldn't have asked you that question right now because I know that I'm not gonna get a straight answer from from you, I'm gonna get an Ed answer and I'm gonna wait, I'll wait until I can speak to my daughter.’ And then walk away” (Fiona)
		Give as little attention as possible	“So I suppose I was ignoring, turning my back and ignoring it as much I could and to talk to Daisy” (Dawn) “the more attention that's paid to it and more and the more focus it’s given, it just increases its power…. I don't try to engage with the anorexic voice” (Linda)
		Remind loved one of life outside of AN	“we also needed to be noticing all the positive character strengths of our son. So, you know, paying more attention to the behaviours we like” (Molly) “I suppose that was me managing the voice…reminding her why she had to do it and you know, so that she could do all these things that she wants to do in the future” (Jackie)
	Stand up to the ANV	Carers being assertive	“she will eat something she'll look at something and say ‘do I have to eat this?’ and we’ll say ‘Yes, you do so….’. The reason, she's doing that, so that she can tell her head, she can tell her voice ‘My mum has told me I have to eat it so you need to go away and shut up’. So that’s kind of a way round it” (Fiona) “I had to be really forceful for her to realize that I wasn't going to give it into it, and I was gonna… she was still gonna have to do what she had to do, irrespective of how much this thing was telling her not to” (Jackie)

		Supporting loved ones to stand up to the ANV	“I realised that again, we were Mike’s ally, we could support him to take back control from this bully that was in his head” (Molly) “We keep just reminding Sally every now and then, she is the strongest being on Earth to fight this” (Sandra) “encouraging her to challenge the voice, to say ‘no, you're telling me a load of rubbish and if I want an ice cream, I'm going to have it.’” (Claire)
	Befriend the bully	Work with the ANV	“I think it's very important to work with the anorexic voice. Because if you excluded it, I mean this is my opinion, but I think if you if you just exclude it, you risk then getting angrier with your child… And risk them then choosing anorexia instead of the helper” (Emma) “I also want to see if I can come alongside this Ed person, and actually almost befriend them so that we have a relationship. I realised that we couldn’t just ignore Ed, we had to have some sort of relationship with Ed” (Molly).
		Embrace the power of the ANV	“Maybe there’s some weird reverse psychology where it could exploit the power that it [the anorexic voice] has” (Linda) “And also ‘that is part of me’ from, you know, Mike’s perspective, and ‘Ed is so powerful and that is part of me, I have that superpower’[…] if we can we befriend it, in terms of befriending the powerfulness of it, I think that’s where you can get into the post-traumatic growth.’” (Molly).
A Helping Hand on a Difficult Journey	Tolerance	The ANV is responsible for challenging behaviour	“so that, ummm when they're being horrible to you, you know that that's not them, it's their eating disorder, talking to you” (Jackie) “I now compartmentalize it because when she's like that, I'm sort of going right, that's not Chloe, that's the eating disorder” (Claire) “so that I am reminded that if she's screaming and shouting at me, that is the anorexia that's doing that” (Linda)
		Makes it easier to cope with	“it makes it easier to bear and to kind of…. umm, you know, just, just tolerate, if you know what I mean, tolerate their behaviour” (Tony)

			“And it's easier to deal with if I'm saying that's not her, that's the eating disorder speaking” (Claire) “I think for… for your own well-being and your own emotional state if you like it's, it's really helpful to be able to just like I know that's her eating disorder because I know that's not her” (Jackie)
	Compassion	Avoid blame	“when they are in the grip of the anorexic voice is not them, it's not part of them, it can't, it shouldn't be punished, it shouldn't be blamed… yes, that's very helpful” (Alan) “the conflict one has as a parent is you're getting to a situation where it's making you hate your child to, to push them away so much once we had Anna we could put our energy against that” (Simon)
		Reserve compassion for loved one	“it would maybe allow parents to have a bit more compassion at the start rather than just seeing their child as being difficult” (Jackie) “it seemed to sort of salvage the love that one had for one’s child” (Simon)
	Hope	Loved one’s former identity is salvageable	“To help you cling on to the thing of like our our I'll get my daughter back sooner later. Do you know what I mean? And… then just gotta be patient and wait for it and then it will happen. So yeah, she she isn't just this eating disorder” (Tony) “we were trying to differentiate the Ed voice to Sally because it helps us to, as a carer, to be able to know that your child is still in there and that it really is an illness… I think that gave us back a bit of sanity and a lot of hope” (Simon)
		Separation indicative of recovery	“it's an indication that the patient is able to see it as a separate entity from them, isn't it? By calling it a name it means that they’re seeing that it's not them that's the problem, it's this other thing that's taken them over” (Jackie) “now she is really happy to differentiate between the two so that that kind of shows you the journey of it. I would have said the process of healing, of recovery” (Sandra)

		Loved one recognising the negative qualities of the ANV	"It was that defining moment that he said it's a bully" (Molly) "I think it's quite good to distance yourself from all that and go 'whoooaaa you're so negative'" (Emma)
	Empathy	Recognising the distress the ANV causes their loved one	"It's days when the voice is loud and constant, that is really, really tough for them" (Claire) "I think they need acknowledgement because they can't fight this voice, or this overwhelming tsunami of strength that takes over their will" (Emma) "I suppose acknowledging that it's there and acknowledging that it's hard for Fern" (Fiona)
		ANV enables empathic conversations	"you can sometimes talk to her about it and say 'is it strong? How is the ED voice, is it strong? Is it calm, is it shouting? Is it…' and and she can say 'it's going mad'. You know, so it's good, it helps me know where she's at or how she's feeling or how I can try and help her" (Fiona) "'it gives me a sense of control, it's my friend, I like the way I look, I'm really good at it, it's my identity', you know all of those things. And then that really helps carers to understand, ok I can understand why my loved one is holding on so tightly to their eating disorder" (Molly)
Externalising Techniques Should Come with a Warning Sign	Loved Ones May Reject the ANV.	Loved ones reject attempts to externalise	"I know they could label it and decide what voice they wanted to call it, that was very much resisted – that trying to separate the person from the anorexia" (Helen) "So that's not the approach [externalising] that's gonna… it's not working with my child" (Nancy) "she didn't like the fact that we were differentiating between the two" (Sandra)
		Loved ones claim no separate AN entity influencing them	"She will still get angry when people, people think it's some something else, and she'll say, 'it's not.. It's just me'" (Linda) "It's not an anorexic voice. It's me" (Alan) "I went, 'Well, you want to eat and everything but the eating disorder won't let you'. She just said, 'Well, that's rubbish, I can eat when I want'" (Tony)

	Externalising Could Create Problems.	Externalising could cause disconnection	“not necessarily the anorexic voice, but phrases like that, this is where she basically deflects and push me away” (Nancy) “be careful talking to the patient in those ways, because it might just make them more upset and more uneasy and more alienated and feeling more weird” (Tony)
		Externalising could cause conflict	“One of the triggers is if I start talking about the anorexic voice as if it's distinct from my daughter, she gets absolutely furious” (Alan) “I think initially when I used to, when I realized that it was happening I would say that to her she would… it would put anorexia into an absolute rage; I would get things thrown at me or shouted at” (Fiona)
	Go gently	Going in strong didn’t work	“she would go ballistic, ballistic. So I don’t know whether it was the timing or this, or I’d be all gun hoe after having done a course” (Helen) “it’s not going in with welly boots” (Molly) “And you might go into ‘Well, the anorexic voice is telling you this, this and this…. Of course, that goes badly!” (Sandra)
		Introduce externalising ideas gently	“I think as a carer, the best thing to do is sew a seed and see whether the seed takes or not…and that seed did.” (Sandra) “we needed to be careful there not to push things too much because, you know, as a mum or dad you see that green shoot you want to rush in and go ‘argh yess’ and you have to have the patience of a saint” (Molly)
		Show curiosity about loved one’s experiences	“We often text and so I might just say ‘do you think that might be [ANV encouraging exercise]?’ (Sandra) “so I might just say ‘do you think that might be Anna telling you?’” (Sandra) “Have you seen the exercise the decisional balance?.... It’s really relevant when you’re thinking about the voices and externalising the illness. So the first quadrant is the benefits of the eating disorder… The second quadrant is, can you think of any disadvantages which is the healthy side of the person. The third quadrant is what might stand in your way, so weighing up

			the pros and cons and what might stand in your way of getting better… And finally the fourth quadrant is helping the person stand up to their eating disorder” (Molly)
	Just for carers	Carers keep the idea for themself	“ I think it’s helpful for carers to think about which part of the person they are communicating with, but they might not be able to name it” (Molly) “I suppose that's kind of why I'm interested in in doing this survey because I just kind of think, well going forward for other parents whether the guidance or the advice could be a bit more refined in a sense of like as a carer potentially it's good for you to separate the person you love from the eating disorder. But, actually, if you do that to them, you know, it could really hurt their brain” (Tony)
		Carers reject too	“Can I relate to this? Yes, yes, it's definitely a side of Naomi but she cannot. So, I'm gonna push it away and I need to understand her own word and her own processing way to be able to help her” (Nancy)
Systemic Issues	Generic Systemic Issues	Generic Systemic Issues	“We were repeatedly told that my daughter could not receive the NICE treatment because it wasn't available. Ridiculous things like it wasn't available because she was too low a weight, but once she recovered, she was too high a weight” (Alan) “so many of them now doing it at home, because I mean even doing NG feeds at home because there's no beds for them” (Jackie) “If this had been nipped in the bud, and we did have the resources and we did have the right teams behind us, I think this could have been nipped in the bud right at the beginning” (Sandra)
	The Impact on the ANV	The ANV grows in power	“And I don't understand where people's priorities lie. You see there's a problem, you act otherwise the problem it gets more expensive for everyone, ruins more lives. You know, I was trying…since … since February to nip, whatever it was in the bud, this emerging monster inside” (Emma) “We went to the doctors and they just weighed her and said she didn’t meet [...] the threshold for the BMI, so she couldn’t get any treatment

			[…] the eating disorder voice was like, 'right, well…we can amp things up and cut food back even more'" (Dawn)
		Externalising only works if the systems around them work	"externalising of the anorexia is in the clinical guidelines [….]The problem is if you're... with a service that can't offer anything, it's not meeting face-to-face, it's one appointment a week … It's not really doing a version of the Maudsley family-based treatment as it's meant to be." (Alan)

Appendix O: End of Study Summary

Exploring Carers' Perceptions of the Anorexic Voice: A Reflexive Thematic Analysis

Background:

Carers' support is crucial to successful treatment for anorexia nervosa, yet research shows that including carers in treatment and research needs improvement.

The anorexic voice is a phenomenon that seems relevant to our understanding of anorexia. Research suggests that the anorexic voice is commonly experienced among people with anorexia. The anorexic voice is often experienced as commenting on individual's shape and weight, attacking self-worth and driving behaviours relating to anorexia.

However, research into the anorexic voice lacked insights from carers. Therefore, this study aimed to explore carers' perceptions of the anorexic voice.

Method:

Thirteen participants were interviewed about their perspectives and experiences of the anorexic voice. Each interview was recorded and transcribed. Data was then analysed using reflexive thematic analysis. This involved reviewing the transcripts and applying codes to remarks which seemed significant to the research aims. Codes were then reviewed to develop broader themes and sub-themes that bought together the codes under meaningful concepts.

Findings

1. **Carers held varying definitions of the anorexic voice -** for example, some carers had experienced their loved one hearing a voice very different from their own. In contrast, for other carers, the anorexic voice was more of a metaphor that helped them to separate their loved one from anorexia.

2. **The anorexic voice attracted both advocates and opponents –** for most participants, it fit with how they understood their loved ones' difficulties. For a minority, however, the anorexic voice did not fit with their experiences.

3. **Advocates of the anorexic voice saw how it invaded and bullied their loved ones –** carers noticed how the anorexic voice 'seduced' their loved ones by initially offering value, such as a sense of friendship, before becoming a powerful bully. Carers also highlighted the contrast between their loved ones and the anorexic voice.

4. **The anorexic voice bought up strong feelings for carers –** the most common feelings were hate, grief and powerlessness.

5. **Carers shared their challenges and successes relating to the anorexic voice –** many shared experiences of being drawn into conflict by the anorexic voice. Although challenging, carers had found ways to interact with the anorexic voice that seemed to have positive outcomes, for example, standing up to, ignoring or befriending the anorexic voice.

6. **Many carers found the idea of the anorexic voice helped them in their role –** for example; it allowed them to separate their loved one from anorexia which helped them to tolerate challenging behaviours and remain compassionate and hopeful.

Understanding how distressing the anorexic voice was for their loved one also generated empathy.

7. **Carers warned that separating their loved ones from the anorexic voice could cause harm –** carers shared heart-breaking experiences whereby they had tried to attribute loved ones' behaviours or remarks to the anorexic voice (called externalising), which had led to arguments, and disconnection. Carers therefore advised to use externalising techniques gently or keep it as an idea that they used, but kept private from their loved ones.

8. **Most carers shared heart-breaking experiences of not being able to access appropriate support –** carers explained how struggling to access support in the early stages of their loved ones' presentation meant the anorexic voice grew in strength.

Suggested implications

- To increase the effectiveness of treatment, it would be helpful to include carers in therapeutic approaches which support people with anorexia to develop a healthier relationship with their anorexic voice.
- Healthcare professionals need to recognise that each person will experience the anorexic voice differently, and some will not experience it at all. Therefore, they must invite curiosity about the anorexic voice rather than make assumptions or impose certain views.

Suggested future research

- To conduct more in-depth research to understand how people with anorexia and carers define the anorexic voice.
- To conduct more research into ways of using externalising that reduces harm to people with anorexia and their families.

Appendix P: End of Declaration

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