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Doctoral Thesis

Experiences of Stigma and the 'Eating Disorder Voice' within People with Eating Disorders

Doctorate in Clinical Psychology

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Word Count

Thesis Section	Text	References, figures/tables, appendices	Total
Abstract	229		
Systematic Literature Review	7999	15902	23901
Research Project	7858	11209	19067
Critical Appraisal	3972	1402	5374
Ethics	3436	4050	7486
Total	23634	32563	55968

Thesis Abstract

The first paper is a systematic literature review, exploring the influence of stigma on help-seeking for an eating disorder. It yielded 14 qualitative studies surrounding help-seeking experiences within people with eating disorders, and the stigma they faced. A meta-ethnography was used to synthesise the findings. Stigma was found to pose a significant barrier to help-seeking, as it contributed to the minimisation of eating disorders, in particular the dismissal of psychological symptoms. This increased feelings of invalidation, and decreased motivation to seek help.

The second paper is a research project exploring inner-speech and voice-hearing experiences within the context of an eating disorder, namely the ‘eating disorder voice’ (EDV). The stories of ten young women with lived experience of the EDV were elicited using an experience-based co-design informed method. Data was analysed using narrative analysis. Findings suggested that the EDV can be experienced as a prominent feature of an eating disorder, eliciting complete control over an individual and posing a barrier to recovery. However, psychological elements such as the EDV were described to be dismissed by eating disorder services, resulting in continuation of the disorder.

The third paper is a critical appraisal, which reflects on the process of completing the above papers, and a review on their strengths, limitations, and areas for future research. Overlapping and complimentary findings between the two papers are also discussed, alongside their clinical implications.

Declaration

This thesis represents work undertaken for the Doctorate in Clinical Psychology course at Lancaster University. The work presented is the author's own (except where due reference is made) and has not been submitted for any other academic award.

14th March 2024

Acknowledgements

I would like to thank all the participants who took the time to share their stories. I hope this research serves a useful purpose.

I would also like to thank my research supervisor, for her ongoing support and guidance through the thesis project, and her shared passion for this important research area. Also thank you to my field supervisor and facilitator from Voice Collective for their valuable expertise.

Contents

Section one: Systematic Literature Review

How can stigma influence help-seeking for eating disorders?

Word count: 7999

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Abstract

Purpose

Eating disorders are a serious mental health condition, affecting people's physical and mental health, and opportunities in life. Eating disorders carry a mortality rate two times higher for bulimia, and over five times higher for anorexia, compared to the average population. Eating disorders remain a highly stigmatised condition. Help-seeking is often delayed due to perceived stigma and discrimination. Delays lead to poor treatment outcomes. It is important to understand the role stigma plays within help-seeking behaviours to promote timely help-seeking and support. Consequently, this review explores how stigma influences help-seeking for eating disorders.

Method

A systematic search of three databases (MEDLINE Complete, PsychINFO and Academic Search Ultimate) yielded 14 original qualitative studies describing people's experiences of stigma whilst seeking support for an eating disorder. A meta-ethnography approach was used to synthesise the findings.

Results

14 papers from six different countries and with a total participant number of 1,076 (959 female, 114 male, 3 transgender, age range 14-65) were deemed suitable for inclusion, determined by the eligibility criteria. The papers were quality assessed prior to analysis. Three main themes were identified, describing different circumstances where stigma was experienced: (1) Familial Stigma, (2) Stigma faced from services, and (3) Societal and internalised stigma. Stigma was found to affect help-seeking in several ways including dismissal from family, negative experiences with professionals and limited treatment options within services. These were found to hinder access to support.

Conclusion

Additional education targeted at the public and specific training for healthcare professionals, focused on the psychological factors encompassing an eating disorder, should be prioritised to address stigma. If people experience less stigma within their social milieu, they will feel more able to access support and achieve recovery from their eating disorder.

Introduction

Eating disorders affect an estimated 1.25 million people in the UK (Beat, 2023). Eating disorders are characterised in the DSM-5 by a persistent disturbance in eating behaviours and the presence of distressing psychological symptoms, affecting several areas of functioning (American Psychiatric Association, 2022). Eating disorders can severely impact quality of life, frequently affecting social functioning, participation in education or employment (Van Hoeken & Hoek, 2020). Eating disorders can also pose a significant risk to life due to physical health complications (Peebles & Sieke, 2019) and suicide (van Eeden et al., 2021). People with anorexia nervosa and bulimia nervosa have a particularly high mortality rate (National Eating Disorders Collaboration, 2022), which is two times higher for bulimia, and over five times higher for anorexia (van Hoeken & Hoek, 2020) compared to the average population. Clearly, eating disorders remain a serious mental health condition and effective intervention should be prioritised.

Despite the negative effects on social functioning and risk to life posed by eating disorders, people with eating disorders often face barriers to support, which can result in delays and prevent timely treatment (Austin et al., 2021), with the average time between onset and seeking treatment being 5 years (Hamilton et al., 2022; Maier et al., 2014). Consequently, the duration of illness is often prolonged (Griffiths et al., 2015) and there is often an economic burden as the person is less able to maintain their work and more intensive treatment for severe symptoms is often needed (Ágh et al., 2016). Understanding significant barriers to help-seeking can lead to earlier intervention and lessen the human and financial costs to the individual, families, and systems (Hamilton et al., 2022).

Stigma and Mental Health

Stigma is defined as the shaming, undervaluing and rejection of a person due to attributes they possess, which are deemed unacceptable by others (BPS, 2009; Subu et al., 2021). Stigma is particularly relevant within mental health contexts and settings. People report being seen as ‘crazy’, ‘annoying’ and ‘dangerous’ due to their mental health issues (Subu et al., 2021), and ignored and rejected by both healthcare professionals and their families (Potterton et al., 2020). Mental health stigma can also be influenced by cultural contexts, dependent upon beliefs and values (Ahad et al., 2023). Stigma towards mental health conditions has consistently been shown to impede access to professional support (Aguirre Velasco et al., 2020; Schnyder et al., 2017). Delays can lead to more severe symptoms or more extensive treatment (Corrigan et al., 2014; Rüsch et al., 2014). Some people have even stated that the stigma they have faced was virtually as distressing as the symptoms themselves (Vigo, 2016). Research shows that people are likely to under-report mental health symptoms (Bharadwaj et al., 2017). Therefore, it remains important to enhance our understanding of exactly how stigma can pose as a barrier within help-seeking, to address it and promote people to access timely support.

In summary, much of the current research suggests stigma serves as a barrier for seeking psychological support. However, when stigma is consciously and critically experienced, rather than internalised, stigma can promote help-seeking and enhance adherence to treatment (Cerully et al., 2018). This process is thought to be fuelled by a determination to avoid negative responses from others, such as the anticipated stigma, by proactively reducing symptoms or eradicating their stigmatised disorder altogether (Lambert et al., 2018). This pattern of proactive resistance to experiencing stigma has been found in the context of other stigmatised conditions, such as HIV and obesity (Lambert et al., 2018; Latner et al., 2009) and problem gambling (Horch & Hodgins, 2015). People have also reported engaging in treatment to hide issues from others and avoid prejudice (Lambert et al., 2018; Latner et al., 2009). It was also believed, aligning with societal stereotypes, that people had a ‘personal responsibility’ to overcome conditions, therefore increasing motivation to seek help (Horch & Hodgins, 2015). Based on varying evidence, the concept of stigma within help-seeking is still not fully understood and should be explored further to establish its function.

Stigma within eating disorders

Within mental health conditions, eating disorders are among the most stigmatised (Ebneter & Latner, 2013; O'Connor et al., 2021), often attributed to a lack of public understanding. Stigma is a common fear and lived experience for people with eating disorders, as demonstrated throughout systematic reviews (Foran et al., 2020; O'Connor et al., 2021). Compared to other conditions, several negative beliefs are held by the public, such as the person being blamed for their eating disorder (Lupo et al., 2020), being associated with more negative personality traits (O'Connor et al., 2021), and being seen as less preferable to socialise with (McNicholas et al., 2016). Eating disorders can be perceived by others as 'silly' and 'childish' (Griffiths et al., 2018), and be believed to be associated with a 'weak personality' (Jones et al., 2013). Understandably, this stigma is often internalised (Byrom et al., 2022) and can lead to people with eating disorders feeling alienated, as though they are not a valued member within society (Griffiths et al., 2018).

However, it has been suggested that people with eating disorders face less discrimination in comparison to other mental health conditions (Bryant et al., 2023). Despite the relatively high mortality rates associated with some eating disorders, this perspective has been attributed to eating disorders not being viewed as 'dangerous', therefore being less feared within society (Bryant et al., 2023). However, when eating disorders are viewed as a superficial illness (Ebneter & Latner, 2013; Griffiths et al., 2015), and within the person's control (Malova & Dunleavy, 2022), finding help can be more difficult. Clearly, if the above perceptions do prevent discrimination, they remain an unfavourable and largely untruthful narrative of eating disorders, dismissing feelings of shame, hopelessness, and isolation (Eiring et al., 2021; Puhl & Suh, 2015), and high levels of suicidal ideation (Thörel et al., 2023; van Eeden et al., 2021) which reside alongside the condition. In fact, an internalisation of these negative beliefs can be a further factor in help-seeking being delayed. People with eating disorders reported they never felt their symptoms were 'bad enough' to warrant professional support, feeling as though they should be able to handle their eating disorder alone, despite being evidently unwell (Byrom et al., 2022; Tsong et al., 2023). Consequently, this allows eating disorders to become more enduring and entrenched.

Rationale and objectives

Research thus far has confirmed that stigma exists within mental health conditions, particularly within eating disorders, and that seeking support for this condition is often delayed or met with ambivalence (Austin et al., 2021). Gaining a deeper understanding of the role of stigma within help-seeking can help provide clarification on this, as well as inform services and treatment guidelines. Previous reviews have explored help-seeking behaviours within eating disorders (Nicula et al., 2022) and general barriers and facilitators to treatment (Daugelat et al., 2023). Therefore, this review aimed to explore how stigma can influence help-seeking, with the objective of highlighting any barriers it may pose to improve access to treatment. Qualitative literature was synthesised from a range of age groups, genders, and cultures to provide a novel overview of the process to inform future clinical practices, policy, and research.

A meta-ethnographic approach was considered most suitable to address the topic of this review, as it provides novel insights into people's lived experiences (Sattar et al., 2021), which can identify gaps within mental health support and obtain unique insights on navigating systems (Sunkel & Sartor, 2022). Meta-ethnography also allows for the generation of evidence for healthcare guidelines and policies (Classen & Alverez, 2015), providing practical recommendations. This remains beneficial considering the established need for improvement within eating disorder guidelines and interventions (National Institute for Health and Care Excellence [NICE], 2020) due to poor treatment outcomes (Franko et al., 2018; Svaldi et al., 2019), and perspective shifting in public health. The structured approach of a meta-ethnography enables an in-depth analysis of literature, synthesised into recommendations for practice, policy, and research, from an international perspective.

Methods

The meta-ethnography was conducted using the seven steps developed by Noblit and Hare (1988), enriched with more recent guidelines on meta-ethnography within a healthcare context (Sattar et al., 2021) to achieve a comprehensive review. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021) were also followed.

Eligibility Criteria

Inclusion criteria for the papers were as follows: (1) a qualitative approach was used to collect data, (2) peer reviewed, (3) written in English, (4) contained themes or concepts focused on stigma and help-seeking. There were no strict criteria regarding the dates the papers were published, as I wanted to ensure significant papers were included and compare experiences of people over a timespan, capturing potential differences. All ages and genders were included to include a range of individual experiences. People with self-reported eating disorders as well as a formal diagnosis were included, to ensure no unique experiences were missed, and to observe potential differences in help-seeking experiences. Exclusion criteria were: (1) experiences of the individual could not be overtly retrieved, (2) did not specifically refer to experiences of stigma or help-seeking for eating disorders.

Information Sources

The next step of the meta-ethnography involved examining the literature around people with eating disorders and the stigma they experienced. This highlighted the focus of the review, due to limited literature on how stigma specifically influenced help-seeking. Relevant papers were collated used the following databases: MEDLINE Complete, PsychINFO and Academic Search Ultimate.

Search strategy and selection process

Benefitting from the expertise of a specialist academic librarian, the literature search included the following areas: eating disorders, stigma, and help-seeking (table 1). The searches took place in January 2023. The databases used were then set to alert me if any new relevant papers were available until July 2023. Following the initial search, duplicates were removed and remaining titles were screened for relevance. Abstracts were then screened against the eligibility criteria. Remaining papers were read in full.

Certainty assessment

The quality of the studies was assessed using the Critical Appraisal Skills Programme (CASP, 2018; Table 3), as it is a systemic approach to assess the strengths and weaknesses of a study, designed for a healthcare context (Singh, 2013). Employing tools to aid with quality assessment within qualitative research has been debated (Majid & Vanstone, 2018; Toye et al., 2013). Some argue they can focus on methodology over conceptual integrity (Sattar et al., 2021), discounting the potential impact of qualitative findings (Melia, 2010). Appraising certain elements within qualitative research remains challenging, and can be subjective (Dixon-Woods et al., 2007). However, it remains important that the quality of studies is assessed if they are to be used to inform clinical practice or research (Mays & Pope, 2000). The CASP tool allows for the assessment of reliability, validity, and value of papers, and is commonly applied within psychological research (CASP, 2023). The support of the use of the CASP tool is also outlined in the guidance around conducting a meta-ethnography from Sattar and colleagues (2021), in keeping with the overall approach of this review.

Due to the mixed views within research regarding quality appraisal, the CASP tool was used to aid critical analysis rather than to exclude any of the papers. Papers were assessed using ten questions measuring the strength and usefulness of the papers as well as their standard of reporting. The answer to each question was given a score of zero to two. Zero points were awarded for a lack of or inadequate descriptions of a specific area, two points were awarded for areas which were addressed but did not include a full description, and three points were awarded if the area was described in detail (Nichols et al., 2020). The highest possible score was 20, with papers scoring between 14 and 19. Although the guidance from CASP suggests not to score papers (CASP, 2018), using guidance from Sattar et al. (2021) and other research (Nichols et al., 2020), I felt assigning a score to each paper allowed for clarity on its perceived quality. I carried out the initial quality appraisal, before referring to a colleague who carried out a further appraisal. This was to maintain reliability as much as possible. Differences between scores were discussed between us, and a final score was decided upon for each paper.

Synthesis methods

The process described by Noblit and Hare (1988) continued to be followed, as well as the guidance by Sattar et al. (2021). I read through each paper several times, ensuring I became familiar with the key concepts. The definition of a concept in this context was derived from Britten et al., (2002), ensuring the concept had analytical power without being overly descriptive. I then extracted the raw data from the papers, this being the first and second order constructs (Cahill et al., 2018). I used a data extraction form for this process (Malpass et al., 2009; Table 4). The data was kept verbatim, to preserve significant data and terminology (Atkins et al. 2008). I chose this method over summarising the data, which can lead to the loss of valuable detail (Sattar et al. 2021). Overall, the chosen method achieved a clear yet comprehensive synthesis of original narratives and interpretations from the papers.

Translation of studies

To analyse the relationship between the papers, I examined them for common and recurring concepts (Noblit & Hare, 1988). I developed a list of themes from each paper, of which related themes were then grouped into categories (Atkins, 2008; Appendix 1). I then compared the concepts found within each paper (Noblit & Hare, 1988). Due to a lack of detailed instructions on how to undergo and record this step (France et al. 2019), the guidance of Sattar et al. (2021) was again applied. The papers were arranged from the highest scoring to the lowest scoring derived from the CASP tool, and a summary of each theme and concept was developed (appendix 2). This began with summarising paper 1, then paper 2, continuing until all the papers were synthesised, providing a synthesis of the primary author interpretations (i.e., second order constructs) (Britten et al., 2002). The similarities and differences between them are discussed within this synthesis.

I then conducted a reciprocal translation of the first and second order constructs due to the concepts of the papers being sufficiently similar (Sattar et al. 2021). I used this process to develop the third order constructs: the reviewers' higher order interpretations of both the first and second order constructs (Britten et al., 2002) by drawing out the major points to develop new understanding and levels of analysis (Scott & Grant, 2018). The process concluded with a clear table (table 5) portraying my third order constructs in relation to each concept.

Results

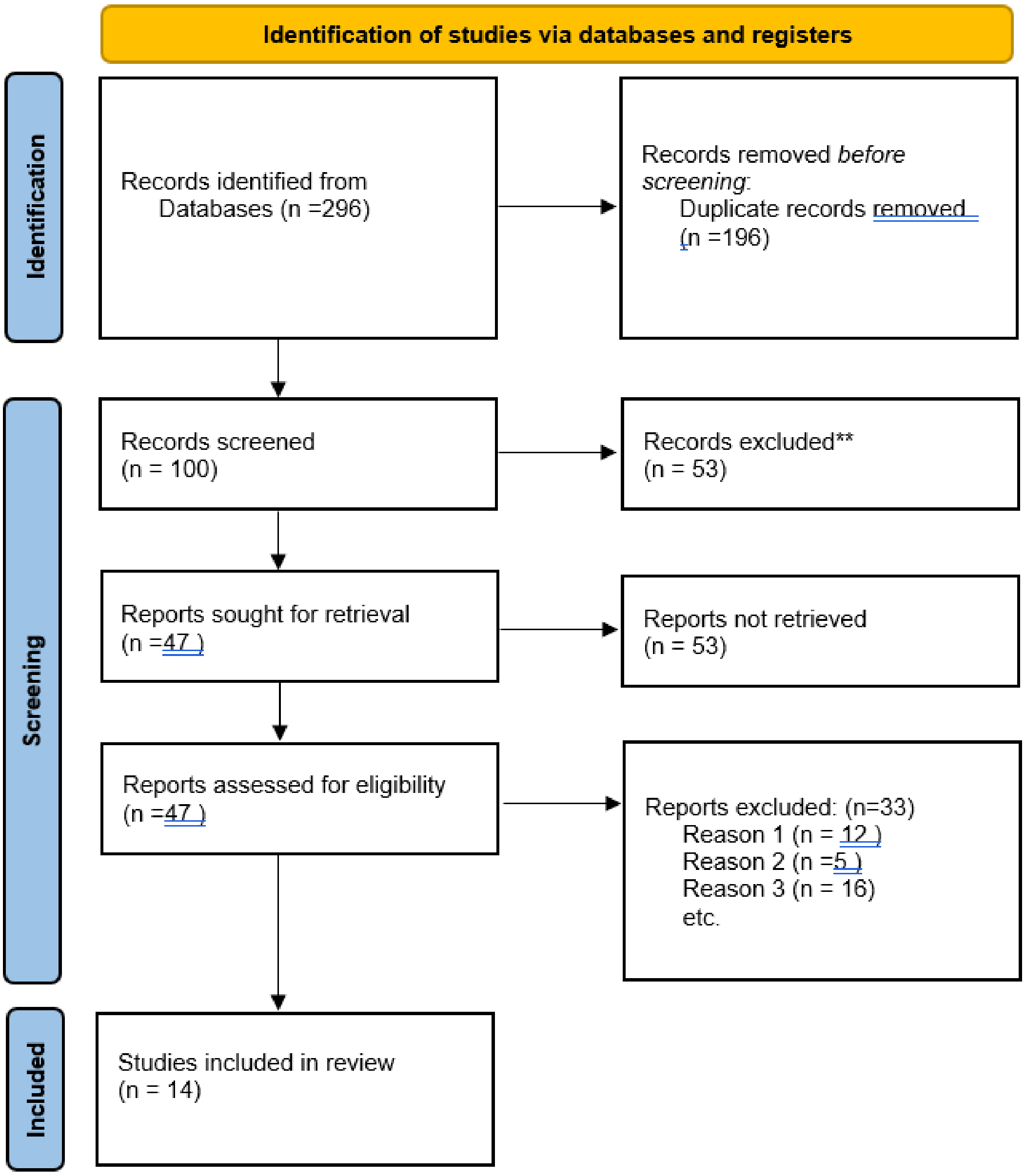
Study selection and characteristics

The initial search produced 296 papers, reduced to 100 when duplicates were removed, and the remaining titles were screened for relevance. 11 papers were excluded due to them using purely quantitative approaches to collect data. Abstracts were then screened against the inclusion and exclusion criteria, following which 47 papers remained. These papers were read in full. Finally, 14 papers were determined suitable for inclusion in the review due to the other papers not meeting eligibility criteria. Of these papers, three used a mix of quantitative and qualitative methods. The data obtained using qualitative methods was extracted from these papers, due to the data being deemed significant and relevant to the research. Study characteristics can be found in Table 2.

The PRISMA diagram (Page et al., 2021) outlining this process can be found in Figure 1. Data was extracted from the 14 papers surrounding people with eating disorders and their experiences with stigma and help-seeking.

Figure 1

PRISMA diagram detailing the literature search process (Page et al., 2021)


Identification of studies via databases and registers
Identification
Records identified from Databases (n =296)
Records removed *before screening*: Duplicate records removed (n =196)
Screening
Records screened (n = 100)
Records excluded** (n = 53)
Reports sought for retrieval (n =47)
Reports not retrieved (n = 53)
Reports assessed for eligibility (n =47)
Reports excluded: (n=33)
Reason 1 (n = 12)
Reason 2 (n =5)
Reason 3 (n = 16)
etc.
Included
Studies included in review (n = 14)

Results of syntheses

Following the synthesis, three main themes were developed: (1) Familial Stigma, (2) Stigma faced from services, and (3) Societal and internalised stigma. These themes centred around different types of stigma faced, and how each type had a specific impact on help-seeking behaviours.

Theme 1: Familial stigma

Responses from family appeared significant when seeking support for an eating disorder. For example, people with an eating disorder described feeling unsupported and unheard due to their parents failing to address their symptoms, assuming it was a passing phase (Eiring et al., 2021). Throughout six of the papers, people reported their eating disorders being viewed as trivial and not warranting treatment. One person described her mother declining to support her towards “the cost of treatment for body image-related issues” (Tsong et al., 2023, p. 159). The language used here appears to reduce an eating disorder to simply a concern with body image, and thus, a choice. When a person’s eating disorder is acknowledged, there appears to be a worry of how others may perceive the fact that their child has an eating disorder: "my mum didn't even want me to go out of the house in case somebody saw me and knew what I was suffering from” (Evans et al., 2011, p. 278). This results in people with eating disorders feeling unsupported and ashamed.

Some families appeared to hold openly stigmatised views around treatment for mental health. For example, a family’s belief that “psychologists were mere con-artists taking people’s money” (Tsong et al., 2023, p. 159) Mental health issues relating to body image and eating were seen as a “personal weakness” that should be dealt with by oneself. This further facilitated a lack of motivation to seek help. Families also appeared to have different but evidently negative views around mental health support: “there’s doctors, professionals, there to help you, but if you go there, you are ‘crazy’” (Goel et al., 2023, p. 104). These views were often influenced by religious beliefs. For example, families promoting a family member with an eating disorder to engage in prayer and strengthen their relationship with God as a form of treatment.

Contrastingly, it appears that some families put a large amount of faith in professionals to 'fix' an eating disorder: "everyone wants a straight answer... a cut and dry solution or expect the professionals to really have a solution for me but it's pretty much more complicated" (Dimitropoulos et al., 2016, p. 51). This led people with eating disorders feeling pressure to recover, and that challenges related to recovery were not acknowledged.

Further familial views also appeared to be linked to religious or cultural beliefs. For example, one paper portrayed a South Asian family's distrust of Western treatment for mental health, instead promoting alternative or homeopathic remedies (Goel et al., 2023). Issues were also linked to religion rather than mental health, such as a discontentment with God or being possessed by another being. People with eating disorders experienced feelings of disappointment surrounding this: "… it's like, 'oh… Just pray it away', It doesn't do anything" (Goel et al., 2023, p. 104), instead preferring to seek professional mental health treatment, but feeling unable to confide in their parents about their difficulties.

Culture also appears to have a further impact on people seeking help for an eating disorder. Wales et al. (2017) and Goel et al. (2023) describe people of South Asian descent experiencing dismissal and silencing of any mental health issue by their parents, for fear of facing stigma from their community: "People are afraid how others, how the wider society …will see them" (Wales et al., 2017, p. 45). Stigmatized views described were being seen as "crazy", "mental", a "bad parent" and becoming socially ostracized. Fears of information not being kept confidential was also attributed to a delay in help-seeking, due to a worry about judgement from the community. If professional help is sought for an eating disorder, this is often kept secret from the family. The difficulties of great importance being placed on the family's reputation were expressed: "So, it's like, they care, but it's also that aspect of their reputation that they care about too, which I feel like with White people, that's not really how it is" (Goel et al., 2023, p. 105). Overall, people with eating disorders described facing stigma from their family in the form of trivialisation and dismissal. In some cases, families were opposed to professional mental health support due to cultural beliefs and fear of social ostracization, leaving people with eating disorders feeling silenced and shameful.

Theme 2: Stigma faced from health services

People with eating disorders in seven of the papers described experiencing stigma from healthcare professionals, systems, policies, and pathways within eating disorder treatment services. For example, facing unhelpful language such as discussion around weight, diet, and exercise (Tsong et al., 2023), insensitivity and a lack of empathy (Byrom et al., 2022) when expressing eating disorder symptoms to a doctor, leaving people with eating disorders feeling unworthy of support. These ‘in service’ experiences meant services appeared less accessible to people needing help and support.

An additional barrier to seeking help for an eating disorder was the focus on physical appearance: "She [GP] thought I didn't have any problem because I walked in there and I wasn't emaciated” (Evans et al. 2011, p. 278). People were also denied access to treatment due to having a ‘stable’ weight or BMI (Eiring et al., 2021; Byrom et al., 2022). These encounters resulted in people with eating disorders feeling ‘not sick enough’ to receive support, pressure to ‘prove’ their illness or saw it as “encouragement to continue”, engaging in intentional intensification of restrictive eating disorder behaviours in the hopes to access treatment (Eiring et al., 2021). People who did meet the weight-based threshold for eating disorder treatment perceived themselves as “lucky”, despite this meaning they were acutely unwell (Byrom et al., 2022). This approach to treatment reinforces unhelpful stereotypes that people with eating disorders ‘should’ look underweight, despite many people with eating disorders not presenting as underweight (Byrom et al., 2022). If people assume rejection from services due to their weight, this can increase the level of risk to the person with the eating disorder psychologically and physically.

People with eating disorders who were South Asian and American Asian described experiencing discrimination and stigmatization from healthcare professionals when asking for support (Goel et al., 2023; Tsong et al., 2023). Symptoms were dismissed or attributed to their cultural background. For example, Asian American women being assumed by professionals to be ‘well-adjusted and naturally petite’ (Tsong et al., 2023), therefore not susceptible to eating disorders. Within almost a third of papers reviewed, services’ focus on physical appearance within eating disorders, combined with cultural assumptions around size and shape, could mean some people were denied access to support and put at greater risk as a result.

Additionally, men feel particularly stigmatized when seeking help for an eating disorder (Corcoran et al., 2021; Malova & Dunleavy, 2022). Healthcare professionals appear to have difficulties recognising symptoms within men with eating disorders (Malova & Dunleavy, 2022) due to a lack of male-centred assessment tools or guidelines. Men describe occasions where they were refused referral by GPs due to their gender (Corcoran et al., 2021), and any support that is offered remains limited, missing gender-specific aspects within their eating disorder, for example an intense desire to be ‘muscular’ as opposed to ‘thin’ (Malova & Dunleavy, 2022). Men expressed feeling the “odd one out” if accessing eating disorder treatment, due to it being female dominated. The above in-service experiences exacerbated men’s feelings of isolation and shame, and facilitation of the stereotype of an eating disorder being a ‘girl’s condition’ (Corcoran et al., 2021; Malova & Dunleavy, 2022). In summary, people with eating disorders, particularly those with a ‘stable’ weight, men, and people who were non-White, faced discrimination from health services when accessing support, often attributed to a lack of understanding, inclusive guidelines or treatment pathways.

Theme 3: Societal and internalised stigma

Gender-based stigma

Internalising societal stigma surrounding eating disorders can also impact help-seeking. For example, gender stereotypes of men being “strong, bold characters” can contribute to a lack of help-seeking in men with eating disorders (Corcoran et al., 2021). Men denied the seriousness of their eating disorder due to feeling “weak”, and were told to “man up” if they admitted to needing support (Malova & Dunleavy, 2022). It appears that gendered stereotypes can be particularly damaging for men, inducing shame for seeking help for any mental health issue, particularly for an eating disorder.

Cultural influences

People with eating disorders described feeling shameful and undeserving of support, compounded by cultural factors. For example, knowledge of their parents' distressing experiences within the immigration process led to them deeming their own issues as trivial in comparison (Goel et al., 2023). Additionally, Asian American people described how mental health conditions were seen as a weakness within their community, linked to a "fear of losing face" (Tsong et al., 2023). They believed their eating disorder was a "personal weakness", that it would reflect poorly on them for "having issues" and therefore should remain hidden. The findings above suggest some people may be more susceptible to internalised stigma due to their culture and beliefs. Experiences of silencing around eating disorder symptoms within families, alongside overly normalising healthcare professionals, can result in a 'catch 22' for people within some cultures.

Broader societal stigma

Seven papers highlighted how wider societal stigma can affect help-seeking for an eating disorder. For example, public beliefs that eating disorders are "easily fixed" by "just eating" and do not warrant treatment (Dimitropoulos et al., 2016; Wales et al, 2017), or that they are a 'choice' rather than a mental illness (Dimitropoulos et al., 2016). Minimisation of an eating disorder's psychological elements enables the narrative of it being unworthy of support, decreasing motivation to seek help and increasing feelings of shame within people who do.

In addition, negative character traits can be attributed to people with specific eating disorders, facilitating the stigma surrounding them. For example, people with anorexia being described as a "bad influence on others" (Hepworth & Paxton, 2007) and binge eating disorder labelled as "easy to treat" (Ali et al., 2020). People with eating disorders can be labelled as "attention seekers" and "self-absorbed" (Dimitropoulos et al. 2016). These stereotypes left people feeling shameful and unable to confide in anyone or seek help for their eating disorder due to a fear of how they would be perceived.

Attempts to avoid other forms of societal stigma can also delay help-seeking. For example, people avoiding weight-based stigma through maintaining the "thin ideal" (Tsong et al., 2023) or a muscular physique (Malova & Dunleavy, 2022) through their eating disorder. As they were aligning with perceived social norms, this led to people doubting their eating disorder and decreased incentive to alter their eating behaviours and relationship with food. It appears that the more egosyntonic the eating disorder behaviour, the higher likelihood that help-seeking will be delayed (Potterton et al., 2020). For instance, controlling one's diet and losing weight are often praised within society, whereas behaviours such as bingeing and purging are often not 'socially desirable' (Hepworth & Paxton, 2007). Therefore, people who experience the latter symptoms are often more likely to seek help to avoid potential stigma (Potterton et al., 2020). It appears that efforts to align with societal expectations and avoid stigma can impact people's motivation to seek help for their eating disorder.

Internalised stigma

Over 50% of the papers demonstrated that specific societal assumptions can be internalised by people with an eating disorder. For example, people viewed their eating disorder to be "a concern with their body" rather than a mental illness, "quick and easy to treat", and not a "real illness", making them undeserving of support for a 'trivial' issue (Tsong et al., 2023). People also considered their eating disorder to be "immature" and "childish" (Potterton et al. 2020). It appears that internalising the stigma experienced can be just as damaging to people's perceptions of their eating disorder, deeming it not serious enough to warrant support.

Across eight of the papers, people with eating disorders appeared to have internalised the belief they were "not sick enough" to require treatment, believing their symptoms were "normal"

(Tsong et al., 2023), and they would be “wasting people’s time” by asking for help. These beliefs could be argued to be a type of eating disorder cognition which can maintain the disorder (Mitrofan et al., 2019). However, the concept of feeling “not sick enough” is likely to be exacerbated by the trivialisation and stereotypes surrounding eating disorders portrayed by society. This is highlighted by many people not viewing their weight as low enough to warrant an eating disorder diagnosis or to receive treatment (Evans et al. 2011), as they were not “extremely thin”, “super- skinny” or “emaciated” (Eiring et al., 2021; Evans et al., 2011; Potterton et al., 2020). It appears that internalisation of stigma surrounding eating disorders can result in people dismissing their own symptoms, enabling the disorder to become more entrenched and severe.

Additionally, people with eating disorders often believed the negative character traits prescribed by society, feeling they were an “attention seeker”, “exhausting to be with” (Maier et al., 2014), and a “weak person” (Evans et al. 2011). People believed they should “solve their own problems” rather than seek treatment (Ali et al., 2020). One person described their bulimic behaviours as “atrocious” and “out of control” (Hepworth & Paxton, 2007), aligning with the concept of bulimic behaviours being ‘socially undesirable’ (Potterton et al., 2020). People with anorexia also expressed embarrassment about not having a “real illness” (Ali et al. 2020), whereas people with binge eating disorder felt they would turn to their friends for support rather than professionals, as their symptoms were “easy to treat” (Ali et al. 2020). Evidently, these are all similar narratives held by society as discussed above. The internalisation of stigma appears to be a significant factor in the delaying of help-seeking for eating disorders, due to resulting feelings of worthlessness. Additionally, normalisation of these conditions within society may also result in people with eating disorders questioning whether mental health support is necessary or appropriate.

Discussion

This review contributes to the understanding around the influence of stigma on help-seeking for an eating disorder, capturing unique individual experiences from an international perspective.

Exploring the role of stigma within help-seeking for eating disorders can help inform the approach of healthcare professionals, services, and treatment guidelines, with aims to make help-seeking more accessible. This is particularly important within the context of eating disorders, due to the need for further advancements in eating disorder guidelines (Byrom et al., 2022; Eiring et al., 2021; NICE, 2020). Continuing to explore factors which may impact help-seeking is crucial, as support for eating disorders is often delayed (Austin et al., 2021). Findings from this review can promote further research into additional factors which may prevent access to support within eating disorders.

Key Findings

The findings from this review demonstrate that stigma poses a significant barrier to seeking help for an eating disorder, often due to the negative emotions it produces. Stigma is encountered throughout the help-seeking process, resulting in detrimental experiences for those accessing support. The three themes identified highlight how people with eating disorders have felt dismissed, invalidated, and shamed. Across the papers, eating disorder symptoms have often been trivialised, resulting in people feeling a lack of motivation to seek help and undeserving of support.

People with eating disorders are stereotyped as being “crazy” (Goel et al., 2023; Wales et al., 2017), “bad” people, a “bad influence” (Hepworth & Paxton, 2007), “attention seeker” (Dimitropoulos et al. 2016), “weak” (Corcoran et al., 2021; Malova and Dunleavy, 2022) and “self-absorbed” (Dimitropoulos et al. 2016). These attributes appear to be prescribed by others and often internalised (Evans et al., 2011; Maier et al., 2014). This heightens feelings of shame (Hepworth & Paxton, 2007; Malova & Dunleavy, 2022) and significantly impacts the likelihood of asking for help (Dimitropoulos et al., 2016; Tsong et al., 2023) or confide in anyone about their difficulties (Goel et al., 2023), resulting in experiences of alienation and isolation (Tsong et al., 2023).

Accessing treatment for eating disorders is met with its own stigma, such as it being “weak” (Ali et al., 2020, Corcoran et al., 2021). This type of stigma can be influenced by cultural beliefs, with psychological treatment being seen as a “con” and you should handle your issues yourself (Tsong et al., 2023), or meaning you are “crazy” (Goel et al., 2023) or “mental” (Wales et al., 2017). These beliefs compound the shame already felt for having an eating disorder, consequently leading to the delaying of help-seeking (Ali et al., 2020; Potterton et al., 2020). It is also worth noting that these negative perceptions around seeking mental health support for an eating disorder, exist within sociocultural norms that promote the maintenance of a low weight.

Interestingly, this review identified a few cases where stigma promoted help-seeking (Potterton et al., 2020), to avoid judgment surrounding eating disorder behaviours that are “undesirable”. This finding aligns with research discussed earlier, with people with other stigmatised conditions engaging in treatment to avoid prejudice (Horch & Hodgins, 2015; Lambert et al., 2018), suggesting that aligning with social norms has a role in help-seeking.

Across three of the papers, people described how their eating disorder was not seen as a mental illness but as a volitional condition, based on an occupation with one’s physical appearance (Corcoran et al., 2021; Dimitropoulos et al., 2016, Tsong et al., 2023). This blaming experience is supported by additional recent research (e.g. Thörel et al., 2021), suggesting it is consistently occurring. The major psychological aspects encompassing eating disorders are largely dismissed (Eiring et al., 2021; Tsong et al., 2023). This is reflected within services, with a weight-based threshold for treatment appearing to be common practice (Byrom et al., 2022; Eiring et al., 2021). This is concerning, as many people with eating disorders may not present as a low weight (Evans et al. 2011). The BMI system is also known to be too euro-figure centric, not inclusive of people of different genders, races, and ethnicities (Buss, 2014; Heymsfield et al., 2016). Using weight as a measure of eating disorder severity results in people who do not meet this threshold being denied treatment (Byrom et al., 2022; Evans et al., 2011), and facilitates purposeful intensification of restrictive behaviour to reach a lower weight and receive help (Eiring et al., 2021). Consequently, this feeds into the stereotype that you need to be an extremely low weight to have an eating disorder (Evans et al. 2011; Potterton et al., 2020). Notably, these findings highlight a discrepancy between the perceptions of high-risk psychological conditions in comparison to physical health conditions. For example, the perception of it being a “choice” to experience an eating disorder, which is unlikely to exist in the context of physical health conditions.

Feelings of exclusion are intensified within groups of people who are not considered within the eating disorder discourse. For example, an eating disorder is often viewed as a “girl’s disease” by society (Corcoran et al., 2021), leaving men with eating disorders doubting their symptoms and feeling unable to seek support (Malova & Dunleavy, 2022). Men also face particular stigma if they do access support for their eating disorder; being told to “man up” (Corcoran et al., 2021; Malova & Dunleavy, 2022). A lack of eating disorder treatment guidelines for men also leads to symptoms being missed, and support not seeming as comprehensive (Malova & Dunleavy, 2022). Consequently, men can be excluded from appropriate eating disorder support, putting them at greater risk.

People with eating disorders from non-Western cultures are also left feeling dismissed and isolated (Goel et al., 2023; Tsong et al., 2023; Wales et al., 2017). This was attributed to a lack of understanding and stereotyping by healthcare professionals (Goel et al., 2017; Wales et al., 2017). The continued facilitation of stigmatising views of how eating disorders should look, can produce negative outcomes within people who already face particular stigma for having a mental health issue and seeking help for it (Corcoran et al., 2021; Tsong et al., 2023).

Clinical implications

The papers reviewed highlight how stigma can act as a barrier to help-seeking by inducing feelings of shame and feeling unworthy of support, making treatment appear inaccessible. Therefore, awareness should be raised around the stigma faced by people with eating disorders, including prevention and management though proposed recommendations. For example, utilising a weight-based threshold to receive support appears to still be in place (Byrom et al., 2022; Eiring et al., 2021), despite national guidance stating that referral for treatment should never be based exclusively on BMI (National Health Service [NHS], 2019; NICE, 2020). Promotion of these guidelines by services and ensuring they are applied can help people access the support they need, limit feelings of “not being sick enough”, and may manage the reported dismissal of psychological elements within eating disorders. This could be via psychoeducational leaflets detailing eating disorder guidance being visible in practices, easily accessible to clinicians and patients, or through eating-disorder specific training within services. This psychoeducation and training should involve promotion of assessments of cognitions such as ‘eating disorder thoughts’, which can encourage restrictive and compensatory behaviour (Pugh & Bell, 2020; Pugh & Waller, 2017), and the dispelling of common stereotypes and stigmatised views faced by people with eating disorders. There is a role for clinical psychologists to design and deliver these, with aims to improve access to treatment and therapeutic outcomes.

When considering examples of more comprehensive eating disorder assessments, a recent systematic review (Hatoum et al., 2023) concluded that the Eating Beliefs Questionnaire (Burton & Abbott, 2018) and the Eating Disorder Inventory Body Dissatisfaction subscale (Garner, 2004) had the most evidence supporting their validity, reliability, and clinical effectiveness. Including measures such as these can facilitate a more effective eating disorder assessment, outside of physical presentation. Assessment of eating disorder cognitions should take place during the first point of contact, due to their ability to increase severity and duration of an eating disorder (Herpertz-Dahlmann, 2015).

Eating disorder interventions should also address psychological elements. Psychological models of eating disorders include the transdiagnostic cognitive model (Fairburn et al., 2003) or schema-focused model (Waller et al., 2007). These models emphasise the importance of challenging eating disorder cognitions and their role in the maintenance of eating disorders (Hatoum et al., 2023). These models can address the core negative self-beliefs and low self-esteem, which are often present within eating disorders and can promote the continuation of eating disorder behaviours

(Pugh & Bell, 2020). A number of systematic reviews have supported the effectiveness of both a transdiagnostic cognitive model (Atwood & Friedman, 2020; de Jon et al., 2018) and a schema-focused model (Maher et al., 2022) for eating disorder treatment, including eating disorders which present as highly complex.

Experiences of individuals feeling judged, stigmatised, and receiving a lack of empathy appeared to be particularly present within primary care settings such as GP practices (Byrom et al., 2022; Tsong et al., 2023). Again, perhaps easily accessible guidance or training may be beneficial, raising awareness around the societal stigma often encountered by people with eating disorders, and the subsequent feelings of shame experienced. In addition, creating a safe space for people to share their problems can ensure they receive the appropriate support. Cognitive and psychodynamic theory states that a safe space can be achieved by containing distressing emotions (Podolan & Gelo, 2023), showing understanding and recognition of a person's problems (Fonagy & Allison, 2014) and being aware of one's own non-verbal signals such as posture and facial expressions (Mair, 2021). The use of reflective spaces for healthcare professionals may also be beneficial, ideally facilitated by a clinical psychologist, to guide professional reflection when supporting people with stigmatised conditions. The above recommendations aim to make it more accessible for people with eating disorders to disclose information within primary care settings and promote timely mental health support.

Ensuring there is gender-informed communication at the point of access to services could reduce feelings of isolation. For example, avoiding and challenging gender stereotypes and assumptions which may particularly affect men with eating disorders, due to the 'feminine branding' of the disorder (Corcoran et al., 2021). Communication should also be culturally sensitive, to help prevent people from being misunderstood (Wales et al., 2017), again avoiding any cultural stereotypes and acknowledging specific barriers and stigma that may be faced by people from different cultures. The importance of the development and utilisation of inclusive eating disorder guidelines is emphasised in this review, and should be promoted where possible within healthcare professionals, to ensure symptoms and experiences are not being missed. This could be through guidance and training for healthcare professionals on the potential differences in symptoms between genders and cultures could be useful. For example, a desire to be muscular as opposed to thin (Malova & Dunleavy, 2022), or increased feelings of shame due to perceptions of an eating disorder being a “personal weakness” (Tsong et al., 2023). Cultural stereotypes around body shape or size should be acknowledged and challenged where possible. Increasing awareness of factors which could influence eating disorder symptoms could limit symptoms being missed (Malova & Dunleavy, 2022), or being inappropriately attributed to an individual’s cultural background (Tsong et al., 2023). This guidance or training could be outlined in a toolkit, psychoeducation leaflet or included in the present NICE guidance (NICE, 2020). Culturally informed training and practice will help to ensure individuals from all cultures feel understood and represented.

Enhancing understanding surrounding eating disorders could also promote family and friends to address potential eating disorder symptoms, rather than “brushing things under the carpet” (Wales et al., 2017). This could be implemented within the media or through posters in the community (as suggested by Wales et al., 2017). Information around the psychological aspects of an eating disorder is important here, to manage beliefs around eating disorders simply being a concern around self-image (Dimitropoulos et al., 2016; Tsong et al., 2023). Anti-stigma campaigns to promote public knowledge around eating disorders should be prioritised. More detail surrounding this can be found in the critical appraisal section.

These recommendations aim to increase overall understanding around eating disorders, with a view to decrease stigma faced by people with an eating disorder within their families, services, and society. This can also influence the internalisation of negative narratives and limit self-stigma, which was also a salient barrier to treatment (Ali et al. 2020; Hepworth & Paxton, 2007). A full list of the above recommendations can be found in appendix 3.

Strengths, limitations, and areas for future research

As is the nature of qualitative research, many of the papers in this review used small sample sizes. For example, one of the papers detailed just one man's experience of an eating disorder. Although this data is valuable, the generalisability of the findings may be limited. However, the novel insights reviewed offer a timely foundation of synthesised knowledge to inform next steps. Additionally, the papers ranged in quality, ascertained by the CASP tool. However, it could be argued that quality appraisals can focus on methodology rather than the impact of qualitative research (Sattar et al., 2021). The findings of this review remain significant and relevant to inform changes in policy in regard to eating disorder treatment. The meta-ethnographic approach used by the current review remains a strength, as it can inform healthcare policy and practice (Sattar et al., 2021). This is particularly beneficial, due to the established need for improvement within eating disorder guidelines and interventions (NICE, 2020) due to poor treatment outcomes (Franko et al., 2018; Svaldi et al., 2019). A meta-ethnographic approach can facilitate development of practical recommendations (Classen & Alverez, 2015), as outlined above.

A clear issue was identified in the current review around specific barriers faced by men and people from non-Western cultures, in relation to stigma and help-seeking. However, people from these groups only made up a small number of papers in this review. Although, it is worth noting that this review captured experiences from a wider range of age groups, genders and cultures as opposed to many other reviews surrounding eating disorders. Nevertheless, further research into the influence of stigma on help-seeking for eating disorders across additional cultures and genders such as transgender or non-binary would be beneficial, to capture other unique experiences and inform services and guidelines.

Furthermore, mental health services, particularly within the UK, are often developing at a rapid pace (Ridge et al., 2023). The oldest paper within this review was published over 15 years ago (Hepworth & Paxton, 2007). Although it served useful to measure individual experiences across a timescale, it could be debated whether these are still occurring today. However, it should be noted that many of the recent papers included in this review, published in 2023, report similar experiences. This perhaps demonstrates a lack of progress in the reduction of stigmatisation within eating disorders over the years.

One factor that hindered help-seeking for an eating disorder is based in weight stigma, avoiding the social undesirability around being ‘overweight’ (Potterton et al., 2020; Tsong et al., 2023) or not being muscular (Malova & Dunleavy, 2022). This is in line with other research, finding that experiences of weight-based stigma can be associated with subsequent eating disorder symptoms such as restricting and purging (Christian et al., 2023; Romano et al., 2021). However, often this research is not focused on help-seeking behaviours. Understanding the role of weight-based stigma in seeking support for eating disorders would be beneficial, particularly as the healthcare system is known to engage in this stigma, resulting in people perceived to be ‘overweight’ facing discrimination and judgment (Rubino et al., 2020). This research could be conducted using similar methods to the current review, exploring people’s experiences of stigma when seeking help for an eating disorder, however with a focus on weight-based stigma.

Conclusion

In conclusion, the present review identified the significant role of stigma as a barrier to help-seeking for eating disorders, across social support systems and services. These findings can inform clinical guidelines and practice by promoting the use of alternative eating disorder assessments and interventions which better meet people’s needs and focus on psychological elements. The findings can also help to inform the design of additional training and guidance for healthcare professionals, including communication and practice which is inclusive of all genders and cultures.

Finally, education to challenge negative social perceptions of this highly stigmatised condition could lessen the barriers faced by people with eating disorders and make support feel more accessible. Raising awareness of this barrier and implementing changes to mediate it aim to improve treatment engagement within eating disorders which are currently poor (Linardon et al., 2017; Svaldi et al., 2019). The overarching clinical recommendation from this in-depth and timely review is to improve the experience of people seeking help for an eating disorder, to improve recovery trajectories for this condition.

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Tables and Figures

Table 1

Table of search terms and approach used for databases

Database	Eating disorders	Stigma	Help seeking
MEDLINE Complete/ Psych Info/ Academic Search Ultimate	(DE "Eating Disorders" OR DE "Anorexia Nervosa" OR DE "Binge Eating Disorder" OR DE "Bulimia" OR DE "Orthorexia" OR DE "Purging (Eating Disorders)") OR TI ("eating disorder*" OR anorexia OR bulimia OR binge* OR binging OR "Orthorexia" OR ((purg* OR regurgit*) N3 (disord* OR food*)) OR "Diabulimia") OR AB ("eating disorder*" OR anorexia OR bulimia OR binge* OR binging OR "Orthorexia" OR ((purg* OR regurgit*) N3 (disord* OR food*)) OR "Diabulimia")	(DE "Gender Role Attitudes" OR DE "Gender Equality" OR DE "Social Acceptance" OR DE "Belonging" OR DE "Social Approval" OR DE "Social Discrimination" OR DE "Age Discrimination" OR DE "Disability Discrimination" OR DE "Employment Discrimination" OR DE "Intersectionality" OR DE "Race and Ethnic Discrimination" OR DE "Sex Discrimination" OR DE "Social Class Bias" OR DE "Stereotyped Attitudes" OR DE "Implicit Attitudes" OR DE "Implicit Bias" OR DE "Explicit Attitudes" OR DE "Labeling" OR DE "Prejudice" OR DE "Religious Prejudices" OR DE "Stigma" OR DE "Mental Health Stigma" OR DE "Self-Stigma") OR TI (stigma* OR bias* OR prejudi* OR discriminat* OR attitude* OR acceptance OR approval OR self-stigma* OR shame*) OR AB (stigma* OR	(DE "Help Seeking Behavior" OR DE "Health Care Seeking Behavior") OR TI (((help OR care OR support OR healthcare) N3 (seek*)) OR help-seeking) OR AB (((help OR care OR support OR healthcare) N3 (seek*)) OR help-seeking)

	bias* OR prejudi* OR discriminat* OR attitude* OR acceptance OR approval OR self-stigma* OR shame*)

Table 2

Characteristics of included studies

Authors	Location	Setting	Participants (number, age range, gender, nationality/ethnicity)	Data collection method	Data analysis method
Dimitropoulos et al., (2016)	Canada	Inpatient	19 19-44 years Women Range of ethnicities	Semi-structured interviews	Thematic analysis
Evans et al., (2011)	Australia	Community	57 18-42 years Women Australian	Qualitative interviews	Framework analysis
Wales et al., (2017)	Leicester	Community	28 18-65 years Women and men South Asian	Focus groups, semi-structured interviews	Thematic Analysis

Eiring et al., (2021)	Norway	Community	7 21-47 years Women Norwegian	Semi-structured interviews	Interpretive Phenomenological Analysis
Potterton et al., (2020)	England	Community	14 18-25 years Men and women Range of ethnicities	Semi-structured interviews	Thematic analysis
Malova & Dunleavy, (2022)	Online	Online	25 18-35 years Men Nationality/ethnicity not disclosed	Video samples retrieved via YouTube and transcribed	Thematic analysis
Hepworth & Paxton, (2007)	Australia	Community	63 18-62 Women Mix of ethnicities	Semi-structured interviews	Concept mapping

Byrom et al., (2022)	Across UK	Community	18 18-24 years Women White British	Semi-structured interviews	Thematic Analysis
Maier et al., (2014)	Germany	Community	36 15-24 years Women Ethnicity/nationality not disclosed	Questionnaires including open questions	Qualitative analysis method not disclosed
Corcoran et al., (2021)	Northwest UK	Community	1 Man Age and nationality/ethnicity undisclosed	Semi-structured interview	Qualitative analysis method not disclosed
Griffiths et al., (2015)	Australia, USA, UK	Community	317 14-54 years Women and men Mix of ethnicities	Stigma scale	Qualitative analysis method not disclosed

Tsong et al., (2023)	Online	Online/community	143 Average 23 years Women Asian American	Questionnaire containing open ended questions	Grounded Theory/Consensual Qualitative Research-Modified
Ali et al., (2020)	Australia	Community	291 18-25 years Men and women Australian	Questionnaire containing open ended questions	Qualitative analysis method not disclosed
Goel et al., (2023)	USA	Community	57 Average age 20 years Women South Asian American	Focus groups using semi-structured interviews	Thematic Analysis

Table 3

Table of quality appraisal scores for each paper, using the CASP tool

Paper	Statement of Aims	Methodology	Research Design	Recruitment Strategy	Data Collection	Reflexivity	Ethical Issues	Data Analysis	Statement of Findings	Value of Findings	Total Score
Dimitropoulos et al., (2016)	Yes	Yes	Can't tell	Yes	Yes	No	Can't tell	Yes	Yes	Yes	16/20
Evans et al., (2011)	Yes	Yes	Can't tell	Yes	Yes	No	Can't tell	Yes	Yes	Yes	16/20
Wales et al., (2017)	Yes	Yes	Can't tell	Yes	Yes	No	Can't tell	Can't tell	Can't tell	Yes	14/20
Eiring et al., (2021)	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Yes	17/20
Potterton et al., (2020)	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Can't tell	Yes	Yes	17/20
Malova & Dunleavy (2022)	Yes	Yes	Can't tell	Yes	Yes	Can't tell	No	Can't tell	Yes	Yes	15/20

Hepworth & Paxton (2007)	Yes	Yes	Can’t tell	Yes	Yes	Can’t tell	Can’t tell	Yes	Yes	Yes	17/20
Byrom et al., (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	19/20
Maier et al., (2014)	Yes	Yes	Yes	Can’t tell	Yes	Can’t tell	Can’t tell	Can’t tell	Yes	Yes	16/20
Corcoran et al., (2021)	Yes	Yes	Yes	Yes	Yes	No	No	Can’t tell	Can’t tell	Yes	14/20
Griffiths et al., (2015)	Yes	Yes	Yes	Yes	Yes	Can’t tell	No	Can’t tell	Yes	Yes	16/20
Tsong et al., (2023)	Yes	Yes	Can’t tell	Yes	Can’t tell	Can’t tell	No	Yes	Yes	Yes	15/20
Ali et al., (2020)	Yes	Yes	Yes	Yes	Yes	Can’t tell	Can’t tell	Yes	Yes	Yes	18/20
Goel et al., (2023)	Yes	Yes	Yes	Can’t tell	Yes	Yes	Can’t tell	Yes	Yes	Yes	18/20

Table 4

First and second order constructs within the raw data

Paper	Themes (key concepts)	First Order Constructs (participant quotes)	Second Order Constructs (primary author interpretations)
Dimitropoulos et al. (2016)	**Anorexia nervosa is not a mental illness**	"they think that we're crazy and that we can't deal with reality..." "stigma in society really motivates you to continue [eating disorder behaviours]..." "mental illnesses are not explored as much as physical illnesses..." "I think a lot of people don't see it as a disease ... so rather than cancer or something that is innate within you, I don't think that is how anorexia is seen" "cancer patients don't have the choice whereas this is [AN] a choice for us"	• The general public underestimates the seriousness of this illness by trivializing and minimizing associated psychological and medical challenges • Cancer was the primary source of comparison - participants were contrasting their illness to one that the general public typically does not assign personal responsibility to, that engenders fear as cancer is treated as a serious and life-threatening illness.
		"I believe that people think that you make the choice to become anorexic ..."	• Participants felt that others viewed AN as volitional. • Participants believed that attributing AN to the desire to achieve thinness perpetuated the myth that people with eating disorders are seeking

Volitional nature of AN influenced by socio-cultural explanation for this illness	“it's a choice that we're making to not eat for attention ... we could stop if we wanted to, we're self-absorbed or we have this unrealistic image to be perfect...” “people who have it do not ask for it and do not choose it... it's just such a painful, isolating, spiralling thing that is really hard to get out of" “...our choice has been taken away by the illness. We're not doing it to harm the people that we love the most, we're not doing it to die, it's just not a choice anymore, once it gets to that point” “... there are a lot of misperceptions about it; that this illness is very image based, it's very self-centered. Usually girls who get it are very conscious of their appearance, are superficial" “...I think they think it's a pretty-princess syndrome ... I don't think they understand or know the complexity around it" “...just immature girls trying to seek attention, trying to be the next Kate Moss and they got carried away... because of that stigma and... the connotation it carries, and how polar opposite it actually is, and how shallow it is perceived, I'm terrified to tell anyone who	attention and obsessing about their physical appearance

		doesn't care enough to appreciate it or who I feel would judge me" "they think it's something that people can get over quickly" "friends, family begging me to do something about it... Like everyone wants a straight answer- cut and dry solution or expect the professionals to really have a solution for me but it's pretty much more complicated"	
	The consequence of these attitudes and beliefs is that the general public views treatment as quick and fairly easy –"Just eat"!	"you have to go through the anxiety and the body image ... you can't just eat your way out of it; if you still can't cope with the factors that led you there in the first place, you're going to go back to square one" "It's not as easy as saying 'just eat', that there's a lot behind it and that it would be good if more people were more understanding and could be more supportive"	• The general public perceives minimal professional support is required to facilitate recovery from AN, treatment is time limited, and recovery fairly easy to achieve. • Even when others recognized the seriousness of AN, few acknowledged the challenges associated with eating and gaining weight
Evans, et al. (2011)	**Factors Contributing to a Positive Experience of Help-seeking: non judgmental, understanding, trust, no**	“[professionals] very understanding and non-judgemental" "understanding of my situation"	• Rapport and non-judgmental attitude came up most often as a facilitator to accessing treatment

	feelings of stigma from professionals	"trust." "I got no feeling about any sort of stigma being attached to it. It was just very matter-of-fact."	
	Factors Contributing to a Negative Experience of Help-seeking: feeling judged, perceived stigma, frustration, disappointment	"I just felt like he didn't like me he thought I was a weak person and couldn't see beyond the eating disorder." "feeling scared they're not going to take you seriously ...pretend like it's not really a problem. You're not demonstrating to them that the problem is severe and it's impacting on your life because you're scared of their perception of you physically." "my mum didn't even want me to go out of the house in case somebody saw me and knew what I was suffering from. It was real stigma. And I just felt very unsupported ..." "I don't think that they really took the eating thing into consideration as much as my actual mental health because I was seeing them for different reasons. I don't think they understood that my eating problems were as important to me."	• Perceiving judgement from the professionals they consult which can act as a barrier to accessing treatment. • frustration and disappointment of not being asked regarding eating, even when seeking help for weight-related issues. Many patients would welcome such questions from health professionals - may serve as an invitation to discuss a topic which they find difficult to raise due to feelings of shame or a fear of stigma • Sense of disappointment or frustration that the issue of their eating was not taken seriously by professionals

	Specific barriers to seeking help: Shame	"She thought I didn't have any problem because I walked in there and I wasn't emaciated. And that was so detrimental to me." "the only barrier there is my own shame ... [the health professional] didn't do anything to shame me, it was just how I was feeling."	
Wales et al. (2017)	**Lack of knowledge about eating disorders**	"I'm more aware if it because of the media, I see programmes about it I see magazine articles." "…our parents don't know much about it, especially if they're from places like India and Pakistan and Africa …" "…a lot of the second generation girls…they won't have a history of eating disorder or a language for this whole thing of dieting and wanting to be thin ...their mums will have come from India… women didn't diet, you were lucky if you managed to find enough food …So these girls will come from families where you don't have …'oh yeah my mum always dieted'…that understanding of size…that will not be understood. So for them I think there will l be that added sense of isolation actually they can't talk to perhaps their mothers, aunts about it."	• Lack of awareness and understanding about ED's is potentially key in not seeking help when suffering from an ED

"...eating disorders they're easily fixed so why go seek help if you can do it yourself? … You have your family, you have support…someone who has diabetes something like that is more severe and they need to go to a doctor. Someone who has anorexia, sort it out yourself."

"A lot of that stems from people thinking about what others will think about that… not so much the problem itself …will they see us as crazy mental people they don't want to associate with?... that is the reason for the circle of secrecy. People are afraid how others how the wider society …will see them"

"...they brush so much under the carpet... issues are coming through now this generation that wasn't dealt with... their objective when they came to the UK was come here settle, work, get a roof on top of their heads, everything else was just sort yourself out and that escalates now into problems I think... kind of blinded still."

"I saw a young girl recently... she presented very late. She's now in her early 20's but... purging since she was 11. Her brother says it's been known in the family, she's been a BMI of 14 for years now which is very sad as she's already chronic... she's had no treatment at all. One of the barriers there is the family just not willing to think about mental health there's a big stigma, a barrier about that…"

Stigma around mental health	"I've had 2 or 3 (Asian males) who were more bulimic who've presented years after it started, always avoided coming…the ones I've seen … have been very ashamed…something that's hidden".	• Lack of help-seeking also stemmed from concerns about stigma. This may lead people to either ignore or keep the issue within the family.
Difficulties keeping privacy within the family (if seeking professional help)	"I went to counselling once and I always made an excuse at that time of that week…I didn't want to tell my in-laws where I was going". "…you all know the confidentiality rule applies but probably, self-consciously, they're thinking it won't apply because they're Asian communities"	
Worries about confidentiality	"…one of the…Asian patients I worked with... she was worried that her GP would tell… her parents that she'd been…I don't think it had happened to her but she perceived it as a worry and it delayed her going." "It's not unusual to see an Asian patient has requested not to see an Asian therapist" (for fear of confidentiality issues)	• Concerns that information may be shared, by healthcare professionals, with other family members can hinder health seeking.
	"I think now some of the Bollywood films are now starting to put mental health issues into the films. … things like autism as well…but it's quite lighthearted…"	• Information regarding ED's displayed outside of healthcare settings could be helpful to

	Reducing stigma to improve access to services	"…sometimes when we're watching EastEnders, Coronation Street and certain topics like this come up, normally as a family we discuss it, … maybe not many Asian families have that discussion". "The temples and mosques…they have noticeboards…that in itself would say maybe it is ok for us in this community to talk about eating disorders" (displaying posters about EDs) "...defining what it is. Everybody's perception of anorexia or eating disorders may be different…" (displaying posters about EDs)	promote discussion, improve education and reduce stigma, and improve education around EDs, those who were considered "not sick enough" by others
Eiring et al. (2021)	**Dealing with the focus upon one's physical appearance while battling a mental illness:** **Not skinny enough to have an ED**	"when I started to recover and reached normal weight…. they point blank don't believe that I've ever had an ED because they didn't see me as being skinny enough." "…everyone came up to me surprised and said "God, if you have an eating disorder…I know people [with EDs], but they are superskinny, and you are not that skinny!" "I was a little bit ashamed of having gained that much weight because I was thinking that now, they don't know… that I was life	• The tendency of others to focus on physical measure of illness, such as weight, while psychological aspects of the illness were overlooked or under-recognized.

	threateningly ill, sort of, so it is important that I gain weight.”	
Weight-based threshold to access treatment	“...they told me “no”, they said... there’s nothing now that indicates that we need to take action because your weight is relatively stable, and your blood samples are fine” “After multiple rejections... what’s the point then? Why should I fight for something that nobody cares to fight for with me? Like three months went by until the doctor realized that this [the relapse] was serious, but by then my weight had gone drastically down.”	• symptoms were disregarded or trivialized by others—based on physical measures—as not serious enough to warrant, access, or continue treatment – led to feelings of despair, lack of trust and ambivalence to treatment • experiences of being discharged based upon meeting a weight threshold, without sufficient regard to the level of ED psychopathology, or being denied readmission following a relapse regardless of spikes in ED-related behaviors and cognitions
Project “perfect”: under pressure to prove oneself	“I experienced… that I wasn’t... sick enough... so I made myself a goal that I would be f******* sick enough for her to tell me that “now you need help”.	• some participants directly linked trivialization of symptoms to an intentional intensification of restrictive eating behavior to “prove” their illness or to gain access to treatment
The importance of being seen and heard: **The lack of congruence between the internal experience of the individual and the response from the external environment**	“...comments from health professionals that I’ve gotten are completely out of touch, where I don’t think they understand how sick you really are...” “asking me questions... really weird ones, like, “are you gay?”, “have you... had a traumatizing childhood?”... all those things I answered “no” to… she asked me how I ate on a	• Feeling supported by healthcare providers is also a particularly salient predictor of

		normal day. I explained how I had eaten in January, when things were going well. Now things were much worse. But by that point in the assessment, I didn't dare to tell her…" "I'm left feeling very betrayed... not to be seen, but I thought... in fact your own parents didn't do anything because they thought it would pass." "it's very much like… "Okay, we can see that there is something wrong with her, but we won´t ask her about it."	treatment engagement and satisfaction • feeling unseen or unsupported by family members who clearly recognized a problem yet didn't take action or ask questions.
Potterton et al. (2020)	**Symptom egosyntonicity (viewed as acceptable to yourself, in line with your values/self image)**	"I just thought I was doing a good thing, sort of exercising more, trying to be healthy, trying to lose a bit of weight."	• Dietary control and consequent weight loss were positively appraised and perceived to boost confidence and help cope with stressful situations (egosyntonic), therefore lacking motivation to seek help
	Self esteem	"It gave me a sense of achievement and I felt good about myself."	
	Binge-eating and compensatory behaviours & Social Functioning	"I became more understanding of [my condition] with the bingeing, [whereas] with the restricting I felt like I was just following a healthy diet."	• Several participants reported that over time they started to experience bingeing and compensatory behaviours. These behaviours lacked the social desirability of dietary control and were therefore more negatively appraised.

		• The gradual nature of this reappraisal (and ongoing shame and embarrassment about symptoms) was such that many participants experienced a period of uncertainty about whether they had an ED or not, and/or ambivalence towards the idea of seeking and receiving help. Help-seeking was on a knife-edge (i.e. as likely to happen as not).
Help-seeking at transition points	“I thought like new job, I’m in a new place as well, [I can cope on my own].”	• Some participants wanted to change their symptoms but did not seek professional help because they hoped that a “fresh start” or “change of scene” would be sufficient help in itself, thereby forgoing the embarrassment associated with help-seeking.
Scaffolding by others	“I felt it was kind of just brushed under the carpet. To me it was like, maybe I don’t have an eating disorder […]. It just made me ignore it even more.”	• For many participants, friends and family not raising concerns about their symptoms, or doing so in a vague or generic way (e.g. “is everything OK?”), were interpreted as disconfirming their suspicions that they might have an ED. Such interventions

			therefore did not bolster their confidence in seeking help, and in fact increased their belief that such problems were shameful or embarrassing
	Feelings of exclusion from eating disorder discourse	“You have to be extremely thin to have an eating disorder” “I was afraid they wouldn’t see me as ill. I thought that if I told any of my friends, they would just laugh in my face and tell me “that’s not true””	• Participants reported awareness of dominant constructions of EDs. When participants felt they did not fit within this discourse, they believed that asking for help would be embarrassing and shameful, and their concerns would be rejected • Many participants expressed the belief that EDs are characterised by extreme low weight. They described how they did not see themselves as being sufficiently low weight to have their concerns accepted, both by friends and family and by key professionals.
		“Eating disorders are teenage illnesses” “I am 22 […], I’m not 16. How did I get into this? Why am I not able to snap out of it? It’s such a stupid issue, and I’m just ashamed of it.”	• Several participants described beliefs that EDs were “immature” and “childish” illnesses, commonly experienced by teenagers.

		“I was a bit embarrassed or cautious about telling my family. I tried very much to handle it by myself.”	• circumnavigating help-seeking from family and friends or key professionals, choosing to cope with their problems alone.
	Utilisation of self-help resources		• Several participants described turning to self-help resources to avoid the embarrassment associated with help-seeking. Participants noted resources increased their confidence that their concerns would be taken seriously. Resources which incorporated other (non-adolescent) people’s experiences of EDs were particularly impactful, and helped participants feel less embarrassed.
	Seeking help independently of parents		• Several participants described considering accessing professional help independently of their parents’ involvement to avoid embarrassment. However, participants perceived it as difficult to do so - described how they did not go to key professionals (e.g. GP:

		teachers), for fear any information confided would be shared with their parents
Indirect disclosure of difficulties	"I just couldn't speak about it [with the GP] because […] it's embarrassing, and it's just, I didn't really know what to say?"	• feeling excluded from ED discourse and resultant fear of rejection and embarrassment meant they found it difficult to communicate their difficulties, to both close others and key professionals - this meant they sought alternative, indirect ways to communicate their need for help. - face to face was associated with a particularly high potential for embarrassment. - so used written communication instead
Generic communication of distress		• high level of embarrassment - prospect of using the term "eating disorder" or specific diagnoses, or outlining in specific detail their eating or compensatory behaviours, - important to be able to express their difficulties in vague or ambiguous way (e.g. using non-specific descriptions) and still be understood and taken seriously

	Physical Health Concerns		• focusing on physical health concerns to communicate their difficulties – deemed most likely to be acceptable and least embarrassing. • Scheduling appointments with healthcare professionals ostensibly for physical health concerns (e.g. medication review with psychiatrist; blood test results from GP), even if their hope was to receive help for their eating problem
Malova & Dunleavy (2022)	**Bullying**	“Bullying in seventh and eighth grade caused me to become insecure, and I coped with my insecurities with restricting. Summer before my sophomore year, my life was a rollercoaster, and I turned back to old coping habits. Insecure about my body and crazy things happening in my life, I became depressed and used behaviors to feel numb. There is always ana’s [AN] voice in my head telling me to restrict and that I need to lose more weight.” “The only person I was close to was my partner at that time. I had issues with my insecurities, so I decided to lose weight and become “healthy” to help our relationships.”	• Individuals reported being “overweight” in school or college - being criticized and bullied by their peers. • connections between appearance improvement and relationship development may stem, for example, from social appearance anxiety, the fear that one will be negatively

Drive for muscularity	"To make friends, you need to look a certain way, to be a thin muscular guy. The more weight I lost, the more I wanted to lose. People spoke to me. I had more friends." "security and the feeling of superiority."	evaluated because of one's appearance
Self-regulation	"I loved being anorexic. That feeling of control of yourself in a moment, denying yourself food, such an important part of your life, gives you that feeling of "yes, I am on top of it.	
Barriers to recovery: **Shame and stigma**	"girl's disease" "it needs a lot of courage and seems to be much easier for females than for a manly man who is into fitness." "Men will refuse to come forward and admit that they have an ED because there is such a massive stigma that it is a woman's disease, and the men should just men up … and it's dangerous, and it kills people. " "ED have no gender, and I hope that in 20 years, it would be almost ridiculous to say that men get ED too." "If enough people are brave enough to stand up and admit it, then more and more people will be helped."	• Individuals mentioned the "girl's disease" label attached to ED

		"It is crucial that we speak up about it and break the stigma."	
	Lack of knowledge and information	"I thought I was getting fitter, not thinner. I did not know a clue about ED. The only thing I knew was that young girls got it. I did not appreciate how serious it was." "I went to the University and decided that I needed to run a lot and restrict my calories. I was not educated about anything. I just thought I needed to starve myself, and I needed to exercise a lot." "I remember being diagnosed with anorexia in October 2010. And I was like, 'what is this? Just girls get that.'"	• individuals reported that they had no knowledge about symptomology, manifestation, and consequences of EDs • The men admitted that they were not educated about the principles of healthy eating and safe exercising in general • Low perceived susceptibility to a 'girl's disease".
	Low level of perceived doctor-patient communication	"I tried to get help with my GP [general practitioner], who told they will not be able to get me any help based on the fact that I was a male … to have the door shut on you because you are a male coming forward for an ED was ridiculous."	• insufficient recognition of ED among men - stigma and shame prevent men from seeking medical help for a "female disorder." • critical role of doctors in diagnosing and treatment of ED - doctors are not always able to help due to stigma around the health issue, lack of insurance coverage, and low level of

			perceived doctor-patient communication. • general stigmatization of ED as an easily controllable disease - the “female disorder” label stigmatizes men with ED as somehow violating traditional gender norms and could reduce attempts to seek medical help thereby increasing under-reporting of ED among men. • most ED assessment tools are female-centered, health professionals have difficulties recognizing the presence of ED in males
Hepworth & Paxton (2007)	Fear of Stigma and Shame	‘‘I thought that people would judge me. I thought that people would be disgusted with what I was doing and that they wouldn’t want to know me anymore.’’ ‘‘I felt ashamed, I did the most atrocious things. I went through so much food and didn’t want anyone to know what I was doing.’’	• The most prominent barriers to treatment included Fear of Stigma and Shame • Words frequently found in this theme included ‘‘think,’’ ‘‘thought,’’ ‘‘people,’’ ‘‘judge,’’ and ‘‘laugh,’’ suggesting that participants held concerns regarding the negative

	evaluation of others about treatment seeking. • Embarrassment'' and ''ashamed'' were common words associated with this theme. • concept map indicates a degree of overlap between the themes Shame and Fear of Stigma suggesting that concerns about negative evaluation of the self and by others are associated. • most likely reason for delay in help-seeking is concern about negative evaluation by others and perceived stigma - people with EDs are perceived negatively by the general public, who hold the belief that eating disorders are self-inflicted and therefore not deserving of empathy.
Specific stigma/self stigma around Bulimia	• many indicated that they experienced greater distress when suffering from bulimia compared to anorexia. • They also reported less acceptance and validation in

support groups and hospital settings and attributed this to the less overt nature of their condition. The impulsive and secretive nature of bulimic behaviors may be less socially acceptable than highly controlled behaviors and therefore subject to greater stigma.

- Self-stigma is a barrier to treatment, linked with shame, embarrassment and guilt surrounding bulimic behaviors and feelings of lack of control.

- public disapproval and judgement of bulimia and binge eating disorder is often internalized by sufferers, and subsequently hampers treatment seeking

- as the age of onset for bulimia is 19–20 years - destigmatizing eating disorders in adolescence and young adulthood is especially important.

Byrom et al., (2022)	**It is not easy to ask for help**	*"[I] never thought it was bad enough to get help,"* *"I wouldn't want to waste anybody's time."* "It is really difficult to disclose one's struggle with such mental disorder to someone from the "outside" world as it makes one feel out of control and more vulnerable. Although one might feel that it is the right time to seek help, it is at the same time extremely difficult to admit to oneself that he/she is suffering from such disorder. Equally, there is a fear of being judged or misunderstood so often people would not opt for such services."	• Participants feeling undeserving of support - feeling not 'ill' enough to receive help, not fitting the criteria for services, and not wanting to waste anybody's time • Substantive barriers to help-seeking were identified including self-stigma and vulnerability associated with disclosing • Social concerns related to the reactions of others such as being judged or misunderstood and lacking trust in others - stated that they had found it difficult to seek support because of shame, stigma and a lack of motivation. • Self-stigma is a substantive challenge, with individuals not feeling they are deserving of support, not wanting to lose control or admit they have a problem, and being worried about being judged by others
	Stigma within professionals/services		• Difficulties seeking help from the GP included GPs being

	"I didn't like the GPs, they were really insensitive to mental health". "As someone who struggled with bulimia, I am a normal weight. Consistently been told I can't access specialist services as I am not underweight." “When my [ED] issues first started I couldn't access NHS help due to the guidelines stating I needed a BMI [below] 17.0 (despite displaying every other symptom) which was taken as encouragement to continue." *"[The] only reason it was quick was because I was at a high suicide risk."* *"I was 'lucky' in that my BMI at the time of seeing a GP made access to support easy."*	perceived to be judgemental, unempathetic, not understand EDs and not respond to requests for support • Challenges relating to treatment criteria - referral thresholds being too high, or criteria too limited. - being told that their BMI was either 'too high' or 'too low' to qualify for treatment. • Difficulties accessing support included complex referral pathways, including strict limitations on referral criteria • The majority of eating disorders are not accompanied by very low BMI and it is common for individual with an eating disorder to have comorbidities. The presence of comorbidities and the absence of very low weight were identified here as barriers to accessing treatment. • The focus on weight in referral criteria may exacerbate unhealthy cognitions, encouraging individuals to

		define themselves by their weight • Participants recognised that it was easier for them to access support due to the severity of their difficulties and being considered high risk. They perceived themselves as 'lucky' for managing to access support • it can be hard to say, "I think I have an ED; I need help." - the current complex referral pathway and siloed treatment services that young people must navigate often demands that they have to say this repeatedly. This repetition may encourage damaging internalization of an eating disorder narrative, further shaping identity around the eating disorder.
Maier et al. (2014)	**Criticism and Stigma**	• Participants reported receiving considerable criticism because of their eating disorder symptoms, mainly formulated by the patients' parents, less commonly by their boyfriends,

physicians, strangers/in the public, siblings, classmates/colleagues and friends.

- They reported that they were very often treated as less competent, primarily by their parents.

- Reported that others thought negatively about them because they had received psychiatric or psychotherapeutic treatment

- Participants felt stigmatized by the public opinion, resulting in disadvantages in everyday life

- They felt they were being treated differently to other people due to their anorexia, feeling as though they would not be employable, not accepted as a friend

Self stigma reported:

-feeling different from others in their age group
-avoid telling other people about their ED
-feel responsible for their ED

-see themselves as ‘trying to get attention’ through their ED
-could ‘pull themselves together’ if they needed to
-they ‘cannot be healed’
-feel differently to other people
-it is exhausting to be with them
- feel like their parents (mostly mother) felt/were held responsible for their ED
-accusations and criticisms of an ED put stress on their parents

- Most of the patients reported feelings of alienation and self-blame

- Stereotypes towards anorexia were mostly agreed with by patients

- participants reported that they waited a considerable time before visiting a physician due to fear of being criticized and blamed.

- participants waited to undergo treatment due to fear of being excluded or degraded

- Questions about stigmatization and discrimination in general were more often affirmed than those about concrete personal experiences of prejudicial factors

- This indicates that stigmatization is not limited to concrete experiences, but is also associated with a more general perception of stigma related to mental illness.

- substantial amount of perceived stigmatization and discrimination toward patients with AN, as well as a remarkable degree of self-stigmatization, as indexed by high rates of agreement with stigmatizing statements. These rates were similar to or even higher than rates in the general population

- The high rates of patients' feelings of responsibility for their disorder and concealing their symptoms suggest that they applied at least some of these stereotypes to themselves.

			• stigmatization of patients with AN can lead to delayed treatment initiation. • supports the hypothesis that stigmatization is an underlying reason for the fact that more than 20% of patients with AN remain untreated until 5 years after the onset of the disorder
Corcoran et al. (2022)	**Missing out on the crucial "early intervention" stages**	"primary issue could be the invisibility of males in services, as there are no specific male treatment programmes or guidelines, most likely because current approaches are based on research specific to females, ... diagnostic criteria have until recently emphasized female-specific characteristics too. As was the case for myself, it could be that other males would also feel uncomfortable participating in treatment programmes which are likely to be predominantly female, something which is supported by other research suggesting that males often feel like the "odd one out" in current, "female-dominated" eating disorder treatment environments" "being the only male, I often compared myself to the females on the unit, and my recovery could become stuck depending on how well they were doing."	• Not seeking help may in part be due to the feminine branding of AN which has evolved, which is likely to contribute towards the stigma that already exists for males seeking mental health support • They may feel too ashamed or embarrassed to admit that they are experiencing something which (mythologically) only occurs in teenage girls • Lack of research/general void in male-centred knowledge at present suggests that this figures for EDs in males could be higher, and that males might not be the "minority" in the eating disorder population

	"During my first mealtime after I arrived at the unit, I looked around at what everybody else had been served. The other girls were so small, skinny and frail, but when I saw their plates, there was hardly anything on them compared to mine. I felt so greedy and fat because I was eating far more, and no matter how many times the staff reassured me that I needed to eat more than them because I was a lot taller than them, I just couldn't get my head round it"	at all, but rather the misunderstood
Comparisons to females with Eds	"the vast majority of the literature relating to young people's experiences of inpatient admission consists of female participants only, excluding males and the different pros and cons that they might experience."	
Lack of male representation	"When I was poorly, there were no males who were open about suffering from an eating disorder. I genuinely believe that if there was and I had the chance to speak to them, it might have given me the hope I needed to recover. I met plenty of females who had recovered but this didn't engage me because I wasn't like them, the illness affected me differently."	
Gender roles	"There is this stigma in society whereby men are perceived to be strong, bold characters who cannot be seen as weak. This stigma stops them from admitting when they are not okay	

		and holds them back from asking for help. It needs to change”	
Griffiths et al. (2015)	**Specific stigma around Bulima**		• Participants with bulimia nervosa were more frequently stigmatized as having no self - control than participants with anorexia nervosa and EDNOS
	Gender Roles		• male participants were more frequently stigmatized as being less of a man than female participants were stigmatized as being less of a woman
	Specific stigma towards Anorexia		• People with anorexia seen as being a ‘bad influence on others’ • an increased frequency of stigmatization was consistently associated with more damage to well - being, more eating disorder and depression symptoms, more self - stigma of seeking psychological treatment, and lower self -

esteem. – also associated with longer duration of illness

- Stigmatizing attitudes faced included:
  - ‘attention seeker’
  - bad influence
  -incompetent
  -loser
  -pull myself together
  -shameful

- “I should be able to just pull myself together” and “I am personally responsible for my condition”, were found to be both particularly often experienced and particularly damaging

- An individual with more marked eating disorder symptoms may be more visible and thus attract more stigma. Alternatively, frequent stigmatization may adversely affect the well - being of an individual, potentially increasing the severity of their eating disorder.

- a heightened sensitivity to stigmatization among

			individuals with low self - esteem or high self - stigma may contribute to perceptions of more frequent stigmatization. • Results highlight the tendency for eating disorders to be viewed as trivial and/or self - inflicted. • suggests that the stigmatizing attitudes and beliefs concerning eating disorders held by the public are same as those most widely experienced by individuals with eating disorders themselves.
Tsong et al. (2023)	**ED as a personal weakness**	“I can just easily work off my stomach fat, and everything would be good. Apparently, I am too lazy to go to the gym and workout.” “I sought treatment on-and-off for 5 years, and during the ‘off’ times, I refused to seek therapy merely because I didn’t want to face my weaknesses. I didn’t want to accept that I STILL had a problem.”	• participants shared personal reasons for not seeking treatment - having body image concerns or disordered eating was a personal weakness. • Others did not want to accept or acknowledge that they had a problem. • not seeking treatment because they thought their symptoms were not severe enough to

		warrant therapy or that their concerns or disordered eating. Thought their behaviours were “normal”
Shame	“I found it too embarrassing, and I was too ashamed of myself to seek help.” “I never thought to seek treatment because it was an issue that I didn’t ever want to share with others. For me, it was embarrassing to tell others that I had felt terrible about my body and the way I looked.”	• feeling self-defeated, shy, embarrassed, or ashamed for considering seeking treatment. • not wanting to disclose their experiences or difficulties to anyone, including professionals.
Family as a barrier	“family would go bonkers,” “mother is not willing to contribute to the cost of [her] getting treatment for body image-related issues.”	• *Family* was, at times, a barrier to Asian American women’s treatment-seeking experiences.
Negative experiences when seeking help	“I went to a clinic, and I had told the doctor that I had an eating disorder. She continued to tell me about my weight diet and exercise, which are very triggering for people who are suffering from eating disorders.”	
Stigma	“I knew it wasn’t healthy and have tried to stop on my own. I didn’t like the idea of being seen as the ‘broken’ Asian girl with problems.”	• There were both self-stigmas and public stigmas regarding having disordered eating and

	“My family had completely negative biased opinions on the subject and believed psychologists were mere con-artists taking people’s money acting as though they understand how people think and actually help when all they do is act like mind-readers and over-charge people simply asking about feelings. Twisted and negative mindsets towards the field kept me from even considering seeking help.” “I felt like if I tried to get help it would be seen poorly on my behalf for not being able to control my own issues. My friends were largely very thin girls and I was seen as the fat friend. If I got help then I felt like I would lose these girls as friends because they always said that only the sick and hopeless got eating disorders. They also always behaved like those with ED were those who tried to get attention by getting sick like that.”	seeking treatment. Some believed it would reflect poorly on them for “having issues.” • public stigma against therapy and mental health conditions from their (Asian American) community, family, and friends. • Barriers may be exacerbated through Asian American women’s cultural and social locations • intervention strategies need to be culturally informed and specifically designed to address the barriers through the cultural lenses of the community/target group • some of the barriers may contribute to each other. For example, disordered eating cognition may contribute to stigma because it views not being able to control one’s weight/eating habits as a personal weakness, which is self-stigmatizing.

- women in the study stated that they did not seek help because they "did not think the symptoms were severe enough." If Asian American women do not recognize that their psychological distress may be related to their disordered eating or body dissatisfaction and/or are not aware of available treatment options for eating or body image-related issues, a lack of help-seeking behaviors is the unavoidable outcome.

- the "thin ideal" in Asia can be more restrictive than in the U.S. Asian American women who are immersed in or in frequent contact with Asian media and cultural practices may not recognize their symptoms or do not view them as severe because they experience or endorse Asian standards of beauty

- self-stigma may be particularly prominent for Asian Americans because mental health conditions are often connected to the "fear of losing face" or interpreted as a sign of weakness for both the individual and their family members

- To avoid a loss of face, those with mental health conditions and their family members may be reluctant to recognize the existence of mental illness, resulting in low utilization of services or discouragement of help-seeking behaviors

- Traditional Asian cultural values on withstanding hardship and tolerating distress may discourage one’s help-seeking behaviors and limit and reduce tolerance and recognition of personal distress in others

- Traditional Asian values emphasize the importance of self-control. If these women consider themselves personally responsible for weight concerns or not being able to achieve the ideal weight and body shape, the cultural emphasis on self-control and the implications on self-worth

			may exacerbate their disordered eating cognitions • The myth that Asian American women are well adjusted and naturally petite may also lead mental health professionals to either skip EDs assessment altogether or misdiagnose their symptoms
Ali et al. (2020)	**Barriers to help seeking: Stigma**		Most common items identified to be barriers: • I am embarrassed about my problems • I don’t want anyone to know about my problems • I am afraid of being labelled (e.g. crazy, mentally ill, having an ED) • Other people believe that EDs are not real illnesses • I am afraid of being discriminated against • I think seeking treatment is a weakness • I believe that EDs are not real illnesses
	Denial and low motivation		• Other frequently endorsed barrier overall was "I think I should solve my own problems" and denial and the

		failure to perceive the severity of the illness • denial and failure to perceive the severity of the illness were frequently endorsed barriers to help-seeking. • consistent with the literature on low motivation to change among many individuals with eating disorders, for whom the perceived positive functions of the symptoms outweigh recognition of their negative consequences
	Specific stigma around certain EDs	• Participants, particularly those from the AN and BN groups, frequently endorsed being embarrassed about their problems, an indicator of internalized stigma and "Other people believe that eating disorders are not real illnesses" • participants from the BED and OED groups were more likely to endorse the barrier "If I need help, I will turn to my friends" • Despite the elevated psychosocial and functional

			impairment associated with BED there is a perception in the community that BED symptoms are less impairing, less severe, and easier to treat which may have contributed to a preference for more informal, low intensity resources among the BED group.
Goel et al. (2023)	**Distrust of Western medications for mental health**		• Older South Asians (SAs) distrust Western medications for a variety of reasons. As alternatives, many parents prescribe homemade medicine or suggest pseudoscience cures for their children's mental health symptoms. participants were wary of following their parents' unsubstantiated health tips, however they were more accepting of their parents' use of homeopathic remedies.
	Religion	"… it's like, "oh… Just pray it away." It doesn't do anything; there's doctors, professionals, there to help you, but if you go there, you are crazy. "Oh, you're saying you have	• parents and older relatives viewed religion as both an explanation and intervention for mental health concerns. when they attempted to discuss mental health concerns

Stigma around mental health	a mental illness, are you not content with God or something like that?" "… they like understand and recognize there's a problem, but they know that the *moment* it goes from their inner little circle to anywhere else, it'll spread like a wildfire and they feel like that's gonna be shameful. … and then socially like, "oh like what are people going to say? "… I know a lot of women who struggle with eating disorders that might be like [from] a minority group often will like tell their friends, tell an American teacher, but they won't tell their parents. if you think there's stigma in your community, then you are less likely to go and approach it directly."	with their parents, they were told their problems betray a mistrust in God, or that they might be possessed • Mental health concerns are rarely discussed in the SA community. In the infrequent cases when they *are* acknowledged, they are viewed as temporary, and people with these conditions may be labeled as "crazy" or "contagious." • participants reported that older SAs, including their parents, silenced conversations about mental health - due to parents' fear that if community members discovered their children had any mental health issue, their families would be shamed, judged, and socially ostracized. This fear of *social stigma* appears to maintain a culture of silence around mental health, and thus, poses a strong barrier to treatment-seeking. • many participants reported rarely feeling comfortable

		confiding in their parents about their struggles, and thus, felt generally unsupported and alone. • Older generations generally deny the existence of mental health concerns, including EDs, so these issues are not acknowledged until symptoms become severe enough to be physically obvious and/or warrant medical attention. • mental health stigma was identified as a potent treatment-seeking barrier - a particular *social stigma* emerged that is tied to a fear of judgment by fellow community members. Other research has described a similar type of stigma, called courtesy stigma, which socially devalues family members of an individual with a mental illness
Invalidation through comparison of difficulties	… I remember one time in high school I was so stressed … and I was like, "I'm stressed" … my dad overheard me saying that and he got so mad he said, "you have no right to say that you're stressed, you don't know what stress *is* and you	• Many participants reported suspecting that their parents silently suffered from mental health issues. - they also thought their parents perceived these conditions as

		don’t know what *anxiety* is. You don’t know what this or that is like—you don’t have a *right* to *feel* that… that shouldn’t even be in your vocabulary." So, you know it’s a thing when even the *symptoms* are looked down upon and they’re like, "no you’re supposed to be happy because you have everything you could possibly ever want.”	part of life, rather than treatable illnesses. Specifically, participants noted their parents viewed these concerns as natural outcomes of the immigration process • many participants described experiences of having their own concerns invalidated.
	Negative experiences of help-seeking	“Every time I brought something up, my PCP was very quick to be like, "it’s culture." But you don’t know anything about the culture though … Don’t assume that we’re not going through it just ‘cuz you don’t know anything about it "kind-of-thing."	• participants described negative experiences where medical providers were dismissive, culturally insensitive, and/or fat-shaming, and that many attributed their symptoms to their cultural background.
	Consequences of a family member having an ED	“… I feel like if a White woman—if people find out that she has an eating disorder—then she goes to the hospital or something; they do what they should do, they extend their care and they help that person. And I feel like … a lot of South Asians may think about their reputation more than they do about caring about that person. Like, "oh, she’s in the hospital because she has an eating disorder. Now I’m seen as a bad mom … " So, it’s like, they care, but it’s also that aspect of their reputation that they care about too, which I feel like with White people, that’s not really how it is.”	• Participants noted that older SAs do not fully understand or acknowledge the existence of EDs. Parents may avoid seeking mental health care for their child because they fear being judged as a “bad parent.” • participants also noted that if a girl develops an ED while still living with her family-of-origin, her parents may avoid seeking treatment for the same reason

		• interpersonal relationships are especially valued in collectivistic cultural groups. Thus, the actions of any individual might be perceived as a reflection on an entire social network. • Parents’ fears of judgment from other community members appear to be a significant barrier to ED disclosure and treatment-seeking for SA women. Courtesy stigma might explain why parents often blame themselves for their child’s health condition
Lack of understanding around EDs	“I don’t think I’ve ever heard a Brown household talk about eating disorders … I think with eating—like in general, in Brown households—I’ve seen, "oh too thin or too fat" like that and *eating*—and like, *weight* is talked about. But eating *disorders?* They brush it off. It’s not even—like there might be a reason behind how you’re eating, it’s just like, "oh, it’s not enough or it’s too much."	• Participants reported that their parents have difficulty discussing EDs, because they do not have the knowledge or language relevant to these phenomena. Parents do not consider EDs to be real problems, as they do not conceptualize *eating* as a behavior that can be disordered.

			• if a woman is viewed as “too skinny or too fat,” the solution is to “just eat more, or just eat less” • Thus, ED behaviors are sometimes viewed as socially acceptable.
	Lack of representation	“I feel like underrepresentation is also a big thing because if you don’t see people that are like you I guess, feeling depressed, that had anxiety like you, [then you think] "why am I like that, I shouldn’t be like that?" So, you don’t feel the need to get diagnosed or tell your parents because you just feel like it shouldn’t be like that or I shouldn’t be like that. Because you don’t see people that are like you like *that*.”	• lack of SA representation in ED health campaigns and research- many SA American women feel silenced, marginalized, and are more likely to minimize their ED experiences • they rarely encountered SA providers trained in detecting and treating mental health concerns (including EDs), which limited their comfort in seeking care. • regardless of their specialty, many health providers are complicit in perpetuating weight stigma, which can be especially harmful for women of color in larger bodies. Thus, reducing weight stigma within the health care system may

promote ED treatment-seeking for SA women.

Table 5

Table of third order constructs derived through reciprocal translation

Theme/Categories	Second order constructs	Third order constructs
Familial stigma	Parental concerns they will be viewed negatively by their community if their child seeks help Cultural beliefs leading to dismissal of mental health issues and mistrust in western treatment Family assuming eating disorders were a ‘phase’, not requiring support	Stigma within cultures *-Lack of understanding of mental health issues* *- Parental fear of stigma from community leads to silencing of issues* Professional treatment not seen as viable option *-EDs trivialised, not warranting support* *-Western treatment not seen as useful/trustworthy*
Stigma faced from services when help-seeking	Lack of treatment guidelines for men with EDs Perceived judgement, lack of understanding and cultural insensitivity from healthcare professionals Weight-based threshold for ED treatment, dismissal of psychological symptoms	Previous negative experiences from healthcare professionals *-Dismissal of psychological symptoms* *-Unhelpful language* *-Not inclusive of culture/gender* Services are only accessible for those that are women with a low weight *-Exacerbates restrictive behaviours*

	Intentional intensification of ED behaviours to reach a lower weight and ‘prove’ illness and receive treatment	
Stigma faced from society	EDs are volitional and to gain attention EDs do not require professional treatment People with EDs are seen as incompetent EDs are a ‘girl’s condition’, men are weak for seeking help for an ED EDs help maintain social desirability by being thin/muscular Different stigmatisation for each ED Self-help used instead of professional help	Individuals with EDs are ‘bad’ people *-Attention seekers, weak, incompetent* EDs are not a serious condition *-The individual should be able to manage their own issues* Feminine branding of EDs causing further isolation within men Attempted avoidance of body-related stigma continues restrictive behaviours *-Desire to maintain Westernised ideal body type* Alternative forms of help attempted before professional treatment *-Engaging in self-help to avoid stigma*
Self-stigma	Feelings of shame, influenced by culture and gender roles Feeling ‘not sick enough’ - not perceiving severity of symptoms, believing they had to be a low weight to have an ED	Believing you are a ‘bad’ person due to your ED *-Different from others* *-Shameful, weak* *-Not worthy of support*

	Internalising stereotypes and stigmatised views of EDs Feelings of alienation and isolation from others Different self-stigmas in relation to different EDs	My symptoms are not serious enough to be an ED -*EDs are only in those with a low weight* -*Restrictive behaviours normalised somewhat by diet culture*
Lack of representation within ED discourse	Lack of South Asian representation Lack of male representation	ED presentation is doubted/trivialised due to not fitting within the ED discourse -*Continues stereotypes around the physical appearance of an ED*

Appendices

Appendix 1: List of categories

Appendix 2: Synthesis of second order constructs

Appendix 3: List of proposed recommendations

Appendix 1

List of categories including related themes from each paper, formatted following guidance from Sattar et al. (2021)

EDs are a choice

- EDs are not a mental illness (Dimitropoulos et al., 2016)
- It is a phase that will pass (Eiring et al., 2021)
- EDs are volitional (Dimitropoulos et al., 2016; Wales et al., 2017; Potterton et al., 2020; Hepworth & Paxton, 2007; Griffiths et al., 2015; Goel et al., 2023)
- EDs are a way to gain attention from others (Potterton et al., 2020; Griffiths et al., 2015; Tsong et al., 2013

EDs are not seen as a serious illness

- EDs and its symptoms are seen as trivial (Dimitropoulos et al., 2016; Hepworth & Paxton, 2007; Byrom et al., 2022; Griffiths et al., 2015; Goel et al., 2023; Tsong et al., 2023)
- EDs are seen as quick and easy to treat (Dimitropoulos et al., 2016; Ali et al., 2020)
- EDs do not warrant professional treatment (Wales et al., 2017; Hepwroth & Paxton, 2007; Tsong et al., 2023)
- Dismissal of symptoms by others (Dimitropoulos et al., 2016; Evans et al., 2011; Tsong et al., 2023; Goel et al., 2023)
- Problem not being addressed by others (Eiring et al., 2021; Potterton et al., 2020)

Previous negative experiences of help-seeking

- Perceived stigma and judgment from professionals (Evans et al., 2011; Byrom et al., 2022; Goel et al., 2023

- Lack of knowledge/awareness from professionals (Malova & Dunleavy, 2022; Byrom et al., 2022; Wales et al., 2017)
- Not being accepted for treatment due to strict criteria and weight-based threshold (Eirling et al., 2021; Byrom et al., 2022)
- Feeling frustration and disappointment from professionals (Evans et al., 2011)
- Professionals making incorrect assumptions about the causes of the ED (Eiring et al., 2021)
- Lack of congruence between the internal experience of the individual and the response from the external environment (Eiring et al., 2021)

Feeling "not sick enough" to have an ED/receive treatment

- Not fitting the physical stereotype of an ED (i.e. low weight) (Evans et al., 2011; Eiring et al., 2021; Potterton et al., 2020; Hepworth & Paxton, 2007; Byrom et al., 2022; Tsong et al., 2023
- Professionals focusing on physical symptoms, missing psychological symptoms (ED cognitions) (Eiring et al., 2021; Potterton et al., 2020)
- Pressure to 'prove' how sick you are – continuing/increasing ED behaviours (Eiring et al., 2021; Byrom et al., 2022)
- Fear of facing weight-based stigma from professionals if not appearing a low weight (Goel et al., 2023)

Consequences of help-seeking

- Feelings of isolation (Dimitropoulos et al., 2016; Wales et al., 2017; Concoran et al., 2021;
- Feelings of shame (Evans et al., 2011; Maier et al., 2014; Griffiths et al., 2015; Tsong et al., 2023)
- Being misunderstood (Dimitropoulos et al., 2016)
- Feelings of hopelessness (Eiring et al., 2021)

- Low motivation due to perceived positive functions of ED (Ali et al., 2020) and symptom egosyntonicity (Potterton et al., 2020)
- Specific stigma faced around receiving psychological support (Maier et al., 2014)

Cultural factors

- Specific stigma around mental health in some Asian communities (Wales et al., 2017; Tsong et al., 2023; Goel et al., 2023)
- Familial distrust in healthcare professionals (Tsong et al., 2023; Goel et al., 2023)
- Familial silencing of discussion of mental health issues (Wales et al., 2017; Goel et al., 2023)
- Mental health issues being attributed to being disconnected from God (Goel et al., 2023)
- Fear of parents being stigmatised by the community for their child seeking help for mental health issues (Goel et al., 2023)
- Familial lack of understanding about EDs (Wales et al., 2017; Goel et al., 2023)
- Stereotype of EDs being ‘thin white women’ (Tsong et al., 2023; Goel et al., 2023)
- Facing stigma and cultural stereotyping from professionals (Goel et al., 2023; Tsong et al., 2023)
- Increased feelings of isolation due to stigma faced in everyday life plus having a mental health issue (Tsong et al., 2023)
- Seeking help without parental knowledge to avoid negative consequences (Wales et al., 2017)
- EDs are a personal weakness and should be dealt with by the individual (Tsong et al., 2023)
- Cultural emphasis on the ‘thin ideal’ (Tsong et al., 2023)
- Being labelled as ‘crazy’ if you have a mental health condition (Goel et al., 2023)
- People with EDs are ‘hopeless’ and ‘weak’ (Tsong et al., 2023)
- Fear of dismissing parent’s beliefs if seeking professional help (Goel et al., 2023)
- Familial invalidation of issues due to comparisons to their own hardships (Goel et al., 2023)

- Self-control is praised and emphasised, fuelling ED behaviours (Tsong et al., 2023)
- Family not believing individual has an ED due to beliefs (Goel et al., 2023)
- Family denial of symptoms leading to increase in ED cognitions and less motivation to help-seek (Goel et al., 2023)
- Feeling misunderstood by healthcare professionals due to lack of cultural representation (Goel et al., 2023)

Gender Differences

- Symptoms in men being missed guidelines being focused on women (Corcoran et al., 2021)
- EDs are a ‘girl’s disease’ (Malova & Dunleavy, 2022; Corcoran et al., 2021)
- Lack of representation of men with EDs (Corcoran et al., 2021; Malova & Dunleavey, 2022)
- Majority girls and young women in ED treatment services (Corcoran et al., 2021)
- Men comparing their physical appearance to women when in treatment (Corcoran, 2021)
- Feelings of isolation within men with EDs (Corcoran et al., 2021)
- Gender roles of men being seen as ‘weak’ and ‘less of a man’ for having an ED and seeking help (Corcoran et al.,, 2021; Malova & Dunleavey, 2022; Griffiths et al., 2015)
- Lack of awareness or knowledge that their symptoms were an ED (Malova & Dunleavy, 2022)
- Men avoiding social stigma from being overweight or not muscular (Malova & Dunleavy, 2022)
- Men proving to themselves they could remain in control, away from the beliefs of overweight people being ‘out of control’ (Malova & Dunleavy, 2022)

Stigma - experienced, perceived, and internalised

- Individuals having to repeat their ED behaviours/experiences to various professionals/services can increase internalisation of stigma (Byrom et al., 2022)

- Feelings that their EDs make them incompetent (Maier et al., 2014; Griffiths et al., 2015)
- Internalising stigmatised beliefs from others around EDs can increase self-stigma (Maier et al., 2014)
- ‘I have a personal responsibility for my condition’, ‘I think I should solve my own problems’ (Griffiths et al., 2015; Tsong et al., 2023; Alit et al., 2020)
- An ED is self-inflicted (Griffiths et al., 2015)
- Both experienced, perceived and self-stigma can have similar detrimental effects e.g. increase in symptoms, duration and lower self-esteem (Maier et al., 2014
- Levels of self-stigma within individuals can be higher than stigma from others (Griffiths et al., 2015; Maier et al., 2014)
- Avoidance of help-seeking to avoid shame/embarrassment (Potterton et al., 2020; Hepworth & Paxton, 2007; Maier et al., 2014)
- Particular self-stigma within BN (Hepworth & Paxton, 2007)
- Family not addressing problem increasing self-stigma (Eiring et al., 2021)
- Self-stigma significant barrier to help-seeking (Maier et al., 2014)
- Experienced/perceived stigma as a barrier to help-seeking (Evans et al., 2011; Wales et al., 2017; Eiring et al., 2021; Potterton et al., 2020; Malova & Dunleavy, 2022; Hepworth & Paxton, 2007; Byrom et al., 2022; Maier et al., 2014; Griffiths et al., 2015; Tsong et al., 2023; Ali et al., 2020; Goel et al., 2023)

Differing attitudes/stigma towards different EDs

- AN seen as being a ‘bad influence’ (Griffiths et al., 2015)
- Individual with BN is seen as being ‘out of control’ and not like a ‘typical’ ED (Hepworth & Paxton, 2007; Griffiths et al., 2015)
- BED is seen as being ‘easier to treat’ (Ali et al., 2020)
- Fear of facing weight-based stigma from professionals

Differing forms of help-seeking to avoid potential stigma

- Using self-help resources (Potterton et al., 2020)
- Seeking help independently of parents (Potterton et al., 2020)
- Indirect disclosure of difficulties to healthcare professionals, by focusing on physical symptoms (Potterton et al., 2020)
- Face to face help-seeking related to higher level of perceived stigma (Potterton et al., 2020)
- Resources focused on reducing stigma can increase help-seeking (Potterton et al., 2020)
- Form of help-seeking (face to face, direct, written, indirect, with/without parents) different depending on perceived level of stigma, embarrassment, shame (Potterton et al., 2020)

Appendix 2

Synthesis of second order constructs, formatted based on the guidance of Sattar et al. (2021)

Familial stigma as a barrier to seeking help

Synthesis of papers 1, 4, 11 & 13

Findings of paper 1 describe parental concerns around stigma faced from their community; specifically that they will be perceived negatively if their child seeks help for a mental health condition. This is described to be influenced by cultural beliefs and leads to dismissal and silencing of issues. Individuals felt they were not taken seriously and family would not take action until their physical symptoms became noticeable. Similarly, paper 13 describes families dismissing or trivialising eating disorder behaviours due to fear of stigma towards the family, leading to feelings of isolation and invalidation.

Rather than cultural factors, findings from paper 11 showed families not addressing their child's eating disorder due to assuming it was a 'phase that would pass' and not a serious issue. Individuals felt unsupported and unseen due to these familial responses.

In paper 4, families themselves holding stigmatised views around mental health treatment was also described as a barrier, believing it was a 'con' in order to make money. Similarly, paper 13 also showed some families having a distrust in 'Western' treatments, instead providing their children with alternative practices.

Stigma faced from services when help-seeking

Synthesis of papers 2, 3, 4, 5, 11, 13 & 14

Findings in paper 2 and 3 highlights a lack of treatment guidelines for men with EDs, due to research being primarily based on women, which exacerbates feelings of isolation and shame, experiencing a so called ‘girl’s condition’.

Paper 4 described professionals using unhelpful and triggering language around weight, diet and exercise, when individuals had sought help for their eating disorder. This left individuals reluctant to seek help again. Paper 14 also described individuals’ experiences of judgement and a lack of empathy from professionals. Paper 13 showed individuals feeling professionals were culturally insensitive, attributing their symptoms to their cultural background, and even engaging in ‘fat shaming’.

Similarly, paper 5 also described professionals appearing to have a lack of understanding around eating disorders, dismissing individuals due to them not being a low weight. Services’ focus on physical symptoms was also described in paper 11, with a weight-based threshold for treatment meaning many individuals cannot access support. This dismissal of the psychological aspects of an eating disorder led to feelings of helplessness when seeking help, and in some cases, intentional intensification of restrictive eating behaviour in order to ‘prove’ their illness. Findings from paper 14 also showed a strict criteria and focus on BMI to be a significant barrier to help-seeking, particularly within eating disorders such as Bulimia Nervosa, where individuals may not present as underweight.

Stigma faced from society

Synthesis of papers 1, 2, 3, 4, 6, 7, 8, 9, 10, 12

Findings from several papers show that individuals with eating disorders experience stigma within society, increasing feelings of shame and isolation which can hinder help-seeking. Paper 1 shows that common stigmatised views experienced were that eating disorders are ‘easily fixed’ and able to be dealt with by the individual themselves rather than seeking professional treatment.

Similarly, findings from paper 8 showed individuals' beliefs that the public did not view eating disorders as a serious mental illness but rather as a choice, minimising the psychological elements associated with it. This can promote individuals to continue with their eating disorder behaviours rather than seeking help. Papers 4, 7 and 8 also showed other stigmatising views faced from society were that eating disorders were a way to 'gain attention'. In particular, paper 8 highlighted beliefs that eating disorders are seen as superficial and individuals experiencing them are 'self-centred'. Additionally, paper 9 showed the beliefs that eating disorders are 'self-inflicted', and therefore undeserving of empathy, which was a significant reason for delaying receiving treatment.

Paper 6 showed how individuals felt disadvantaged in everyday life due to the stigma faced from their eating disorder, such as being treated differently, being less employable and being seen as incompetent. Feelings of incompetence were also echoed in paper 7.

Individuals being aware of the dominant discourse around eating disorders (i.e. people with eating disorders are teenage girls of a low weight) also hindered help-seeking if they felt they did not fit within this criteria. Paper 10 showed an increase in shame at asking for help, and believing they would be rejected due to the above. This was also seen within men with eating disorders within papers 2 and 3, due to the 'feminine branding' of eating disorders, leaving individuals feeling isolated and doubting their symptoms. Gender roles were also highlighted in papers 2 and 7, with men feeling 'weak' and 'less of a man' for seeking help for their eating disorder, due to the societal roles prescribed to them of being 'strong'. This can prevent men from asking for support.

Avoiding stigma from society has also been found to be a factor in delaying help-seeking, such as maintaining the 'thin ideal' through an eating disorder found in paper 4, and wanting to maintain a muscular physique found in paper 3. Individuals reported that avoiding the stigma from society experienced towards overweight individuals or non-muscular men led them to question whether they had an eating disorder and decreased their motivation to seek support. Interestingly, findings from paper 10 showed that societal stigma faced towards binge eating disorder e.g. having a 'lack of control', actually increased the likelihood of seeking help, due to these behaviours been seen as 'less socially desirable'.

Further specific stigma towards different eating disorders was also found in paper 7 and 9, with the label of 'little self-control' being perceived by individuals with bulimia nervosa. Those with anorexia nervosa in paper 7 also believed they were seen as a 'bad influence on others', which led to lower self-esteem, delaying treatment and longer duration of illness. Paper 12 also showed that binge eating disorder was seen as being 'easier to treat' compared to others, resulting in feelings of shame when asking for support, as they felt they should manage it themselves.

Paper 10 found that due to fear of stigma faced from society, individuals often engage in self-help rather than seeking professional support, preferring to try and 'handle it themselves'. Another alternative approach used was to visit their GP for other concerns, in the hope their eating difficulties would be brought up without them having to disclose it, to reduce potential criticism or rejection.

Self-stigma

Synthesis of papers 1, 2, 3, 4, 5, 6, 7, 9, 10, 11, 12, 14

Self-stigma was also a salient barrier to help-seeking, potentially a result of internalised stigma faced from family, services, and society. Feelings of shame due to this self-stigma was a common finding within the papers. Paper 1 described feelings of shame influenced by cultural factors. Individuals felt undeserving of support, comparing their experiences to their parents' experiences through the immigration progress, which they felt were 'worse' than their issues. Paper 4 also suggested that cultural factors can impact an individual's belief around eating disorders. Individuals believed that eating disorders were a 'personal weakness', with mental health issues being hidden over a 'fear of losing face'. Individuals did not want to seek help as this would be admitting this weakness, and felt as though they should be able to control it themselves. They also felt it would reflect poorly on them for ‘having issues’ and seeking treatment.

Similarly, paper 5 found that individuals with eating disorders also described themselves as a ‘weak person’. Interestingly, paper 12 showed individuals believing that seeking treatment is a form a weakness, rather than the eating disorder itself, believing they should be able to ‘solve their own problems’. Papers 2 and 3 also showed feelings of weakness and shame, related to internalised gender roles. Men felt shameful for seeking help for a mental health issue, compounded by experiencing what they believed to be a ‘girl’s disease’. Paper 3 described men feeling as though they should ‘man up’ and that they were ‘weak’. Paper 7 also found individuals believing they should ‘pull themselves together’ and that they are responsible for their illness.

The belief of ‘not being sick enough’ was also found within several of the papers. Paper 4 described not seeking help due to not perceiving their symptoms to be severe enough, seeing them as ‘normal’. Paper 14 also showed beliefs that their illness was never bad enough to receive support, and that they would be ‘wasting people’s time’ by asking for help. A focus on physical appearance also influenced the belief of not being ‘sick enough’, with paper 5 showing that individuals believed their weight was not low enough to warrant diagnosis of an eating disorder or receive treatment. Similarly, paper 5, 10 and 11 also found that they doubted they had an eating disorder due to believing that you must be ‘extremely thin’, ‘super skinny’ or ‘emaciated’.

Individuals appearing to internalise stereotypes and stigmatising views of people with eating disorders was also a common factor in hindering help-seeking. Paper 4 described individuals seeing an eating disorder as simply ‘a concern with their body’ rather than a mental illness, heightening feelings of shame. They believed that eating disorders were quick and easy to treat, requiring minimal professional support. Paper 12 also showed that individuals believed that eating disorders are not real illnesses, therefore they are undeserving of support. Individuals within paper 10 believed that their eating disorder was in fact an illness, however they thought it to be ‘immature’ and ‘childish’, experienced by teenagers. Further stigmatised views were found within paper 6, with individuals feeling they were an ‘attention seeker’ and ‘exhausting to be with’ due to their eating disorder.

Feelings of alienation and isolation often resulted from this self-stigma, further reducing the likelihood of seeking help. Paper 4 showed that individuals believed that there was ‘something wrong’ with them personally, while those in paper 6 reported feeling ‘different’ from their peers. Paper 7 concluded that stigmatising attitudes and beliefs from others are often also held by the individuals themselves, and self-stigma may heighten perceptions to stigma from others.

Specific feelings of shame and self-criticism appeared to relate to different eating disorders. For example, those in paper 9 described their bulimic behaviours as ‘atrocious’ and felt they were ‘out of control’. Individuals in paper 12 highlighted their embarrassment of their symptoms, particularly within Anorexia and Bulimia. Contrastingly, individuals with binge eating disorder described being able to turn to their friends if they needed help, suggesting an internalisation of the stigma of binge eating disorder being ‘easier to treat’.

Not feeling representated

Synthesis of paper 1, 2, 3, 13

A lack of representation within the eating disorder discourse and treatment guidelines were also found within the papers. Papers 1 and 3 describe rarely seeing a person of South Asian descent experiencing an eating disorder or any mental health condition in the media, therefore increasing the stigma around it in the community. They also describe there not being many available South Asian healthcare professionals, increasing feelings of isolation. Individuals highlight the need for discussion around eating disorders to be improved within South Asian communities, such as using posters in the community or more representation in the media.

However, women in the above papers described being able to read information online about eating disorders, even if it was not completely representative. Whereas men in paper 2 described there being very little awareness or information around men with eating disorders, reflected within treatment guidelines being based on women. Men described that more awareness and discourse around men experiencing eating disorders would help to give those the courage to ask for support, and help to dispel the stigma of it being something that only affects women.

The lack of representation of different genders and cultures increases the stigma of eating disorders only affecting white, teenage girls, therefore reducing motivation to seek help.

Appendix 3

List of proposed recommendations based on the review's findings

Recommendations: to be implemented within primary care services, healthcare professionals, and eating disorder services

- Referral for eating disorder treatment should never solely be based on BMI or weight, in line with national guidance (NHS, 2019; NICE, 2020). The psychological factors which can maintain eating disorders (e.g. eating disorder cognitions) should be considered at first point of contact. Eating disorder referral guidance should be easily accessible to healthcare professionals and patients, for example in the form of psychoeducational leaflets.
- Additional training around eating disorders for healthcare professionals should similarly have a focus on psychological factors such as eating disorder cognitions and thoughts which can encourage restrictive and compensatory behaviour (Pugh & Bell, 2020; Pugh & Waller, 2017).
- Eating disorder assessments should also be inclusive of psychological factors. Examples of validated eating disorder assessments which measure eating disorder cognitions are the Eating Beliefs Questionnaire (Burton & Abbott, 2018) and the Eating Disorder Inventory Body Dissatisfaction subscale (Garner, 2004). Assessment of eating disorder cognitions should take place during the first point of contact, due to their known influence on eating disorder behaviours (Aya et al., 2019) and ability to increase severity and duration of an eating disorder (Herpertz-Dahlmann, 2015).
- Support for eating disorders should also address psychological elements. Examples of effective psychological models of eating disorders are the transdiagnostic cognitive model (Fairburn et al., 2003), or schema-focused model (Waller et al., 2007). These models

emphasise the importance of eating disorder cognitions and their role in the development and maintenance of eating disorders (Hatoum et al., 2023).

- Easily accessible guidance around the societal stigma often faced by people with eating disorders should be implemented, particularly within primary care settings such as GP practices. Creating a safe space for people with eating disorders to share their problems can ensure they receive the appropriate support. This could be through the facilitation of trust and containment (Podolan & Gelo, 2023), showing understanding and recognition of a person's problems (Fonagy & Allison, 2014) and being aware of one's own non-verbal signals such as posture and facial expressions (Mair, 2021).
- Ensure there is culture/gender-informed communication at the point of access to services. For example, avoiding and challenging gender/cultural stereotypes and assumptions, and acknowledging specific barriers and stigma that may be faced by people with eating disorders of different genders and cultures. Potential differences in eating disorder symptoms between genders and cultures should also be considered, and the development/inclusion of more inclusive assessment and treatment guidelines should be prioritized.
- Increasing overall awareness and education around eating disorders, particularly within groups that are not often included within typical eating disorder discourse, remains important. This could be implemented through the above training and guidance within healthcare professionals and services, as well as within the community (e.g. posters, social media).

Section two: Research Project

Exploring inner-speech and voice-hearing with girls and young women who self-report an eating disorder voice

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Abstract

Purpose

Eating disorders remain a complex and serious condition globally. Eating disorders pose a significant threat to physical, mental, and emotional health, and even life though physical health complications and suicide. Therefore, it is essential that practitioners have the research and resources to inform timely and effective interventions. However, recovery and remission rates for eating disorders remain poor, even following professional mental health support. A particularly under researched phenomenon that can commonly occur alongside an eating disorder and maintain the power of the disorder is voice-hearing, which can worsen severity and duration of an eating disorder. Often, this phenomenon is described as or termed the 'eating disorder voice' (EDV), which can contribute to the maintenance and promotion of eating disorder behaviours. The EDV appears particularly prevalent within young women, who are already disproportionately affected, with up to 75% of eating disorders occurring within adolescent women. It is important to understand the role of the EDV in the maintenance of an eating disorder to promote tailored and targeted responses to promote recovery, particularly with young women. Therefore, the current study explores voice-hearing within the context of eating disorders with young women to inform treatment options.

Method

An experienced-based co-design (EBCD) informed method was utilised to elicit stories from ten young women who had experienced the EDV within the context of an eating disorder. The study comprised of three stages: obtaining multi-modal data from participants that reflected their individual experiences, followed by two online group discussions, in which participants viewed a stimulus presentation and offered their feedback based on their own experience, to form a cumulative emancipatory narrative of the EDV. Narrative analysis was used to interpret and synthesise the findings to support the storytelling ethos of the study.

Results

The common concepts and themes following analyses of the narratives are reported through the following sections: (1) The EDV as collections of others’ narratives, (2) Form and dialogue of the EDV, (3) The use of imagery to describe the EDV, (4) Changing relationship with the EDV and its role in recovery. The EDV was found to be a fundamental factor within participants’ eating disorders, contributing to its maintenance, causing psychological distress, and posing a barrier to recovery. However, it could often be dismissed by mental health professionals.

Conclusion

Increasing awareness and understanding around the presence of an EDV alongside eating disorders could promote services to address the EDV within talking therapies for eating disorders. A more comprehensive intervention could increase its effectiveness and improve recovery trajectories.

Introduction

Girls and young women have been shown to be disproportionately affected by eating disorders, with up to 75% of eating disorders occurring in women (Beat, 2021) within adolescence or emerging adulthood (Ward et al., 2019). Therefore, the experiences of girls and young women when accessing treatment for an eating disorder remains particularly significant to explore. Notably, young women have reported shortfalls within eating disorder interventions, which are focused on weight (Smith et al., 2014) and feature minimal psychological therapy (Rance et al., 2017). When attempting to access eating disorder support, women faced insensitivity and lack of understanding from mental health professionals (Mitrofan et al., 2019; Tsong et al., 2023), and felt dismissed and invalidated due to not presenting as a low weight (Byrom et al., 2022; Eiring et al., 2021), despite guidelines recommending that eating disorder interventions should provide support for psychological issues (National Institute for Health and Care Excellence, [NICE], 2020). Women have expressed the need for eating disorder treatment which considers wider psychological issues as opposed to recovery of physical symptoms, and implementation of individualised care (Mitrofan et al., 2019). These findings are reflected within a meta-analysis, which demonstrated that specialised eating disorder interventions such as CBT and family therapy do not appear to improve overevaluation of weight and shape (Murray et al., 2019), and any positive physical changes were not maintained. These findings have been consistent across a range of different eating disorders (Eiring et al., 2021; Monteleone et al., 2022). Based on the evidence base, current eating disorder interventions appear ineffective, particularly at addressing the psychological symptoms of eating disorders, despite it being a significant factor (Tomba et al., 2019). Notably, more than 50% of people with eating disorders do not reach full recovery following treatment (Monteleone et al., 2022; Watson & Bulik, 2013). There appears to be key elements missing within eating disorder interventions which need to be explored to improve recovery trajectories.

Voice-hearing is not necessarily affiliated to a mental health challenge (McCarthy-Jones, 2012; Sommer et al., 2010). However, eating disorders are included in the range of diagnoses where voice-hearing can be present. Eating disorders significantly affect quality of life and social functioning (Van Hoeken & Hoek, 2020), and pose a substantial risk to life through physical health complications and suicide (Peebles & Sieke, 2019; van Eeden et al., 2021). Anorexia nervosa and bulimia nervosa have a particularly high mortality rate (National Eating Disorders Collaboration, 2022), which is two times higher for bulimia, and over five times higher for anorexia (van Hoeken & Hoek, 2020) compared to the average population.

If voice-hearing is experienced alongside an eating disorder, it increases self-criticism (Noordenbos et al., 2014; Tierney & Fox, 2011), and maintains eating disorder behaviours such as promoting a negative body image and damaging self-worth (Aya et al., 2019; Pugh & Waller, 2017). This can increase the severity and duration of the eating disorder, worsening prognoses (Herpertz-Dahlmann, 2015; Miotto et al., 2010). Voice-hearing within eating disorders remains to be under researched, particularly within young people (Mensi et al., 2020). This is especially concerning, as both eating disorders (Micali et al., 2013; Potterton et al., 2020) and voice-hearing (Maijer et al., 2018) are more common within young people. Additionally, young people’s needs are often not met by eating disorder interventions, reflected by increased hospital admissions and overall poorer clinical outcomes (Care Quality Commission, 2018; Mitrofan et al., 2019). Clearly, it is important to further explore young people’s experiences of eating disorders including voice-hearing, to inform services and develop more effective interventions.

As eating disorder interventions often discount psychological elements, the addition of voice-hearing experiences alongside an eating disorder increases the likelihood of treatment outcomes being poor, particularly as it remains so under researched. Voice-hearing is also likely to be under-reported within people with eating disorders, as it poses an added layer of stigma within an already stigmatised condition (Eiring et al., 2021; McCarthy-Jones et al., 2015). Lack of research around voice-hearing within eating disorders also means this comorbidity is unlikely to be suitably assessed upon referral. This is reflected by current eating disorder guidance (NICE, 2020) not highlighting the presence of potential voice-hearing experiences, despite evidence demonstrating its occurrence (Solmi, 2018; 2019) and its role in the maintenance of an eating disorder (Herpertz-Dahlmann, 2015; Pugh & Waller, 2017). Increasing awareness and understanding around voice-hearing alongside eating disorders can inform interventions within services and improve recovery trajectories, addressing an important clinical priority for research.

The eating disorder voice

A common example of how voice-hearing is experienced within eating disorders is the presence of an ‘eating disorder voice’ (EDV), most prevalent in girls and young women (Noordenbos & van Geest, 2017). The EDV can contribute to the maintenance of an eating disorder through facilitation of a negative body image (Pugh & Bell, 2020) by commenting critically on eating habits and weight, promoting restriction or compensation (Pugh & Waller, 2017). This form of running commentary poses similarities to other voice-hearing experiences and inner speech (Leudar & Thomas, 2000).

The concept of the EDV has been controversial. For example, there remains difficulties in differentiating the EDV to other cognitions, such as negative automatic thoughts or amplified beliefs surrounding weight and body shape (Pugh, 2016). However, initial research demonstrates individual ability to distinguish between their EDV and other cognitions surrounding self-criticism (Noordenbos et al., 2014). For example, the EDV is often experienced internally, but is distinct from the self (Fox et al., 2012), again highlighting similarities to inner speech and voice-hearing. The EDV is often experienced as a powerful and prominent feature of an eating disorder (Pugh, 2016), and causes feelings of entrapment (Aya et al., 2019) and uncertainty around recovery (Tierney & Fox, 2011). The prevalence of an EDV appears significant but unclear, with estimates ranging from 33-96% across various eating disorders (Noordenbos & van Geest, 2017; Pugh et al., 2018; Wentz et al., 2001).

In summary, research into the EDV is still in its infancy (Aya et al., 2019). There is a recognised need for novel approaches for eating disorder interventions (NICE, 2020), due to poor treatment engagement (Linardon et al., 2017; Svaldi et al., 2019) and high relapse rates (Franko et al., 2018). Addressing the EDV using externalisation and interpersonal approaches can be key when recovering from an eating disorder (Duncan et al., 2015; Jenkins & Ogden, 2012). Within voice-hearing interventions, changing the appraisal of the voice’s power can reduce its severity and dominance (Birchwood et al., 2014; Craig et al., 2017). The development of voice-related interventions may be beneficial for eating disorders. Therefore, it remains important to further research the EDV and its role into eating disorder maintenance, with a view to incorporate the EDV into eating disorder guidelines and interventions to improve treatment outcomes.

Aims and rationale

The EDV is seen as a significant element within many eating disorders (Pugh & Bell, 2020; Pugh, 2016). The current study aimed to explore inner-speech and voice-hearing with girls and young women who self-report an eating disorder voice, using the research question: “How is inner speech and voice hearing experienced by girls and young women who report an eating disorder voice?”. How the EDV is experienced will be explored, with aims to establish its role in the maintenance of an eating disorder. Understanding the impact of the EDV can be used to inform eating disorder services and treatment guidelines, which are currently insufficient (Mitrofan et al., 2019; Murray et al., 2019), therefore enhancing treatment outcomes.

Research surrounding the EDV is often focused on anorexia (Chua et al., 2022; Graham et al., 2019), and does not highlight the importance of the EDV with a view to inform eating disorder interventions. Therefore, the current study employed a methodological approach that empowers young women, known to be disproportionately affected by eating disorders (Beat, 2021; Ward et al., 2019), with lived experience of an EDV to tell their stories. The study aimed to facilitate rich idiographic data collection, forming an in-depth understanding of personal experiences through narrative synthesis (Cleland, 2017). Stories were captured via multi-modal data and group discussion. Narrative Analysis was used to interpret the data, to understand the stories of participants and how this is was constructed using their own experiences (Locock et al., 2019).

Methods

Participants

A total of ten participants took part in the research, recruited through social media accounts specific to the project, a dedicated webpage and video on the Lancaster University website, and via a podcast episode. Posts on the social media accounts (appendix 1) were used to explain the project and invite participants to take part. Participants were aged between 20-24 years and were all female (table 1).

Inclusion and Exclusion Criteria

Participants were eligible to take part in the research if they (1) identified as a woman, (2) were aged between 16 and 25 years old, and (3) reported experience of an eating disorder and EDV. Participants were not eligible to take part if they (1) identified as male, (2) were not within the age range stated above, and (3) had not experienced an eating disorder and/or an EDV. This research aimed to capture both adolescents and those within emerging adulthood, due to the previously discussed lack of research within young people.

Design

The methodological approach of this research was informed by Experience-Based Co-Design (EBCD). EBCD brings together narrative-based research with expertise from people with lived experience of mental health and services to further knowledge, collaboration, and service design (Green et al., 2020). This approach is in line with national guidance, which supports service user involvement where possible, to inform policies, guidelines, and interventions (NICE, 2013). EBCD aims to address complex issues across individuals, including gaining clarity around various phenomena (Robert, 2013), making it a useful method to explore a poorly understood concept such as the EDV. EBCD's use of collaborative work can result in effective resolutions benefitting and empowering the individuals involved (Robert, 2013). For example, a variety of health services have shown notable improvements using EBCD, such as positive changes in practice, enhancing relationships between services and the individuals using them, and facilitating future involvement of people with lived experience within practice (Farr, 2011; Piper & Iedema, 2010).

This research aimed to facilitate the co-design of knowledge related to the experience of the EDV, providing a richer understanding of this under-researched phenomenon. Participants were invited to submit their own individual story, reflecting their experience of voice-hearing alongside an eating disorder. This story could be in various forms, dependent on individual preference, for example through written text, artwork, or voice recording. However, all stories submitted during the project were in written form. Data characteristics and be found in table 4. EBCD can involve obtaining lived experiences through interviewing or group discussions, and presenting identified 'emotional touch points' from these experiences to participants through a stimulus film (Point of Care Foundation, 2021). This was the process used during further stages of the research, described in the below sections.

Epistemological Stance

I adopted a critical realist stance within this research. Critical realism is a philosophical approach first developed by Bhaskar (1975), offered as an alternative to positivism and constructivism (Smith, 2011). Critical realism distinguishes between the 'real' world and our knowledge of it: the ‘observable world’ (Bhaskar, 1975). Critical realism views our knowledge of the world as being constructed of perceptions and experiences (Archer et al., 2013).

Critical realism can be used within research to develop a representation of the ‘real’ world via analysis of lived experience within participants (Lawani, 2021). The primary aim of this approach is to develop knowledge surrounding factors which contribute to an event or phenomenon (Archer et al., 1998). Therefore, I felt it useful to maintain a critical realist stance towards my research as it was exploring the phenomenon of the EDV. Critical realism also has a focus on the potential for change and transformation (Sayer, 2000), again highlighting its utility when considering the implications of the EDV for eating disorder understanding and interventions. Critical realism also allows for innovative and flexible application (Archer, 2016), further aligning with this research due its novel approach to obtaining data.

Materials and procedure

The research consisted of three stages (figure 1 & 2). In stage one, a Qualtrics questionnaire (appendix 4) was used to obtain consent from participants, contained additional questions surrounding their lived experience of an eating disorder and EDV, and directed them on how to submit their individual story for the research. Ten participants answered the questions on Qualtrics, and six of these participants provided submitted a written reflective story in addition.

Stage two and three comprised of a reflective group discussion (Raynor et al., 2020) held online via Zoom and Microsoft Teams. Three out of the ten participants attended the first group discussion, two of which had also taken part in stage one. One of the ten participants attended the second discussion, who had taken part in all the stages. Within the reflective groups, participants were shown a stimulus film, presenting themes from the previous collated stories submitted (appendix 2). A semi-structured interview approach was used, allowing space for participants to provide feedback on how accurately the stimulus film represented their experience (Marwaa et al., 2023). Figure 2 outlines of the participants' journey throughout the project.

Methodology, design, and data collection were partially completed alongside another trainee (figure 1), as our projects both related to voice-hearing experiences within the context of eating disorders. Conducting recruitment and initial stages of data collection jointly ensured efficient use of participants' time, reducing burden and minimising participant recruitment challenges. It also provided opportunities for collaboration, peer review and critical discussion of data and interpretation, particularly relevant when researching a construct still being clearly defined. The final stage of the project (the second group discussion) was completed independently, to specifically address the research area of my project: "Exploring inner-speech and voice-hearing with girls and young women who self-report an Eating Disorder Voice".

Participatory Process

Stage one: Ten participants with lived experience of the EDV were recruited via social media, aged 20-24 years. Nationalities/ethnicities included White British, White, Brazilian, Filipino and Australian. A link within the social media posts took participants to a Qualtrics page providing the research details, information sheet and consent form. If consent was provided, participants were asked to submit their multimodal data contributions through Qualtrics (e.g., written text, artwork, voice recording), and were then provided a debrief sheet. Copies of information sheets, consent forms and debrief sheets can be found in the appendices of my ethics section. Participants were asked if they wished to take part in stage two and/or stage three of the research, and to be kept up to date with the outcomes of the research. All contact information and transcriptions were kept in encrypted files. This layer of data was examined using narrative analysis, to form a stimulus film created via Microsoft Powerpoint. Participants were informed they had ten working days to withdraw their story from the research following their submission. This is due to the iterative nature of the analysis.

Stage two: Three participants took part, aged 20-22 years. Nationalities/ethnicities included White British and White. Participants from stage one who gave consent to take part stage two, or participants recruited independently, were invited to join an online reflective group discussion, hosted via Zoom. Participants were given the option to use a pseudonym during the group. The group was facilitated by myself, another trainee and a development worker from Voice Collective, a community which supports young people who hear voices. A live illustrator was also present, who summarised the group discussions into an infographic (figure 3). Participants were shown the initial stimulus film (appendix 2), and gave feedback around how our understanding represented their experiences of voice-hearing and eating disorders. Participants were then provided with a debrief sheet. The feedback was gathered via written notes and recorded discussion, transcribed verbatim to form the second layer of data collection, analysed using narrative analysis. This data was analysed independently from the other trainee, in relation to my specific research question, focused on the experiences of voice-hearing and inner speech and how this influenced an eating disorder.

Stage three: Participants were invited back to join a second online reflective group, hosted via Microsoft Teams. Due to attrition, one participant aged 21 years who was White British took part. Consent was obtained prior to the discussion which was facilitated independently from the other trainee. A final stimulus film was developed and shown to the participant (appendix 2), specifically in relation to experiences of voice-hearing and inner speech alongside an eating disorder within young women. A final debrief sheet was provided. Recorded and transcribed feedback from this stimulus film formed the final data collection process, analysed using narrative analysis.

Narrative Analysis Approach

The first stage of narrative analysis was completed alongside another trainee, to identify emerging themes within the participants' stories and develop the first stimulus film. Guidance was sought from my research and field supervisor. The second and third stages of narrative analysis were completed independently to address my specific research question. Specific analytic frameworks were followed for different modes of data. Crossley's (2008) narrative analysis framework (table 2) was followed for written data. Below details how each stage of the framework was applied to the study:

(1) familiarisation of the data: all data obtained by participants from both the Qualtrics questions, submitted stories and group discussions was examined a number of times to ensure appropriate understanding and knowledge of each narrative.

(2) identifying important concepts: elements that were emphasised by participants or related to the research question from both the Qualtrics questions, submitted stories and group discussions were highlighted and discussed with the other trainee when completed jointly, to begin to develop potential themes.

(3) identifying narrative tone: the 'atmosphere' or tone created by participants' stories were noted, for example distress or reflectiveness.

(4) identifying imagery and themes: common themes or imagery used by participants to aid description of their experiences were pinpointed and discussed when completed jointly.

(5) weaving the above into a coherent story: significant themes, narrative tone, and imagery were incorporated from all the data to form a story reflecting the similarities and differences within the narratives.

Visual data within the illustrator's infographic during the first group discussion (figure 3) was analysed using Collier's (2001) technique (table 3). This involved the following stages:

(1) familiarisation with the data: visual data from the infographic was examined and discussed thoroughly with the other trainee

(2) categorising the data based on the research question: data that aligned with my research question was specified.

(3) producing detailed descriptions of the categorised data: elements of the visual data was expanded upon and described in relation to the research question

(4) developing overarching layers of ‘meaning and significance’ based on the full data set: the data’s context and connotations were established and concluded

This process was relatively brief in comparison to the written data, as there was limited visual data collected. Nevertheless, the imagery remained effective to emphasise significant concepts experienced by participants. The analysis of both written and visual data was brought together to form the final emancipatory narrative describing participants’ experience and relationship with their EDV. Extracts of data analysis can be found in table 5 and 6.

Narrative analysis aligns with a realist epistemological approach, focusing on the content of a story, assuming a connection between language and how the ‘self’ is experienced (Crossley, 2008), which was thought to be appropriate for the research question. Narrative analysis reflects the creative process of the EBCD methodology, constructing a story from participants’ own experiences (Locock et al., 2019), generating core narrative themes (Smith, 2016).

The use of thematic analysis was considered, which can be useful for identifying common themes within data (Braun & Clarke, 2006), however it was felt that breaking down participants’ stories into sections or codes may diminish their meaning, and it was preferable to allow whole stories to be heard through narrative analysis (Smith, 2016). Narrative Analysis can also describe differing dynamics and context within individual stories (Floersch et al., 2010), aligning with the ethos of the research. A combination of both inductive and deductive strategies was utilised to allow for a more in-depth comparison of stories.

Ethical and Practical Issues

Ethical approval was obtained from Lancaster University's Research Ethics Committee.

Retention of Participants

Having multiple stages meant a risk of attrition between stages, or participant hesitation when agreeing to take part in the study. Participants had the opportunity to enter into a prize draw of £25 at the end of each stage to promote continued engagement, and could choose to engage in as much of the project as they wished. This approach facilitated further recruitment prior to each stage if additional participants were needed for an adequate amount of data for analysis.

Data Storage

Data was stored in encrypted files on password protected computers, stored securely in the University's Onedrive with only the researchers and supervisor with access. Audio recordings will be destroyed and/or deleted once the research is submitted for publication/examined. Participants' personal data was kept confidential and separated from the rest of the data. Data will be stored on PURE for 10 years, with the programme's research director as custodian.

Distress Protocol

Potential distress was anticipated due to the sensitive nature of the topics during the group discussions. A distress protocol was developed to help contain this (appendix 3), which was outlined at the start of the group by the facilitator. Details of support lines were posted into the chat function for participants to access throughout the group if necessary. There were collaborative discussions around how the group would like to handle distress, using check-ins and breaks. No visible distress appeared to occur during the group, however the group facilitators were accessible if needed.

Confidentiality and anonymity

As the research involved two online groups, this posed the risk of participants sharing details outside of the group. Therefore, 'group rules' were established during group, collaboratively generated by participants in accordance with NHS guidance (NHS England, 2016), including agreement of confidentiality and its limits to ensure they felt safe to share personal experiences. No known issues relating to confidentiality or anonymity arose during the project.

Reflexivity

I was aware throughout this project that it was important to remain impartial to the research, particularly considering my background knowledge of having worked within the area of eating disorders. This was managed using monthly research supervision, where I discussed my decision making, specifically when analysing data and developing themes, to acknowledge potential assumptions or biases within the research. Completing part of the research alongside another trainee, who did not have background knowledge of the area, also helped to ensure impartiality as much as possible.

Findings

Following analyses of the narratives obtained, the findings will be split into the following sections: (1) The EDV as collections of others' narratives, (2) Form and dialogue of the EDV, (3) The use of imagery to describe the EDV and (4) Changing relationship with the EDV and its role in recovery. These themes reflect how participants experienced and described their EDV within their eating disorder, and its effects.

Section 1: The EDV as collections of others' narratives

Parental influences

Two participants described that the EDV can be experienced as a collection of others' narratives, such as the voices of parents depicting a critical tone, in the form of "rules" enforced around food and calorie intake, which was then "played back" by the EDV: "it has a little tape player in my head... it can just play these memories when it wants to trigger me". These occurrences promoted participants to comply with the EDV, to avoid the negative emotions that comes with reliving these memories. This experience demonstrates how the EDV can perpetuate eating disorder behaviours, and mirror both inner speech and voice-hearing experiences, through the presence of others' voices (Knappik et al., 2022; Langland-Hassan, 2021) and retrieval of episodic memories (Wilkinson & Fernyhough, 2017).

Diet culture

Six participants described their EDV to be internalised messages derived from diet culture: the focus on thin as an ideal body type and assigning moral value to food and behaviours surrounding it (Kinavey & Cool, 2019). One participant described her EDV using the phrase "nothing tastes as good as skinny feels" to help "motivate" her to continue her eating disorder behaviours. Another participant expressed that their EDV prohibits them to consume any food labelled "unhealthy", in efforts to "fit an ideal image" that had been endorsed by diet culture. One participant described how the EDV can use these societal expectations as 'fuel': "you can't avoid diet culture... the EDV will pick on anything it can". It appears that messages derived from diet culture can be part of the EDV's content and contribute to the maintenance of eating disorder behaviours.

Narratives from services

Two participants also identified their EDV as being compiled of narratives from healthcare professionals and eating disorder services. One participant was labelled by a professional as having a "severe and enduring" eating disorder, leading to her EDV "latching on" to this and "using it against" her. This led to feelings of helplessness that she would never reach recovery. One participant also felt they were not taken seriously by services due to not being a low weight: “...they didn't understand that this eating disorder was impacting every hour of my life. I couldn't go out, I couldn't work... all they see is weight”. This experience led to participants’ EDV repeating phrases such as “you're not really that sick, your BMI isn't low enough”, inducing doubt around their eating disorders. Participants felt unworthy of support, and considered deliberate intensification of eating disorder behaviours to access help. Therefore, participants of this study described the harmfulness of using certain diagnostic labels and employing a weight-based threshold to determine the severity of an eating disorder. The ability of an EDV being able to “latch on” and distort comments can promote the continuation of eating disorder behaviours. This was described as typically an external experience, suggesting elements of a voice-hearing experience as opposed to inner speech, as it appears to be out of participants’ control (Knappik et al., 2022).

Section 2: Form and dialogic nature of the EDV

Six participants described the EDV as being an ever-present separate entity: “it has a mind of its own”, “like a shadow on my brain”, “someone talking over my shoulder”. The EDV was perceived as “critical”, “a dictator” and “relentless”. The EDV was disparaging of many aspects in their life, not limited to body image or food intake: “It literally dictates your every move. It dictates what I do... where I go...”. This “constant nagging” left participants feeling “exhausted”. The EDV also constructed consequences around eating: “if you eat, everyone will hate you”, which lowered self-esteem. The EDV was also compared to an “abusive partner” or “predator” which has the power to isolate: “it’ll cut you off from everyone... from people that would keep you safe”. Fighting the EDV was described as an “invisible war”, increasing isolation as others are unable to see or understand the experience.

It appears that participants’ attempted dialogue with the EDV are often in vain. The EDV was described as a “powerful presence” which was “stronger” in comparison to their “own voice”. This resulted in a “constant internal battle” and “endless loops of thoughts”, arguing with the EDV around every decision. The relentless nature of the EDV appears to be all-consuming, with attempts to challenge it being futile. The ability to form a sort of reciprocal conversation poses similarities to both inner speech and voice-hearing (McCarthy-Jones & Fernyhough, 2011), whereas the EDV being perceived as a stronger presence and separate entity appears to be more in line with a voice-hearing experience (Knappik et al., 2022), suggesting an overlap between the two phenomena.

Interestingly, for four participants, the EDV was heard as a “loud screaming”, while in two participants it was a “whisper”. Despite the EDV’s manifestation, all participants described being “unable to say no to it”, as it was delivering “orders” they “had to obey”. This suggests that the EDV’s power lies in its content rather than its exhibition. The EDV’s critical nature was described to worsen following attempts to challenge it, therefore promoting compliance.

Section 3: The use of imagery to describe the EDV

Control and isolation

Four participants used imagery when describing the controlling nature of the EDV, such as a “claw machine at an arcade... grabbing thoughts... putting ideas in my head”. Examples of these thoughts were “you might never get better” and “your life isn’t really worth living... you may as well go backwards”, resulting in feelings of worthlessness and a lack of hope surrounding the prospect of eating disorder recovery. Further imagery demonstrating the EDV’s control was described: “I’m a dog on a leash... being dragged around”. One participant described times where she was able challenge the EDV as being “on a rampage”, demonstrating the perceived severity of EDV non-compliance. Following a “rampage”, the participant described her EDV quickly being able to “regain control... through rules and rituals”, leading to feelings of guilt. This description provides insight into the emotional consequences of challenging the EDV.

The infographic developed by the live illustrator (figure 3) also highlighted imagery that participants used to describe their EDV experience. One participant compared the EDV to a “ninja” or “invisible opponent in a boxing ring”, able to “sneak up on you... you can never quite relax”. These comparisons reflect the covert nature of the EDV, and the subsequent difficulty of overcoming it. Further imagery from two participants, captured by the infographic, was being “trapped in a bubble” as a result of the EDV, containing a “radio”, delivering “constant noise”, reflecting the dialogue of the EDV and its running commentary. The bubble was described as a “defence mechanism... to keep other people away”. This imagery demonstrates the level of seclusion experienced due to the EDV, and its never-ending narration. One participant expressed that she had to “pop the bubble”, that “no one else can do it for you”. This personal responsibility surrounding recovery increases feelings of isolation, and may reflect feeling unable to rely on external support.

Loss of identity

Five participants described a loss of identity due to the EDV. The EDV was described to be “adapted for survival”, becoming “camouflaged”, “silent and invisible”, whereas initially it was “screaming and shouting”, louder and more obvious. Over time the EDV became “subtle and harder to spot”, making it difficult to distinguish between the EDV and participants’ own thoughts: “It camouflages itself amongst my own thoughts and feelings like tangled balls of wool in two different shades of grey... recognising my own ideas to be the voice of my ED is like spotting a needle in a haystack.” The EDV becoming difficult to identify further hindered recovery, with participants left “fighting themselves”. The EDV was also compared to a “parasite”, “demon” or “snake” which “took over” their being, leaving them a “prisoner”, “no longer recognisable... an animal... not human”. These experiences demonstrate how the EDV can consume a person, to the point they no longer feel like themselves.

The EDV could also take the form of participants' own voices, appearing to be a more inner speech-based experience, adding a layer of complexity. This experience exacerbates feelings of a loss of identity, confusion and fear when attempting to challenge the EDV. Contrastingly, the EDV can also be participants' "own thoughts" but in an unfamiliar voice, which can be features of inner speech and voice-hearing (Langland-Hassan, 2021; Wilkinson & Fernyhough, 2017), demonstrating the parallels between the EDV and both of these phenomena. The complex nature of the EDV's presentation appears to further cloud participants' relationship with the EDV and their recovery from it.

The EDV can also appear to make decisions around everyday life, compounding feelings of a loss of identity: "did I choose the same breakfast option as yesterday because I genuinely love pancakes? Or because it felt like a safer option?... I don't know what I like to eat", "do I want to walk because I am taking in all of the sights, or to compensate for the food I am eating? I don't trust my decisions". Being unsure of usually inherent preferences demonstrates the power of the EDV and its ability to dominate one's personality, consciously or not, further enhancing the complexity of recovery.

The EDV particularly impacted participants socially and occupationally. For example, being unable to feel present when with others, due to "so much going on inside my head" and "worrying about managing food", "constantly having a conversation with it [the EDV]". This could lead to feeling "dissociated from real life... constantly thinking about food". Difficulty engaging in a world outside of the EDV led to feeling like a "walking, talking eating disorder", "seeing everything through this lens of the EDV", further increasing isolation and fear of recovery for participants.

Section 4: Changing relationship with the EDV and its role in recovery

It appears that the relationship with the EDV can change over time. The EDV was viewed positively by three participants when it initially developed, seen as a "coping mechanism", “protector”, and “calming, responsible, older figure” who “gave advice” and “saved” them, leading to feelings of “compassion for it”. These experiences could highlight how the EDV can persevere, appearing to ‘help’ if a person is in a vulnerable stage of their life. However, this companionship with the EDV appears to be short-lived. The EDV was described as being “disguised as protection” and “love-bombing” participants: “it slowly made me feel unloved... that people hated me”, “there was a split second of it being my friend... before it went back to its bitchy little self”. The negative effects on participants’ self-esteem due to the EDV left them in pursuit of its validation, however brief this may be. Conversely, one participant could never identify the EDV as a “friend”, and “never found comfort” within their relationship, instead feeling they had “nowhere to turn” and “no choice” surrounding it, again reflecting the EDV’s controlling nature. Whether participants’ relationships with their EDV changed over time or remained the same, it appears to remain mostly negative.

Two participants also reflected how their behaviour in relation to the EDV changed over time. At first, demonstrating “misdirected anger towards others” to comply with the EDV, changing to “anger towards the EDV” for leaving them feeling “stuck”, “helpless” and “missing out on life”. Changes in appraisal of the EDV appear to only become apparent when already “trapped” within its control, demonstrating the EDV’s insidious nature. When challenging the EDV, participants reported gradually identifying the ‘illogical’ elements of it, referring to previously followed rules as “ridiculous” or “bonkers”. This suggests that addressing the EDV may be an important element towards recovery within eating disorder interventions.

When discussing eating disorder recovery, three participants described the experience of “losing” their EDV: “it feels like a piece of you is missing... leaving you with no purpose or direction”. This leaves participants feeling “lost”, compared to a “breakup” from a partner: “I can’t live without it, I’ve got nothing and no one else”, “without it I don’t know who I am”. These feelings emphasise the loss of identity, reliance and fear facilitated by the EDV when contemplating recovery.

In summary, young women with an EDV may view recovery as a frightening concept with necessary losses and sacrifices, rather than a goal. Their perspective appears to be related to feeling as though the EDV has become their identity, therefore recovery may seem incomprehensible, risky, and unachievable.

Discussion

Key Findings

Overall, the four sections within the emancipatory narrative enhance understanding around the EDV, using the lived experiences of young women. The EDV presents as a significant element within eating disorders and can take over one's identity. These experiences highlight the EDV's role in eating disorder maintenance, posing an added barrier to recovery. Therefore, the importance of addressing the EDV as part of eating disorder treatment is emphasised, which can inform services, clinical guidelines, and future eating disorder research.

Form of the EDV

The EDV can be experienced as a separate entity, controlling many aspects of daily life outside of food intake and body image. Participants felt compelled to obey the EDV to avoid worsening criticism. The EDV was described as an "abusive partner", manipulating participants using personal insecurities. This form of the EDV appeared to have more similarities to voice-hearing as opposed to inner speech. Challenging the EDV was an "invisible war", leaving participants feeling helpless around recovery, aligning with previous literature (Aya et al., 2019; Tierney & Fox, 2011).

The role of the EDV for recovery

The EDV could become so engrained that it became indistinguishable against participants' own thoughts, adding further complexity surrounding recovery, as they were "fighting themselves". This was particularly challenging when the EDV was experienced in participants' own voices, in a more inner speech-based experience. The EDV could consume one’s identity, leaving participants unsure of their own decisions and preferences, affecting participants socially and occupationally. The EDV facilitated dependence and fear, leaving participants feeling lost when contemplating recovery and losing their EDV, feeling they were missing a part of themselves, compared to break-up from a partner.

This concept aligns with previous work from Bruch (1973), which described people with eating disorders having difficulty defining their ‘psychological self’, leading to the belief that they are incomplete and helpless unless they comply with their eating disorder. This was further discussed by Oldershaw et al. (2019;2023), describing issues with emotional processing within an eating disorder, resulting in losing one’s ‘emotional self’.

Within the current study, the EDV was seen initially as a protective figure and coping mechanism, however over time it became volatile, leaving participants feeling more trapped the longer the EDV persisted. Participants identified the key role of challenging the EDV when changing their eating disorder behaviours, highlighting this to be an important part of the recovery process, particularly within the initial stages of an eating disorder. Expectedly, eating disorder recovery can be predicted by increased mood (van Bree et al., 2023), self-empowerment (Wetzler et al., 2019) and reduced psychological distress (Kline, 2023). As the EDV was described to impact self-esteem and self-worth, it is likely that challenging it can promote recovery.

The EDV’s content could be formed of critical narratives from others, diet culture or services. Experiences of being dismissed by services due to not being a low weight appeared particularly damaging for participants, as their EDV facilitated the belief they were not unwell and did not require support, even promoting purposeful intensification of eating disorder behaviours. This form of the EDV appears more in line with a voice-hearing experience as opposed to inner speech, due to its ability to distort narratives and influence unhelpful behaviour (Fernyhough, 2014; Knappik et al., 2022).

Clinical implications

Overall, the presence of an EDV alongside an eating disorder had significant effects for participants, facilitating the maintenance of eating disorder behaviours and decreasing motivation to recover. This is in line with previous research showing the EDV can worsen duration and prognosis of eating disorders (Herpertz-Dahlmann, 2015; Miotto et al., 2010). However, research often focuses on the EDV's commentary surrounding food intake and weight (Pugh & Waller, 2017), whereas the current findings suggest the EDV encompasses much more than this, using threats and personal insecurities. This appears detrimental to self-worth, which hinders the process of eating disorder recovery if not properly addressed (Tecuta & Tomba, 2018). Therefore, future eating disorder research should explore the influence of the EDV aside from observations on diet and weight.

Definition of the EDV can be difficult. Therefore, additional evidence supporting its occurrence is critical to promote addressal of the EDV in eating disorder interventions, including across services where people may first present with an eating disorder, such as Children and Adolescent Mental Health Services and Community Mental Health Teams. Evidence surrounding the EDV could also change existing understanding of eating disorders, steering away from a focus on body image and diet (Eiring et al., 2021; Tsong et al., 2023). Rather, capturing the psychological complexity surrounding eating disorders, and how the presence of a voice can compound distress and maintain symptoms, as found in the current study.

Incorporating the EDV into eating disorder interventions may improve its comprehensiveness and therefore recovery trajectories. The approach would need to be individualised. For example, thought challenging may be useful to combat critical statements generated by the EDV, or trauma-focused work may mediate distress if the EDV is reiterating previous negative events. Using psychoeducation around the EDV or voice-hearing may increase understanding and reduce fear in people who experience it alongside an eating disorder. Specific details around proposed interventions are discussed in my critical appraisal.

The benefits of combating the psychological symptoms of an eating disorder are considered fundamental aspects of recovery, such as improving psychological wellbeing (de Vos et al., 2017) and quality of life (Tomba et al., 2019), including within ‘chronic’ eating disorders (Kotilahti et al., 2020). Addressing the EDV is likely to be beneficial considering its psychological impact on people who experience it. It appears important to challenge the EDV in the initial stages of an eating disorder intervention, as the current findings demonstrate it becoming more entrenched the longer it persists. Moreover, participants attributed challenging their EDV to being less adherent to the “rules” of their eating disorders, suggesting the effectiveness of combating the EDV.

Eating disorder recovery criteria appears to focus on weight restoration rather than psychological wellness (Tomba et al., 2019), reflected by participants’ in-service experiences in the current study. This is despite national guidance stating that services should not base eating disorder support on weight or BMI (NICE, 2020). Evidently, eating disorder interventions should be developed to ensure they are comprehensive and appropriate.

Strengths, limitations, and future research

The current findings add idiographic and nuanced first person accounts to the current understanding of the EDV and its effects on eating disorders for young women, which is a currently under researched. The use of EBCD-informed methodology obtained collaborative, valuable, in-depth narratives, informing recommendations for research and practice to aid service improvement and development of care pathways (Green et al., 2020). The use of multi-modal data and group discussions provided participants with more flexibility, eliciting richer data compared to questionnaires or structured interviews (Moser & Korstjens, 2017). Narrative analysis facilitates development of ‘thick’ data, providing insight into sequences of events or influences which formed individual experiences (Cleland, 2017), deemed highly beneficial for the research topic.

As the sample size used in the current study was relatively small, this may reduce theoretical generalisability. Although, the sample was still felt to be methodologically appropriate given the research question and explorative nature of the study. However, it remains difficult to provide specific recommendations for interventions to address the EDV, due to lack of research and differences in presentation. Nevertheless, the novel insights obtained in the current study offer a timely basis of synthesised knowledge to inform next steps. Future research employing EBCD through different recruitment methods may reach a larger sample size and improve generalisability. For example, recruiting people with eating disorders of different ages, genders and cultures will acquire additional evidence relating to its presentation and influence, further informing services around intervention design. Improving inclusivity through wider representation of minoritized groups remains crucial, as eating disorder interventions have historically been based upon white, cisgender girls and women (Becker & Stice, 2017; Cook-Cottone et al., 2017)

In summary, future research should explore the effects of the EDV within eating disorders across all areas of individuals’ lives and increase diversity of participants. Exploring how individuals in eating disorder recovery have been able to challenge their EDV and what strategies have been useful may also help to inform interventions, ensuring they are appropriate and effective.

Conclusion

The current study explored the presence of an EDV within the context of an eating disorder. Narratives were obtained from young women with lived experience of the EDV. Following analysis, it was clear the EDV can significantly compound and exacerbate an eating disorder. Participants described how the EDV could control, isolate, and consume their identities, facilitating the maintenance of eating disorder behaviours and posing an added barrier to recovery.

A key finding was that certain psychological complexities of eating disorder presentations, such as the EDV, are not a focus within existing interventions. This is reflected by services often utilising a weight-based threshold as a means to accessing eating disorder treatment. This may be a factor in the current poor recovery rates in people with eating disorders. The findings of the current study aim to increase awareness and understanding around the EDV and its influence within eating disorders, promoting further research into the EDV and advocating for the inclusion of the EDV within clinical guidelines and practice.

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Tables and Figures

Table 1

Participant characteristics

Participant ID	Gender	Age	Ethnicity / Nationality	Eating Disorder Type
1	Female	24	White British	Anorexia
2	Female	20	White British	Anorexia
3	Female	20	White British	Bulimia
4	Female	20	White British	OSFED
5	Female	23	Brazilian	Anorexia
6	Female	22	Filipino	Bulimia
7	Female	22	White	Anorexia
8	Female	22	Australian	OSFED
9	Female	21	White	Binge-eating
10	Female	21	White British	Binge-eating

Table 2

Summary of the narrative framework used for written data (Crossley, 2008)

Step	Description
Step 1: Reading and familiarizing	The very first step in the analysis consists of repeatedly reading through the whole transcript (or alternative data source) about five or six times in order to familiarize yourself with the material and to obtain a very general gist of emerging and significant themes.
Step 2: Identifying important concepts to look for	The second step is to develop a grasp of the principal elements of the 'personal narrative' that you need to identify. *(a) Narrative tone:* Narrative tone is conveyed both in the *content* of the story and also the *form* or *manner* in which it is told. For example, the tone can be predominantly optimistic or pessimistic. *(b) Imagery:* Every personal narrative contains and expresses a characteristic set of images. Pay careful attention to the kind of language used in describing and characterizing life chapters and key events. When you have identified the characteristic set of imagery

	employed in your own case, try and explore the *genesis* of that imagery. *(c) Themes* : What are the dominant themes in your narrative? Underlying the many events reported in your account, can you see any pattern?.
Step 3: Identifying ‘narrative tone’	In order to identify narrative tone, you need to look at both what you have reported in relation to the content of the story, and the way in which you have done so.
Step 4: Identifying ‘imagery’ and ‘themes’	Look for both imagery and themes together, to identify any overlap. Work through the narrative in a systematic fashion. Imagery and themes should be identified in relation to each question. The aim is to draw up a kind of ‘rough map’ of the picture emerging from the narrative.
Step 5: Weaving all of this together into a coherent story	Having constructed a rough, ‘working map’ of the various images and themes emerging from your interpretation of the data, your next step is to weave all of this together into a coherent story.

Table 3

Summary of the narrative framework used for visual data (Collier, 2001)

Stage	Description
First Stage	Observe data as a whole. Listen to its overtones, to discover connecting contrasting patterns. Make note of them. Write down questions that the images trigger in your mind.
Second Stage	Make an inventory of all your images. Design your inventory around categories that reflect and assist your research goals.
Third Stage	Structure your analysis. go through the evidence with specific questions. Produce detailed descriptions.
Fourth Stage	Search for meaning significance by returning to the complete visual record. Respond to the data in an open manner so details from structured analysis can be placed in a context that defines their significance. Re-establish context, view images in entirety. Write your conclusions as influenced by the whole.

Table 4

Data characteristics

Item	Data Description	Participant ID	Analysis
1	Text – answers to open ended questions Stage 1	1	Written data: Crossley (2007) - Narrative analysis framework
2	Text – answers to open ended questions Stage 1	2	
3	Text – answers to open ended questions Stage 1	3	
4	Text – answers to open ended questions Stage 1	4	
5	Text – answers to open ended questions Stage 1	5	
6	Text – answers to open ended questions Stage 1	6	
7	Poem – 2 pages	6	
8	Text – answers to open ended questions Stage 1	7	
9	Poem – 1 page	7	
10	Text – answers to open ended questions Stage 1	8	
11	Submitted written piece – 2 pages	9	
12	Text – answers to open ended questions Stage 1	9	
13	Text – answers to open ended questions Stage 1	10	

14	Group transcript (04.07.23) - Stage 2	3 Participants Participants: 7, 9, 11	
15	Illustration from group (04.07.23) (text)	Discussions from group (04.07.23)	
16	Illustration from group (04.07.23) (images)	Discussions from group (04.07.23)	Visual data: Collier (2001) - Visual Analysis

Table 5

Extract of preliminary data analysis

Data Set	Analysis summary
1 (Qualtrics)	Focus of the voice was food intake and numbers
2 (Qualtrics)	Imagery – shadow on my brain, someone talking over shoulder. Theme of the voice telling them what to do. Demanding.
3 (Qualtrics)	Consuming – taking over life, impact on social life. Regimented restrictions – connotations of military and control. The voice is described as critical and demanding alongside this.
4 (Qualtrics)	Changing relationship – would describe it differently at different points of her eating disorder. Imagery of a war that is invisible to others. Described the voice as commanding, and the experience of managing this to be relentless. The struggle between the truth/logic vs irrational thinking/lies – "selling me lies". Imagery of making setbacks in recovery - "fall into that hole one too many times" – can link to believing the lies. Imagery of the EDV being parasite The idea that it is isolating as it is invisible and internal. An enemy and best friend at the same time. Destroying her life – social life, physical impact The voice is stronger than her own and is very different to her own thoughts. A narrative from professionals being that her eating disorder was a form of self harm.
5 (Qualtrics)	Imagery of snake/demon/Dictator vs Prisoner – whispering orders that she has to obey. Sees the voice as a separate entity which takes over. Talks about her compulsion and losing control – obsessive and endless loops of thoughts. Intrusive and vivid experience Body dysmorphia experience – comparisons to others and how she views her body impacting

	how her body feels (bigger when eaten, smaller and lighter when she hasn’t).
6 (Qualtrics)	Theme – aspects of life that it takes away – social, academic Theme – I am unloved, undesirable, friends and significant other hate me, bad appearance/personality, feelings of shame of how she feels in their body compared to others. Theme – control “They” decide what I eat, she reflects that she is losing control.
7 (Poem)	Use of popular phrases “nothing tastes as good as skinny feels” – the narratives within society through different generations of food and body image. Imagery of how her body feels when throwing up – burning tunnel, producing fluids. Capturing trying to distance herself from the EDV – conflicted. Calling the voice baby – is she trying to reassure the voice, is it an immature version of her. Refers to the voice as she and describing how the voice thinks. Fear of calories Imagery of body image – “flesh is bouncing”, later it has stopped bouncing, breathing in her stomach to “hold it secure”. Living vs dying – living like I’m dying, dying to live Help not helping – language which suggests minimising the issue – has this come from the “help” which she has internalised? Or is she minimising her eating disorder to just anxiety.
8 (Qualtrics)	Labelling foods as healthy vs unhealthy Relationship with EDV/headmate – giving advice, calming, responsible, older figure. Restricting the number of meals
9 (Poem)	Onomatopoeia – describing the sounds of the kitchen in association with making food. Kitchen being an overwhelming environment, which is negative. Coping strategy is avoidance – don’t make food, order it instead, and the list of types of food she doesn’t like. Specific – in terms of food she doesn’t like and the sounds that she doesn’t like.

	Doing what you have to to survive Language shows no enjoyment or comfort from food “okay” “fine” – deems it as either healthy or unhealthy in terms of food but also like habits, and a person can be either healthy or unhealthy. Manages the idea of “too much of anything is unhealthy” thought through restricting the number of meals she has a day.
10 (Qualtrics)	Imagery of mental battle and hell Separation of self from EDV – imitates her but it’s “trying to kill me”
11 (Written piece)	Imagery was used within the written piece to demonstrate how she is able to distinguish between the EDV and her own thoughts – coloured wool. There was a theme that the EDV has adapted for its survival e.g. hiding, camouflaged, silent and invisible, and these differences in the coloured wool are more subtle and hard to spot. There were reflections on how this has made her ED recovery difficult as she doubts herself and does not trust whether her thoughts are her own. Fear theme – that it will never get better and also that she can’t cope without it. This motivates her into recovery yet also breaks her into a what’s the point mentality “will always be a person with ED”. Critical parents – reflected in the EDV, sometimes hears all of them at once. Messy and jumbled – links back into the idea of detangling thoughts imagery. The voice is critical of her abilities. No comfort in relationship – reflections that the EDV has never been her friend. “Saved her life” – owes the voice something? Theme of loss – she writes about trauma and loss she has experienced and how the voice uses this weakness against her. Has the fear of losing her identity “without an ED I don’t know who I am”.
12 (Qualtrics)	EDV is her own thoughts but not her own voice, not recognisable as anyone else’s voice Hard to explain

13 (Qualtrics)	Separation between self/own thoughts and the EDV or whether it is a generic voice. Critical voices of parents is reflected on.
14 (Group discussion transcript)	P1: - “consider myself recovered” - self identifying, not necessarily from a professional. - Experienced voice hearing first, then developed an ED. - “cutting out from life” - went to a different school, isolated – imagery the comparisons between the EDV and an abusive partner. - Tricking her to think it’s protecting her, “keep you safe” “be your safety net” - used the word “destructive” as the goal of the eating disorder - Different voices – “adam” vs “the scientists” - different ways they spoke to her – spiritual beam so needed to dim her light to protect her family, and needing to be smaller to avoid criticism from the scientists as then they wouldn’t be able to see her. - Always watching – idea of loss of identity and power as a result of the EDV - Loss of the voices – being a break up, “leaving you with no purpose or direction”, lost that protector. - The impact it had on others – they might find it difficult. - Affecting different parts of her life not just food – feeling anxious in social situations - Parent is understanding due to own difficulties - She described it as an compulsive behaviour in response to threats (voices threating her and her family) – calling these behaviours “ridiculous” - is now able to look back on this more rationally - Described her EDV as “having a mind of its own” and that it picks up on what she is thinking and feeling and “parrots it back to me”. Had a powerful presence that she felt she couldn’t say no to it.

- Dissociation - “so much going on inside head” makes it difficult to be fully there and cannot pay attention
- Fighting metaphor – at the beginning of her recovery she couldn’t relate to it as she felt so intwined with the ED that “it’s will became mine”. So when other people would say to fight it she was felt like that meant having to fight/destroy herself? Can reflected now that she could see it was a parasite that was separate to her. Identity.
- Effects of having an ED – affecting your brain function and cognitive abilities.

P2:

- Times I’ve felt close to recovery – what does recovery mean/look like for her? Ups and down, set backs to recovery (Narrative – told in a present tense, current and active in ED).
- Important to her – showing understanding to others with an ED.
- Identity - “doesn’t sound like me or anything else”, difficult to describe, separating her thoughts from the EDV (wool imagery). This has got worse the longer she has had an eating disorder. Identity has changed – harder to distinguish, in disguise.
- Never been a friend – “constant nagging”, “bitchy little self” – the relentless nature has fuelled this anger and hatred speak towards the voice. “bitchy” - connotations that the voice has been talking down to her (bully?) and she is standing up to it now? What are the power dynamics within this relationship.
- Split second of positive – praise received for losing weight.
- Loss like a breakup – the relationship - “had enough but don’t want to let go”
- Loss as the identity of self and EVD – “piece of you is missing” is she incomplete without it? “Gapping hole” “The longer I’ve been unwell = it’s taken up more of me and more of my life”.

- “choosing to get better” - where has this narrative come from? Does she see recovery as a choice or purely related to motivation? Isolating narrative?
- Hard for others to understand (parents) - the ED was a coping mechanism “protection, managing and coping”. “could have been alcohol” - nurses perspective. Vicious cycle – wanting others to understand – internalised diet culture narrative from childhood and then use ED to cope – vicious cycle.
- Beginning of her story - “wasn’t a choice because of circumstances” “little 13 yo me had nowhere else to turn” “saved me”. ED behaviours being rules that parents gave me that EDV then reinforced.
- Self conscious - from childhood, parts of her body that had been commented on from childhood. EDV = collection of own thoughts, and things said to me.
- Angry at the beginning – push people away as the EDV didn’t want me to be comforted and cared for, so if I did get that from others wouldn’t need the ED. Angry at herself but that misdirected to others and not her ED. People being frustrated with your ED but you take that as being frustrated with you as ED is in you. Controlled anger – smashing the plates. Now – angry at the ED for what she’s lost.
- Started off as screaming and shouting but now it’s sneaky – changing relationship. “secretive and subtle”. Imagery – grabber machine of thoughts (not in control?) “might not get better” “90% recovered isn’t worth it”. “Wish it was a screaming voice not some kind of riddle”. The EDV uses conditional thoughts praying on her insecurities “If you eat at the wedding, everyone hates you.” based on weaknesses? Has it evolved because I’ve grown up or would it have changed anyway?
- Mirroring the above – Used to outwardly portray I have an ED with anger/wanting people to know but now I don’t want people to know and don’t

talk about it. Shame? Why is this – wanting to avoid the frustration whereas younger it was eliciting care.

- "I can't live without it, you've got nothing and no one else" - the switching between the I and You – the narrative of her identity and it being interwined. Seeing it as another entity or person.
- Helplessness feelings have increased the longer she's had the eating disorder. "If I don't do what they say it's pointless" (professionals, therapists etc), sense of responsibility "it has to be me that fix me". That responsibility adding to helplessness.
- This year in her story – tiny thing tipped her back even when in recovery – what if I can't break the cycle, self doubt, forgot what she'd achieved, felt helpless. "Endless cycles and loops". Recovery is always on a knife edge, tightrope.
- "I don't trust my own decisions, were they my choices" "I don't know what I like to eat" - identity – stuck in a loop and can't get out, feeling trapped.
- Using ED as a get out card – is this avoidance from things that are difficult.
- Didn't see thoughts as irrational at the time but now she can.
- Dissociation – constant noise, dissociated from real life and whirring in my head.
- Imagery of the protective bubble but actually trapped "smaller over time" "more suffocating" "isolating". Only you can pop the bubble "responsibility"
- Only I can hear the voices – "bonkers" stigma surrounding voice hearing. People usually talk about voices in a negative way.
- Makes surviving hard – the most basic level of being, not living. Recovery is then even harder - "why am I doing this". Imagery – swimming against the tide, comparison to others being in calmer waters. Exhausting to make decisions to go against the tide when it

would be easier to do what the EDV is saying at the time.

- Constantly fighting myself – argument in my brain until I'm too exhausted to fight it anymore. Fighting something invisible - don't know where it is or where it comes from fighting against own voice? Identity? Could just write down the argument but would just go on forever and ever because it is constant.
- Beginning – in the dark, hide away, wasn't missing out but now in a bubble and can see out but can't get to it, hyperaware of life passing by. Everyone else is miles ahead of me – societal pressure of where you should be at a certain age in your life.

P3:

- Eating difficulties stem from a fear of starvation – this has been isolated out into a single person in the system.
- Multiplicity since 5yo
- "troubled relationship with food" - reluctance to label it as an ED? "constantly thinking about food".
- Overprotective - "protecting me from a fear of something happening to me again" - experiences in her childhood.
- Feeling of guilt – the impact it has on their system. "Frustrated by my existence" "enemy vs a pet that everyone tolerates". Imagery of dog on a lease, lose control and too strong, just drags you around. I am more than my EDV but I am dragging them down by existing – the system is fighting something within me (parasite/imposter)
- Rampages – no control, without thought or memory of it happening. Feelings of shame/stigma is how she knows that she's done it.
- Control then regained by the system through rules and rituals.
- Parents not understanding – they do not acknowledge them being plural,

- Eat myself sick alone, get a boost out of it.
- Internalised = DID - "play out different child that the parents wants out of them" fit an image over what you've gone through" "sometimes I feel like they don't want me anymore".
- "loud screaming" - this has been constant.
- Hunger = not human animal life, just wants one thing. Relentless, consistent constantly yearning for food. Disturbing others in the system to get food.
- Identity – takes over so no longer recognisable, not human anymore. "I don't know what life will be like if I didn't, I feel I am the EDV".
- Internal family – still trying to understand, ongoing process why we're attached, the roles within the system. They're important, worries about losing them. Like a family – care stems from compensating lack of care from parents. Grateful for this. But can also be an internal struggle "astronomically irrelevant to other people". Strained relationships within the system, "mutually abusive or beating each other until silent and complaisant" "repeating patterns of behaviour from childhood"
- Coming to terms with being plural – through therapy, others accepting you as individuals has been valued and helps manage the internal conflict and battle. However – doesn't bring up DID to parents due to stigma, and others manipulating her with knowledge of her triggers – more guarded.
- Responsibility theme – "Am I the problem, Am I crazy" - is this internalised? Being forced to go down a specific recovery path – being blamed "stop hitting yourself mental health message", feeds into those negative connotations. Lack of accommodation for people with DID too.
- Imagery – stuck on a tree, want to get to safety, this seems safe enough but don't know where to go or how to get

	there – trapped theme. Disguised protection? Feeling of being cornered in the ring?
16 (Text on infographic)	- Change in relationships – from loud to sneaky, from positive to negative. - Feelings of anger which leads to isolation - The voice being a combination of internalised things others have said to me or what I've seen diet culture wise – fitting an ideal image. - It's toxic – seeing how the ED impacts others (shame attached to this), and the impact that has on self esteem I don't deserve to be loved. - Compulsive behaviour in response to threats. - Feeling trapped and helpless by the voice, knowing I need to help myself – personal responsibility. - The illusion of protection – coping mechanism at the start. - Identity – EDV or own thoughts - It won't let me explain how I feel, I internalise it, and cope with an ED. - 2 years of recovery and the tiniest thing can tip me over - Experiences of EDV within a system – linked to a fear of starvation from childhood experiences – my internal family.
17 (Visuals on infographic)	- Person by themselves – isolated from the group of people - Person in a bubble Theme – What others tell you - Sun - Magazine Theme – being responsible for recovery - Holding a broken heart together - A pin Theme – Being in disguise/sneaky - Wool showing the imagery of identity being lost - Ninja

Table 6

Extract of further data analysis

Data Set	Analysis summary
1 (Qualtrics)	This data is from participant 1, aged 24 years old. They simply used the diagnostic term of ‘anorexia’ to describe their eating disorder. They also used the term ‘psychosis’ when describing their experience of hearing voices, expressing that it was focused on their intake of food and numbers. Observations/Tone – The participant uses single words related to diagnostic criteria – “anorexia”, “psychosis” – is this how they would describe it themselves or how others e.g. professionals have described it? The voice’s focus on food intake and numbers may describe a controlling/obsessive nature.
2 (Qualtrics)	This data is from participant 2, aged 20 years old. They described their eating disorder as “a shadow that lives in my brain” and expresses that it “tells me what to do”. They described their experience of hearing voices as like “someone talking over my shoulder”, again reiterating that it is “telling me what to do”. Observations/Tone – describing the eating disorder as a “shadow” could suggest they see it as dark and sinister. Experiencing the eating disorder as something that “lives in my brain” could suggest they see it as within them, part of them rather than a separate part. Contrastingly their experience of hearing voices was described as more of a separate individual entity – “someone talking over my shoulder”. Both the eating disorder and voice hearing was reported to be instructing them on what they should do, suggesting a controlling and commanding nature.
3 (Qualtrics)	This data is from participant 3 aged 20 years old. They describe how their eating disorder “takes over my life” and the different things it stops them doing such as social events. They describe having “regimented” times when they eat and feeling as though they have to eat

	the same food. However they report that they are able to “challenge” the eating disorder when they feel able to. They described finding their eating disorder treatment difficult. They described their experience of hearing voices as instructing her on what not to eat or berating her for eating something. She also describes it as “the anorexic voice in my head”. Observation/tone – eating disorder appears to be consuming, taking over their life and having an impact on their social life. Using terms such as “regimented” and “restrictions” has connotations of military and control. The voice appears to be critical and demanding.
4 (Qualtrics)	This data is from participant 4 aged 20 years old. They express that their eating disorder could be described differently throughout its different stages, and that it is difficult to find the words to summarise it. They describe it as being “relentless” and “fighting a war inside your own mind”. They describe feeling isolated due to it being “invisible to others”. They describe the battle of the irrational aspect of the eating disorder and the logic surrounding recovery, and adhering to the eating disorder despite it “trying to ruin your life”. They describe “believing the lies” of the eating disorder and a pursuit for happiness in relation to weight loss despite knowing this is not true. They describe the eating disorder as “destroying” many aspects of their life such as friendships and their own personality, and making it very difficult to maintain employment or hobbies. They discuss the negative physical aspects of the eating disorder such as lack of concentration and energy. The eating disorder is also described as a “parasite in your brain”, and the conflict of it being both your friend and your enemy. The eating disorder voice was described as it being their own voice, however it is “commanding and critical” and difficult to stop due to it becoming stronger if you ignore it. They also expressed experiencing other multi-sensory experiences such seeing, hearing and feeling things in the context of flashbacks, dissociation, stress and cognitive impairment due to malnutrition, which is different to her “daily eating disorder voice”.

	Observations/tone – the ED as a changing relationship – would describe it differently at different points of her eating disorder. Imagery of a war that is invisible to others. The struggle between the truth/logic vs irrational thinking/lies – “selling me lies”. Imagery of making setbacks in recovery - “fall into that hole one too many times” – can link to believing the lies. Imagery of the EDV being parasite. The idea that it is isolating as it is invisible and internal.
5 (Qualtrics)	This data is from participant 5, aged 23 years old. Their eating disorder is described as being a separate entity that “takes over”. They describe their eating disorder as involving “compulsion eating” and how they would lose control during these times. They described themselves as a “prisoner, just watching” and not being able to stop themselves. They then describe their experience with anorexia, and how it was a “snake”, “demon” and “dictator”, instructing her and “whispering on my ear intrusively”. Their experience of hearing voices was described as “vivid” and “intrusive”. They described it having control over them and having to adhere to it. There was a focus on calories and nutrients and when they should or shouldn’t eat. They also described other multi-sensory experiences of seeing their body expanding following eating and feeling “heavier”, and feeling “lighter, smaller and skinner” following not eating. Observations/tone – Imagery of snake/demon/Dictator vs Prisoner. Body dysmorphia experience – comparisons to others and how she views her body impacting how her body feels (bigger when eaten, smaller and lighter when she hasn’t).
6 (Qualtrics)	This narrative is from participant 6, aged 22 years old. They described the eating disorder voice as being in control as they decide what she eats, in contrast to this she reflects on how she is losing control over herself. The eating disorder voice holds a power over her, it makes her think that she is unlovable, undesirable, and other people in her life, e.g.

friends and family, hate her even if she loses weight. The feelings of shame she has held onto about her body overtime have caused her self-esteem to lessen. Finally, she talks about what the EDV has taken away from her in life – her ability to be social, and her academic abilities.

Observations/Tone - It is evident that this is a current difficulty with the use of present tense, and the overpowering nature of the eating disorder voice has over time impacted her thoughts, behaviours and self-esteem.

7 (Poem)

This narrative is from participant 6, aged 22 years old. The use of popular phrases within this poem like “nothing tastes as good as skinny feels” demonstrates that the influence media and the diet culture has impacted on this individual’s narrative and potentially contributed to them developing an eating disorder. These messages have been internalised and she suggests that these messages are the only ones that the eating disorder voice knows. The eating disorder has caused a heightened awareness of her body, in how it looks and feels, as she describes a need to hold secure her stomach to stop the “flesh bouncing”. Her method of coping with these overwhelming sensations is to control her eating and use purging techniques as she described her throat as being a burning tunnel. There is evidence of conflict within her narrative about trying to distance and separate herself and her identity from her EDV “I’m a problem, I’m a problem, It’s a problem”. The relationship with the eating disorder voice is compassionate and understanding as she calls the voice baby, almost as if to reassure it, as though it is a younger version of herself. There is no anger or resentment towards the eating disorder voice. This is evidence in her understanding that help offered won’t do anything and the voice has tried, the voice believes this is healthy and only knows the messages of the media. This is a current narrative experienced by the individual as they state “I don’t want to stay this way” but there is evidence that their behaviour does not match their wishes “Live like I am dying, dying to live”

	which could demonstrate a conflict or being stuck in a loop or cycle which even professional help cannot help them break currently. Observations/Tone - A compassionate and understanding relationship with the eating disorder voice that is then contrast by calling it a problem – this internal conflict about identity and separating self from the EDV could be a maintaining factor within their experience? The evidence of media influences is really clear within this narrative.
8 (Qualtrics)	This narrative is from participant 7, aged 22 who identifies as plural. They describe their experience of the EDV and difficulties with food as separate to their plurality. These members in their system provide them with advice and help them to calm down, they described the members as being responsible older figures in their journey. Within the narrative, it is evident that external influences such as media, or within their childhood may have shaped her perception of food as they label them as healthy, or unhealthy foods, and they restrict the number of meals they have a day as a method to compensate for potentially breaking these rules of what you should eat. Observations/Tone - black and white thinking – either healthy and unhealthy – how has that impacted them, if there is only a right and a wrong – how do they view themselves when they are “bad/wrong/unhealthy”
9 (Poem)	This narrative is from participant 7, aged 22 who identifies as plural. The poem has a focus on the sounds that are commonly associated with the kitchen, with use of onomatopoeia words such as “hmmm” and “beep”. The kitchen and the sounds it makes are described negatively throughout, due to its level of noise and how this makes the individual feel overwhelmed. They therefore describe avoiding cooking any food in the kitchen, preferring to get food delivered instead. The theme of healthy vs unhealthy is present within the poem, expressing that “too much of anything can be unhealthy”, following describing them restricting their meals to try and rectify this. They then talk about “surviving” but not feeling “healthy”. They then

	list which foods they do not like so stay away from, which is a specific but varied list. Observations/tone – “surviving” rather than living -bare minimum. Wanting to avoid sounds/danger of a kitchen but also lots of food they don’t like. Potential guilt of getting food delivered, leading to restricting meals? – “okay”, “fine”, not very expressive terms
10 (Qualtrics)	This narrative is from participant 8, aged 22. This individual’s experience of the EDV shows that it has its own motives and intentions “it’s trying to kill me”. There is a description that shows that the EDV is a changing presence for her, sometimes it imitates her own voice and sounds like her, but the narrative omits how it sounds the rest of the time. She uses imagery within her narrative which depicts living with the EDV as a mental battle, which holds combatitive connotations, and hell which suggests an inescapable experience. Observation/Tone - the use of present tense shows that they are telling their story as it happens to them. There is a tone of helplessness, feeling trapped in this experience. The voice sounding like herself brings up ideas of how she can identify her self as separate from the EDV but this is quite a fluid process of the impact it has on her identity.
11 (Written piece)	This narrative is from participant 9, aged 21 years old. Her narrative explores the Eating Disorder voice which she states has controlled her life for the last 8 years. She reflects that at the beginning of her story that this voice saved her from the trauma and loss she experienced at this young age. A key part of her narrative in these early years is reflections on her critical parents being echoed by the EDV, she described the voice to often sound messy and jumbled that is critical of her abilities. The imagery through her piece demonstrates that the EDV has adapted for its survival over these 8 years. It has become a camouflaged, silent and invisible being to her that has slowly entwined itself with her own thoughts. In doing so, she has lost her own self and is unable to distinguish between her own thoughts and the EDV. She uses the imagery of

	two different colours of wool mixed together, which overtime have changed from contrasting colours to two shades of grey – impossible to distinguish. This has had an impact on her progress with recovery, as her confidence in being able to distinguish her thoughts causes self-doubt and a lack of trust in her own thoughts could have maintained her eating difficulties. It is evident that this is where this individual is currently at in their narrative – struggling to separate herself from the EDV and feeling unable to move on without it. There was a theme through the narrative of a fear that she would not be able to cope without the EDV, despite it never offering a comforting friendship to her. She states that without an Eating Disorder she doesn't know who she is, a weakness she feels the EDV weaponises and uses against her, placing doubt in her mind about her ability to recover and therefore increasing her reliance on the EDV. Observations/Tone - A query of whether she owes the voice something as it saved her when she was younger and this contributes to that being unable to let go of it now. There is a tone of feeling loss and helplessness within this piece, almost stuck in a cycle of recovery and self doubt which is controlled by the EDV.
12 (Qualtrics)	This narrative is from participant 9, aged 21 years old. At the time they submitted their story, it is evident that they are still struggling with understanding the voice, whether they would consider it a voice or just an extension of their own thoughts. It does not have a recognisable voice to her. She also describes hearing the voices of her parents in a critical tone due to past trauma, however it is unclear whether this is part of her EDV. Observations/Tone - What does not having this understanding cause – feeling anxious/scared/isolated? Navigating identity confusion alongside an eating disorder?
13 (Qualtrics)	This narrative is from participant 10, aged 21 years old. She describes a confusion and a conflict in trying to separate the EDV from her self. Sometimes she can attribute the voice sounding like her critical parents which

relates to trauma she experienced, whereas other times it can be a generic voice. She describes that they are her thoughts but not in her own voice.

Observations/Tone - this demonstrates that the voice may change frequently in how it is experienced/heard. The tone suggests a lack of clarity in navigating the relationship with the voice, and her identity outside of the EDV.

14 (group discussion)

P1

This narrative is from participant 11, aged 21

This participant begins by expressing that she "considers herself recovered", suggesting at this point she is not experiencing an active eating disorder. She describes first experiencing voice hearing before developing an eating disorder. She describes how she missed out on stages of her life such as having to go to a different school when she was very unwell and how this made her feel isolated. She uses the imagery of an eating disorder voice being like an "abusive partner", tricking you into thinking it is protecting you however this is not true. She described the eating disorder as being "destructive". She expressed how she experienced different voices at different times, however voices called "Adam" and "the scientists" were the ones that focused on food, with this being a part of a "bigger plan", aiming to protect her family from harm by being smaller and "dimming her light" so she could not be identified. The concept of identity was present during this narrative, as well as losing this identity as a result of the eating disorder voice. Losing the voices was compared to a "break up", and a feeling of losing its protection.

She reflected on the impact an eating disorder may have on others, that they may find it difficult to be around, and how it effected her socially. She expressed however that her parent is understanding of it due to her own issues with eating. The eating disorder was also described as a compulsive behaviour in response to threats, however she reflected that these now seem "ridiculous" when looking at them retrospectively. She described the eating disorder voice as having a "mind of its own", knowing what particular phrases may affect her and “parrots it back” to her. She described it being so powerful that she felt unable to say no to it. She also described the feelings of dissociation she felt when experiencing the eating disorder voice, not being able to pay attention or be fully present. She described not feeling able to relate to the metaphor or an eating disorder being a “fight” due to feeling as though it was a part of her so she would be fighting herself. However she can now reflect on how it was a “parasite” and separate to her, that affected her brain function and cognitive ability.

Observation/tone – identity strong theme throughout, both being part of her identity then losing it. Feelings of isolation and fear evident, through abusive partner comparison and responding to threats towards her and her family from the voices.

P2

This narrative is from participant 9, aged 21 years old. She describes her ED journey starting at 13 years old, when she had no-where else to turn and it felt like developing an ED wasn’t a choice, but it saved her from the current circumstances in her childhood that caused her to internalise diet culture and negative views on her body within her family. At the beginning, she experienced the EDV as a loud screaming voice, which she portrayed outwardly through anger – this anger pushed people away and made her feel isolated. She related to hiding in the dark and feeling frozen in time during early years of her eating disorder. She tells us about how the EDV didn’t want her to be comforted or cared for, so by pushing people away she became more reliant on the EDV for that comfort. Over time the EDV has changed to become sneakier, secretive and subtle, this has made it hard to separate her own thoughts from the EDV’s and can make her feel like she’s fighting something invisible. This change was mirrored in herself as she now hides her eating disorder from others due to shame and feelings exhaustion whereas previously wanted people to know and care. The longer this goes on the harder it seems for her to separate the EDV from her own self –

there is evidence of a loss of identity of who she is without the EDV. She feels that if she was to lose the EDV it would be like losing a part of herself and being incomplete without it, she compared this to feeling like a breakup. The feelings of helplessness have also increased the longer she has been trying to recover, she described it as constantly walking on a tightrope, with the tiniest thing tipping her back into an active eating disorder. She forgets what she has achieved in her recovery and is thrown back into these endless cycles and loops which reinforces the idea that recovery is uncertain and unstable for her. She described currently feeling trapped and suffocated within a bubble, isolated from the world yet hyperaware of what she is missing out on.

Observations/Tone – Clear that anger has been present throughout her journey, from being angry at others to now being angry at what the EDV has caused her miss out on. Combative tone – fighting it, the change in power dynamics within the relationship that standing up to it is key to recovery. Some of the language used shows this hatred “constant nagging”. “bitchy little self”. Yet this is balanced with being lost without it, and who is she without the EDV.

P3

This narrative is from Participant 7, aged 22. This individual identifies as being plural stating that they have experienced multiplicity since the age of 5. They describe that DID allowed her to play out the roles of different children their parents wanted them to be. Gaining their approval and coming to terms with the idea that they are not accepting of them seems to be an ongoing difficulty they are experiencing. They described their system as an internal family who have taken on the role as caregivers, which she reflects stems from the lack of care she received from their parents. Although positive, they also have strained relationships within their system, where they can be mutually abusive of eachother, almost repeating patterns of behaviour present within their childhood. Gaining understanding of their system has also been ongoing through their journey and in recent years through engaging with therapy they have been able to come to terms with it. An important feature in this journey for them has been other people also understanding them and this helping to manage the internal conflict that they feel. However, this is not resolved for them and the stigma associated with being plural is an ongoing battle for them. For example, they have not been able to discuss with their parents and they do not offer support in terms of accepting them and their plurality. Although many people in their life are understanding, they have experienced others manipulating them by use of her triggers or knowing how to manipulate certain alters within their system. This has resulted in them becoming more guarded around others, and a reluctance to discuss their experience of multiplicity openly.

In terms of their eating difficulties, they were able to label experiences in their childhood which has caused them to develop a fear of starvation. To manage this overwhelming fear, they are now constantly thinking about food and described almost being overprotective to ensure that the same experiences don't happen again. A lot of the imagery used to describe their binge eating had connotations of being animalistic calling them rampages with no control or memory of it happening, with the urges being relentless and consistent as if constantly yearning for food. They are then reliant on their system to regain that control through the rules and rituals they have in place for them. They describe after the eating has taken a place, a shame and guilt from the realisation of what has happened. Especially about the impact their behaviours has on the system, as they feel they are frustrated by her existence, a pet that they tolerate. They described themselves using this analogy of being a dog on a leash, that the system sometimes loses control of and they drag the system around. However, their relationship with their system is one of gratefulness, the system know that they are more than their EDV and that the system is not fighting them but instead fighting something inside of them. She uses the imagery of a parasite, something that has infected her and taken over control, and causes this animalistic behaviour she experiences. This is contrasted with their own views of being able to separate themselves from the EDV and no longer being able to recognise themselves, a sense they are the EDV. This is mirrored by their sense of responsibility for the EDV thinking "Am I the problem, Am I crazy". This seems to be where this system is currently at in terms of their narrative having a sense of responsibility to make a change but feeling stuck on a tree, wanting to get to safety but don't know where to go or how to get there. Trapped in this reliance on their system, and shame and guilt on doing so.

Observations/Tone - There is a clear impact on this individual's identity and self esteem, which could stem from childhood and their relationship with their parents. How they have described themselves as an animal in their behaviours, and lesser than human. In some parts they are able to separate themselves from this idea, that the EDV is instead that animal, a parasite that has taken over, but the responsibility, shame and guilt they feel for the impact this has on their system keeps them trapped in this cycle. The idea that they are currently stuck in this loop is portrayed in their imagery of being stuck in a tree, that their system is offering a sense of safety but this is almost disguised protection and cannot fully prevent them from the rampages they continue to experience.

15 (Written text on infographic)

There is a focus on emotions caused by the EDV – "angry", "fearful", "exhausting", "helpless". Negative words are used to describe it – "toxic", "abusive", "sneaky" vs some positive terms – "protective". Theme of isolation is present – "cut me off from family an friends", "it wont let me explain how I feel". There was evidence of some personal responsibility of recovering from the illness – "I know I need to help myself" vs feelings of not being able to "trust myself" making recovery difficult. EDV is described as both an internalization of things said to you "I grew up with diet culture all around me" and a compulsive behaviour "it told me I needed to be smaller, to shine less brightly to protect my family". How the EDV has affected others has

	also been expressed and how this affects self-esteem – "I don't deserve to be loved". Feelings of loss when losing the EDV were also described. The experiences of the EDV within a system of personalities was also described.
16 (Images on infographic)	Theme - Isolation Person by themselves – isolated from the group of people Person in a bubble Theme – What others tell you Sun Magazine Theme – being responsible for recovery Holding a broken heart together A pin Theme – Being in disguise/sneaky Wool showing the imagery of identity being lost Ninja

Figure 1

Flowchart illustrating the data collection processes of the project

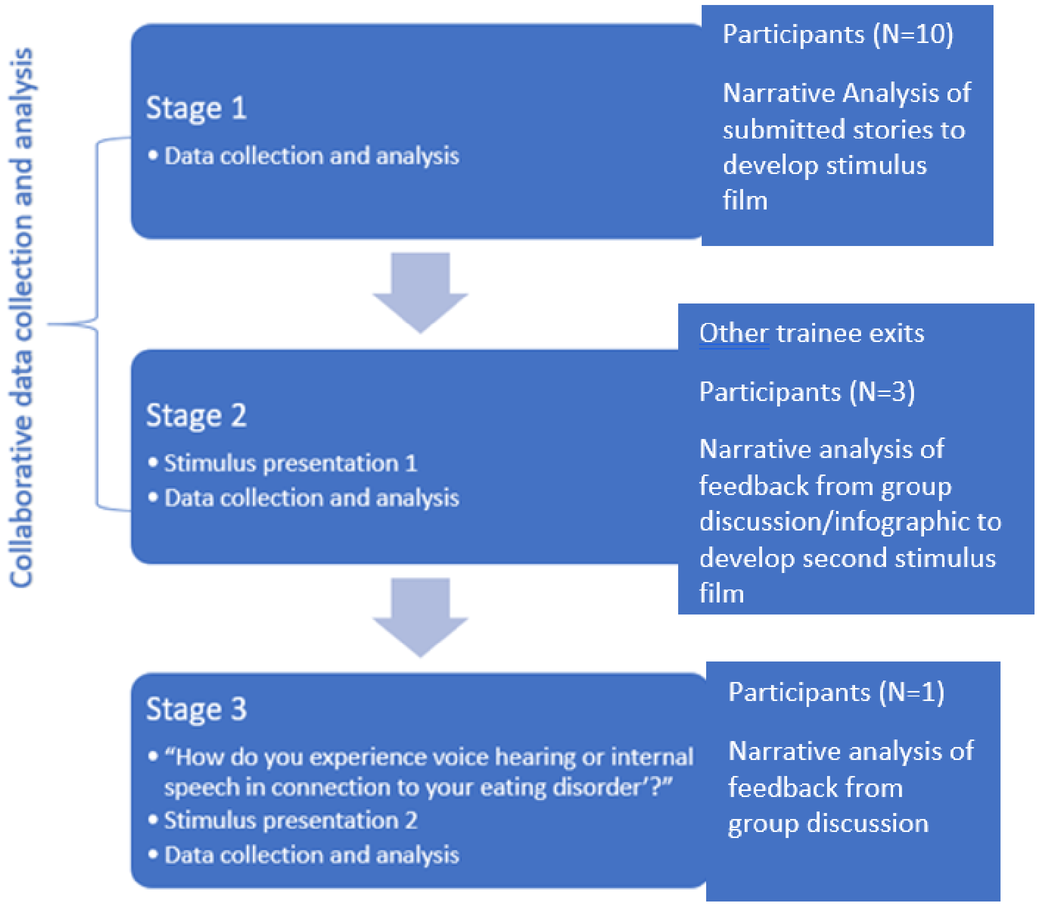


Figure 2

Flowchart illustrating participants' journey throughout the project

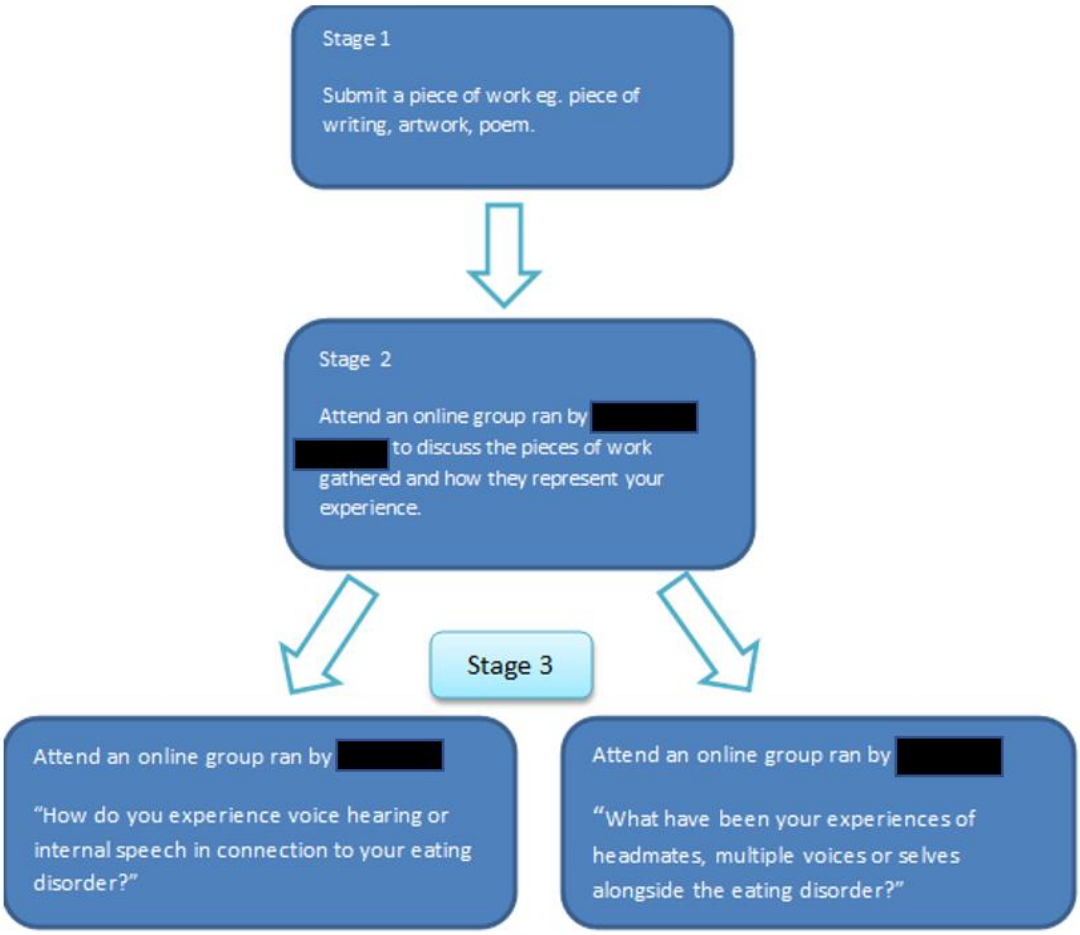


Figure 3

Infographic developed by the live illustrator during the first group discussion

Appendices

Appendix 1: Advertising materials

Appendix 2: Stimulus film used within group discussions

Appendix 3: Distress protocol

Appendix 4: Qualtrics Questionnaire

Appendix 1

Advertising posts on social media used to recruit participants during stage one and two

Exploring Voice Hearing in Eating Disorders

Postgraduate research project

Any questions, contact [redacted]

Survey link

16-25 years old? Do you also identify as a woman?

Experienced hearing voices, feeling more than one self or another multi-sensory experience?

Have you ever lived with an eating disorder?

We want to hear from you!

Exploring voice hearing and eating disorders with girls and young women

4th July 2023, 7:00-8:30pm

A live illustration webinar with Emma Paxton

@EDVStudy

Do you identify as female?

*

Aged 16-25?

*

Have you heard a voice or voices during an eating disorder?

*

Email

[redacted]

We are trying to learn about the 'Eating Disorder Voice' with young women to inform options for support. If you share this experience, please join us for a live illustration webinar with Emma Paxton and researchers from Lancaster University to see how collective stories of experience can inform research. Attendees will receive an e-copy of the illustration shortly after the event.

Further information: https://www.lancaster.ac.uk/health-and-medicine/research/eating-disorder-voice/

Appendix 2

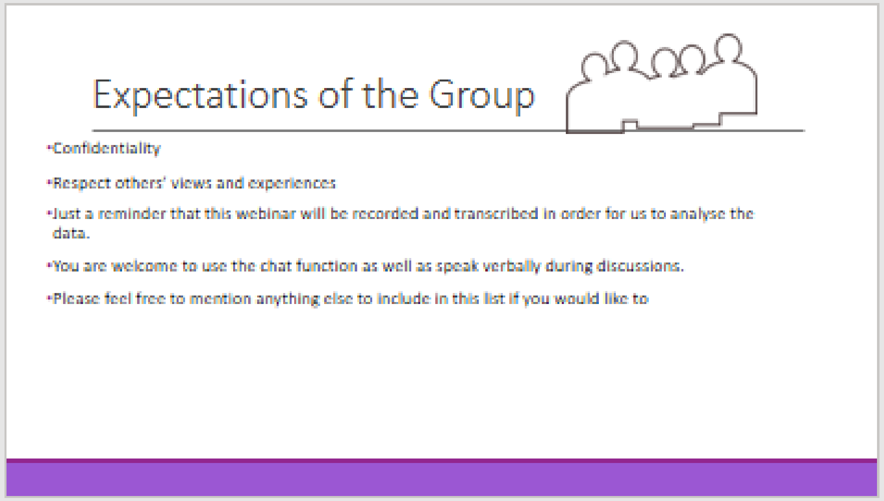
Stimulus film used for the two group discussions

Exploring Voice Hearing and Eating Disorders with Girls and Young Women

Lancaster University

Voice Collective

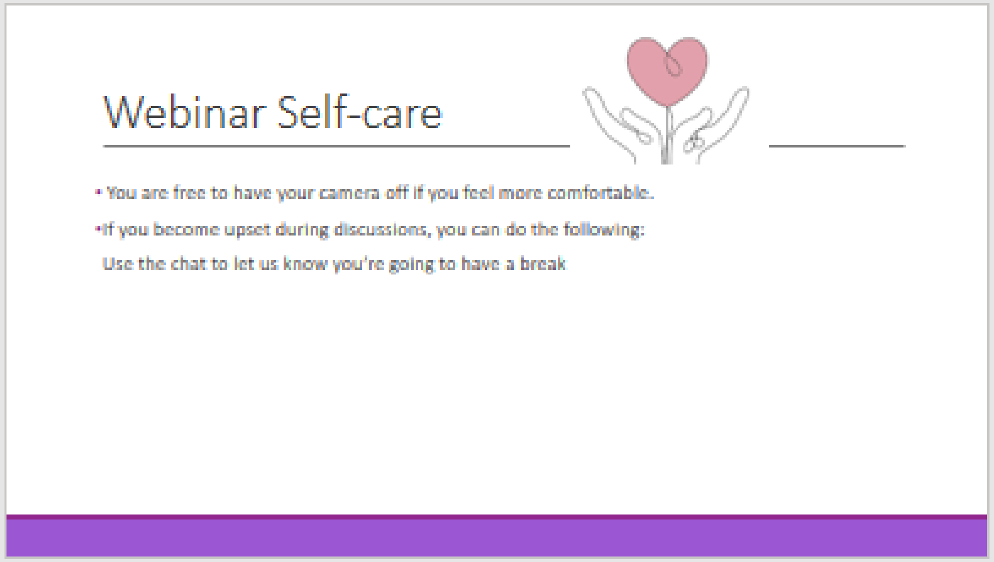
1



Expectations of the Group

- Confidentiality
- Respect others' views and experiences
- Just a reminder that this webinar will be recorded and transcribed in order for us to analyse the data.
- You are welcome to use the chat function as well as speak verbally during discussions.
- Please feel free to mention anything else to include in this list if you would like to

2

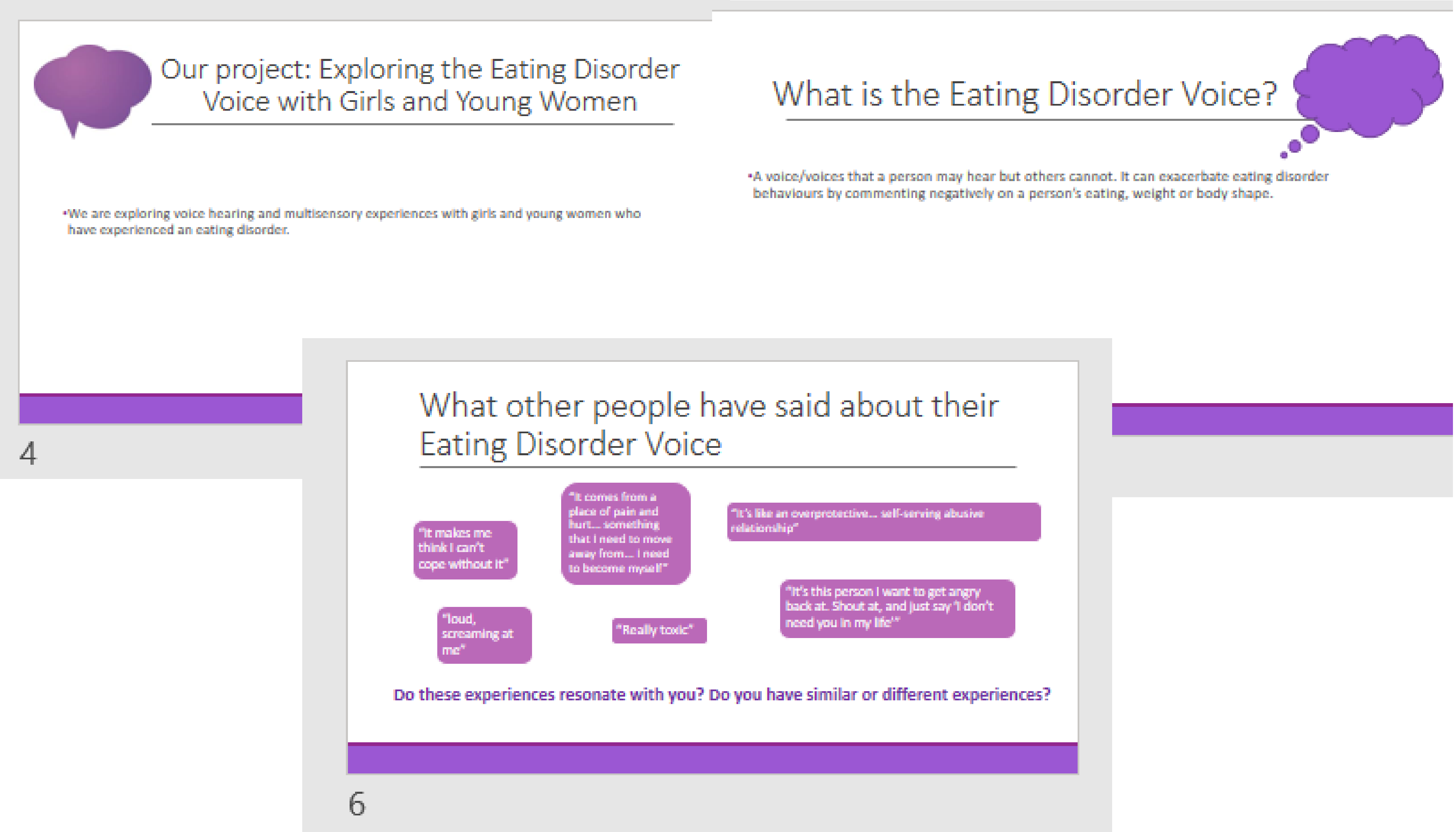


Webinar Self-care

- You are free to have your camera off if you feel more comfortable.
- If you become upset during discussions, you can do the following:

Use the chat to let us know you're going to have a break

3



Our project: Exploring the Eating Disorder Voice with Girls and Young Women

- We are exploring voice hearing and multisensory experiences with girls and young women who have experienced an eating disorder.

What is the Eating Disorder Voice?

- A voice/voices that a person may hear but others cannot. It can exacerbate eating disorder behaviours by commenting negatively on a person's eating, weight or body shape.

What other people have said about their Eating Disorder Voice

"It makes me think I can't cope without it"

"It comes from a place of pain and hurt… something that I need to move away from… I need to become myself"

"It's like an overprotective… self-serving abusive relationship"

"loud, screaming at me"

"Really toxic"

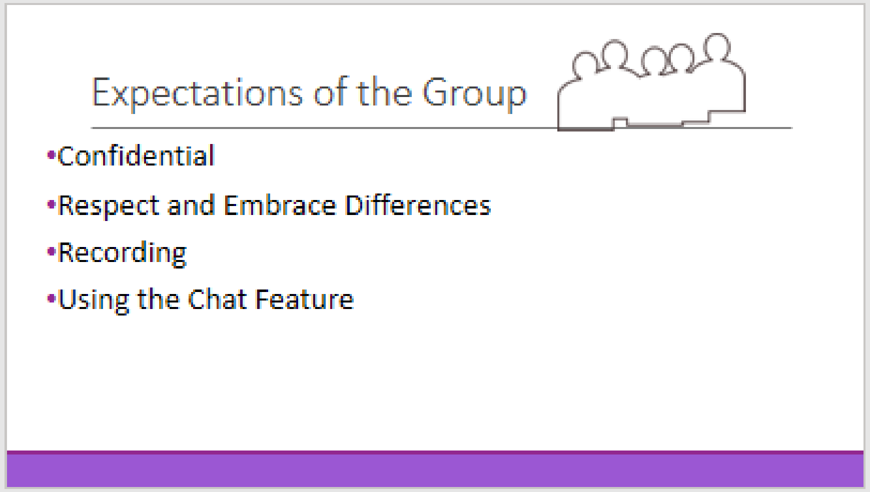
"It's this person I want to get angry back at. Shout at, and just say 'I don't need you in my life'"

Do these experiences resonate with you? Do you have similar or different experiences?

Exploring Voice Hearing and Eating Disorders with Girls and Young Women

Lancaster University

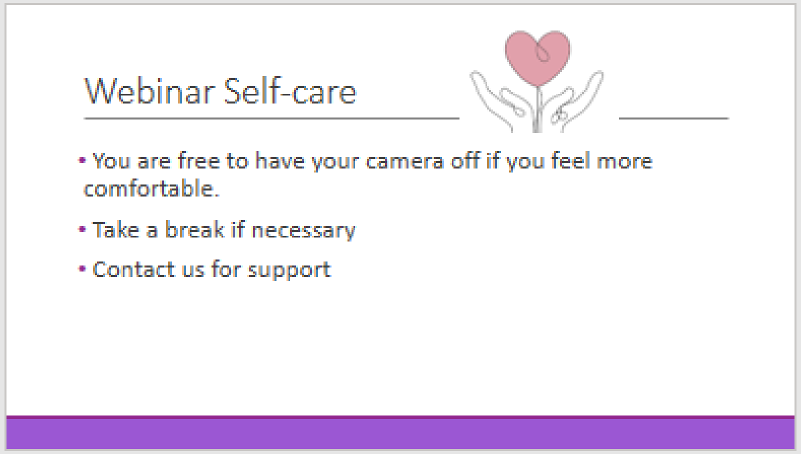
1



Expectations of the Group

- Confidential
- Respect and Embrace Differences
- Recording
- Using the Chat Feature

2



Webinar Self-care

- You are free to have your camera off if you feel more comfortable.
- Take a break if necessary
- Contact us for support

3

Findings from last webinar and submitted reflections about the EDV

Both a separate entity and a part of me

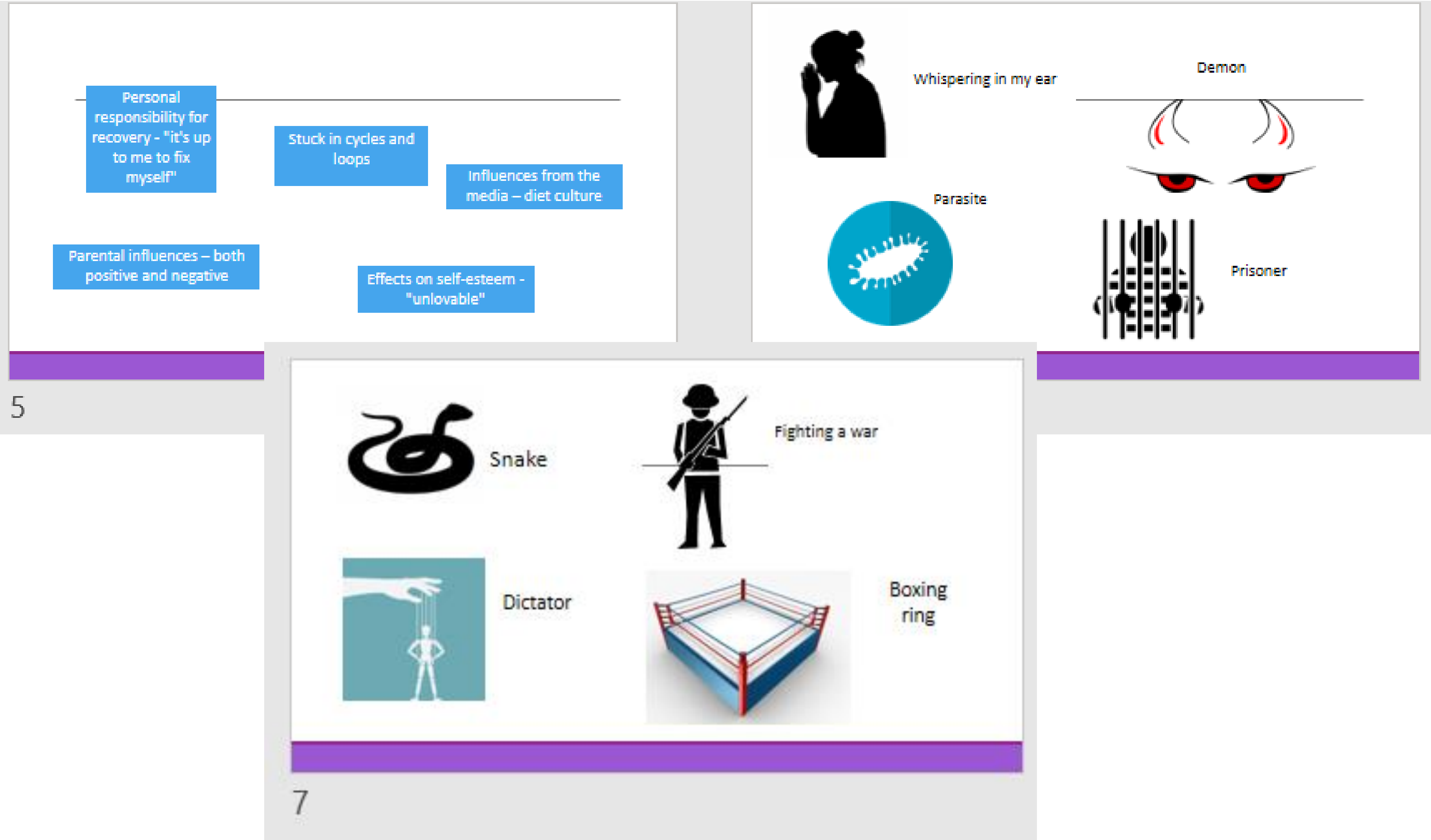
Both your friend and your enemy

All consuming - affects social life, academic ability and employment

Some level of compassion towards it

Loss of identity

4



Personal responsibility for recovery - "it's up to me to fix myself"

Stuck in cycles and loops

Influences from the media – diet culture

Parental influences – both positive and negative

Effects on self-esteem - "unlovable"

Whispering in my ear

Demon

Parasite

Prisoner

Snake

Fighting a war

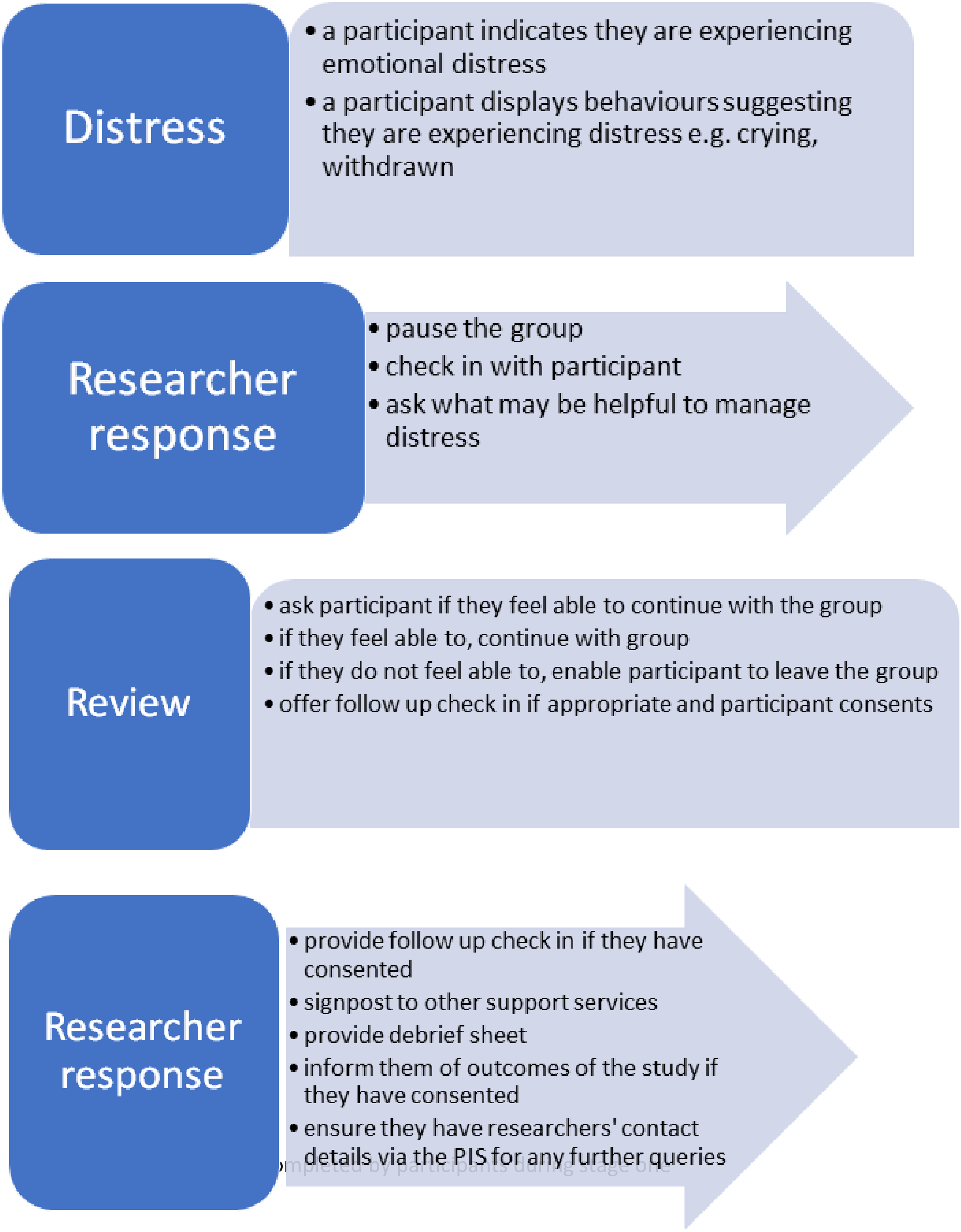
Dictator

Boxing ring

Appendix 3

Distress protocol used during stage two and three

DISTRESS PROTOCOL: MANAGING DISTRESS WITHIN A RESEARCH FOCUS GROUP



Distress

- a participant indicates they are experiencing emotional distress
- a participant displays behaviours suggesting they are experiencing distress e.g. crying, withdrawn

Researcher response

- pause the group
- check in with participant
- ask what may be helpful to manage distress

Review

- ask participant if they feel able to continue with the group
- if they feel able to, continue with group
- if they do not feel able to, enable participant to leave the group
- offer follow up check in if appropriate and participant consents

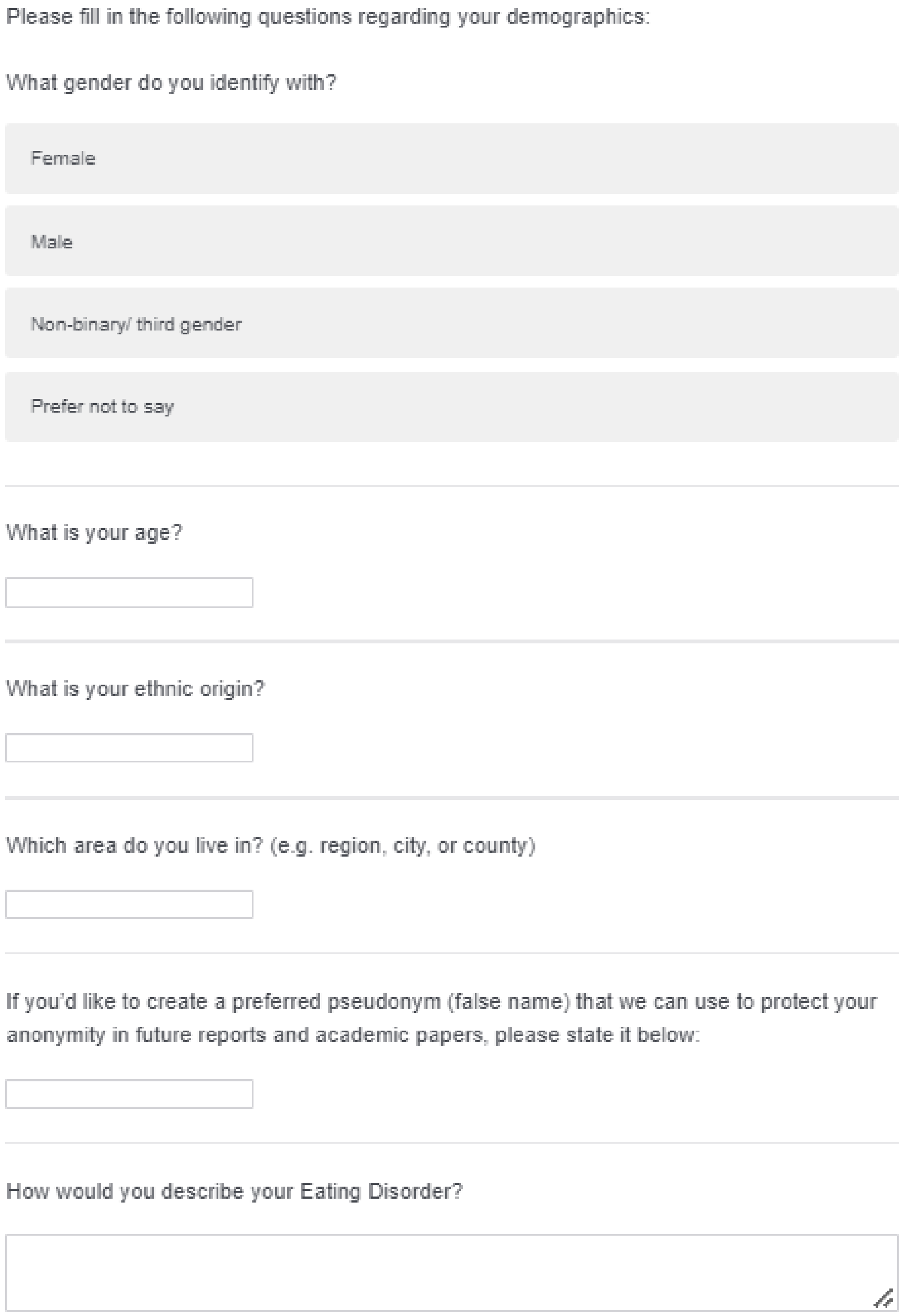
Researcher response

- provide follow up check in if they have consented
- signpost to other support services
- provide debrief sheet
- inform them of outcomes of the study if they have consented
- ensure they have researchers' contact details via the PIS for any further queries

mpleted by participants during stage one

Appendix 4:

Qualtrics Questionnaire completed by participants during stage one



Please fill in the following questions regarding your demographics:

What gender do you identify with?

- Female
- Male
- Non-binary/ third gender
- Prefer not to say

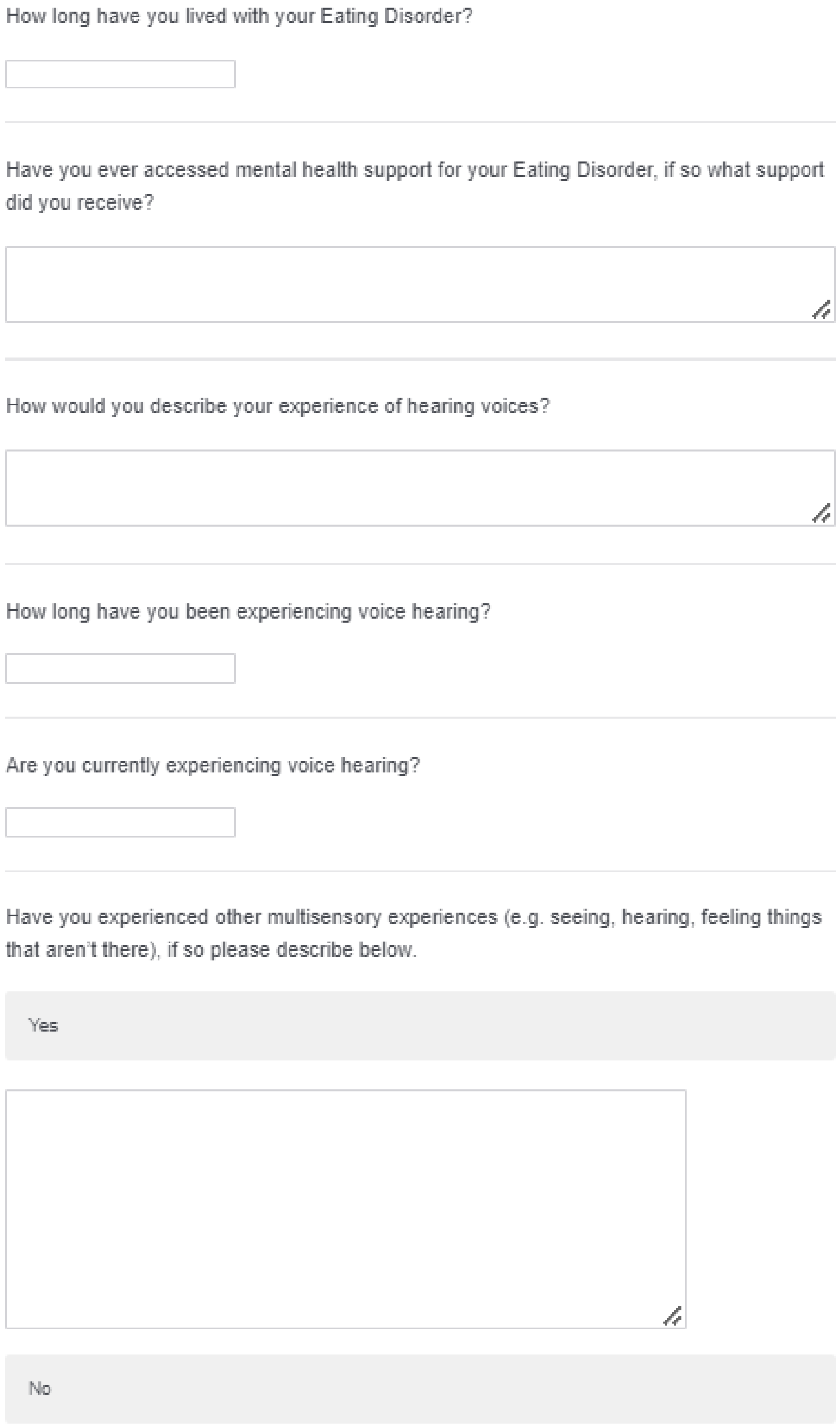
What is your age?

What is your ethnic origin?

Which area do you live in? (e.g. region, city, or county)

If you'd like to create a preferred pseudonym (false name) that we can use to protect your anonymity in future reports and academic papers, please state it below:

How would you describe your Eating Disorder?



How long have you lived with your Eating Disorder?

Have you ever accessed mental health support for your Eating Disorder, if so what support did you receive?

How would you describe your experience of hearing voices?

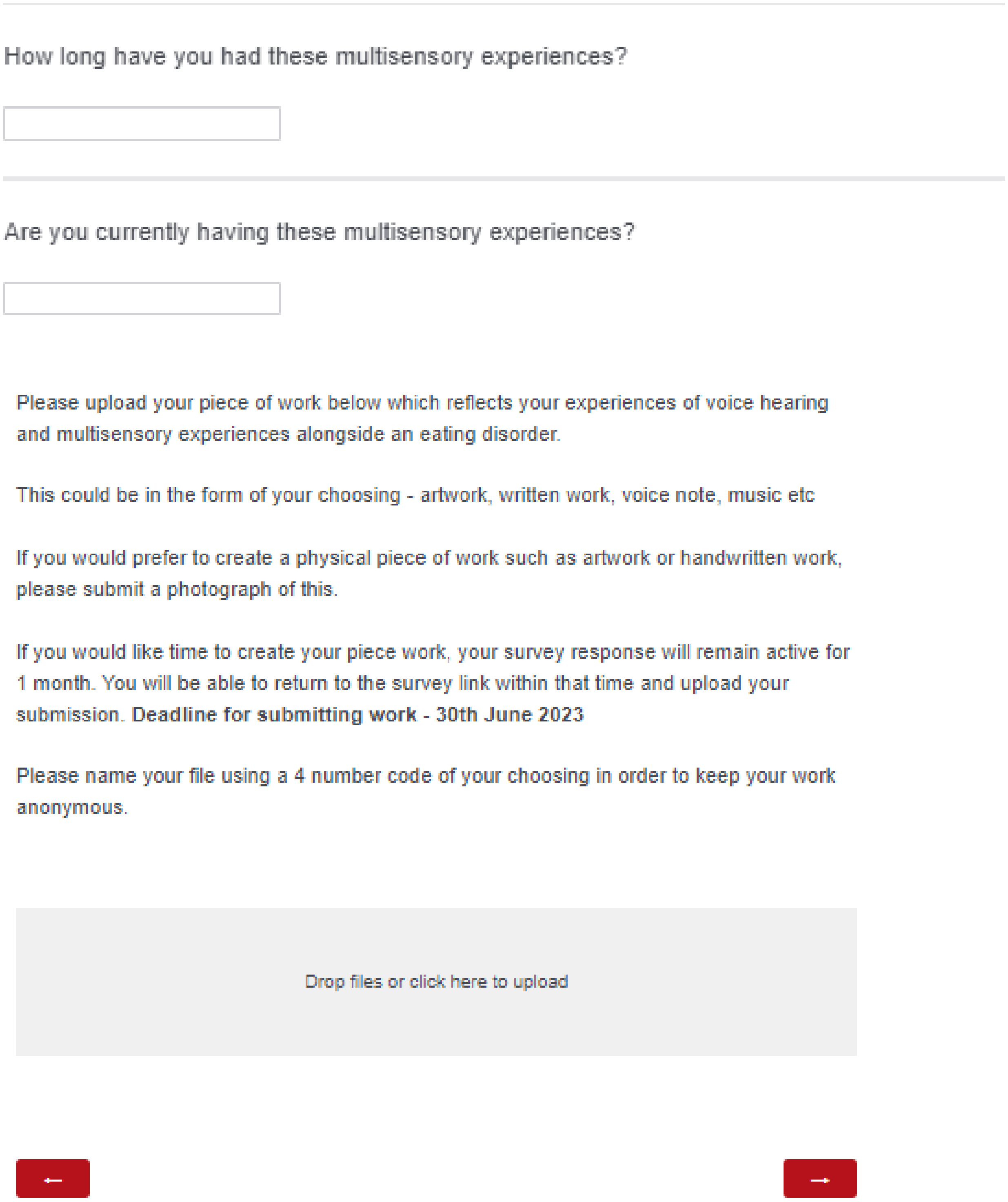
How long have you been experiencing voice hearing?

Are you currently experiencing voice hearing?

Have you experienced other multisensory experiences (e.g. seeing, hearing, feeling things that aren't there), if so please describe below.

Yes

No



How long have you had these multisensory experiences?

Are you currently having these multisensory experiences?

Please upload your piece of work below which reflects your experiences of voice hearing and multisensory experiences alongside an eating disorder.

This could be in the form of your choosing - artwork, written work, voice note, music etc

If you would prefer to create a physical piece of work such as artwork or handwritten work, please submit a photograph of this.

If you would like time to create your piece work, your survey response will remain active for 1 month. You will be able to return to the survey link within that time and upload your submission. **Deadline for submitting work - 30th June 2023**

Please name your file using a 4 number code of your choosing in order to keep your work anonymous.

Section three: Critical Appraisal

Critical reflections on a systematic review and research project exploring stigma and the eating disorder voice

Word count: 3972

Trainee Clinical Psychologist

Doctorate in Clinical Psychology

Lancaster University, Lancaster, UK

Critical Appraisal

Within my thesis so far, two pieces of work have been presented. The first was a systematic literature review exploring how stigma can influence help-seeking for eating disorders. The second was a research project exploring the eating disorder voice within girls and young women. The aim of this critical appraisal is to reflect on the process of completing both pieces of work, review their strengths and limitations, and highlight clinical implications and areas for future research.

Critical reflections on the research project

The purpose of the research project was to explore inner-speech and voice-hearing experiences within the context of an eating disorder, often termed the 'eating disorder voice' (EDV) (Noordenbos & van Geest, 2017). The project aimed to inform eating disorder guidelines and interventions, due to current interventions being insufficient (Mitrofan et al., 2019; Murray et al., 2019), often focusing on physical presentation rather than psychological factors (Byrom et al. 2022; Eiring et al., 2021). The stories of ten young women with lived experience of the EDV were elicited using an experienced-based co-design (EBCD) informed method. The study comprised of three stages. The first stage involved obtaining multi-modal data from participants which detailed their individual experiences. The second and third stage involved online group discussions, where participants were shown a stimulus film and provided feedback. These layers of data formed an emancipatory narrative of participants' experiences of the EDV. Data was analysed using narrative analysis. The project findings suggest that the EDV is a significant part of an eating disorder, experienced by participants as both a separate being and mirroring their own voice, incorporating elements of both inner speech and voice-hearing. The EDV appears to have control over several areas of daily life, often consuming participants' identity, which can maintain eating disorder behaviours and poses a barrier to recovery. Despite the EDV appearing to be a primary factor within participants' eating disorders, the psychological elements encompassing an eating disorder, namely the EDV, were reported to be dismissed by services. Instead, physical presentation (i.e. weight and BMI) were the focus, resulting in the eating disorder continuing.

Strengths, limitations, and future research

Types of data collected

The findings of this research project contribute to the understanding of the under-researched phenomenon of the EDV, using the lived experiences of young women. Inviting participants to submit differing modes of data within the first stage of the project allowed for richer data to be elicited. However, within the project, participants only submitted written data. This data remains to be valuable, providing unique insight into the poorly understood concept of the EDV. Written data is also arguably less subjective when conducting analyses, compared to artwork, for example. Although, obtaining other data such as participant-created images may have been an even more powerful and novel contribution to enhance understanding around the EDV. Reasons why participants only chose to submit written data is unclear. The creation of visual images and artwork can elicit feelings of vulnerability (Wilcox, 2017), compounded by the knowledge that it would be viewed by others. It could be that this added vulnerability was a barrier to participants, particularly as this was the first stage of the research project, so there was not yet an opportunity to meet with them. Future studies could perhaps aim to build rapport with participants before inviting them to submit visual data, which may allow them to feel more comfortable.

To increase data variation and develop richer understanding, the decision was made to have a live illustrator present within the first online group. The illustrator summarised the content from the group discussions into an infographic, which highlighted imagery used by participants when describing their experience with the EDV. Alongside the transcribed group discussions, this provided added novel data and the opportunity to use different frameworks to analyse the data (Collier, 2001), to develop overarching layers of understanding. The imagery was useful to identify important concepts emphasised by participants in relation to the EDV. Analyses of the written and visual data was synthesised to form a layered final narrative. Future research into similar poorly understood phenomena such as the EDV would also benefit from the inclusion of multi-modal data, to provide deeper understanding.

Recruitment and participant sample size

Initially, it was proposed that for the first stage of the research project, around 20 participants would be recruited. When beginning recruitment, it became apparent that this process may take time and pose a relative challenge due to a lack of engagement when promoting the research project on Twitter. Lack of engagement may have represented the barriers faced by people with eating disorders when engaging with research as well as treatment, such as fear of stigma (Mitrofan et al., 2019; Tsong et al., 2023) or feelings of shame (Ali et al., 2020; Potterton et al., 2020), compounded when experiencing an added voice-hearing experience (Herpertz-Dahlmann, 2015; Miotto et al., 2010), such as the EDV. Additionally, Twitter may not have been the most effective platform to reach the desired younger audience. Instead, Instagram was used to promote the project and broaden the outreach, as well as a dedicated webpage and video promoting the project displayed on Lancaster University’s website and social media. The project was also promoted via a podcast episode. Through expanding recruitment methods, there was a definite increase in engagement and participant numbers recruited.

Despite the increase in participant numbers, the final sample size remained relatively small (N=10). Qualitative research often contains smaller sample sizes (Green et al., 2020), and the sample size felt methodologically appropriate and reflective of the explorative approach of the project, as well as practical when facilitating group discussions. However, the theoretical generalisability could be increased in further research by using alternative recruitment methods to reach a wider population. For example, recruitment through the NHS may increase the pool of potential participants. This project was also time limited due to it being a doctoral thesis, however if recruitment continued for longer, a larger sample size may also be obtained.

This project focused on young women's experiences of the EDV, as this population is affected most significantly by both eating disorders and the EDV (Noordenbos & van Geest, 2017; Ward et al., 2019), therefore this felt an appropriate population to begin with when exploring an under researched area. The majority of participants within the research project identified as White or White British. Further research could expand participant samples and focus on people from certain communities, such as other genders, cultures, and ages to capture other unique experiences, such as differences in EDV presentations or barriers faced when accessing support for an eating disorder, to further inform services and intervention design. As eating disorder interventions are often based on white women who are cisgender (Becker & Stice, 2017; Cook-Cottone et al., 2017), there is a role for clinical psychology as a profession to explore individual differences within eating disorders to ensure treatment is inclusive.

During the second online discussion in stage three of the research project, only one participant took part. This may have been a consequence of the recruitment strategy or due to attrition. However, this was not felt to majorly impact the findings, as data collected from this participant remained extensive and highly valuable, particularly surrounding the barriers they faced when accessing support for their eating disorder and EDV. Some attrition was anticipated as the project contained multiple stages. However, these stages were necessary to facilitate the EBCD approach, to identify 'touch points', which were emotionally significant for participants (Fylan et al., 2021) and facilitate the storytelling approach of the project. Although an incentive was provided to participants within individual stages, being entered into a prize draw to win £25, attrition was still a factor. There were limitations surrounding what incentive was feasible to employ due to the project being part of a doctoral thesis, having a limited research budget. Perhaps future research could provide an enhanced incentive to improve levels of attrition. Checking in more regularly with participants in between project stages may also be beneficial for future research, to maintain rapport and increase the likelihood of participants attending further stages.

Another factor that may have influenced attrition was the sensitive nature of the topic, although it remains important to explore the under researched concept of the EDV in order to inform treatment guidelines. A distress protocol was in place for both group discussions of the project, and researcher contact details were made available for participants to contact in between stages. However, perhaps an additional protocol could have been developed for use in between stages, to manage any potential distress.

In summary, issues surrounding recruitment and variety of data were overcome using novel methods such as different recruitment platforms and a live illustrator. These approaches remain a strength of the project, as it enabled the recruitment of participants who may not have been reached via usual methods, and the capturing of additional themes. Recommendations for future research include continued use of multi-modal data and increased diversity of participants, to further inform eating disorder guidelines and treatment in relation to the EDV.

Critical reflections on the systematic literature review

The purpose of the review was to explore how stigma may influence help-seeking for an eating disorder. A systematic review of three databases was conducted, yielding 14 qualitative studies detailing help-seeking experiences of people with eating disorders, and their experiences of stigma. A meta-ethnographic approach was used to synthesise the review findings. Three main themes were developed: (1) Familial Stigma, (2) Stigma faced from services, and (3) Societal and internalised stigma. These themes described different circumstances where people with eating disorders faced stigma. Stigma was found to influence help-seeking by facilitating the trivialisation of eating disorders and dismissal of psychological symptoms, therefore limiting treatment options. This led people with eating disorders to feel invalidated and unworthy of support, having little motivation to seek help and feeling pressure to recover on their own.

Strengths, limitations, and future research

Diversity of participants

As mentioned above and within the discussion of my review, further research should be conducted focusing on people with eating disorders of different genders, cultures and ethnicities, to explore types of stigma faced by people from minoritized groups, likely to be compounded by the presence of an eating disorder. The limited research focused on people with eating disorders who are gender-diverse identified gender-based stereotypes, such as symptoms being dismissed in those who do not identify as female (Hartman-Munick et al., 2021). This was also demonstrated within my review, with men with eating disorders describing the feminine branding of eating disorders and the subsequent dismissal by healthcare professionals (Corcoran et al., 2021; Malova & Dunleavy, 2022). It seems that, even within recent eating disorder research, people who do not fit the gendered stereotype of an eating disorder often feel disregarded. Therefore, importance is emphasised for future research to explore specific barriers to help-seeking for an eating disorder within people who are gender nonconforming. Hartman-Munick and colleagues (2021) also identified racial stereotypes within the context of eating disorders, such as the assumption that the illness is not present within Black people, indigenous people, and other people of colour. Similar findings were also present in my review, with people with eating disorders who were non-White facing cultural insensitivity from healthcare professionals (Goel et al., 2023; Tsong et al., 2023), such as symptoms being inappropriately attributed to people’s race or culture (Tsong et al., 2023). This was attributed to a lack of culturally-informed treatment guidelines. Again, recent research consistently demonstrates gaps in knowledge and poor help-seeking experiences faced by people from ethnic minority groups. Therefore, future research should focus on specific barriers faced by people from non-White cultures when help-seeking for an eating disorder, with aims to help address these barriers, inform treatment guidelines, and improve inclusivity and treatment outcomes.

Intersecting themes and complimentary findings within the research project and systematic literature review

When comparing the findings of my research project and systematic literature review, there were several cross-cutting themes. For example, familial influences appeared to affect the development and maintenance of participants' eating disorders throughout both studies. Parents' demonisation of certain food groups was a factor in the onset of some participants' eating disorders within the research project, whereas some participants' eating disorder symptoms were dismissed by families within the systematic review, deeming it as "body image concerns" instead of a mental health condition. Unhelpful guidance around eating and trivialisation of symptoms from families of people with eating disorders appeared to facilitate the normalisation and maintenance of the illness. These findings highlight the importance of promoting the recognition of eating disorders as a mental health condition, to validate people with eating disorders and promote help-seeking within families.

People with eating disorders also faced unhelpful narratives from healthcare professionals and services when seeking help. People within both studies described the use of insensitive and triggering language in relation to eating disorders, such as discussions around weight and diet. Within the research project, healthcare professionals reportedly labelled participants' eating disorders negatively, such as "severe and enduring", which diminished feelings of hope towards recovery. Intersecting negative experiences within services highlight a lack of understanding around eating disorders and appropriate support.

Experiencing stigma from others was also a theme across both studies, particularly focused on the physical presentation of people with an eating disorder. Participants across both studies described being rejected by eating disorder services due to not presenting as a low weight, again reflecting a lack of understanding around eating disorders and the psychological factors which encompass them. In addition, participants in the systematic review described developing eating disorder behaviours to avoid weight-based stigma, being praised by others for attaining the ‘ideal’ body type which motivated their continuation. Within the research project, participants also attributed the effects of diet culture, such as promotion of weight loss through social media, to be a factor in the maintenance of their eating disorder. It appears that across both studies, stigma around the ‘typical’ presentation of an eating disorder and normalisation of the desire to lose weight can hinder motivation and access to support, feeling “not sick enough” to warrant intervention. Therefore, public health messages should be promoted, portraying the damaging effects of physical stereotypes and diet culture on eating disorders to improve awareness and education within services.

Internalisation of experienced stigma was also identified across both studies. Participants described feeling isolated, shameful and a ‘personal responsibility’ to recover as a result of the stigma faced in relation to their eating disorders, seeing their illness as a ‘weakness’ they needed to overcome alone. This belief around recovery was often linked to cultural beliefs within participants in the review, whereas it appeared to be influenced by narratives from healthcare professionals within participants in the research project.

In summary, common themes across the findings of the research project and systematic literature review include the influence of family, experiences within services, and stigma. The intersecting experiences of participants reflect a lack of knowledge, trivialisation, and inappropriate support for eating disorders. This leaves people feeling less motivated to seek help, facilitating the continuation of their eating disorder. The themes above demonstrate the need for further education surrounding eating disorders, both in society and services, to emphasise their psychological complexity, combat stigma and improve treatment outcomes.

Clinical implications for eating disorder treatment

Therapeutic models to address the EDV

Findings from the research project demonstrated how the EDV was significantly impactful for participants. The EDV was described to use threats, prey on personal insecurities, and distort narratives obtained from others and services, severely impacting self-esteem. The EDV consumed participants' identities, facilitated the continuation of eating disorder behaviours and made the prospect of recovery seem unachievable.

Therefore, tailored interventions to address the EDV through talking therapies should focus on nurturing hopefulness, self-compassion and self-worth, and a self-identity beyond an eating disorder. This is particularly relevant for clinical psychologists who may work directly or indirectly with people with eating disorders. Therapeutic models which can be adapted for voice-based work may be effective to support people experiencing the EDV. For example, Compassion Focused Therapy (CFT) (Gilbert, 2009), when applied to voice-hearing, proposes the concept of "multiple selves", helping people differentiate between parts of them that arise when linked to negative emotions or events (Heriot-Maitland & Levey, 2021), and resolve internal conflicts using compassion (Gilbert, 2021). Considering the difficulties expressed by participants of being unable to distinguish themselves from their EDV, and the EDV's content often relating to previous negative experiences, CFT may be beneficial. CFT can also help combat feelings of shame (Gilbert, 2009), which is often elicited by the EDV and experienced within people who hear voices (McCarthy-Jones et al., 2015). CFT can help reduce self-criticism and increase self-compassion within people with eating disorders (Steindl et al., 2017), therefore using this model to combat the EDV may have added effectiveness. There is a role for clinical psychologists to deliver training on using CFT in eating disorder treatment, design or deliver interventions, and/or supervise clinicians who may be working with people with eating disorders.

Participants in the research project expressed feeling compelled to obey the EDV due to its perceived power. Therefore, other interventions to address the EDV could focus on the appraisal of the voice and strategies to challenge it. Applying a voice-focused lens to commonly used therapeutic models for eating disorders, such as CBT, may be useful. When used to support people experiencing voice-hearing, CBT can reduce the frequency and severity of voices, and voice-related distress (Pontillo et al., 2016). Strategies to achieve this include reducing the perceived power of the voices by challenging negative self-beliefs that may be fuelling the voice's power and compliance towards it (Van der Gaag et al., 2014). CBT can also help develop coping strategies and support emotional regulation to manage responses to the voices (Smailes et al., 2015). Within both the research project and systematic review, participants described that support for eating disorders can often be based on physical presentation (Byrom et al. 2022; Eiring et al., 2021). Therefore, a focus on the psychological elements encompassing the EDV and ways to manage it could be useful. Again, there is a key role for clinical psychologists to help facilitate change in how eating disorder treatment is assessed and delivered, whether this be in intervention design and delivery, training, or supervision.

An example of a technique that has been used across therapeutic models and within voice-focused contexts is chair work: the facilitation of dialogue between different voices or parts of the self, represented by the positioning of chairs (Pugh, 2019), with a view to enable therapeutic change (Pugh et al., 2021). Chair work can be effective for people who experience voice-hearing, allowing development of more assertive dialogue and reciprocation with the voices (Hayward et al., 2017), increasing perceived control and reducing distress (Longden et al., 2021; Steel et al., 2020). This could be a beneficial approach to address the EDV, due to the high levels of control it possesses over individuals. There has been limited research on the use of chair work within people who experience the EDV, although positive effects have been demonstrated, such as resolving internal conflict derived from the critical voice of the EDV (Dolhanty & Greenberg, 2009). It would be useful to develop this intervention further within the context of the EDV, to measure potential effects such as perceived control over the voice, as this appeared to be a significant element of the EDV. Clinical psychologists may again benefit by conducting research such as this, to inform eating disorder interventions and training for other healthcare professionals.

Addressing stigma towards eating disorders

Considering the influence of stigma identified across both studies, methods to address this would be beneficial to improve treatment options and quality of life for people with eating disorders. Research has demonstrated the positive effects of media coverage such as advertisements and social media campaigns specifically aimed at reducing societal stigma around mental health issues. A focus on dispelling myths surrounding mental health conditions and improving education can lead to enhanced public knowledge and decreased discrimination (Gronholm et al., 2017; Thornicroft et al., 2014). Education-based interventions, focused on addressing stereotypes and providing additional training, have also been effective in reducing stigmatising attitudes and practices within healthcare professionals in relation to mental health conditions (Henderson et al., 2014), as well as increasing empathy and knowledge. As participants across both studies described facing stigmatising views from both society and services in relation to their eating disorders, it would be beneficial to prioritise similar interventions specific to eating disorders, to challenge stereotypes and improve education. These interventions may also promote more appropriate treatment for eating disorders which address the psychological factors rather than relying on physical presentation.

When addressing self-stigma, approaches such as CBT, which aims to challenge stigmatising self-beliefs and enhance coping skills, can significantly reduce self-stigma, as well as improve self-esteem and likeliness to seek help (Mittal et al., 2012). Acceptance and commitment therapy (Hayes et al., 1999), in the form of a self-help intervention (Mills et al., 2020), can also combat self-stigma, specifically in relation to help-seeking, and improve negative emotions resulting from self-stigma such as anxiety and depression (Mills et al., 2020). Psychoeducation surrounding stigma (e.g. myths around mental illness, the impact of stigma), in the form of self-help (Mills et al., 2020) and delivered intervention (Yanos et al., 2012), can also improve levels of internalised stigma (Yanos et al., 2012) by enhancing understanding. The use of effective interventions to reduce self-stigma may be useful as an additional treatment option for people with eating disorders that present with internalised stigma, increasing their motivation to seek help.

Overall reflections

The experience of completing both my research project and systematic literature review has significantly enhanced my knowledge around eating disorders, the EDV and help-seeking. It has been challenging but simultaneously enlightening and rewarding. To structure my reflections usefully, I will refer to the guidance of Johns' (1995) Model of Reflection (figure 1).

Although the aim of my review was to explore stigma, the reality of how frequently it is experienced by people with eating disorders was concerning, and has promoted me to facilitate change wherever possible, including using this research. The presence of a voice alongside an eating disorder in the form of the EDV was also highly interesting to gain insight into during my research project. Hearing the stories of young women who experience the EDV has highlighted to me how much development is needed within eating disorder treatment to address maintaining factors such as this.

I have learnt a lot from both pieces of research and want to thank the participants who were involved for sharing their stories. I am keen for further research to be conducted to develop understanding within different communities, as this was not wholly achieved by this research. However, gaining more insight into the experience of an eating disorder and accessing support has motivated me to promote change on a systemic level wherever possible in my future research and clinical work.

Conclusion

My research project and systematic review identified that the presence of an EDV and perceived stigma within the context of an eating disorder can exacerbate eating disorder behaviours, impact self-esteem and pose as a barrier to recovery. Despite some methodological challenges around participant recruitment and sample sizes, the findings of the research remain valuable and useful to inform eating disorder research and interventions. Future research exploring the EDV and stigma using a larger and more diverse participant sample would be beneficial to further increase understanding. This research has provided a starting point to guide clinical practice and facilitate change into how eating disorders are understood and how best to support people. The findings have also highlighted the role for clinical psychology to broaden the interventions available to people with eating disorders, ensuring they are effective in addressing the important psychological elements, namely the EDV and perceived stigma.

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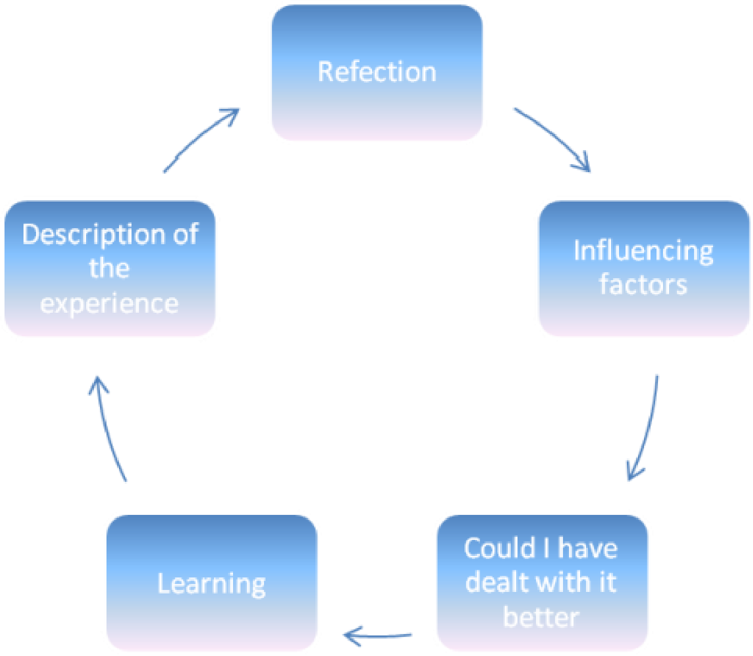
Tables and figures

Figure 1

Johns' Model of Reflection (Johns, 1995)



Section four: Ethics

Word count: 3436

Trainee Clinical Psychologist

Doctorate in Clinical Psychology

Lancaster University, Lancaster, UK

Thesis Proposal Form

Doctorate in Clinical Psychology | Lancaster University

This form should be completed in discussion with your research supervisor(s). Once completed please send it to your research supervisor to sign off before you submit it. The completed version of the form should be no more than 3,500 words (including the text on the form, citations and the reference section, but excluding your supervisor's comments).

Title

This should be a concise description of the study (max 15 words)

Exploring inner-speech and voice-hearing with girls and young women who self-report an Eating Disorder Voice

Date of proposal submission

10/08/22

Trainee Name

XXXXXX

Research Supervisor(s)

At least one of whom must be a member of the Lancaster University DClinPsy Research team

(add more rows if you have more than two supervisors)

Name	**Job role**	**Organisation/Address**	**Supervisory role** e.g. indicate whether theoretical, methodological, clinical expertise
XXXXX	Clinical Psychologist	Clinical Psychology, Health Innovation One, Lancaster University, Lancaster, LA1 4YG	Research Supervisor – theoretical and methodological

XXXXXX	Lecturer in Mental Health Nursing	King's College, London	Field Supervisor - Clinical and theoretical

Research Supervisor approval

To be completed by the primary research supervisor.

Comments	
Sarah has worked hard to develop a good understanding of the EBCD methodology and her topic area. We have discussed potential challenges throughout the project with stakeholders and this had led to a number of decisions at this stage: - To recruit through social media and peer support groups, which will be supported specifically through Voice Collective - To collaborate with XXXXX for the initial pool of data collection to develop a stimulus film, from which Sarah's individual approach to EBCD and data collection will follow. - To invite a range of contributions from participants to reflect the multimodal communication observed through peer support forums (e.g. poems, pictures, voice notes, etc.). Online participation in such studies has repeatedly proven more acceptable to participants than in person approaches.	
Name: XXXXX	**Date: 5.5.22**

Lay summary

A standalone 200 word summary of the study in non-specialist language. This should not include any references.

The study will look at how girls and young women with an eating disorder experience voice-hearing, known as an ‘eating disorder voice’. This voice can comment on a person’s weight and body shape, and can maintain the eating disorder. This can mean that support for an eating disorder may not be as effective.

This study will take place online, and participants will be invited to join through social media. Participants will send in a piece of work which shows their experience of an eating disorder voice. This could be writing, drawing or voice notes. It will be the participants’ choice what they would like to send in. This work will be made into a short film to show our findings. This film will be shown to participants, and they will feed back to us their thoughts on it. Another film will then be made using both the piece of work and the feedback. This film will again be shown to participants. They will again give their feedback on what they thought of it. This information will then be reviewed using a method called ‘narrative analysis’. This will aim to show the stories of the participants to help us understand the meaning behind them.

Summary of the research

This should be a concise summary of your proposed research, providing a clear rationale for the study and the research design. It is not intended to be a fully developed protocol (as for an ethics application) but should provide sufficient detail to enable the reviewer to assess the robustness and feasibility of the proposal.

1. Brief background/rationale

This should be a 500-700 word justification for why the study should be conducted, including references to key theoretical, research and policy literature and a clear rationale for your main research question(s) and for the relevance of the study to clinical psychology.

Inner speech can be defined as experiencing language in one's mind without articulation (Alderson-Day & Fernyhough, 2015). This is also referred to as inner speaking or an internal dialogue, as people often report their inner experience as being verbal (Baars, 2003). Voice hearing (auditory hallucinations) can refer to hearing a voice in the absence of another person speaking (Wilkinson & Fernyhough, 2017). Distinctions between inner speech and voice hearing are often difficult to define. Fernyhough (2014) suggests that when a person hears a voice, this may be in fact a production of inner speech, but this is not recognised by the brain. The voice therefore is experienced as coming from an external source. However, due to the subjectiveness of voice hearing and its many forms, there are differing arguments surrounding its explanation (Fernyhough, 2014).

Although voice hearing is commonly associated with psychosis and schizophrenia, this has been argued to be inaccurate (Fernyhough, 2014), with voice hearing also being experienced within other diagnoses. Presently, there has been little research on voice hearing occurring comorbidly with other disorders. For instance, voice hearing has been found to be present within eating disorders (Solmi et al., 2019), with significant correlations between the two (Solmi et al., 2018). Many girls and young women diagnosed with an eating disorder report hearing an 'eating disorder voice' which may remark on their eating habits and weight, and may encourage restriction or compensation (Pugh & Waller, 2017). The comorbidity of further potential psychiatric conditions within eating disorders can result in adverse prognoses, worsening severity and chronicity (Herpertz-Dahlmann, 2015). Despite this, comorbidity of eating disorders and voice hearing is under researched, particularly within young people, resulting in a lack of conclusive evidence (Mensi et al., 2020). It is likely that voice hearing within eating disorders may be missed by services, as the focus will be on their primary diagnosis. Therefore, my thesis project will explore the eating disorder voice with girls and young women who have an eating disorder, to capture lived experiences and how the eating disorder voice influences the experience of an eating disorder, with aims to inform aspects of treatment within eating disorder support services. Using experience-based co-design (EBCD) allows participants to be actively involved, using their lived experience to facilitate collaboration and provide richer data and understanding. EBCD can build new knowledge using participant's stories, promoting further understanding for services to take forwards. Using Narrative Analysis to interpret the data allows for an understanding of the stories of participants, and how this is constructed using their own experiences.

2. Research question(s)

This should be a brief statement of your main research question(s), following on from your rationale.

How are inner speech and voice hearing experienced by girls and young women who report an eating disorder voice?

3. Study design/methodology

Please state your overarching methodological approach, with brief rationale.

Data collection is to be partially completed alongside XXXXX (Trainee) as we will use the data collected in the first of three stages (detailed below) to create a common language for this programme of research. I will then conduct a second stage of data analysis and final layer of data collection and analysis to address my individual research question. By conducting recruitment and initial stages of data collection together, XXXXX and I can ensure the efficient use of the participants' time, reducing participant burden.

The methodological approach of this research will be Experience Based Co Design (EBCD), an approach that allows participants to share their stories and experiences to facilitate collaboration, provide richer data and promote further understanding for services to take forwards. Studies that have utilised EBCD report participants feeling "listened to" and included (Bowen et al., 2013), with EBCD providing the opportunity to understand their experiences on a personal level (Piper et al., 2012). This design uses a narrative approach which will enable us to develop new understanding of lived experience in an impactful yet respectful manner.

There will be three layers to the EBCD process:

Stage 1 – Completed with XXXXX (trainee)

Participants will submit a reflection of their personal experience of an eating disorder voice, and how this has influenced their eating disorder. This data can be multi-modal (e.g., written text, artwork, voice note, poem, etc.). They will be recruited through social media (via a study specific Twitter account) and peer support groups/networks (Voice Collective, Hearing Voices Network newsletter). A link will take participants to a Qualtrics page where they will be presented with an information sheet and consent form (appendix 1 &2). Participants will be advised to read the information sheet and will need to agree to the terms of the consent form to continue. Participants of stage 1 will also be asked whether they wish to be involved in Stage 2 and 3 of the research, with an option to opt in to be kept up to date with the research project and its outcomes. Participants will also be advised that they can withdraw from any stage of the study at any time and given instructions on how to do this, alongside a debrief sheet (appendix 3). Information about relevant helplines, coping with voices, and the phone number and email address of Voice Collective will be visible on every page of the Qualtrics survey to ensure participants can access support if needed.

Stage 1 is required to collect the first layer of data from participants, to explore how the eating disorder voice is experienced by individuals with an eating disorder. The novel opportunity for participants to submit multi modal data of their choice aims to increase the richness of the initial data which otherwise may not be elicited from standard interviews. The first layer of data collection will undergo narrative analysis to form a stimulus film of collective experiences and perspectives.

Stage 2 – Completed with XXXXX

Participants from Stage 1 who have consented to take part in stage 2 of the research will be taken through the consent process again (using a new information sheet and consent form; appendix 1 & 2) on a new Qualtrics link. They will then be invited to a live webinar, hosted via Microsoft Teams, facilitated by myself and XXXXX. They will be shown the initial stimulus film (via Microsoft Powerpoint or similar) and feedback to the film in the form of written notes and discussion will form the second layer of data.

Stage 2 is required to form the second layer of data, providing further in-depth information regarding exploration on how the eating disorder voice is experienced by individuals with an eating disorder. This will be facilitated through discussion around the personal reflections (multi-modal data) gathered, and how these collective experiences and perspectives represent their experience. This data will be analysed independently in relation to the specific research question of my individual project (detailed above).

Following stage 2, participants will be provided another debrief sheet (appendix 3) asked via a Qualtrics link/page to give general feedback following the session i.e. things that went well and things to improve on. They will also be asked their preference for which research question (myself or XXXX's) they would like to take part in for stage 3. This will then be considered when allocating participants to different groups for the second webinar for stage 3.

Stage 3 – Completed independently

Participants who have consented to take part in stage 3 of the study will be invited back to a second live webinar, hosted via Microsoft Teams, and facilitated independently. Using both layers of data, a final stimulus film will be developed specific to my research question. Feedback and discussion within the group will form the final data collection process. Discussions will be recorded and transcribed verbatim. All data will be analysed using narrative analysis.

Stage 3 is required to develop the third layer of data, specific to my research question: "How are inner speech and voice hearing experienced by girls and young women who report an eating disorder voice?". Further detail will be acquired, such as the participants' experiences of the sound, tone and content of the voices heard, how this may have made them feel and how this has influenced their eating disorder.

4. Participants

Who will your participants be? Inclusion/exclusion criteria? How many? Include justification of numbers and power calculation as appropriate.

Participants will be girls and women between the ages of 16-25 who self-report an eating disorder and experiencing an eating disorder voice. Up to 20 participants will be recruited during stage 1 of the study, and up to 12 participants will be recruited from those who have consented to participating in stage 2 and 3.

A small sample of participants will be invited to allow for in-depth data analysis, leading to a deeper understanding of experiences. Smaller discussion groups should afford participants the opportunity to speak in a welcoming and safe space, sustaining engagement.

5. Recruitment plans

Where will you recruit participants from? How many recruitment sites? Recruitment methods?

Stage 1 (completed with XXXXX)

- A study specific account on Twitter will be developed to act as an online platform for recruitment.
- Participants will be recruited via the Twitter account and peer support groups/networks (Voice Collective, Hearing Voices Network newsletter).

Stage 2 (completed with XXXXX)

- Participants from Stage 1 who gave consent to participate in stage 2 and 3 will be recruited, again using the Twitter account if required.

- Participants will self-select which research question they would like to take part in for stage 3 via a Qualtrics page (detailed above).

Stage 3 (completed independently)

- Stage 2 will be repeated for my individual study. Participants from stage 1 who consented to take part in stage 2 and 3 will be recruited for stage 3 via the Twitter account.

6. Data collection

Interviews, questionnaires, specific measures to be used etc., with a brief rationale.

Stage 1 (completed with XXXXX)

- Individuals will submit a reflection on their personal experience of an eating disorder voice. This reflection can be multi-modal data (e.g. written text, sketches, paintings, diary entries, voice notes, poem, etc.)

Stage 2 (completed with XXXXX)

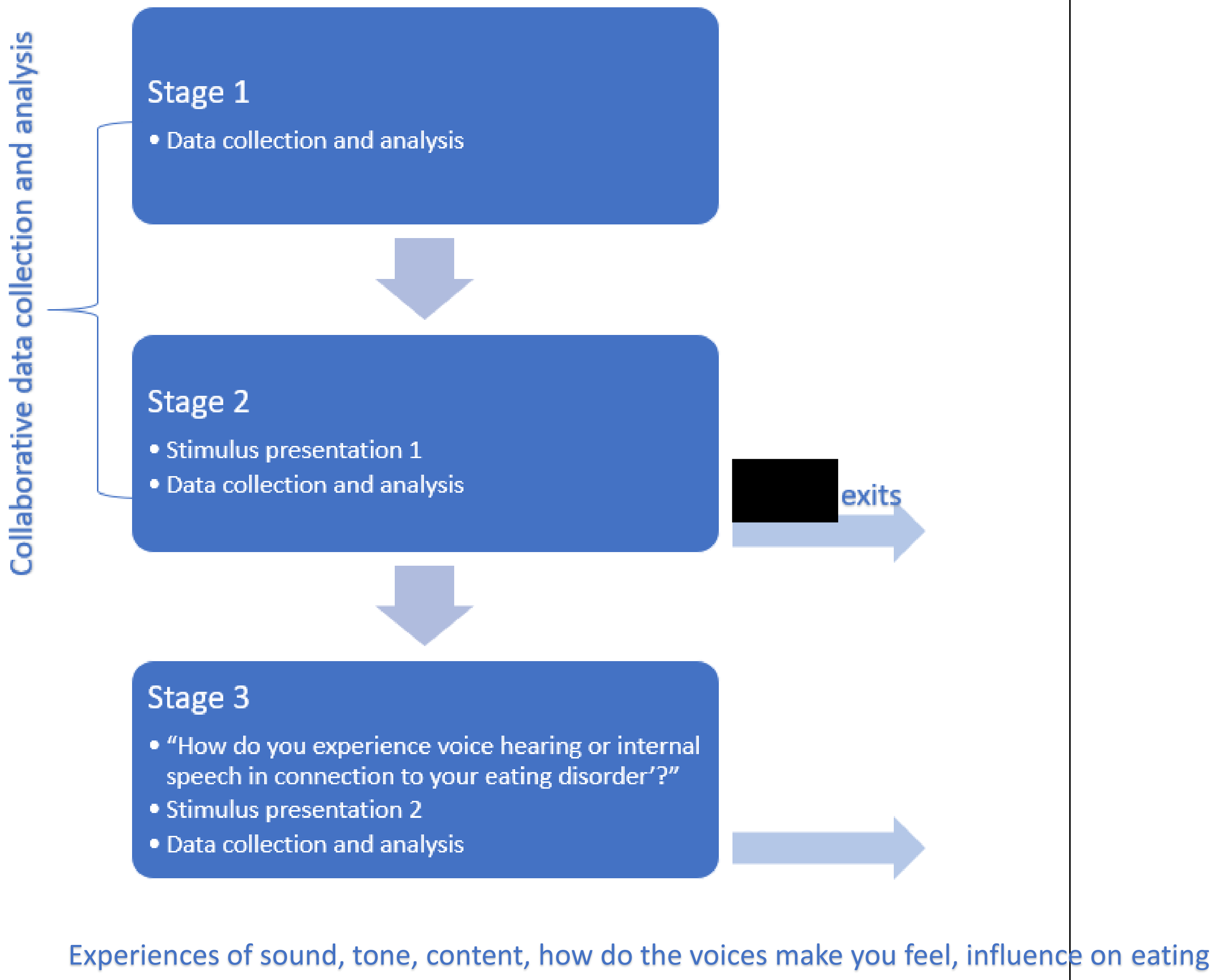
- Participant feedback to the stimulus film in the form of written text (Microsoft Teams chat) and discussion (recorded and transcribed verbatim) will form the second layer of data.

Stage 3 (completed independently)

- Feedback from participants after viewing the final stimulus film will form the final data collection process. Discussions will be recorded and transcribed verbatim.

Utilising multimodal data and participant feedback allows for richer data and facilitates an understanding of a complex experience which may not be able to be gained through other methods such as standard interviews.

Please see diagram below to further demonstrate the data process:



7. Data analysis plan

Please state what methods of analysis you intend to use, with a brief rationale.

All data will be analysed using narrative analysis. This compliments EBCD as it also involves eliciting individual's stories, helping individuals construct new narratives regarding their experiences. Narrative analysis allows for diverse and purposeful findings and interpretations as the focus can be on different principals, such as the structure and meaning of individual's stories

(Allen, 2017). Narrative analysis also uncovers the complex nature of individual's experiences, and how they make sense of this (Sharp et al., 2019).

Data analysis during stage 1 and 2 will take an explorative approach, using multimodal data and participant feedback to elicit initial interpretations. Data analysis in stage 3 will be specific to my research question, using participant feedback from viewing the second film.

8. Research governance approvals

What ethical and other research governance approvals will the study need e.g. NHS/HRA, University Ethics, other?

Approval from Lancaster University Ethics (appendix 4)

9. Particular research governance/ethical/practical/design issues

Please mention here any issues specific to the project that are likely to need particular consideration (e.g. risk issues, potential recruitment difficulties) and say how you plan to address them.

Some participants in the study could be vulnerable, reflecting upon distressing experiences. Measures to address this will involve an advisory distress protocol in place on managing difficulties, e.g. pausing the group if necessary, checking in with participants, asking what may be helpful to manage distress, signposting to other support services after the study, providing a debrief for participants, ensuring they are informed of the study outcomes if they have given consent. I will also discuss supportive approaches with individuals with lived experience e.g. Fiona Malpass (Senior Development Worker, Voice Collective), and circulate 'safe space principles' (e.g. confidentiality, respecting different experiences, awareness of what is shared) prior to the webinars, with a reminder at the beginning of the event, to maintain a safe space. Information about relevant helplines, coping with voices, and contact details of Voice

Collective will be visible on every page of the Qualtrics survey to ensure participants can access support if needed.

All participatory materials will be adapted for online participation. Participants will be required to read the information sheet to complete the consent form. Participants will not be able to progress to the study pages until the consent form is complete. My contact details will be available on each page if participants have questions at any stage.

10. Service user/stakeholder involvement

How will you involve service users or other groups of people affected by the issue being researched (e.g. particular staff groups) in the design and conduct of the study? If you are not planning any involvement please give reasons.

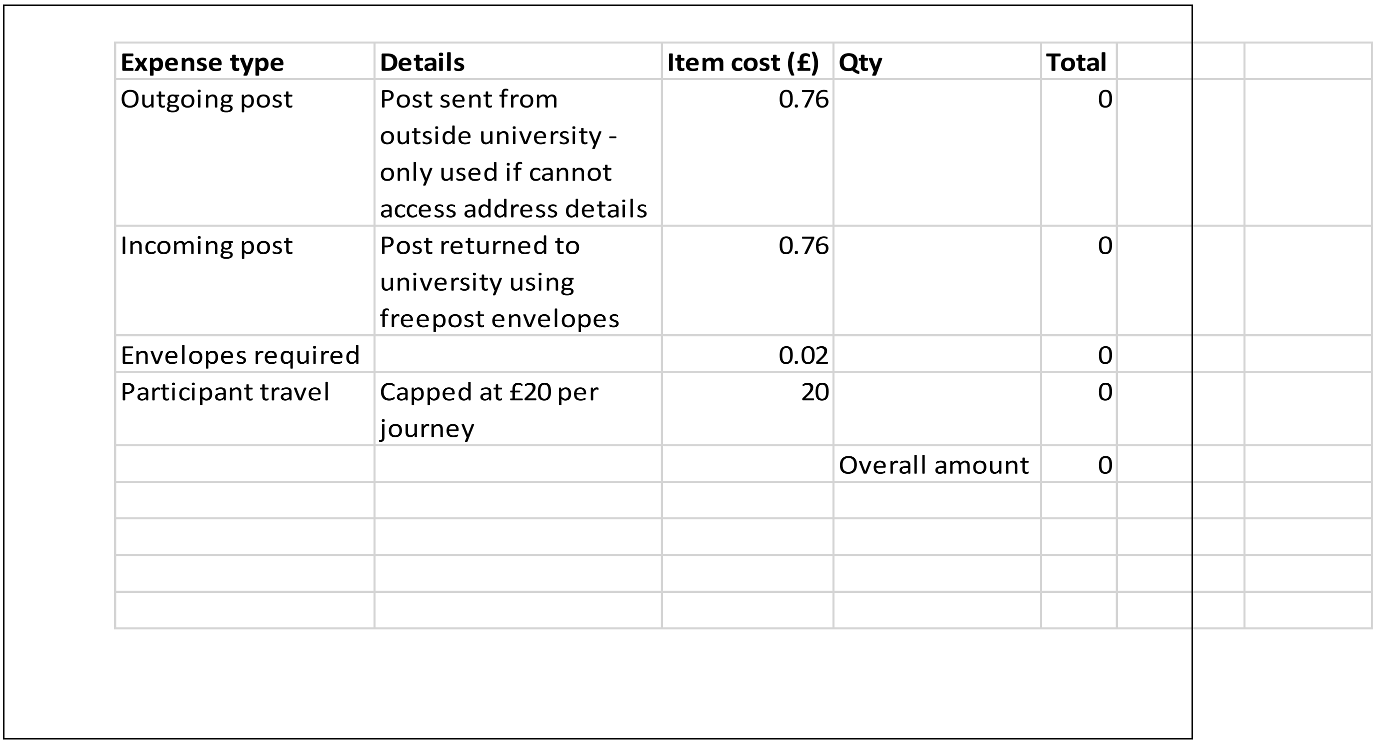
Participants will be involved throughout the study, submitting a reflection on their personal experiences with an eating disorder voice. A collaborative approach will be upheld with the participants through EBCD, and by keeping them up to date with the study findings if they have consented. Participants will be able to give feedback after each stage of the study e.g. recommendations on how to feel safe during the webinar, how to facilitate conversations, to help with its development.

I participated in a consultation event where I provided an overview of my project to gain perspectives from professionals and stakeholders, with aims to recruit a field supervisor. I gained valuable information regarding managing potential participant distress and the importance of using appropriate language when referring to individual’s experiences.

11. Estimated research costs

The programme has a limited amount of funds that can be used to support research expenses in some cases, subject to the approval of the Research Director. It is important that any cost implications of the research are considered. Please see the research expenses section of the programme handbook: http://wp.lancs.ac.uk/dclinpsy/research-expenses/ for more information.

Please use the below table to provide expected costs for the study.



Expense type	**Details**	**Item cost (£)**	**Qty**	**Total**		
Outgoing post	Post sent from outside university - only used if cannot access address details	0.76		0		
Incoming post	Post returned to university using freepost envelopes	0.76		0		
Envelopes required		0.02		0		
Participant travel	Capped at £20 per journey	20		0		
			Overall amount	0		

12. Details in relation to unusual/large expenditure

Expense Type	**Item Cost**	**Quantity**	**Total**
Paid consultancy	**£100**	**1**	**£100**
Prize draw	**£25 per stage**	**3**	**£75**

		Overall amount	**£175**

13. Case for the use of any unusual/large expenditure

If you have included any items in the above table please outline the case for this.

XXXXX is a senior development worker within Voice Collective. Eliciting paid consultancy from her will provide lived experience, a peer support perspective and insight into how to ensure the project will serve as a 'safe space' for individuals, managing any potential distress caused. This is due to the sensitive nature of the topic discussed and the inclusion of participants who may be considered to be vulnerable.

Prize draws of £25 for each stage of the study will encourage recruitment. Young people are often difficult to recruit (particularly for projects with multiple stages). Such incentives are likely to increase participation rates.

14. Dissemination plans

Including plans to publish in academic journals, sharing summaries with participants etc

A study summary will be emailed to participants if they have consented, and to the representative on the ethics committee. Information on the study could be presented as a poster at conferences (e.g. Hearing Voices Network), a blog for an online magazine (e.g. 'Women For'), or as guidelines for clinicians working with girls and women with eating disorders. The study could also be published in a mental health journal (e.g. *Psychosis*). A newsletter could also be developed for Voice Collective to acknowledge their contributions.

15. Timetable for completing the study

ACTIVITY	DATE
Submit ethics proposal	June 2022
Data collection (stage 1)	October 2022
Data analysis (stage 1)	January 2023
Data Collection (stage 2)	April 2023
Data analysis (stage 2)	June 2023
Data collection (stage 3)	July 2023
Data analysis (stage 3)	September – November 2023
Submit first draft of literature review to supervisor	September – October 2023
Submit second draft of literature review to supervisor	November – December 2023
Submit first draft of research paper to supervisor	January 2024
Submit second draft of research paper to supervisor	February 2024
Submit first draft of critical review to supervisor	Early March 2024

Submit second draft of critical review to supervisor	Early April 2024	
Submit thesis	May 2024	

16. References

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Appendices

Appendix 1: Participant information sheets

Appendix 2: Participant consent forms

Appendix 3: Participant debrief forms

Appendix 4: Evidence of ethical approval

Appendix 1

Information sheets for all stages of the study

Participant Information Sheet – Stage 1

Exploring voice hearing and multi-sensory experiences with girls and young women who self-report an Eating Disorder Voice

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

Invitation to research

Hello, our names are XXXXXXX and we are Clinical Psychology Doctorate students at Lancaster University.

Our research study aims to develop understanding around voice hearing and multisensory experiences in young women who live with an eating disorder. We are particularly interested in the Eating Disorder Voice (when the voice heard says negative things about the individual's eating or weight) and whether these experiences make it harder for a young woman with an eating disorder to get better. We hope by developing a clearer understanding we can improve the services that support those with an eating disorder.

Why have I been invited?

You have been invited to take part in this research study as you:

- identify as a woman.
- are between the age of 16 and 25 years old.
- Currently or previously experience voice hearing or another multisensory experience.
- Currently or previously have experienced an eating disorder.

We are hoping to gather 20 young people's pieces of work around their experience of voice hearing alongside an eating disorder so we can understand how this impacts their recovery.

Do I have to take part?

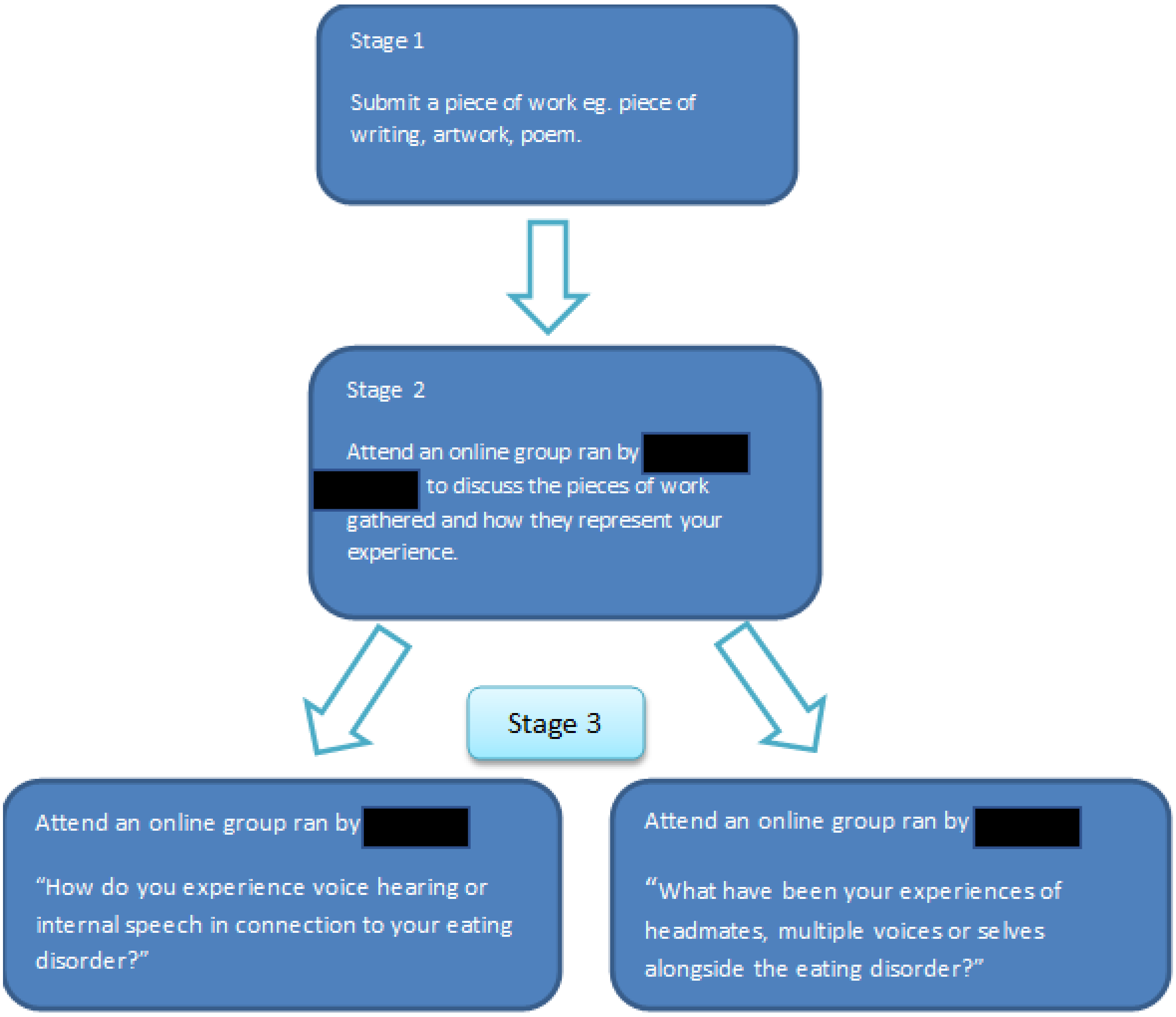
No. It is completely up to you to decide whether or not you take part. The study will be described, we can go through this information sheet and answer any questions you might have. You will then be asked to sign a consent form which will show you have consented to take part. You are free to withdraw from the study at any time, and you do not have to give a reason for this.

If you do decide to withdraw your consent, please contact the researchers at XXXXXXXX Any personal information taken will be destroyed.

What will I be asked to do?

If you have consented to take part in the study, you would be asked to submit a piece of work to us via an online platform. This work will reflect your experiences of voice hearing alongside an eating disorder. It is completely up to you what type of work you wish to submit. It could be a piece of writing, artwork, voice note etc. This work along with other participants' work will be made into a short film to represent our findings and interpretations.

If you choose to submit a piece of work, you will then be asked if you would like to take part in further stages of the study. Here is a guideline of the research project's stages:



Stage 1

Submit a piece of work eg. piece of writing, artwork, poem.

Stage 2

Attend an online group ran by [redacted] [redacted] to discuss the pieces of work gathered and how they represent your experience.

Stage 3

Attend an online group ran by [redacted]

"How do you experience voice hearing or internal speech in connection to your eating disorder?"

Attend an online group ran by [redacted]

"What have been your experiences of headmates, multiple voices or selves alongside the eating disorder?"

It is completely up to you to decide whether you take part in any further stages.

Are there any risks?

If you experience any distress when creating or submitting your piece of work, you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

If you are worried about anything to do with the research study, either before or after taking part, you can contact one of the researchers who will answer all questions, or let you know of additional support available.

Are there any benefits to taking part?

There is a chance to win £25 for participating in this stage of the research project. The winner will be selected at random after everyone in the study has submitted their piece of work.

You may find participating in the study interesting, and your involvement within this research and the information who share will also help us to further understand how voice hearing and multisensory experiences impact individuals with eating disorders. This will help us to improve the support that services can offer to this community.

Will my data be identifiable?

The data collected for this study will be stored securely via University' Onedrive, and only the researchers conducting this study and their research supervisor will have access to this data.

- Any audio recordings will be destroyed and/or deleted once the project has been submitted for publication/examined
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
- Your submitted piece of work be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your work may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- All your personal data will be confidential and will be kept separately from your submitted piece of work.

There are some limits to confidentiality: if what is included in your piece of work makes us think that you, or someone else, is at significant risk of harm, we will have to break confidentiality and speak to a member of staff about this. If possible, we will tell you if we have to do this.

What will happen to the results?

At the end of the research study, the results will be summarised and reported in our thesis projects as part of our university course and may be submitted for publication in an academic or professional journal. You will not be identifiable as no names will be used and all information will be anonymised. The findings and some direct quotes from your piece of work might be used in the thesis, in research papers or presentations. You will not be identifiable as no names will be sued and all information will be anonymised.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researchers: XXXXXXXXX

Alternatively, if you have any concerns and you do not wish to speak to the researchers, you can contact the Research Supervisor:

XXXXXXXXX

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

XXXXXXX

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

XXXXXXX

THANK YOU FOR CONSIDERING PARTICIPATING IN THIS PROJECT

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

Voice Collective

Supporting young people who hear, see and sense things others don't. Non-crisis email, support service, multiple resources www.voicecollective.co.uk

Samaritans Freephone

Support line to talk and voice concerns and feelings
116 123

NHS

NHS (England) in case of a mental health crisis or emergency
111

Participant Information Sheet – Stage 2 & 3

Exploring voice hearing and multi-sensory experiences with girls and young women who self-report an Eating Disorder Voice.

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

Invitation to research

Hello, our names are XXXXXXX, and we are Clinical Psychology Doctorate trainees at Lancaster University.

Our research study aims to develop understanding around voice hearing with young women who live with an eating disorder. We particularly interested in experiences of voice hearing in connection with disordered eating, this is sometimes called the Eating Disorder Voice. Voice hearing experiences can make it harder for young women with an eating disorder to get better. We hope by developing a clearer understanding of this experience, it can lead to recommendations for improving support services.

Why have I been invited?

You have been invited to take part in this research study as you:

- identify as a young woman.
- are between the age of 16 and 25 years old.
- Currently or previously experience voice hearing
- Currently or previously have experienced an eating disorder.

Within this stage of the research, we are hoping to speak to around 8-12 young women with personal experiences of voice hearing experiences alongside their eating disorder in an online group so we can understand how this impacts their recovery. All stories that have been analysed so far will be discussed, and you will be asked for your feedback on how accurately these reflect your own experience.

Do I have to take part?

No. It is up to you to decide. The study will be described and you will be taken through the information sheet, which will be given to you. You will then be asked to sign a consent form to show you agreed to take part. You are free to withdraw at any time, without giving a reason.

If you are involved in the focus group and then withdraw, your data will remain part of the study as it is part of an ongoing conversation and cannot be destroyed. The researchers will try to disregard your views when analysing the focus group data, but this will not always be possible.

If you do decide to withdraw your consent, please contact the researcher at XXXXXXX

Any personal information taken will be destroyed.

What will I be asked to do?

If you consent to taking part in this stage of the research study, you will be invited to attend a group discussion online via Zoom. You do not need a Zoom account for this. The discussion would last between one and two hours. You will be asked to watch a short presentation of findings and interpretations from the work previously gathered, and feedback provided in a previous group discussion. You will then be asked to provide feedback on whether it accurately represents your experiences of voice hearing and eating disorder accurately.

If you do not feel comfortable, you do not need to turn your camera on, as only the audio of the conversation will be recorded. Only the researchers will be able to access the recording. We will keep the audio recording until I have written up a transcription of the interview, and then it will be deleted. The write up will not include your name or any personally identifiable details. This is explained more below.

Are there any risks?

If you experience any distress, or don't want to carry on with the group discussion, that is okay and you are able to leave the meeting. There will be information shared at the beginning of the group discussion of support you can access should you need to. You do not have to answer any questions you don't want to within the group discussion.

If you are worried about anything to do with the research study, either before or after taking part, you can contact one the researchers who will answer all questions, or let you know of additional support available.

Are there any benefits to taking part?

There is a chance to win £25 for participating in this stage of the research project. The winner will be selected at random following the online group discussion.

Your involvement within this research and the information you share will also help to provide further understanding on how voice hearing impacts individuals with eating disorders. This will help to improve the support that services can offer to this community.

Will my data be identifiable?

- Any audio recordings will be destroyed and/or deleted once the project has been submitted for publication/examined.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself is password protected.
- The typed transcript of the group discussion will be made anonymous by removing any identifying information including your name.
- Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- All your personal data will be confidential and will be kept separately from the group discussion transcription.

There are some limits to confidentiality: if what is said within the group discussion makes us think you, or someone else, is at significant risk of harm, we will have to break confidentiality and speak to a member of staff about this. If possible, we will tell you if I have to do this.

What will happen to the results?

At the end of the research study, the results will be summarised and reported in our thesis projects as part of our university course and may be submitted for publication in an academic or professional journal. You will not be identifiable as no names will be used and all information will be anonymised. The findings and some direct quotes from the group discussion work might be used in the thesis, in research papers or presentations. You will not be identifiable as no names will be used and all information will be anonymised.

Who has reviewed the project?

This research project has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about this study, please contact the main researchers:

XXXXXXXX

Alternatively, if you have any concerns and you do not wish to speak to the researchers, you can contact the Research Supervisor:

XXXXXXX

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researchers, you can contact:

XXXXXXX

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

XXXXXX

THANK YOU FOR CONSIDERING PARTICIPATING IN THIS PROJECT

Resources in the event of distress:

Should you feel distressed as a result of taking part, or in the future, the following resources may be of assistance.

Voice Collective

Supporting young people who hear, see and sense things others don’t. Non-crisis email, support service, multiple resources www.voicecollective.co.uk

Email: info@voicecollective.co.uk | Tel: 020 7911 0822

Samaritans Freephone

Support line to talk and voice concerns and feelings

116 123

NHS

NHS (England) in case of a mental health crisis or emergency

111

Appendix 2

Consent forms used for all stages of the study

Lancaster University

CONSENT FORM : STAGE 1

Project Title: Exploring Voice Hearing and Multi-sensory experiences with girls and young women who self-report an Eating Disorder Voice

Name of Researchers: XXXXXX

Email: XXXXXX

Please tick each box

1. I confirm that I have read and understand the information sheet 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 during my participation in this study and within 2 months after I took part in the study, without giving any reason. If I withdraw within 2 months of taking part in the study my data will be removed.	☐ ▪
3. I understand that any information given by me may be used in future reports, academic articles, publications or presentations by the researchers, but my personal information will not be included, and all reasonable steps will be taken to protect the anonymity of the participants involved in this project.	☐ ▪
4. I consent to information and quotations from my submitted piece of work being used in reports, conferences and training events.	☐ ▪
5. I understand that data will be kept according to University guidelines for a minimum of 10 years after the end of the study.	☐ ▪

6. I understand that the researchers will discuss data with their supervisor as needed.	☐ ▪
7. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the researchers may need to share this information with their research supervisor.	☐ ▪
8. I agree to take part in the above study.	☐ ▪

___________________________ _________________ __________________

Name of Participant Date Signature

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Signature of Researcher /person taking the consent__________________________ Date ___________ Day/month/year

Signature of Researcher /person taking the consent__________________________ Date ___________ Day/month/year

One copy of this form will be given to the participant and the original kept in the files of the researcher at Lancaster University

Lancaster University

CONSENT FORM: STAGE 2 & 3

Project Title: Exploring Voice Hearing and Multi-sensory experiences with girls and young women who self-report an Eating Disorder Voice

Name of Researchers: XXXXXX

Email: XXXXXXX

Please tick each box

1. I confirm that I have read and understand the information sheet 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 during my participation in this study and within 2 months after I took part in the study, without giving any reason. If I am involved in focus groups and then withdraw, my data will remain part of the study. I understand that as part the focus group I will take part in, my data is part of the ongoing conversation and cannot be destroyed. I understand that the researcher will try to disregard my views when analysing the focus group data, but I am aware that this will not always be possible.	☐ ▪
3. If I am participating in the focus group, I understand that any information disclosed within the focus group remains confidential to the group, and I will not discuss the focus group with or in front of anyone who was not involved unless I have the relevant person's express permission.	☐ ▪
4. I understand that any information given by me may be used in future reports, academic articles, publications or presentations by the researchers, but my personal information will not be included, and all reasonable steps will be taken to protect the anonymity of the participants involved in this project.	☐ ▪
5. I consent to information and quotations from the focus group being used in reports, conferences and training events.	☐ ▪
6. I understand that the focus group will be audio-recorded and transcribed, and that data will be protected on encrypted devices and kept secure.	☐ ▪

7. I understand that data will be kept according to University guidelines for a minimum of 10 years after the end of the study.	☐ ▪
8. I understand that the researchers will discuss data with their supervisor as needed.	☐ ▪
9. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the researchers may need to share this information with their research supervisor.	☐ ▪
10. I agree to take part in the above study.	☐ ▪

_________________________ ________________ _________________

Name of Participant Date Signature

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Signature of Researcher ___________________________ **Date** ___________ Day/month/year

Signature of Researcher ___________________________ **Date** ___________ Day/month/year

One copy of this form will be given to the participant and the original kept in the files of the researcher at Lancaster University.

Appendix 3

Debrief forms used for all stages of the study

Debrief Information - All Stages

We would like to thank you for participating in our study.

The prize draw of £25 will take place once all participants have submitted their piece of work. The winner will be selected at random and notified via email. If you would like to enter, please provide your email address below:

Would you like to be kept up to date via your provided email address with the progress of the study?

Yes

No

What happens next?

As previously mentioned, there are further stages of this study that you may be interested in taking part in. The next stage would involve attending an online group run by XXXXX to discuss the pieces of work gathered and how they represent your experience.

Alternatively, if you have just completed stage 3 of the research project, the final stage is now over. You do not need to do anything else.

Would you be like to be contacted to take part in further stages of the study via your provided email address?

Yes

No

Resources in the event of distress

Should you feel distressed, either as a result of taking part, or in the future, the following resources may be of assistance:

Voice Collective

Supporting young people who hear, see and sense things others don't. Non-crisis email, support service, multiple resources www.voicecollective.co.uk

Samaritans Freephone

Support line to talk and voice concerns and feelings

116 123

NHS

NHS (England) in case of a mental health crisis or emergency

111

Researcher contact details

If you feel you have been affected by this study and would like to discuss this further, please contact the main researchers: XXXXXX

Alternatively, if you have any concerns and you do not wish to speak to the researchers, you can contact the Research Supervisor: XXXXXXX

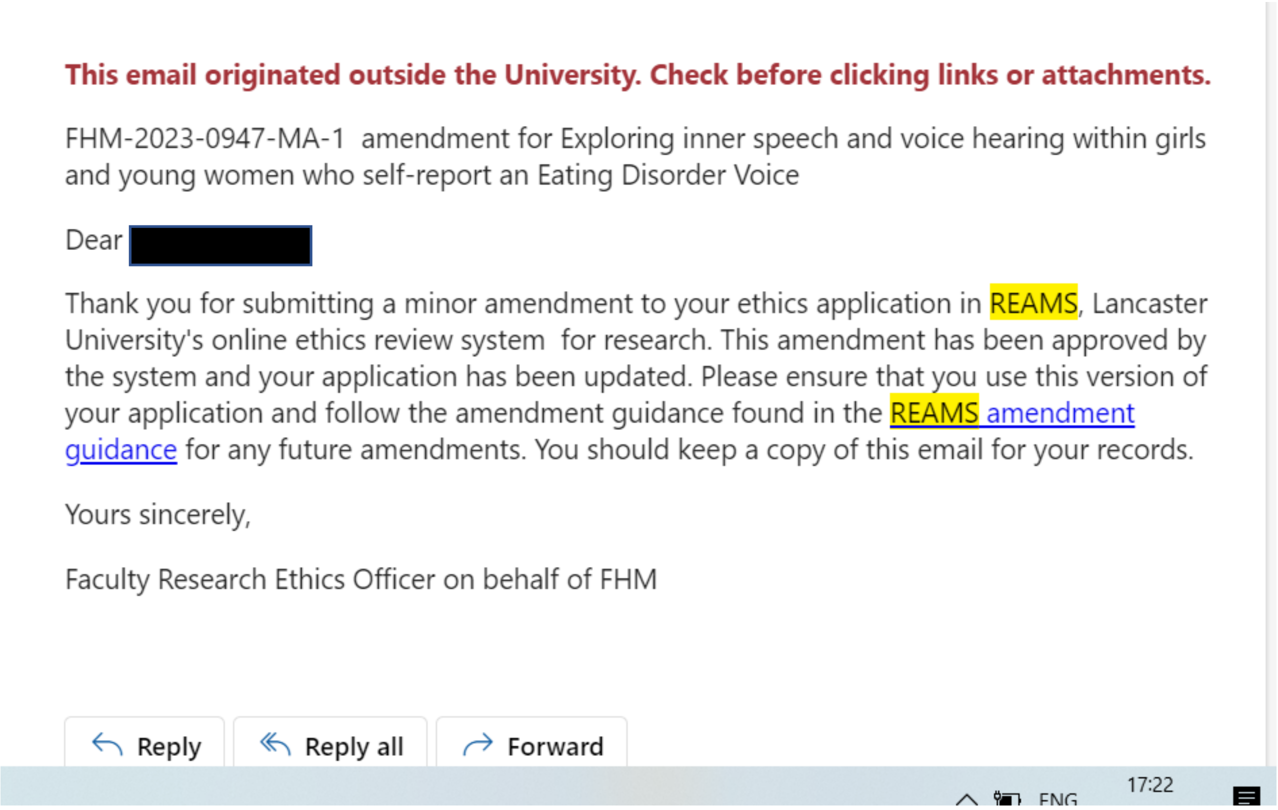
Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact: XXXXXXX

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact: XXXXXX

Appendix 4:

Evidence of ethical approval from Lancaster University Ethics Committee



This email originated outside the University. Check before clicking links or attachments.

FHM-2023-0947-MA-1 amendment for Exploring inner speech and voice hearing within girls and young women who self-report an Eating Disorder Voice

Dear [redacted]

Thank you for submitting a minor amendment to your ethics application in REAMS, Lancaster University's online ethics review system for research. This amendment has been approved by the system and your application has been updated. Please ensure that you use this version of your application and follow the amendment guidance found in the REAMS amendment guidance for any future amendments. You should keep a copy of this email for your records.

Yours sincerely,

Faculty Research Ethics Officer on behalf of FHM