

"A Meta-ethnography exploring Service Users Experiences of CBT for Anxiety and a Grounded Theory Analysis Investigating the Impact of the Anorexic Voice on CBT-E"

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PREFACE

Cognitive behaviour therapy (CBT) is a psychological intervention focused on altering individuals' maladaptive behaviours and thoughts by challenging them and introducing adaptive coping strategies. CBT is used to treat a range of psychological disorders but despite this, little is known about how individuals experience this intervention. Understanding service users' experiences of the process through therapy is helpful for informing interventions and can be used to improve treatment efficacy. Therefore, this thesis looks at service users' experiences across two mental health disorders where CBT is recommended as the frontline treatment; anxiety disorders and anorexia nervosa (AN). These disorders somewhat overlap; there are symptoms of anxiety within AN, and the two are highly comorbid, often occurring together. Therefore, synthesising the experiences of CBT for anxiety may also provide insights into the experiences of CBT-E for AN and so help inform this research.

Paper 1 presents a meta-synthesis of qualitative research investigating service users' experiences of CBT for anxiety disorders, the class of mental health disorders with the highest prevalence rate. CBT is the recommended treatment, yet only 50% reach remission status following it. Understanding how service users experience this intervention can help inform recommendations for improving remission rates. The aim of paper 1 is to understand how service users with an anxiety disorder experience the process of CBT, including which aspects are perceived as helpful and why. In order to do so, Noblit and Hare's meta-ethnographic methodology was followed. A systematic literature search of PsycINFO, MEDLINE, Embase and CINAHL identified relevant papers were assessed for quality before being synthesised to create new insights into service users' experiences. A central concept of 'the role of the therapeutic relationship' was identified from analysis which ran through all other themes within the synthesis and appeared to influence how individuals experienced aspects of CBT to be helpful. Three other themes were identified as influencing individuals' experiences: 'the

influence of preconceptions', 'perceptions of CBT techniques' and 'service users' style of engagement'. The key reason for people experiencing these aspects as helpful is depicted in the theme of 'developing insight'; individuals felt they developed an understanding of their anxiety, themselves and others as a result of CBT. However, not all experienced CBT to be helpful and these experiences are captured within the theme of 'perceiving CBT to be unhelpful'. These themes are developed into a line-of-argument synthesis which is expressed in diagrammatic and narrative form. These findings mirror service users' experiences of CBT for other disorders, as well as existing frameworks of common factors in psychotherapy. The findings have clinical implications for the delivery of CBT for anxiety disorders. In particular, therapists should work to build trusting and collaborative therapeutic relationships in order to improve engagement, and hopefully remission rates.

Paper 2 presents a grounded theory analysis of individuals' perceptions of whether the anorexic voice (AV) had an impact on their enhanced cognitive behaviour therapy (CBT-E). Clinical guidelines recommend the use of CBT-E for the treatment of AN, but only 30-50% of those who start this treatment complete it, and approximately one third of those show no improvements. One theory within literature is that the AV interrupts individuals' ability to engage with CBT-E, thus reducing its efficacy. The AV is a critical and hostile voice experienced by up to 90% of individuals with AN, that comments on their eating behaviours, weight and shape in the third person. Many experience it as dominating and more powerful than their own thoughts. Therefore, the aim of paper 2 is to qualitatively investigate whether individuals perceive there to be an interaction between the AV and CBT-E, and if so, how this interaction looks. Twelve participants took part in interviews, which were analysed using grounded theory analysis. In order to understand the process throughout CBT-E, a cross-section of participants was recruited, some in treatment and others in recovery. Eight themes were identified in analysis: development of the AV; current relationship with the AV;

considering life without the AV; challenging the AV creates a battle; voice as a barrier to engagement; learning to cope without the voice; CBT-E had no impact on ability to fight voice; the recovery voice. The AV was perceived to make engagement with CBT-E challenging due to its dominance and participants' relationship with it. CBT-E was also perceived to make the AV more powerful. The importance of reducing reliance on the relationship with the AV, as well its power, were considered important factors in ensuring CBT-E was beneficial.

Clinically, CBT-E practitioners should remain aware of the influence the AV may have on individuals' ability to engage with therapy, as well as the inner battle faced as CBT-E increases the AV prominence. Therapists should work hard to challenge the AV alongside service users in sessions.

Service Users' Experiences of individual Cognitive Behaviour Therapy based protocols for Anxiety: A meta-ethnography

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³ This paper is prepared in accordance with the author guidelines for *Psychology and Psychotherapy: Theory, Research and Practice* (Appendix 1). For the purposes of thesis submission, the DClinPsy word limit of 8000 words has been used to ensure all relevant information could be demonstrated. APA 7th style has been used for references. To ease readability, tables and figures are embedded within the main body of text and will be removed and placed at the end for journal submission.

ABSTRACT

Purpose: Anxiety disorders are the class of mental health disorders with the highest prevalence rate: 11.6% worldwide. Despite CBT being the recommended treatment within clinical guidelines, remission rates are only 50%, recognising a need for improvement.

Consequently, it is important to understand service users' perceptions of CBT in order to understand how treatments can be enhanced. The purpose of this meta-ethnography is to understand how service users with an anxiety disorder experience the process of CBT.

Method: A systemic literature search was conducted of qualitative research looking at service users' experiences of a mixture of individual CBT based protocols for anxiety disorders.

Results from the 12 studies meeting inclusion criteria were analysed using Noblit and Hare's meta-ethnographic method.

Results: A central concept of 'the role of the therapeutic relationship' was identified and mediated other themes. Three other factors were considered important by service users: 'the influence of preconceptions', 'perceptions of CBT techniques' and 'service user style of engagement'. These were considered helpful as they assisted participants in developing new insights into their anxiety and their relationships with others. These themes were developed into a line-of-argument synthesis, expressed as a model for understanding service users' experiences of the process of CBT.

Conclusion: Findings of this meta-synthesis supplement existing research looking at common factors in psychotherapy, by considering why these factors are important and how they interact during the process of CBT for anxiety. Recommendations for clinical practice are discussed that aim to improve remission rates of CBT for anxiety disorders.

Keywords: Cognitive behaviour therapy, anxiety disorders, service users, meta-ethnography

INTRODUCTION

Anxiety disorders are defined as "excessive fear and subsequent avoidance, typically in response to an object or situation and in the absence of true danger" (Otte, 2011, p. 413).

Under the umbrella of anxiety disorders, the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) states 11 diagnoses. Anxiety disorders are the class of mental disorders with the highest prevalence rate: 11.6% worldwide (Carpenter et al., 2018), highlighting the importance of identifying an effective treatment.

Cognitive behaviour therapy (CBT) has proven efficacy for anxiety disorders, across different protocols such as individual therapy-led CBT and internet delivered CBT (CBTi), in comparison to other therapies and control groups (Hofmann & Smits, 2008; Norton & Price, 2007; Tolin, 2010; Carpenter et al., 2018; Olatunji et al., 2010; Pasarelu et al., 2016). For example, Hofmann and Smits (2008) identified an effect size of 0.73 for anxiety severity measures, as compared to a placebo group. As such, CBT is the recommended intervention for the treatment of anxiety in clinical guidelines (National Institute for Health and Care Excellence [NICE], 2011, 2013; National Psychological Therapies Management Committee, 2017).

Despite these promising effect sizes, response and remission rates present a less optimistic view. Loerinc et al. (2015) state that effect sizes do not reflect whether individuals respond positively to treatment and so are less clinically meaningful. Response and remission rates provide a clearer clinical picture, and these are around 50% (Loerinc et al., 2015; Springer et al., 2018). If only half of individuals undertaking an empirically supported treatment are responding well and reaching remission, this indicates room for improvement. This suggests

different research methodologies, other than randomised controlled trials (RCTs) and metaanalyses, are required to understand the CBT process and consider areas for improvement.

Qualitative methodology allows an in-depth understanding of how factors interact to form peoples' perspectives and guide behaviour (Rich & Ginsburg, 1999), thus allowing the development of hypotheses about how individuals respond to treatment. Furthermore, metasyntheses allow for these qualitative findings to be compared across the literature and integrated to develop new insights and theories (Dixon-Woods et al., 2006), thereby potentially allowing the development of new theories for clinical practice. Additionally, Knowles et al. (2014) state syntheses provide a vigorous and comprehensive platform to guide evidence-based clinical practice. Thus, meta-syntheses are a useful methodology to inform therapeutic processes and efficacy.

Although there are currently no meta-syntheses exploring service users' experiences of individual CBT based protocols for anxiety disorders, there are some looking at experiences of CBT for other mental health difficulties including psychosis and depression (Berry & Hayward, 2011; Khan et al., 2007; Knowles et al., 2014). Across these meta-syntheses there are some common themes in participants' experiences of the process of CBT, including the use of coping strategies in providing a sense of control and understanding about their difficulties.

Berry and Hayward (2011) discuss therapy providing a sense of normalisation, as well as a change in participants' perceptions of themselves and their psychosis. Participants in Knowles et al (2014) highlight CBT creating an increased sense of empowerment and highlight the need for the therapy process to be personalised. Khan et al (2007) recognise the value of the therapeutic relationship in participants' engagement with the process of therapy. These meta-syntheses identify some common experiences of the CBT processes and depict important areas to consider in the delivery of CBT to these populations.

As recognised within Kahn et al (2007), the therapeutic relationship plays an important role within CBT and has been well evidenced within CBT literature as an important factor in improving outcomes and compliance within CBT for anxiety (e.g. Cummings et al., 2013; Hara et al., 2017; Liber et al., 2010). As such, therapeutic alliance is recognised as a core competency in delivering CBT interventions to people with anxiety disorders or depression (Roth & Pilling, 2007). The therapeutic relationship is therefore likely to play a role in how service users experience individual CBT based protocols for anxiety, just as it did in Kahn et al (2007).

With regards to anxiety disorders, there are qualitative studies investigating individuals' experiences of CBT, but these have never been synthesised. Given that only 50% of individuals with an anxiety disorder reach remission post CBT, there is a need to understand how and why individuals respond to this treatment as they do: synthesising the literature allows this exploration. With this new understanding, recommendations for clinical practice can be developed, with a view to improving response and remission rates.

Following the precedence set by meta-analyses in the area, this meta-synthesis looks at the class of anxiety disorders together. CBT protocols for anxiety disorders contain overlap where the focus is on exaggerated appraisal of threat, a key element underlying pathological anxiety (Carpenter et al., 2018). Given this overlap, and the fact that there is not currently sufficient literature to look at each anxiety disorder separately, it was felt appropriate to look at the experiences of CBT for anxiety disorders as a whole. The researchers are aware of the risks of collapsing the diagnoses and potentially losing possible nuances between disorders. Where possible, and relevant, these differences across disorders are drawn out and discussed.

Additionally, this meta-synthesis investigates service users' experiences across a range of modalities and individual CBT based protocols for anxiety disorders, rather than focusing on one specific method of delivery. Again, this was due to insufficient literature looking at specific CBT protocols and because it was felt that all service users offered valuable insight into the process of CBT for anxiety disorders. Where relevant, differences amongst these protocols are extracted within results.

The aim of the current meta-synthesis is to understand how service users with an anxiety disorder experience the process of individual CBT across a range of CBT based protocol and modes of delivery. This includes which aspects of CBT they perceive to be beneficial, and why these factors are significant in their experience. From this, recommendations for clinical practice can be identified.

METHOD

Systematic Literature Search

The following databases were searched for qualitative research investigating service users' experiences of CBT for anxiety disorders: PsycINFO; MEDLINE; Embase; CINHAL. No date restriction was applied to the search as it was felt to be unnecessarily restrictive. Table 1 presents an exhaustive list of the search terms used across the four databases.

Reference lists of all papers included were manually searched as well as key CBT journals such as Cognitive Behaviour Therapy, Journal of Cognitive Psychotherapy, and Behaviour Research and Therapy; this process did not identify additional papers. 580 papers were identified once duplicates were removed, as shown in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram in Figure 1.

Category	Search terms
Cognitive behaviour	Subject headings – cognitive behavior therapy, cognitive behavioral therapy,
therapy	cognitive therapy
	Title, abstract keyword search – (cognitive adj2 behavio?r therap*)
	OR cognitive adj2 therap* OR CBT* OR cognitive behaviour* therap*
Anxiety disorders	Subject headings – anxiety disorders, elective mutism, separation anxiety
	disorder, phobias, social phobia, panic disorder, agoraphobia, generalized
	anxiety disorder, mutism, phobic disorders, panic, social anxiety disorders
	Title, abstract, keyword search - anxiety disorder* OR separation anxiety*
	OR elective mut* OR selective mut* OR phobi* OR social phob* OR social
	anxiety* OR panic* OR agorapho* OR generalized anxiety* OR generalised

anxiety* OR substance-induced anxiety* OR medication-induced anxiety*

OR drug induced anxiety* OR acrophob* OR claustrophob* OR ophidophob*

OR school phob* OR *phobi* OR animal phob* OR blood-injection phob*

OR dental phob* OR flying phob* OR neophob* OR phonophob*

PsycINFO qualitative filter - (((("semi-structured" or semistructured or

Qualitative research

PsycINFO qualitative filter - (((("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide or guides) adj3 (interview* or discussion* or questionnaire*)) or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant")).ti,ab,id. or exp qualitative research/ or exp interviews/ or exp group discussion/ or qualitative study.md.) not "Literature Review".md.

MEDLINE qualitative filter - ((("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) adj2 (interview* or discussion* or questionnaire*))).tw,kw or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant").tw,kw or interviews as topic/ or focus groups/ or narration/ or qualitative research/ Embase qualitative filter - ((("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) adj3 (interview* or discussion* or questionnaire*))).ti,ab. or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant").tw,kw or qualitative research/ CINAHL qualitative filter - ethnography OR qualitative OR grounded-theory OR thematic-analysis OR patient experiences OR client experiences OR client perspectives OR patient perspectives OR content-analysis OR observationalmethods OR constant-comparative-method OR field-notes OR participantobservation OR narratives OR field-studies OR (audiorecording or focusgroups) OR client attitudes

Inclusion and exclusion criteria

To identify relevant papers for the research question, strict inclusion and exclusion criteria were applied (Table 2). A total of 12 papers were included: the PRISMA diagram in Figure 1 identifies how these were screened and assessed. An independent researcher, unrelated to this research, screened a random 25% of the full-text articles to identify whether they fit the criteria. Any discrepancies were discussed between the first author and the independent researcher until there was 100% agreement about which papers should be included or excluded. No further articles were excluded as a result of this process.

With regards to the interventions included within the current meta-synthesis, individuals must have received predominantly CBT for their anxiety disorder. In some papers, a selection of participants received sessions of motivational interviewing (MI) prior to CBT for their anxiety disorder, whilst other participants received only CBT for anxiety. These papers were included as individuals did receive individual CBT for their anxiety disorder and so excluding them would have removed valuable insight into service users' experiences of CBT for anxiety. The researchers recognise the potential shortfalls of including those who have had MI as a pre-treatment to CBT and where relevant have identified these differences throughout the paper.

For the purposes of the current meta-synthesis, individual CBT could be delivered in any format, as long as it followed a CBT based protocol for anxiety. It was felt to be overly restrictive to include only in-person therapist led CBT as this is not representative of how CBT is delivered clinically. Those receiving individual CBT via the internet, telephone or skype are still receiving individual CBT for their anxiety disorder and so offer valuable information for

understanding service users' experiences. Where relevant, differences between these formats are explored throughout the meta-synthesis.

In order to ensure the meta-synthesis is as valid as possible, group CBT was excluded as people receiving therapy in the context of others are likely to have different experiences to those receiving it on an individual basis. It was felt that the inclusion of group CBT would therefore confuse the data and make it less comprehensive. As a result, protocols such as mindfulness-based cognitive therapy were excluded.

Similarly, CBT that was delivered indirectly or to more than one individual in the system was excluded. This meta-synthesis looks at the experiences of CBT from the perspective of individuals who have an anxiety disorder. Parent-led CBT, family-based CBT and couples CBT all involve delivering CBT to the system around the person with an anxiety disorder. Therefore, gathering these experiences would not include only the experiences of CBT from the perspective of the individual with an anxiety disorder, thus not meeting the aims of the meta-synthesis and reducing the validity of the review.

Study parameters	Inclusion criteria	Exclusion criteria
Sample/population	Any age and gender	Any other diagnosis of a primary mental health
		difficulty
	Anxiety disorder, as defined by the DSM 5, as	If researchers look at more than one diagnosis and
	primary diagnosis	have analysed the data together so it is not possible
		to extract data from those with an anxiety disorder
Intervention	Individual cognitive behaviour therapy is defined	Mindfulness-based cognitive therapy
	as the intervention being delivered to one	
	individual at a time	
	Predominantly individual cognitive behaviour	
	therapy, or cognitive therapy, for one of the DSM-	CBT focusing on more than one individual or
	V anxiety disorders	delivered indirectly e.g. parent-led CBT, family-
	Individual CBT can be delivered in any format e.g.	based CBT, couples CBT, group CBT
	in-person, via skype or telephone, internet	
	delivered	
Study focus	Studies that explore patient experiences of CBT	Studies that explore experiences of anyone else e.g.
	for anxiety	professionals, carers, family members
Methodology	Qualitative research, or mixed method design,	Studies that only use quantitative analysis
	where established methodology is stated and	
	referenced	
	Raw qualitative data can be extracted	Unable to extract qualitative data from results
	Researchers state which screening or diagnostic	Self-identified diagnosis i.e. no screening or
	tool is used to identify anxiety disorder	diagnostic tool used to confirm diagnosis
Study type	Peer reviewed journal article and able to access	Book reviews, opinion pieces, unpublished thesis,
	full text	non-peer-reviewed journals, literature reviews,
		meta-analyses, meta-syntheses, grey literature
Language	Studies written in English	Studies not written in English

Table 2: Inclusion and exclusion applied in systematic literature search

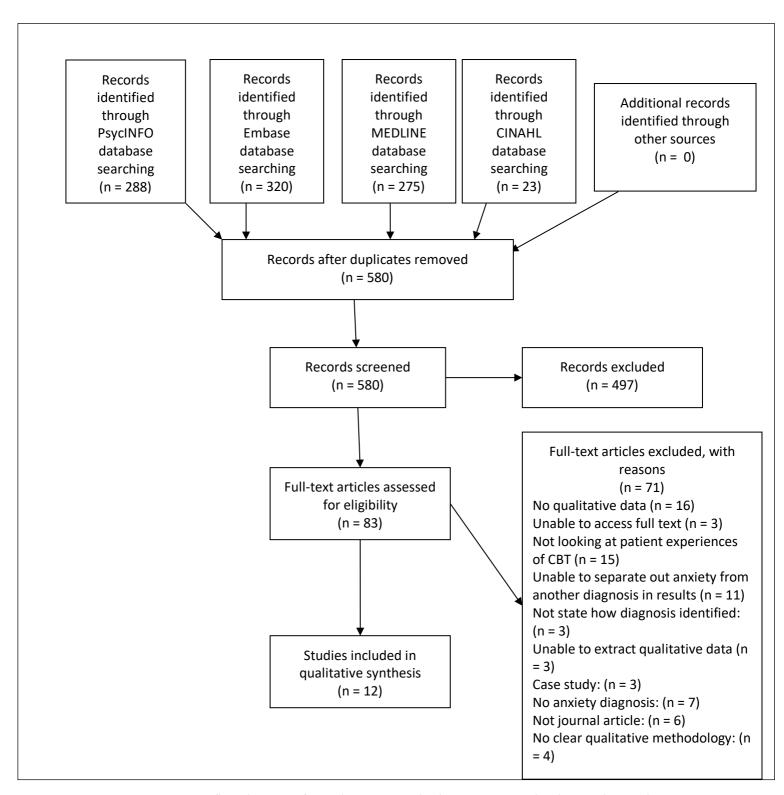


Figure 1: PRISMA flow diagram of search process and selection strategy (Moher et al., 2009).

Quality appraisal process

The Critical Appraisal Skills Programme (CASP, 2018) checklist for qualitative research was used in order to assess the methodological quality of the included papers (Appendix 3). CASP was chosen due to its extensive years of experience assessing the quality of qualitative healthcare research. Additionally, the CASP checklist has commonly been used to assess quality in other meta-syntheses in the literature (Fox et al., 2015; Graham et al., 2020; Kowlessar et al., 2014; Wittowski et al., 2016; Sirdifield et al., 2016; Quinn et al., 2013; Wyatt et al., 2013). The CASP checklist includes ten questions, nine are scored with a point being given if they meet each criterion and half points being awarded if it is only partially fulfilled. Question ten does not require scoring but is used to recognise how valuable the research is by identifying its contribution to current understanding, future research, and the wider population.

Given that the key aim of this synthesis was to ascertain service users' views on their experience of CBT, it was also regarded as important that there was a clear fidelity to an evidence-based model as this may influence experiences. As a result, an additional question regarding whether the CBT was evidence based was added to the quality assessment criteria so this data could be considered throughout the current meta-synthesis. The addition of quality assessment questions specific to the aims of the review has been implemented in other meta-syntheses (e.g. Fox et al., 2015). This question was given a score in line with the CASP scoring methodology; papers were awarded one point if they stated the CBT was evidenced, with half points being given to those who did not explicitly state the evidence base in their paper but did in an RCT where participants were recruited. Zero points were awarded if researchers did not state the evidence base for the CBT protocol used.

A summary of the quality appraisal criteria and individual question scores can be found in Table 4.

Each paper was awarded a total score out of ten. In line with other meta-syntheses (Fox et al., 2015; Graham et al., 2020; Kowlessar et al., 2014) studies were graded from A to C to indicate methodological quality based on their score. 'A' classifies studies with a low likelihood of methodological flaws (eight and a half or higher), 'B' identifies studies with a moderate likelihood of methodological flaws (five to eight), and 'C' represents research with a high likelihood of methodological flaws (less than five). Table 5 includes the final quality appraisal scores and grade.

An independent researcher re-rated a proportion of the included studies using the CASP qualitative checklist (Appendix 3). There was a 78% agreement between the researchers; disagreements were discussed by comparing the paper to the CASP question and resolving discrepancies until there was 100% agreement between both researchers.

Data synthesis

Noblit and Hare's (1988) meta-ethnographic method for synthesising qualitative studies was used for the current meta-ethnography for a number of reasons. First, meta-ethnography is one of the most commonly used approaches to synthesise qualitative data and provides clear guidelines on how to do so (Bondas & Hall, 2007; Dixon-Woods et al., 2007). Secondly, this approach allows all types of qualitative research to be synthesised together, meaning a wider range of research could be included in the meta-ethnography (Wittowski et al., 2016).

The current meta-ethnography followed the seven steps identified by Noblit and Hare (1988), with additional guidance from Walsh & Downe (2005) and Britten et al. (2002), as shown in

Table 3. Throughout the meta-ethnography process, Schütz's (1962) first, second and third order constructs were kept in mind. To control for the potential influence of the researcher's own biases and prior knowledge, all stages of the meta-ethnography were discussed with an independent researcher to ensure the constructs were as close to the data as possible.

Getting started

This stage involved identifying an area of interest. This meta-ethnography explores service users' experiences of CBT for anxiety disorders.

Deciding which studies to include

Inclusion and exclusion criteria were carefully considered to guarantee literature relevant to the area of interest was identified, whilst also ensuring the search was broad enough so relevant articles were not missed. Reviewing reference lists also confirmed all applicable articles were included.

Reading the studies

Included articles were read and re-read so relevant themes and concepts were identified, with attention being paid to the detail of the research. The synthesis was registered on PROSPERO (Appendix 2).

Determining how the studies are related

The key concepts within each of the studies were extracted and closely compared with one another to determine how the studies were related. To do so, concepts and themes from all the papers were tabulated and compared (Appendix 4).

Common concepts across the 12 papers were identified as: making sense of anxiety; relationship with the therapist; barriers to therapy; evaluation of treatment; active vs passive approach; expectations; outcomes of therapy. These concepts were based on second order constructs (the original authors' interpretation of the participants understanding).

Noblit and Hare (1998) describe three potential relationships at this stage; reciprocal translation (studies are directly comparable), refutational translation (studies contradict one another), line of argument (studies successively build a new interpretation). The studies were deemed similar enough to allow reciprocal translation, there were no studies that contradicted the others and so refutational translation was not necessary.

Translating the studies into one another

During the translation stage concepts and themes from one study are compared to the next in order to identify if they can be translated into one another. In order to do this a table was created in Excel, as suggested in Britten et al (2002). The common concepts identified in stage 4 were noted in the first column. Each of the subsequent 12 columns included the first and second order constructs identified within each of the studies.

In a constant comparison process, the concepts from paper one were compared to paper two to identify if they were similar enough to each other and the common concept identified, to allow reciprocal translation. This process was repeated until all papers had been translated. An example of this process for the 'making sense of anxiety' concept can be seen in Appendix 5.

These concepts were translated into superordinate themes through third order interpretations, Appendix 6 demonstrates the development of one of these themes.

Synthesising translation

During this process the researchers are required to make the "whole into something more than the parts alone imply" (Noblit & Hare, 1988, p.28). The superordinate themes were synthesised into a line of argument and were organised into a conceptual framework shown in Figure 2.

Expressing the synthesis

The synthesis was expressed via the conceptual framework and accompanying narrative.

Table 3: Description of meta-ethnography process

RESULTS

Quality appraisal

All papers had a quality rating of A or B meaning none were considered to have a high likelihood of methodological flaws. In line with other meta-syntheses using the CASP rating system, no papers were excluded on the basis of quality rating (Atkins et al., 2008; Attree, 2004; Graham et al., 2020; Kowlessar et al., 2014; Wyatt et al., 2013). Instead, quality ratings were used to determine how much weight was given to papers in the overall contribution to the synthesis.

Table 4 states CASP scorings. As question 10 does not require scoring, it is presented within the table as a summary of the key areas it covers to indicate the contribution of each paper to prior knowledge, future research and wider populations. This table also includes the scoring of the additional quality assessment question regarding evidence for CBT.

Quality Appraisal Criteria	1	2	3	4	5	6	7	8	9	10	11	12
	(Tzavela	(Mukherjee	(McManus	(Halmetoja	(Burke	(Johansson	(Westra	(Button	(Khattra	(Kertes	(Morrison	(Macaulay
	et al.,	et al., 2006)	et al., 2010)	et al., 2014)	et al.,	et al., 2015)	et al.,	et al.,	et al.,	et al.,	et al., 2017)	et al., 2017)
	2018)				2019)		2010)	2019)	2017)	2011)		
CASP Criteria												
1) Was there a clear statement of the	1	1	1	1	1	1	1	1	1	1	1	1
aims of the research?												
2) Is a qualitative methodology appropriate?	0.5	1	1	1	1	1	1	1	1	1	1	1
3) Was the research design appropriate to address the aims of	0.5	0.5	1	1	0	1	0.5	0.5	0	0.5	1	1
the research?												
4) Was the recruitment strategy appropriate to the aims of	0.5	1	1	1	0.5	1	0.5	1	0.5	0.5	1	1
the research?												
5) Was the data collected in a way that addressed the	1	1	1	1	0	1	1	1	1	1	1	1
research issue?												
6) Has the relationship between researcher and participants	0	0	0	0.5	0	0.5	0.5	0	0	0.5	0.5	0
been adequately considered?												

Quality Appraisal Criteria	1	2	3	4	5	6	7	8	9	10	11	12
	(Tzavela	(Mukherjee	(McManus	(Halmetoja	(Burke	(Johansson	(Westra	(Button	(Khattra	(Kertes	(Morrison	(Macaulay
	et al.,	et al., 2006)	et al., 2010)	et al., 2014)	et al.,	et al., 2015)	et al.,	et al.,	et al.,	et al.,	et al., 2017)	et al., 2017)
	2018)				2019)		2010)	2019)	2017)	2011)		
7) Have ethical issues been taken into consideration?	1	1	0.5	1	0.5	1	1	0.5	0	0	0.5	0
8) Was the data analysis sufficiently rigorous?	1	0.5	1	1	1	1	1	1	0.5	1	1	1
9) Is there a clear statement of findings?	1	1	1	1	1	1	1	1	1	1	1	1
10) How valuable is the research?												
10a) Do the researchers discuss contributions to existing	✓	✓	✓	✓	√	✓	✓	√	√	√	✓	✓
knowledge or understanding?												
10b) Do the researchers identify new areas where research is	√	√	✓	✓	√	✓	✓	√	√	√	×	X
necessary?												
10c) Do the researchers discuss how the findings can be	√	√	X	√	×	×	×	×	×	√	√	√
transferred to other populations or consider ways the												
research may be used?												

Quality Appraisal Criteria	1	2	3	4	5	6	7	8	9	10	11	12
	(Tzavela	(Mukherjee	(McManus	(Halmetoja	(Burke	(Johansson	(Westra	(Button	(Khattra	(Kertes	(Morrison	(Macaulay
	et al.,	et al., 2006)	et al., 2010)	et al., 2014)	et al.,	et al., 2015)	et al.,	et al.,	et al.,	et al.,	et al., 2017)	et al., 2017)
	2018)				2019)		2010)	2019)	2017)	2011)		
Do the researchers state which evidence-based CBT protocol	0.5	0.5	1	1	1	1	1	0.5	0.5	1	0.5	0.5
is used?												

Table 4: Quality appraisal scoring for each paper

Study	Authors	Title	Aim	Participants	Method of	Data collection	Analysis	Quality
					verifying diagnosis			rating
1	Tzavela	Treatment engagement in	"our aim was to answer the questions:	Nine females and three males aged	SCL-90 Greek	Semi-	Grounded theory	7 (B)
	et al.	the early phase of	(1) How does treatment process	between 24 and 64 years were	Standardised	structured	(Strauss & Corbin,	
	(2018)	cognitive-behavior therapy	develop in the early phase of EBCBT for	recruited from a behaviour therapy	Version	interview	1990)	
		for panic disorder: A	PD? (2) What are the elements that	unit for anxiety disorders. All	(Derogatis, 1977)			
		grounded theory analysis	characterize early engagement vs.	participants' primary diagnosis was				
		of patient experience	disengagement in therapy? (3) What	panic disorder (PD) with or without				
			early treatment characteristics are	agoraphobia.				
			linked favourable (retention) or					
			unfavourable (dropout) treatment					
			outcomes?" (pg. 844)					

Study	Authors	Title	Aim	Participants	Method of	Data collection	Analysis	Quality
					verifying diagnosis			rating
2	Mukherj	Adherence to treatment	"to better understand disadvantaged	Fourteen women and seven men	Composite	Semi-	Grounded theory	7.5 (B)
	ee et al.	among economically	patients' views on mental health care	aged between 23 and 59 years	International	structured	(Glaser & Strauss,	
	(2006)	disadvantaged patients	received in primary care settings and	were recruited from university-	Diagnostic	interview	1967)	
		with panic disorder	provide an opportunity for them to	based primary care clinics. All	Interview (CIDI;			
			express their needs and explain their	participants had a principle	World Health			
			service and treatment options" (pg	diagnosis of panic disorder.	Organisation,			
			1746).		1997) in previous			
					randomised			
					effectiveness trial			

Study	Authors	Title	Aim	Participants	Method of	Data collection	Analysis	Quality
					verifying diagnosis			rating
3	McManu	Learning to change a way	"to attempt to understand patients'	Six females and two male	Anxiety disorders	Semi-	Interpretative	8.5 (A)
	s et al.	of being: An interpretative	experiences during one of the	participants aged between 23 and	interview	structured	phenomenologica	
	(2010)	phenomenological	established cognitive-behavioral	41 years were recruited from an	schedule (ADIS-IV;	interview	l analysis (IPA;	
		perspective on cognitive	treatments for SP, with the aim of	outpatient NHS service for anxiety	DiNardo et al.,		Smith & Osborn,	
		therapy for social phobia	understanding how different aspects of	disorders. All participants met	1995)		2003)	
			the treatment impact on the patients"	criteria for social phobia (social				
			(pg. 582)	anxiety disorder).				

Study	Authors	Title	Aim	Participants	Method of	Data collection	Analysis	Quality
					verifying diagnosis			rating
4	Halmetoj	Experiences of internet-	"to add to the body of knowledge	Nine female and three men aged	SCID (First et al.,	Semi-	Grounded theory	9.5 (A)
	a et al.	delivered cognitive	regarding participants' experience of	between 28 and 67 years were	1996) in previous	structured	(Pidgeon &	
	(2014)	behaviour therapy for	guided iCBT, their own views on the	recruited from a controlled trial of	RCT	interviews	Henwood, 1996)	
		social anxiety disorder four	treatment, but also their reports	guided internet delivered (iCBT) for				
		years later: A qualitative	regarding gained knowledge about SAD	SAD (Andersson et al., 2012) where				
		study	and its treatment and what they found	participants were recruited via a				
			to be of use to them in the long term	web page. All participants had a				
			perspective" (pg. 159)	principle diagnosis of Social Anxiety				
				Disorder (SAD).				

Study	Authors	Title	Aim	Participants	Method of	Data collection	Analysis	Quality
					verifying diagnosis			rating
5	Burke et	Helpful and hindering	"gain an understanding of the helpful	Twenty-five females and 11 males	Generalized	The	Descriptive and	6 (B)
	al. (2019)	events in internet-	and hindering events and associated	aged between 18 and 45 years	Anxiety Disorder	Helpful/Hinder	interpretive	
		delivered cognitive	impacts of iCBT for GAD symptoms,	were recruited from a university. All	7-item scale	ing Aspects of	framework (Elliott	
		behavioural treatment in	specifically within a student	participants had a principle	(GAD-7; Spitzer et	Therapy (HAT)	& Timulak, 2006)	
		generalized anxiety	population" (pg. 388)	diagnosis of GAD.	al., 2006)	form		
						(Llewelyn,		
						1988)		

Study	Authors	Title	Aim	Participants	Method of	Data collection	Analysis	Quality
					verifying diagnosis			rating
6	Johansso	Experiences of non-	"to gain more knowledge about the	Six females and one male aged	Generalized	Semi-	Grounded theory	9.5 (A)
	n et al.	adherence to internet-	factors that might play a role in the	between 21 and 69 years were	Anxiety Disorder	structured	(Charmaz, 2006)	
	(2015)	delivered cognitive	decision not to complete an ICBT	recruited from a psychiatric	Questionnaire-IV	interview		
		behaviour therapy: A	treatment" (pg. 138)	hospital. All participants met the	(Newman et al.,			
		qualitative study		criteria for GAD.	2002) and Penn			
					State Worry			
					Questionnaire			
					(Meyer et al.,			
					1990)			

Study	Authors	Title	Aim	Participants	Method of	Data collection	Analysis	Quality
					verifying diagnosis			rating
7	Westra	Therapy was not what I	"evaluated client retrospective post-	Four male and 14 female	ADIS-IV (Brown,	Semi-	Grounded theory	8.5 (B)
	et al.	expected: A preliminary	treatment accounts of both initial	participants aged between 21 and	DiNardo &	structured	(Glaser & Strauss,	
	(2010)	qualitative analysis of	expectations in cognitive-behavioral	59 years. Participants were	Barlow, 1994)	interview	1967) and	
		concordance between	therapy (CBT) to provide an initial	recruited from a previous RCT			consensual	
		client expectations and	understanding of the degree of	(Westra et al., 2009) via community			qualitative	
		experience of cognitive-	congruence between initial	advertisement. All participants had			research methods	
		behavioural therapy	expectations and experience" (pg, 437)	a principal diagnosis of GAD.			(Hill et al., 1997)	

Study	Authors	Title	Aim	Participants	Method of	Data collection	Analysis	Quality
					verifying diagnosis			rating
8	Button et	Client reflections on	"to examine qualitatively client post	Nine females and one male aged	Structured Clinical	Semi-	Grounded theory	7.5 (B)
	al (2019)	confirmation and	treatment narratives of their process	between 20 and 51 years were	Interview for	structured	(Glaser & Strauss,	
		disconfirmation of	expectations in relation to their actual	recruited from a previous	DSM-IV – patient	interviews	1967)	
		expectations in cognitive	treatment experiences in the context	randomised controlled trial (RCT;	version (SCID-I/P;			
		behavioral therapy for	of GAD" (pg. 724)	Westra et al., 2016). All had a	First et al., 1996)			
		generalized anxiety		principal diagnosis of generalized				
		disorder with and without		anxiety disorder (GAD). Five				
		motivational interviewing.		participants received cognitive				
				behaviour therapy (CBT) and five				
				received motivational interviewing				
				prior to CBT (MI-CBT).				

Study	Authors	Title	Aim	Participants	Method of	Data collection	Analysis	Quality
					verifying diagnosis			rating
9	Khattra	Client perceptions of	"to investigate the presence and	Two female participants aged 28	Structured Clinical	Semi-	Grounded theory,	5.5 (B)
	et al.	corrective experiences in	nature of CEs in two clients' first-hand	and 53 years were recruited from	Interview for	structured	using ATLAS.ti	
	(2017)	cognitive behavioral	accounts of their experience of	the Westra et al (2016) RCT. Both	DSM-IV-TR Axis I	interview	scientific software	ļ
		therapy and motivational	cognitive behavioral therapy (CBT) and	participants had a principle	Disorders (SCID-	following the		
		interviewing for	CBT integrated with motivational	diagnosis of GAD. One participant	IP; First et al.,	Patient		
		generalized anxiety	interviewing (MI) for generalized	received CBT, the other received MI	2002)	Perspectives		
		disorder: An exploratory	anxiety disorder (GAD)" (pg. 24)	sessions before commencing CBT.		of Corrective		
		pilot study				Experiences in		
						Individual		
						Therapy		
						(PPCEIT)		
						Interview		
						Protocol		
1	1					1		

Study	Authors	Title	Aim	Participants	Method of	Data collection	Analysis	Quality
					verifying diagnosis			rating
10	Kertes et	The impact of motivational	"to identify how the addition of MI pre-	Eight females and two males aged	ADIS-IV (Brown et	Semi-	Grounded theory	7.5 (B)
	al. (2011)	interviewing on client	treatment to CBT affects the	between 24 and 54 years were	al., 1994)	structured	(Glaser & Strauss,	
		experiences of cognitive	experiences of CBT among individuals	recruited from a previous RCT		interview	1967) and	
		behavioral therapy for	of high worry severity"	(Westra et al., 2008). All			consensual	
		generalized anxiety		participants had a principal			qualitative	
		disorder		diagnosis of GAD. Five participants			research methods	
				received four sessions of MI prior to			(Hill et al., 1997)	
				eight sessions of CBT. Five				
				participants just had the eight				
				weeks of CBT.				

Authors	Title	Aim	Participants	Method of	Data collection	Analysis	Quality
				verifying diagnosis			rating
Morrison	Using interpersonal	"to understand more directly the	Ten women aged between 18 and	SCID-1 (First et al.,	Semi-	Grounded theory	8.5 (A)
et al.	process recall to compare	experiences of patients with GAD in the	57 years were recruited from the	1997) in previous	structured	(Glaser &	
(2017)	patients' accounts of	Westra et al. 2016 trial who were	Westra et al (2016) RCT. Five	RCT	interview	Strauss,1967) and	
	resistance in two	judged to be at risk for resistance	participants were offered MI-CBT		using	consensual	
	psychotherapies for	based on trained observations of early-	(2-4 MI sessions followed by 11-13		interpersonal	qualitative	
	generalized anxiety	in-session change ambivalence" (pg.	CBT sessions). Five were offered 15		process recall	research (Hill,	
	disorder	1525)	weekly sessions of CBT. All		method (IPR;	2012)	
			participants had a diagnosis of GAD.		Elliot, 1986;		
					Jones,		
					Latchford &		
					Tober, 2016)		
	Morrison et al.	Morrison Using interpersonal et al. process recall to compare (2017) patients' accounts of resistance in two psychotherapies for generalized anxiety	Morrison Using interpersonal "to understand more directly the et al. process recall to compare experiences of patients with GAD in the patients' accounts of Westra et al. 2016 trial who were resistance in two judged to be at risk for resistance psychotherapies for based on trained observations of early-generalized anxiety in-session change ambivalence" (pg.	Morrison Using interpersonal "to understand more directly the process recall to compare experiences of patients with GAD in the patients' accounts of Westra et al. 2016 trial who were resistance in two psychotherapies for psychotherapies for generalized anxiety disorder 1525) "to understand more directly the Ten women aged between 18 and 57 years were recruited from the Westra et al. 2016 trial who were Westra et al (2016) RCT. Five participants were offered MI-CBT psychotherapies for based on trained observations of early-generalized anxiety in-session change ambivalence" (pg. CBT sessions). Five were offered 15 weekly sessions of CBT. All	Morrison Using interpersonal "to understand more directly the Ten women aged between 18 and process recall to compare experiences of patients with GAD in the patients' accounts of Westra et al. 2016 trial who were participants were offered MI-CBT psychotherapies for psychotherapies for generalized anxiety disorder [1525] weekly sessions of CBT. All	Morrison Using interpersonal "to understand more directly the experiences of patients with GAD in the patients' accounts of patients' accounts of psychotherapies for generalized anxiety disorder 1525) Morrison Using interpersonal "to understand more directly the Ten women aged between 18 and process recall to compare experiences of patients with GAD in the process recruited from the participants were recruited from the participants were offered MI-CBT participants were offered MI-CBT psychotherapies for generalized anxiety in-session change ambivalence" (pg. CBT sessions). Five were offered 15 process recall participants had a diagnosis of GAD. Elliot, 1986; Jones, Latchford &	Morrison Using interpersonal "to understand more directly the et al. process recall to compare experiences of patients with GAD in the resistance in two judged to be at risk for resistance psychotherapies for generalized anxiety disorder 1525) Morrison Using interpersonal "to understand more directly the experiences of patients with GAD in the experiences of patients with GAD in the process recall to compare experiences of patients with GAD in the experiences of patients were recruited from the postpart of the process recall to compare experiences of patients with GAD in the process recruited from the postpart in the process recall to compare experiences of patients were experienced from the process recall interview of the process recall using consensual of the process recall process recall interpersonal interpersonal interpersonal experiences of patients were offered MI-CBT (2-4 MI sessions followed by 11-13 (2-4 MI sessions followed by 11-13 (2-4 MI sessions followed by 11-13 (2-4 MI sessions). Five were offered 15 (2-4 MI sessions) are weekly sessions of CBT. All process recall pr

Study	Authors	Title	Aim	Participants	Method of	Data collection	Analysis	Quality
					verifying diagnosis			rating
12	Macaulay	Client retrospective	"to elucidate MI-CBT client perceptions	Seven females and one male aged	SCID-1 (First et al.,	Semi-	Modified	7.5 (B)
	et al.	accounts of corrective	of key shifts in views of self, like,	between 20 and 53 years were	1997) in previous	structured	grounded theory	
	(2017)	experiences in	emotions, behaviours, and	recruited from the Westra et al	RCT	interview	incorporating	
		motivational interviewing	relationships, as well as their	(2016). All participants had a		following the	methods from	
		integrated with cognitive	understanding of how these changes	principal diagnosis of GAD.		Patient	Glaser and Strauss	
		behavioral therapy for	happened" (pg. 170)			Perspectives	(1967) and Rennie	
		generalized anxiety				of Corrective	(2000)	
		disorder				Experiences in		
						Individual		
						Therapy		
						(PPCEIT)		
						Interview		
						Protocol		

Table 5: Study characteristics of included studies

Study Characteristics

One hundred and fifty-four participants contributed across the 12 studies. Participants from the Westra et al. (2016) randomised controlled trial (RCT) may have contributed to more than one research paper. Seventy-seven percent of participants were female, their age ranging from 18 to 69.

Eight studies looked at individuals with generalised anxiety disorder (GAD), two with panic disorder (PD) with or without agoraphobia, and two with social anxiety disorder (SAD). Included studies were undertaken in Canada, Sweden, the United States of America, Ireland, the United Kingdom and Greece. Four studies (Button et al., 2019; Khattra et al., 2017; Macaulay et al., 2017; Morrison et al., 2017) recruited participants from the same RCT (Westra et al., 2016). Studies used varying methods of verifying the DSM diagnosis (Table 5).

Eleven studies used interviews to gain qualitative data. Study five used a bespoke tool (Helpful/Hindering Aspects of Therapy; HAT) designed by Llewelyn (1988) where participants describe the most significant events during CBT and whether these were helpful or hindering. All studies investigated individuals' experiences of CBT for anxiety disorders, with some focusing on specific elements of this experience including non-adherence, helpful/hindering aspects, factors influencing engagement.

In five papers (Button et al., 2019; Kertes et al., 2011; Khattra et al., 2017; Macaulay et al., 2017; Morrison et al., 2017) some participants had motivational interviewing (MI) prior to CBT. These were included as all participants received predominantly CBT, thereby meeting inclusion criteria. This research aims to explore service users' perceptions of the process of CBT; participants in these papers discussed their experiences of therapy as a whole including their experiences of CBT, not just MI, thereby providing rich data to meet the aims of this

study. By removing studies where participants had MI prior to CBT, important data would be lost.

Endorsement of themes

Table 6 shows the number of papers endorsing each theme.

Emerging Themes		1	2	3	4	5	6	7	8	9	10	11	12	Total
		(Tzavela	(Mukherjee	(McManus	(Halmetoja	(Burke	(Johansson	(Westra	(Button	(Khattra	(Kertes	(Morrison	(Macaulay	
		et al.,	et al., 2006)	et al., 2010)	et al., 2014)	et al.,	et al., 2015)	et al.,	et al.,	et al.,	et al.,	et al., 2017)	et al., 2017)	
		2018)				2019)		2010)	2019)	2017)	2011)			
Influence of	CBT met expectations	√						√	√					3
preconceptions	CBT was not what I	√						√	√		√			4
	expected													
The role of the thera	The role of the therapeutic relationship			√		√	✓	√	√	√	√	√	√	10
Perceptions of CBT to	echniques	√	√	√	✓	√			√	✓	√	✓		9
Service user style of	Actively engaging	√		√	√				√	√	√	√	√	8
engagement with	with therapy													
СВТ	Passively engaging	√			√						√			3
	with therapy													

Emerging Themes		1	2	3	4	5	6	7	8	9	10	11	12	Total
		(Tzavela	(Mukherjee	(McManus	(Halmetoja	(Burke	(Johansson	(Westra	(Button	(Khattra	(Kertes	(Morrison	(Macaulay	
		et al.,	et al., 2006)	et al., 2010)	et al., 2014)	et al.,	et al., 2015)	et al.,	et al.,	et al.,	et al.,	et al., 2017)	et al., 2017)	
		2018)				2019)		2010)	2019)	2017)	2011)			
Developing insight	Understanding	√	✓	✓		√			√	√	√		✓	8
	anxiety													
	Making change	√	√	√		√			√	✓	√		√	8
Understanding how CBT was not helpful			√		√	√	√							4

Table 6: Number of studies endorsing each theme of the meta-synthesis

Summary of themes

This meta-synthesis identified six core themes that influence how individuals experience CBT for anxiety: the role of the therapeutic relationship; the influence of preconceptions; perceptions of CBT techniques; service user style of engagement; developing insight; perceiving CBT to be unhelpful.

A table of the themes and subthemes is presented in Table 7 as well as a written narrative below. These themes follow the participants' journey through therapy, considering which factors they perceived as important in their experience of CBT, and why.

Theme	Subtheme
Role of the therapeutic relationship	
Influence of preconceptions	CBT lived up to expectations
	CBT was not what I expected
Perceptions of CBT techniques	
Service user style of engagement	Actively engaging with therapy
	Passively engaging with therapy
Developing insight	Understanding anxiety
	Making change
Perceiving CBT to be unhelpful	

Table 7: List of themes and subthemes in meta-synthesis

Role of the therapeutic relationship

This theme depicts participants' experiences of the therapist's characteristics and role within CBT, and why these are important. This relationship is seen as fundamental within this metasynthesis, feeding into all other themes identified and often being a mediating factor between CBT aspects and why they're perceived as helpful.

In nine studies, participants identified valued and helpful characteristics of the therapist; being non-judgemental, validating, genuine, warm, approachable and trustworthy. These enabled participants to be open and honest, disclosing more information about their anxiety, allowing therapists to make better sense of their difficulties.

"I didn't think I was going to be as open and honest and have such revealing sessions where my therapist makes sense of the situation"

(service user with GAD; Morrison et al., 2017, p. 1529)

Essential in the therapeutic relationship, was the development of trust. The characteristics above put service users at ease and created trust in the process of therapy as well as the therapist and their recommendations. This trust is vital for overcoming initial scepticisms and engaging in therapy, as discussed throughout.

"First I needed to see what he [therapist] was like and see if I could trust him. This actually happened in the first session. I felt I could say stuff and he would not look at me as if I were an extra-terrestrial"

Many described these characteristics as a new experience in relationships, not feeling judged as they did in others. Some experienced recognising their pre-existing interpersonal patterns, and challenging these, within the therapeutic relationship.

(service user with PD; Tzavela et al., 2018, p. 849).

"The biggest thing was I sat down and talked to someone that I have no connection with [and] I was really honest with myself...because when you're with family and friends, you kind of keep things away, but with [therapist's name] I just poured everything out, every little detail and then I heard myself" (service user with GAD; Macaulay et al., 2017, p. 176)

These characteristics were identified as lacking by those who experienced the therapeutic relationship to be less positive. Participants in paper one felt the therapist's lack of openness impacted their ability to trust them. Participants in paper 11 expressed difficulty with their therapists when they weren't validating.

"If the therapist is not open then I tend to immediately go into my shell, just as a turtle would do. On the contrary, if she opens up and relays that she is here to help, then I would feel I can trust her"

(service user with PD; Tzavela et al., 2018, p. 849).

As well as commenting on the characteristics of the therapist, participants recognised their role as a valuable part of their CBT experience. Service users predominantly described their therapist as a guide who worked collaboratively with them to provide expertise and solutions. When expertise was doubted it often led to service users finding it hard to trust in the therapist's ability or the process of CBT. Value was given to feeling the therapist worked collaboratively with participants, increasing self-reflection and exploration which resulted in developing insight and considering alternative perspectives.

"The therapist asking me a lot of questions made me really think and gave me a chance to look at things from a different perspective...she would come back with a question, which I would be like, whoa!, she stumped me. And I'd think wow, I never thought of it like that!"

(Service user with GAD; Khattra et al., 2017, p. 30).

Experiencing the relationship as collaborative also developed individuals' personal responsibility and control over the direction of therapy and making changes, increasing

comfort and trust in CBT. This perception of being a co-facilitator is also linked to engagement style and outcomes, as explored further in 'service user style of engagement'.

"I'm thinking like you know when you go to school, and you have the teacher teaching you and you have to do what you're supposed to do. No, it was not like that. I was allowed to talk about what I wanted to talk about and when I wanted to talk, not because she made me talk...it's because I feel like talking. It felt good...like she's not restraining me"

(service user with GAD; Westra et al., 2010, p. 440)

Studies two and four did not report on the therapeutic relationship. In study four participants received internet-delivered CBT (iCBT), so the therapeutic relationship was less of a factor. In study two, research focused on service users expressing their needs and explaining their treatment choices. This focus may have meant the interview schedule did not focus on the therapeutic relationship.

Influence of preconceptions

This theme was reported in four studies and depicts service users' expectations of CBT-E, and whether these were met. Notably, fewer papers endorsed this theme than others, some focused explicitly on confirmation of expectations and therefore contributed significantly to this theme. Generally, it seems participants did not discuss expectations unless prompted to do so.

This theme is linked with 'service users' style of engagement' and 'the role of the therapeutic relationship'. Expectations influenced service users' perceptions of how helpful CBT was, which in turn influenced engagement and outcomes: those starting therapy with positive expectations having positive outcomes. Similarly, those with negative expectations tended to

have poorer outcomes unless scepticisms were overcome. The analysis suggests this relationship between preconceptions and CBT outcomes is mediated by both service user engagement and the therapeutic relationship, as reported in more detail within these themes.

The origin of expectations is generally under-reported within these studies. Some discuss expectations being based on previous experiences of therapy or having researched CBT before starting. Others recognised expectations being influenced by stereotypes of therapy.

CBT lived up to expectations

Areas of CBT perceived to meet positive expectations of therapy included: gaining tools to manage and understand their anxiety, session structure, therapist characteristics and role, and playing an active role in engaging with treatment.

"I knew it was going to involve techniques that would be kind of work-intensive, and I was excited about that. And that is what happened. And they were beneficial" (service user with GAD; Button et al., 2019, p. 442)

CBT was expected to assist service users in developing insight into their anxiety and increase their ability to manage it, and participants were pleased when it met these expectations.

Participants accredit therapists with assisting the development of insight through working in a collaborative manner.

"I have gone to therapy one time before and I knew what I was expecting and it was similar in the sense that [the therapist] listened to me and she always made me think and then she would take what was concerning for the week and she would kind of dissect it and help me understand why I have had this fear" (service user with GAD; Westra et al., 2010, p. 442).

Conversely, participants in paper seven highlighted that negative expectations were confirmed; experiencing therapy to be over generalised and lacking detail. This seems to arise from a lack of explanation or rationale for techniques, thus recognising the importance of the therapist's collaborative role once more.

"[The therapist] had me doing the exercise where I put myself in a stressful situation and write about it and I guess all therapists do that"

(service user with GAD; Westra et al., 2010, p. 442).

CBT was not what I expected

Initially sceptical about the structure and focus of therapy, the therapeutic relationship, and CBT outcomes, some service users overcame these scepticisms when they recognised the value of CBT. Therapists were integral in conquering these scepticisms by providing a clear treatment rationale and collaborative formulation, inspiring trust in the process. This is important for influencing engagement, as explored in 'service user style of engagement'.

"This [treatment rationale] is inspiring and spurs a little more courage in me. She [therapist] inspires me and it makes me come to sessions with pleasure" (service user with PD; Tzavela et al., 2018, p. 853).

However, in study seven reported service users' initial positive expectations not being met.

This study focused on experiences of those with poor outcomes which could explain why these participants report being more let down than others. Short duration of treatment, life events and participants' own compliance were reasons for feeling disappointed in CBT.

Perceptions of CBT techniques

Commonplace within eight studies, this theme illustrates participants' perceptions of which techniques were considered the most, and least, beneficial within CBT. Participants were less likely to discuss the challenging aspects of CBT: only three explored this, possibly due to demand characteristics and participants perceiving a need to answer positively. Additionally, those who had a positive experience may be more likely to participate in research.

Helpful techniques included: psychoeducation; thought records; relaxation; cognitive restructuring; recognising safety behaviours; behavioural experiments; exposure. These developed insight into anxiety, provided normalisation, and allowed participants to develop confidence in managing anxiety.

"The cognitive stuff helped me to really learn how to work through things and recognise what's happening. Also, it pushed me beyond what I feel my limits are...and kinda pushed me to take a little bit more of a risk. I gained confidence doing that" (service user with PD; Mukherjee et al., 2006, p.1747).

In contrast, others experienced psychoeducation and exposure as unhelpful when the techniques were not well explained by the therapist, again highlighting the importance of this relationship.

Participants perceiving psychoeducation as helpful developed insight into their anxiety and increased understanding of their experiences. Perceived as normalising, psychoeducation left service users feeling relieved they were not alone.

"I think it's really like opened my mind and it was really, really useful because first of all I realised that I wasn't the only one...I didn't feel like I was not normal, this can happen to anyone"

(service user with SAD; McManus et al., 2010, p. 584).

However, participants in two studies saw the content as too generic and not specific to their difficulties, making them feel alone and as though they could not relate to the content.

"The examples available are not really like my problems or anxiety. It kind of makes me feel a bit more alone as no one seems to feel the same things I do" (service user with GAD; Burke et al., 2018, p.8)

Whether psychoeducation was perceived to be helpful or not hinged on how individualised the information was, and how collaboratively it was presented. When this was not the case participants found the information difficult to understand and relate to, thus emphasising the importance of the therapist's collaborative role once more.

"She just got a diagram out and said this is a model of what's going on" (service user with SAD; McManus et al., 2010, p. 584)

Interestingly, participants receiving iCBT in paper four found content to be normalising, whereas in paper five it felt irrelevant. Participants in paper four also had an online forum allowing them to speak to others with similar difficulties. This suggests the value of a sense of normalisation and the need for information to be specific to individuals' difficulties, rather than generalised, in order for participants to develop insight into their difficulties.

Likewise, participants responses to the use of exposure techniques during CBT varied.

Exposure is a technique used to reduce fear levels over time. It is generally perceived by

participants as helpful in reducing anxieties, but some in paper ten perceived it to be challenging and to have increased levels of anxiety.

Those who found it unhelpful appeared to have not understood the rationale behind exposure, suggesting therapists' explanations are key. Those who found it helpful recognised it as challenging but trusted the process. Given that exposure requires placing yourself in a fearful situation, it is understandable that having a clear explanation and trust in your therapist is key to how you perceive this technique. This indicates the importance of a positive therapeutic relationship before asking individuals to engage with techniques that are challenging.

"I didn't understand why exposure would be helpful at all ... it ended up being really difficult and painful"

(service user with GAD; Kertes et al., 2011, p. 65).

"I thought exposure was helpful even though I didn't like doing it" (service user with GAD; Kertes et al., 2011, p. 64).

Service user style of engagement with CBT

This theme was pertinent across ten studies and explores whether participants engaged with CBT in an active or passive manner.

As indicated in Figure 2, this theme overlaps with 'perceptions of CBT techniques'; when discussing engagement, participants are referring to their ability to engage with these techniques.

Actively engaging with therapy

This theme identifies service users taking responsibility for their own progress during and post therapy; playing an active role by working hard to make sense of difficulties and implement change.

"Well, I took a very proactive role [in therapy]...I guess I've been frustrated...for a number of, for the last couple of years...trying to find answers to my questions...so, my role...was to, to find my own answers, really, because it's, it's not up to [the therapist] to...do anything...I have to help her decide, what, what I need...she was very good to react to my... needs"

(service user with GAD; Kertes et al., 2011, p. 62)

Once again, the role of the therapeutic relationship was fundamental in helping participants feel able to play an active role. Working collaboratively with the therapist rather than feeling directed was key to allowing the development of deeper insights, rather than simply listening.

"The process was very much driven by me. So, the exercises she would give me ... if I said, 'Yeah I don't really think that's gonna work for me,' it was 'okay, lets figure out something else. How would you approach it?'"

(service user with GAD; Button et al., 2018, p. 729).

Additionally, participants recognised being inspired by the therapist, therefore trusting the process and feeling willing to engage, as referenced in 'influence of preconceptions'.

Conversely, those remaining sceptical, were more likely to engage passively and allow the therapist to direct sessions. This theme therefore links previous ones together; participants arrive at therapy with preconceptions, then as the therapist inspires trust, initial scepticisms are dropped and individuals actively engage in therapy, which in turn has been linked to improved CBT outcomes.

Participants in four studies discussed the importance of remaining actively engaged post therapy in order to see improvements continue, developing a sense of self-efficacy they could take forward.

"I feel like we kinda built a foundation of a house and I'm going to keep building this house but the foundation is a really solid, um, stable base for me to keep kind of growing"

(service user with GAD; Macaulay et al., 2017, p. 177).

An association appears between playing an active role engaging in therapy and feeling motivated to take responsibility for implementing change and making progress. Engaging actively requires more effort and determination than expecting the therapist to fix the problem, thus requiring motivation. Again, this links in with the therapeutic relationship; active engagement seems more likely to happen when the therapist encourages collaborative working.

A significant proportion of the studies contributing to this theme included participants who had MI prior to CBT. Research has explored the addition of MI to improve CBT outcomes, highlighting the importance of motivation in CBT success. This meta-synthesis suggests that active engagement is the mediating factor between motivation and positive CBT outcomes.

Passively engaging with therapy

Some experienced their role in therapy as passive, being compliant but awaiting relief rather than actively attempting change. Here service users highlight a reliance on the therapist to make change, rather than being collaborative. Service users report difficulties engaging actively due to anxiety making it difficult to concentrate, time constraints, and feeling unsupported.

"I rely on her [therapist] I am a bit hesitant. I know the mechanism, the behavioural part but I can't get started. With some pressure, with her control, by perceiving assignments as duties, this would be starting point" (service user with PD; Tzavela et al., 2018, p. 853).

This theme is heavily influenced by both themes of 'service users' preconceptions of therapy' and 'the role of the therapeutic relationship'. Tzavela et al (2018) identifies these two factors as mediating whether participants engage actively or passively. Individuals are more likely to engage actively if they expect therapy to be helpful, and the therapist is key to inspiring trust and improving these expectations. Additionally, reliance on the therapist for those who are passively engaging highlights the importance of the therapist's role, and the need for working collaboratively.

Developing Insight

Rather than factors influencing how helpful people find CBT, this theme considers why people experienced CBT to be helpful by pulling together threads discussed in previous themes.

Generally, people described a process of developing insight into their anxiety, themselves and their relationships.

Understanding anxiety

Participants highlight the role CBT played in facilitating their understanding of anxiety through recognising what triggers and maintains it, as well as what impact their anxiety has on their life. Participants accredit CBT techniques, active engagement in therapy and a collaborative therapeutic relationship in developing these insights.

"The more we talked about what was that thought? Why did you think that way? I started seeing, oh okay, I can stop, look at it, slow it down, and try to reframe it" (service user with GAD; Khattra et al., 2017, p. 29)

Making change

Service users recognised the role of CBT in creating intra-personal change, describing a greater sense of self-efficacy; being more in control of their anxiety and having confidence to manage it alone. This self-efficacy also extended beyond therapy and into implementing techniques after therapy ended.

"This was the first therapy where I thought during and afterwards that I could handle things on my own. Before...it was like I really needed that therapist...so it [therapy] enabled me to be more self-sufficient...I mean, that was surprising."

(service user with GAD; Button et al., 2018, p. 728)

"Just feeling that things have changed and I'm able to effect change, makes me feel hopeful and strong and I can do this on my own too" (service user with GAD; Macaulay et al., 2017, p. 177).

Participants accredited CBT techniques with enabling them to manage their anxiety. However, as noted throughout this meta-synthesis, style of engagement mediates how beneficial some people perceive the CBT to be and those who actively engage in the techniques are more likely to experience an intra-personal change. Additionally, the therapeutic relationship is important for trusting the process and practicing techniques, therefore also influencing the amount of intra-personal change people make. Although service users accredit the techniques, this intra-personal change is likely influenced by these more nuanced issues as well.

Some service users identified a change in their ability to show self-compassion, influenced by developing an understanding for anxiety, perceiving it to be normal, and therefore forgiving themselves. Participants recognised the role of the therapist in modelling compassion, allowing them to offer themselves this compassion.

"I felt like I would like to have that kind of comforting, um, ideally my own conversation with myself a little bit more...not her actual speaking voice but the voice of her, um, being, and I would...incorporate that a little bit more as sort of another option – when I'm thinking and feeling bad things that there's also now this voice of another person who's kind of light-hearted and caring and not judging" (service user with GAD; Macaulay et al., 2017, p. 176)

In addition to intra-personal change, in three studies CBT was perceived as creating interpersonal changes. Interestingly, this was only endorsed by studies in which participants had MI prior to CBT, although some participants within these studies did not have MI and still contributed. Possibly, this is due to the interview schedule used in these studies. For example, paper ten asked specifically about changes in their relationships with others.

Participants discussed their increased assertiveness within relationships and recognised the importance of putting their own needs first. Service users reported developing insight into their unhealthy interpersonal patterns and challenging these.

"I used to do manipulative things to my husband to fulfil my needs...now I recognise it and talk to him about it"

(service user with GAD; Kertes et al., 2010, p. 64)

Again, this is influenced by the therapeutic relationship. As recognised previously, service users identified their relationship with the therapist as being different to others in their lives. Service users describe noticing, alongside the therapist, how these old interpersonal patterns were playing out in the therapy room.

"There are situations now where I will be doing something, I think to myself, do I need to apologise for that? I try and like, go back to therapy"

(service user with GAD; Khattra et al., 2017, p.29)

Perceiving CBT to be unhelpful

Not all participants found CBT to be successful or helpful; some experiencing there to be too many barriers for it to be helpful, others viewing it to create a negative change.

Although many experienced CBT to be helpful, in three studies some perceived CBT to make their anxiety worse or to trigger existing psychiatric symptoms. Importantly, in all of these studies, individuals had iCBT where there is a lack of therapist contact. This may explain why individuals found it harder to engage in therapy and make positive changes, thus once again recognising the importance of the therapeutic relationship in influencing how beneficial individuals perceive CBT to be.

"The social phobia has become worse now, it has not become better, like. It wasn't much help, there are things I might think of but there is a difference between thinking and doing...or it helped me for as long as I was in it, if I put it that way, as long as I was in CBT, but after a while I believe it has, the effect wore off" (service user with SAD; Halmetoja et al., 2014, p. 161).

Studies two and six identified specific barriers participants experienced when engaging with CBT. Personal barriers included: incompatibility with life events; high demands on concentration and literacy ability; feeling unsupported. Logistical barriers included work constraints and transportation problems. These barriers prevented participants from being able to engage in CBT fully, thus experiencing the therapy as unhelpful.

"I thought it was too much to read, and I cannot read anything at all that I need to remember or learn. It goes in here and out there (pointing at the ears)" (service user with GAD; Johansson et al., 2015, p. 139)

Line of argument

This meta-synthesis highlights which factors during the process of CBT are most helpful in the experience of those with an anxiety disorder.

The preconceptions service users brought to therapy influenced their final experience of CBT.

Those who had their positive expectations met, generally experienced CBT to be helpful.

However, those who had their negative expectations met, experienced CBT to be unhelpful.

This relationship was mediated by the therapeutic relationship as this helped overcome negative expectations and reinforce positive ones.

The therapeutic relationship is key across all themes and often appears to be the factor that mediates whether people perceive aspects of CBT to be helpful or not. Being open, warm and genuine allowed people to feel comfortable in the therapy room, and thus allowed service users to develop insight into their anxiety. Development of trust in the therapist and process was key in determining engagement with the CBT techniques. Additionally, acting collaboratively was important for service users to feel responsible for their progress and engage in an active manner with the content.

Participants generally perceived aspects of CBT to be helpful, but when these were poorly explained by the therapist, some service users struggled to understand the process.

Participants' level of engagement in therapy was influential in determining how helpful people experienced CBT to be. Those engaging in an active manner and taking responsibility for their progress, found CBT to be more beneficial than those who passively engaged. Again, mediated by how much people believed in the therapy, in turn mediated by the therapist.

Participants found these factors helpful because they perceived therapy to allow them to develop insight into their anxiety and their relationships allowing them to make positive changes within themselves and interpersonally.

For those who perceived CBT to be unhelpful, this was generally because there were personal and logistical barriers to their engagement, perhaps suggesting this was not the right time for CBT.

DISCUSSION

Summary of findings

This meta-ethnography aimed to understand how service users with an anxiety disorder experience the process of CBT by identifying which factors they considered to be beneficial and why.

Four aspects of CBT were perceived as important; the therapeutic relationship, the influence of preconceptions, perceptions of CBT techniques and service user style of engagement. These interacted throughout the process of therapy; people arrived at CBT with preconceptions and these could be altered by therapists who inspired trust in the process with a clear treatment rationale. Service users were then more likely to actively engage in the CBT techniques if they worked collaboratively with the therapist, which in turn was shown in some papers to improve outcomes. These aspects were considered helpful because they allowed people to develop insight into themselves and their relationships, creating a better understanding of themselves. This finding sits alongside other meta-syntheses focusing on experiences of CBT for other mental health difficulties, which also identified that the techniques helped them to better understand their difficulties (Berry & Hayward, 2011; Khan et al., 2007; Knowles et al., 2014). Service users also experienced aspects of CBT-E to be beneficial due to their normalisation of individuals' difficulties, reducing their sense of isolation with their problems. Berry and Hayward (2011) also recognise the role of normalisation, arguing it helps to reduce the stigma that individuals have experienced previously.

The therapeutic relationship

This meta-synthesis argues that the therapeutic relationship is crucial for participants to feel that CBT was helpful. Developing trusting and collaborative therapeutic relationships allowed individuals to overcome scepticism and actively engage with CBT.

The finding that the therapeutic relationship plays a vital role in CBT for anxiety is not a novel one, and is unsurprising given the evidence associating the therapeutic relationship and treatment outcomes within psychotherapy, including CBT (Martin et al., 2000; Cummings et al., 2013; Evans-Jones et al., 2009; Heins et al., 2013). Previous meta-syntheses, such as Khan et al (2007) have identified that individuals perceive the therapeutic relationship to be important in their experiences of CBT, and so the current meta-synthesis corroborates these findings for CBT for anxiety. The current meta-synthesis furthers understanding of this area by considering what factors are helpful within the therapeutic relationship as well as how this relationship helps individuals to perceive individual CBT as beneficial.

The current analysis indicates this link between therapeutic relationship and CBT outcomes may be via active engagement. This notion is supported by Holdsworth et al. (2014) who reviewed factors influencing engagement with treatment and identified client engagement mediating the association between therapeutic alliance and CBT outcomes. The therapeutic relationship therefore cannot be overlooked when considering ways in which response and remission rates for CBT could be improved.

The contextual model of psychotherapy

A number of common factors have been identified as beneficial within psychotherapy more widely (Feinstein et al., 2015; Thomas, 2006). The contextual model looks at these factors throughout the process of therapy and posits that there are three pathways (factors) through which psychotherapy produces benefits (Wampold, 2015). As in the current meta-synthesis,

the therapeutic relationship, which is based mainly on trust, is key to any of the pathways being activated.

The first pathway, named 'the real relationship' recognises the importance of the therapeutic relationship being genuine. This relationship is acknowledged as often differing from others, remaining confidential and unchanged regardless of the disclosure of personal information. For many, this provides human connection and empathy that should be beneficial. In keeping with this, participants in the current meta-synthesis value the therapeutic relationship as it allows the disclosure of personal information, in turn creating a deeper understanding of themselves. Also, some participants define this relationship as differing to others which allows the recognition, and challenging, of unhealthy interpersonal patterns.

The second pathway is the role of expectations, arguing that people bring preconceptions to therapy that are influenced by society, just as the current meta-synthesis identified. Critical to this pathway is service users developing a belief that treatment will be helpful and accepting it, which was mediated by how well therapists explain the treatment rationale. The current meta-synthesis mirrors this finding, arguing a clear treatment rationale assists in trusting the process of therapy which in turn is linked with active engagement, improving outcomes. The link between positive expectations of therapy and good outcomes has been consistently identified throughout psychotherapy literature (Constantino et al., 2010; Greenberg et al., 2006), including CBT (Fromme, 2001; Tsai et al., 2014). Recognising the importance of expectations in not only perceiving CBT as beneficial, but in improving outcomes and potentially remission and response rates.

Finally, the contextual model recognises the influence of specific techniques in therapy. This model argues techniques can create expectations that individuals can reduce their distress,

and also assist people to reduce their reliance on unhealthy coping mechanisms. As in the current meta-synthesis, the contextual model once again recognises the importance of the therapeutic relationship; without collaborative work, patients are less likely to engage in the specific techniques. This mirrors the findings in the current meta-synthesis; working collaboratively means individuals take greater responsibility for change therefore being more likely to utilise CBT techniques.

The findings from the current meta-synthesis therefore corroborate these factors and model as well as recognising their application to CBT for anxiety disorders. Not discussed within the contextual model, this meta-synthesis furthers understanding by considering how each of these factors influence one another and impact individuals' experiences throughout therapy. It also argues that developing insight is a key mechanism for understanding how these factors are beneficial. Therefore, the current meta-synthesis creates a complimentary framework to the contextual models, as well as why these factors are sometimes not considered helpful.

Clinical implications

Key to individuals' experiences of CBT is the therapeutic relationship. Therapists need to develop trusting relationships by showing true genuineness, warmth, validation and openness. In addition to these characteristics, a clear and personalised treatment rationale is more likely to help individuals overcome their initial scepticisms, trust in the process and actively engage. The presentation of a clear treatment rationale has been shown to improve expectations of CBT in other research (Ahmed & Westra, 2009) which in turn has been linked to improved outcomes (Fromme, 2001; Tsai et al., 2014).

This meta-synthesis repeatedly highlights the importance of therapists using a collaborative style in the delivery of CBT. This not only allows individuals to develop a deeper understanding of their anxiety, but also increases their engagement. Acting collaboratively means including the service users in decisions and input at every stage of treatment. The idea of collaborative empiricism is recognised within CBT literature and notes the importance of working collaboratively in the exploration of misconceptions, setting agendas and deciding on homework (Dattilio & Hanna, 2012). Meanwhile, Dobson and Dobson (2013) recognise that therapists may increase the structure of sessions when feeling anxious and so this collaboration may reduce at times. Supervision is therefore vital for processing therapists' own anxieties to ensure working in a collaborative manner is upheld throughout.

Finally, therapists should be aware that service users might find some of the CBT techniques challenging and that a clear treatment rationale and trust in the process is key to ensuring service users feel able to use these techniques. Personalising this treatment rationale, and psychoeducation, can improve this trust in the process by helping service users develop an understanding of their anxiety and experiencing a sense of normalisation.

Limitations and areas for future research

As over two thirds of the included studies focused exclusively on the experiences of individuals with GAD, this may have biased the results, perhaps making them most relevant for working with this anxiety disorder. Additionally, a significant number of the studies synthesised (41%) included participants who had MI prior to CBT. As their experiences were not analysed separately to those who had only had CBT, it was not possible to determine how much of their CBT experience was influenced by MI.

Only three of the eleven diagnoses under the umbrella term of 'anxiety disorder' were reviewed as there were no other studies identified that looked at experiences of CBT for other anxiety diagnoses. This highlights a need for further research looking into how individuals experience CBT for anxiety disorders other than GAD, SAD and PD to investigate any differences in experiences.

It is important to note that this meta-synthesis did not evaluate service users' experiences of NICE recommended CBT protocols. NICE recommends people receive individual CBT delivered by a trained therapist following evidence-based protocols (NICE 2011; 2013). This review has instead reviewed service users' experiences of a mixture of CBT protocols and modes of delivery, not just therapist led CBT. The decision was consistent with the aims of the review; to understand how service users with an anxiety disorder experience the process of individual CBT across a range of CBT based protocols and modes of delivery. It was felt to be overly restrictive to look only at NICE recommended protocols, as the experiences of individuals receiving different CBT protocols are valuable to informing clinical practice where it is not always possible or necessary to deliver therapist led CBT. Future research could look solely at NICE recommended guidelines to inform the development of clinical guidelines.

This meta-synthesis cannot consider clinical implications for other populations such as children and people with intellectual disabilities. These populations were not explicitly excluded from the review; the inclusion criteria allowed for this diversity. However, no qualitative papers were found exploring the experiences of children or people with intellectual disabilities. Thereby highlighting the need for further qualitative research into this area to understand the experiences of other populations in order to inform clinical practice.

The researcher recognises that the term 'developing insight' maybe a product of the researchers own experiences. Noblit and Hare (1988) recognise that the interpretation of data within a meta-ethnography is largely influenced by the synthesisers perceptions and argue the aim is to create an understanding of the literature, rather than set knowledge or facts. The term insight is used within this review to describe the process of understanding one's anxiety. However, the researcher recognises that it could be perceived as service users being required to accept the therapists westernised understanding of their difficulties and that another researcher may have used different language to name this theme.

CONCLUSION

This meta-ethnography highlights factors that influence service users' perceptions of whether CBT is beneficial, and why. The role of the therapeutic relationship was identified as fundamental in determining whether participants experienced therapy to be helpful and was influential on all other factors, and thus should be a focus for therapists. Although other research has recognised common and important factors within psychotherapy, this meta-synthesis furthers this by considering why these are beneficial. CBT therapists should not overlook the importance of individuals developing insight into their anxiety and their self-efficacy to manage it.

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The Perceived Impact of the Anorexic Voice on Enhanced Cognitive Behaviour Therapy Treatment: A Grounded Theory

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⁶ This paper is prepared in accordance with the author guidelines for *Psychology and Psychotherapy: Theory, Research and Practice* (Appendix 1). For the purposes of thesis submission, the DClinPsy word limit of 8000 words has been used to ensure all relevant information could be demonstrated. APA 7th style has been used for references. To ease readability, tables and figures are embedded within the main body of text and will be removed and placed at the end for journal submission.

ABSTRACT

Objectives: CBT-E is recognised as the recommended treatment for anorexia nervosa in clinical guidelines, despite 30-50% of individuals not completing it. One hypothesis is the anorexic voice (AV) impacts on individuals' ability to engage in CBT-E. Therefore, the aim of this research was to qualitatively investigate whether individuals perceive there to be an interaction between the AV and CBT-E, and if so, how this interaction looks.

Design: Grounded theory analysis was used to develop a theory looking at processes that may explain the interaction between the AV and CBT-E to inform future clinical practice.

Method: Twelve participants were recruited via NHS services and the eating disorder charity, Beat. To understand experiences throughout CBT-E a cross-section of participants in treatment or recovery were recruited. All interviews were audio recorded, transcribed, and analysed using grounded theory. Memos and a reflective journal were kept throughout.

Results: The AV was perceived to make engagement with CBT-E challenging due to its dominance and individuals' relationship with it. CBT-E was also perceived to make the AV more powerful. The importance of reducing reliance on the relationship with the AV, as well as decreasing its power, were considered important factors in ensuring CBT-E was beneficial.

Conclusion: CBT-E practitioners should remain aware of the influence the AV may have on individuals' ability to engage with therapy, as well as the inner battle individuals face as CBT-E increases the AV prominence. Therapists should work to challenge the AV alongside service users in sessions.

Keywords: Enhanced cognitive behaviour therapy; anorexia nervosa; anorexic voice; grounded theory

INTRODUCTION

The Diagnostic and Statistical Manual of Mental Disorders (DSM-V) defines anorexia nervosa (AN) as the restriction of food intake leading to significantly low body weight; characterised as the fear of food and a disturbance in the way in which one views body weight or shape (American Psychiatric Association, 2013). AN is a challenging disorder to treat (Higbed & Fox, 2010; Fairburn et al., 2013; Tierney & Fox, 2011) with a mortality rate of 5-6% (Murray et al., 2018; Watson & Bulik, 2012), greater than any other psychiatric illness (Westmoreland et al., 2016).

Clinical guidelines (National Institute for Health and Care Excellence [NICE], 2017; National Psychological Therapies Management Committee, 2017), recommend cognitive behaviour therapy (CBT) for treating AN. Enhanced cognitive behaviour therapy (CBT-E) is an evidence based transdiagnostic treatment for all eating disorders focusing on core processes within eating disorders such as emphasis on weight/shape, restriction, starvation and perfectionism (Fairburn, 2008). CBT-E for AN focuses on restricted food intake and starvation (Karbasi, 2010). Fairburn (2008) describes two CBT-E versions; one focused exclusively on eating disorder psychopathology, the other with additional modules focusing on clinical perfectionism, low self-esteem and interpersonal difficulties.

CBT-E renders mixed recovery rates despite being the recommended treatment for AN. BMI significantly increases compared to other therapies (Frostad et al., 2018) as does speed of weight gain (Zipfel et al., 2013). Fairburn et al. (2013) also found improvements in people's eating pathology, which were well maintained at 60-week follow up. However, other research reports around a third of those receiving CBT-E make no improvements and 30-50% do not complete the therapy (Byrne et al., 2011; Fairburn et al., 2013). Reviews identify CBT as no more effective than other psychological treatments for AN in reducing symptoms (Kass et al.,

2013; Watson & Bulik, 2012). It is therefore important to understand what limits treatments for AN to improve efficacy and completion rates.

Pugh and Waller (2017) suggested that CBT-E efficacy is limited by the anorexic voice (AV). Research indicates people with AN hear a critical internal voice commenting on actions and consequences related to eating patterns, weight and shape (Higbed & Fox, 2010; Pugh & Waller, 2016; Pugh & Waller, 2017; Tierney & Fox, 2010; Williams et al., 2016). Pugh (2016) indicates that over 90% of individuals report hearing this AV, which has also been noted in other eating disorders, such as bulimia (Broussard, 2005).

There have been controversies over whether the AV is separate to internal critical thoughts (Aya et al., 2019). However, in contrast to eating disorder thoughts or cognitions, the AV comments in the second or third person (Hormoz et al., 2019; Pugh, 2016; Pugh & Waller, 2016, 2017). The AV is considered non-psychotic, being recognised as internally, rather than externally, generated (Pugh & Waller, 2016, 2017).

Initially, the AV may have positive functions for individuals; providing a sense of comfort, distraction from emotions, and assistance in decision making (Tierney & Fox, 2010) but over time becomes hostile and controlling; dominating and critiquing their sense of self (Higbed & Fox, 2010; Pugh, 2016; Pugh & Waller, 2016, 2017; Williams et al., 2016; Williams & Reid, 2012). People feel trapped by the AV, experiencing compulsions to obey, impacting their self-esteem (Tierney & Fox, 2011; Williams et al., 2016; Williams & Reid, 2012). In recovery, people recognise it is no longer achieving positive functions (Tierney & Fox, 2010).

Importantly for treatment, AV characteristics have been linked to eating disorder pathology.

Pugh and Waller (2016) identified negative eating attitudes related to greater AV power, with

lower BMI when the AV was both powerful and malevolent. Lower BMI has also been associated with an increased desire to resist the AV but a greater sense of being unable to escape it (Pugh & Waller, 2017).

This interaction between AV characteristics and more severe eating disorder pathology is likely to impact treatment outcomes if not addressed. Pugh (2016) states that "as a result of entrapment or attachment to the anorexic voice, many individuals struggle to engage in treatments where there is an emphasis on change (e.g. cognitive behavioural therapy), as any attempt to modify eating behaviour is met with internal hostility" (p. 76).

Quantitative research indicates AV characteristics predict treatment outcomes. Hormoz et al. (2019) looked at AV power, benevolence, omnipotence and malevolence before and after CBT or Cognitive Analytic Therapy (CAT) completion. Post therapy, AV power was significantly reduced but other characteristics were not. In fact, greater levels of benevolence and omnipotence at therapy outset were associated with greater reductions in weight concerns at completion. These characteristics may drive greater levels of eating pathology at therapy outset, so participants had more leeway for positive change. These findings highlight the interaction between AV and therapy outcomes, and therefore the importance of this interaction within treatment of AN. However, these researchers do not distinguish between CBT and CAT so differences in interaction between the AV and the therapies cannot be assessed. This quantitative study identified a relationship between the AV and therapy but did not explore why this relationship exists or how the two interact, and only considered the views of those who completed therapy not those during or who dropped out.

In summary research so far indicates the AV plays a significant role in individuals' experience of, and recovery from, AN. Preliminary research suggests the AV and therapy outcomes

interact, possibly due to AV's impact on engagement (Pugh, 2016). The recommended therapy for AN is CBT-E which does not explicitly focus on the AV; outcomes are limited with at least one third not responding. Understanding why and how the AV and therapy interact may develop insight into why some do not respond to treatment.

Therefore, the aim of the current research is to qualitatively investigate whether individuals perceive there to be an interaction between the AV and CBT-E, and if so, how this process looks.

Theoretical sampling was undertaken from a wide cross-section of individuals with AN, from those currently unwell to fully recovered. This was to ensure that constant comparison of data could build a grounded theory of the interaction between the AV and CBT-E throughout the therapy process.

METHOD

Version of grounded theory

A constructivist grounded theory approach (Charmaz, 2014) was used, recognising the researchers' role in constructing meaning from data. Grounded theory was chosen as it focuses on processes within data; this research required understanding the theoretical links and processes underlying the interaction between the AV and CBT-E. Previous research identified an interaction, so to reach the current research aims analysis needed to go further and build a theoretical model of the processes. To ensure this model is truly grounded in data two key techniques of constant comparison and theoretical sampling are applied, their use is discussed in greater detail below.

Reflexivity

The constructivist approach allows researchers to be reflexive about how and why they interact with data as they do. Researchers have their own preconceptions and epistemological stance and these factors interact with researchers' existing knowledge and may influence data collection and analysis. These influences were bracketed out using a reflective journal (Appendix 7) and memos (Appendix 8) to capture, and remain aware of, assumptions about the data throughout.

The lead researcher is a 26-year-old white British woman undertaking a doctorate in clinical psychology, with experience of working in eating disorder services and using CBT protocols for various mental health difficulties. Therefore, the lead researcher had preconceptions about some of the challenges engaging individuals with eating disorders. She also has biases regarding the effectiveness of CBT-E given her experiences of it being used within eating disorder services. In her experience, many people with severe and enduring AN struggled to engage with CBT-E. Therefore, the lead researcher was bringing some expectations about how people respond to this treatment. She remained aware of her preconceptions regarding CBT efficacy generally and with those with AN, as well as her assumptions about engaging this population in therapy. A reflective journal helped monitor these during interview schedule development, within interviews and data analysis.

The research was supervised by a male British clinical psychologist with many years' experience working clinically with people with eating disorders and has published research using grounded theory to investigate the AV. Preconceptions and previous knowledge were noted during supervision to reduce potential bias in data analysis.

The second supervisor is a female British clinical psychologist working for many years in an NHS eating disorder service. Her preconceptions were kept in mind during interview schedule development and recruitment.

Recruitment

Full ethical and NHS Research and Development approval was gained before recruitment began (Appendix 9). Participants were recruited via the NHS and an eating disorder charity, Beat.

Within NHS services, clinicians reviewed caseloads for individuals meeting inclusion criteria (Table 1) and gave appropriate individuals a copy of the participant information sheet (PIS; Appendix 10) to read before deciding on involvement. For those interested contact details were shared with the researcher.

Beat posted the research on their website and advertised it via social media (Appendix 11).

Those interested completed an online questionnaire including a summarised PIS and questions to identify whether people met inclusion criteria, leaving contact details at the end if still interested.

The researcher contacted all those expressing an interest to confirm they met the inclusion criteria. Beat participants were sent a copy of the full PIS.

Initially, those expressing interest were interviewed on a first come first served basis.

However, as the process continued and initial data were analysed, further interviews were guided by theoretical sampling (see below).

Inclusion criteria	Exclusion criteria
Identify as female	Comorbid diagnosis of psychosis
Be 18 years or older	Have attempted suicide in the last six
	months
Reported having a diagnosis of anorexia	
nervosa	
Have experience of the anorexic voice	
Experience of CBT-E (either currently having	
it, or have had it in the past)	

Table 1: Inclusion and exclusion criteria for participants

Participants

Twelve participants were interviewed; ages ranged from 18-47 years with a mean of 27 years. Participants' BMI ranged from 13-23.5, with a mean of 18.6. Six interviewees identified as being in recovery, two of whom were in the final stages of treatment. The other six were currently having CBT-E or another intervention and did not consider themselves recovered.

Table 2 provides more detail on participant characteristics.

Participant (all	Age	Duration of	Self-reported	ВМІ	EDE-Q	GAD-7	PHQ-9
names are		illness	recovery status		global	score	score
pseudonyms)					score		
Amber	18	4 years	In treatment	18.6	3.1	7	12
Laura	23	14 years	In treatment	17.3	3.54	17	27
Katie	24	1 year	In treatment	15.9	1.46	10	4
Florence	26	4 years	In treatment	19.1	0.85	1	4
Gemma	22	9 years	In recovery	18.2	2.6	10	9
Sarah	41	3 years	In treatment (but	20.1	2.7	5	5
			consider self in				
			recovery)				
Amy	24	2 years	In treatment	16.7	5.2	16	21
Becky	32	9 years	In recovery	18.7	3.6	17	9
Hannah	20	10 months	In treatment (but	21.2	2.7	3	5
			consider self in				
			recovery)				
Lisa	47	6 years	In treatment	13	5.6	20	22
Mia	26	10 years	In recovery	23.5	3.4	9	9
Lily	22	1.5 years	In recovery	20.5	0.8	9	9

Table 2: Participant characteristics

Measures

Prior to interview, participants completed four measures (see Table 3). This data was gathered as a way to situate the sample and provide context about their eating disorder pathology and mood, that may influence their experiences.

EDE-Q scores match the self-reported status of being in treatment or recovery, with all who identified as being in recovery having a global score of less than four. Indeed, all but two individuals had a score lower than four, indicating this sample had relatively low eating pathology at the time of interview.

There were relatively high levels of anxiety and depression within the sample; 50% reaching the clinical significance threshold for anxiety, and 67% doing so for depression. This reflects the high levels of comorbid anxiety and depression often seen in individuals with AN (Marucci et al., 2018; Steinglass et al., 2011).

Questionnaire	Description of content and scoring	Clinical cut off point	Internal consistency reliability co-	
			efficient	
Eating Disorder	A 28-item self-report questionnaire covering characteristics of individuals'	Global score of ≥ 4 (Bardone-Cone et al, 2010; Carter	High across the five scores: global	
Examination	eating disorder with additional questions about height, weight, and missed	et al., 2001; Jennings & Phillips, 2017; Mond et al.,	score, α = .95; restraint, α = .85;	
Questionnaire	periods. This transdiagnostic measure can be used to assess all eating	2006).	eating concern, α = .81; weight	
(EDE-Q 6.0;	disorders. Participants are scored along four dimensions, summed and	This cut off point has been used to identify those	concern, α = .83; shape concern, α =	
Fairburn & Beglin,	averaged for the global score: restraint; eating concern; shape concern;	recovered in other research (Williams et al., 2016).	.91 (Aardoom et al., 2012).	
2008)	weight concern.			
Generalised	This questionnaire includes seven questions regarding anxiety levels over the	Clinical cut off point of ≥ 10 (Spitzer et al., 2006)	Internal consistency reliability is high	
Anxiety Disorder	past two weeks. Scores range from 0 to 21; scores of 5, 10 and 15		$(\alpha$ = .89) for the general population	
Questionnaire	representing mild, moderate and severe anxiety.		(Löwe et al., 2008).	
(GAD-7; Spitzer et				
al., 2006)				

Questionnaire	Description of content and scoring	Clinical cut off point	Internal consistency reliability co-	
			efficient	
Patient Health	A nine item self-report questionnaire covering symptoms of depression over	≥ 9 represents clinical levels of depression (Kiely &	High internal reliability with a	
Questionnaire	the past fortnight. Total scores range from 0 to 27; scores of 5, 10, 15 and 20	Butterworth, 2015).	Chronbach's $lpha$ of .89 (Kroenke et al.,	
(PHQ-9; Kroenke	representing mild, moderate, moderately severe, and severe depression		2001).	
et al., 2001)				

Table 3: Description of questionnaires administered

Theoretical sampling

Recruitment paused following the first four interviews and initial coding was completed. Data was reviewed and the interview schedule altered to explore emerging themes.

After another four interviews, recruitment paused. Initial and focused coding was completed for the first eight interviews, as well as memos, to identify common themes and gaps within the data.

Discussion of focused codes and memos recognised a need to recruit individuals with a more recent diagnosis to explore an emerging interaction between length of diagnosis and willingness for AV to leave. The researcher phoned participants expressing an interest and asked preliminary questions. These questions were: whether participants considered CBT-E to be a success; when they received their AN diagnosis; whether they were in treatment or recovery. Based on answers, the most appropriate participants were theoretically sampled for the final four interviews.

Interview schedule development

Guided by literature and the research question, the final version of the interview schedule focused on AV characteristics, and individuals' relationship with it as well as its interaction with CBT-E. Understanding the AV's nature was considered important in fully understanding its interaction with CBT-E.

The final interview schedule was developed in consultation with the research team and individuals with lived experience, who were contacted via Beat. These reported that questions were appropriate and sensitive, and identified a need to avoid questions specifically

about weight, as these may be triggering. This consultation also led to the consideration of the AVs prominence at different times during CBT-E sessions.

The final interview schedule comprised 14 open-ended questions with prompts covering service users' experiences of the AV, CBT-E sessions, and interaction between the two. Following grounded theory principles, the interview schedule was altered twice to allow exploration of emerging themes. A final version is in Appendix 12, with questions added throughout the process highlighted.

Interview procedure

Interviews were semi-structured, ensuring key themes were covered whilst responding to information from participants. The lead researcher interviewed all participants, none of whom had received therapy from her.

Prior to interview, participants read the PIS and could ask questions. The researcher informed participants she was not part of their clinical team and would not be sharing their interview. Participants gave informed consent (Appendix 13) and GP details were obtained in case safeguarding issues were identified during interview. None were raised and GP details were destroyed on interview completion.

Participants then completed the three questionnaires above (Appendix 14), followed by the interview. Interviews lasted between 44 and 82 minutes. Participants were offered a break half-way through and were advised they were not required to answer any questions they were uncomfortable with to mitigate distress. Seven interviews were completed in person, five via phone. Following each interview, all participants had a chance to debrief verbally and were provided with a debrief form including helpline details if required (Appendix 15).

Data analysis

Interviews were audio recorded and transcribed verbatim. All interviews were analysed by the lead researcher using NVIVO software which stored raw data, codes and memos. The reflective journal was kept in a separate document.

Analysis steps are outlined below in Table 4 and presented in a linear fashion for ease of reading, in reality this was a dynamic process. Coding was carried out alongside, and informed subsequent data collection. Data was constantly compared with data and codes as they emerged. Every level of coding involved more than one analyst, either the research supervisor or an independent researcher. Sections of coded transcript are in Appendix 17.

Data collection

Data was collected, audio recorded and transcribed verbatim (Appendix 16). This continued until theoretical sufficiency was reached; whereby the researcher felt that there was sufficient data within each of the codes for theory development.

Line-by-line coding

Each transcript was coded line-by-line, creating initial codes grounded in the data to capture meaning. These were constantly compared to other initial codes as they developed. As themes emerged, the interview schedule was adapted for further exploration.

Focused coding

Initial codes were lifted into focused codes. For constant comparison, codes were compared with codes and the raw data. Focused coding aims to determine which initial codes carry the most analytical power by looking at those which are more common and appear to carry the most theoretical weight, thus indicating the theoretical direction of the research.

Theoretical sampling

As key themes emerged new data was theoretically sampled in light of this to explore any data gaps.

Memo writing

Throughout these stages of coding, memos were kept identifying potential themes, links between themes, and links to existing theories. Memos ensured assumptions about the data were made explicit and kept in mind.

Conceptual category development

Focused codes were reviewed and similar ones collapsed together if deemed appropriate through constant comparison to initial codes and transcripts. Focused codes with the most theoretical weight were lifted into conceptual categories and other focused codes collapsed into these.

Development of theory

Theoretical coding was used to identify links between the conceptual categories, leading to development of an interpretive theory and framework (Figure 1).

Table 4: Process of grounded theory

Reliability and validity

Elliott et al. (1999) provides guidelines for ensuring qualitative research is valid and reliable that require subjective elements of analysis to be monitored and reported. To ensure researchers owned their own perspective, a reflective journal and memos were kept throughout. For credibility of data analysis, multiple analysts were consulted as well as participants. Codes and themes were discussed in supervision and with an independent researcher not involved in the study. The final theoretical framework was triangulated by comparing it to the raw data, previous literature, and consulting participants. For coherence, the results of this grounded theory are presented as both a diagrammatic framework and a narrative.

Respondent validation

Respondent validation allowed the results and diagrammatic summary to be corroborated with the participants to ensure they accurately reflected their experiences and made sense. 50% of the participants who had taken part in the research agreed to be consulted on the emergent theory. A copy of results and model were emailed to these participants and their responses were incorporated into the final theory.

Feedback identified that the results and model resonated with their personal experience and were comprehensible. Participants felt the findings sensitively explained their journey through CBT-E and they agreed with the researcher's interpretations. Two responses noted the importance of recognising the fluctuation of the voice. For example, participants highlighted that 'considering life without the voice' was not necessarily stable, rather it fluctuated depending on their current relationship with the AV. This nuance is discussed in more detail in the relevant categories below.

RESULTS

From the data, an interpretive theory was developed starting with an explanation of the AV and how this influences therapy engagement motivation, before exploring the interaction between the AV and CBT-E throughout therapy. A tabulated summary of conceptual categories and subthemes is in Table 5, followed by a narrative summary.

Conceptual category	Subtheme		
Development of the anorexic voice			
Current relationship with the anorexic voice	Impact of voice on sense of self		
	"The voice is my coping mechanism"		
Considering life without the voice			
"It only became a fight when I fought against it"			
Voice as a barrier to engagement			
Learning to cope without the voice	CBT-E helped to win the fight		
	Extra therapeutic factors that challenged		
	the voice		
CBT-E had no impact on ability to fight the voice			
"The recovery voice"			

Table 5: Tabulated summary of conceptual categories and subthemes

Development of the anorexic voice

Participants describe the AV initially developing to serve a positive function, and generally perceived it to be friendly and helpful.

The AV appeared when participants were lonely and isolated, reducing these feelings by acting as their only friend or ally who understood how they were feeling.

Becky - " I didn't feel understood by anyone apart from it, and I felt close with it and, and I-, when I felt distant from everyone else in my life"

Others experienced it to improve self-esteem, making them feel superior to others.

Amber - " It was kind of like someone was kind of like giving you that praise for like sticking to something and kind of almost like feeling that I was better than other people and could do something that they couldn't"

For some the AV initially helped manage emotions, improving mood.

Laura – "And I can remember at that point having this sort of like 'that's what you need to do, this is going to make you a better person' umm 'this is going to make you feel better"

These initial AV functions seem to remain despite the voice becoming critical over time, as explored below.

Despite initially being positive, participants depict how the characteristics of the AV changed and fluctuated during eating disorder development.

Often friendly and praising at first, the AV allowed people to rule-break without repercussions, clarifying how participants can perceive the voice as a friend when first recognised. Overtime the AV became more critical or hostile, generally as people attempted to change.

Florence - "I think originally it would be more praising me for doing good things, but it was very forgiving if I didn't"

Amy - "If I felt like I'd gained weight it was like, and then it got more-, progressively, like, more, like-, not aggressive, but that kind of thing. Like, it wasn't as positive as it was initially."

Others experienced the voice shifting from initially being quiet to more prominent, powerful and controlling as AN developed, becoming quieter again in recovery.

Interviewer – "How would you describe the voice back then?"

Gemma - "Um, a lot more controlling than it is now. I still, like-, image-wise I still picture it the same. Um, but it was a lot more dominant, a lot harder to fight against. Um, and the majority of my thoughts, thinking about it in a day, were probably more taken over by the voice than things that I wanted to actually be thinking about."

At the time of interview, most described the AV as hostile or critical, dominating thoughts and enforcing rules. Some recognised the AV impacting sense of self, especially self-esteem, where previously the AV improved this.

Sarah - "I suppose it just domineered. It was louder than my thoughts. [...] It was harder to ignore because it was louder"

Lisa - "The words that go through my head are very-, quite cruel and, you know, and designed, designed to make you feel bad about yourself "

Predominantly focused on food intake, weight and shape, participants also acknowledged the AV's commentary in other aspects of life, especially work and social situations. Here the AV comments on their abilities or others' perceptions of them and uses this sense of failure to link back to the need to restrict as compensation, impacting self-esteem.

Becky - "So it will use food and exercise as punishment, but it will be-, the initial criticism will be through something that I've done or if I was late to something or if I was-, didn't-, I don't know, if it-, the work, piece of work I did wasn't perfect, that kind of thing. It can relate to anything"

Current relationship with anorexic voice

Impact of voice on sense of self

Participants recognised how the AV influenced their perceptions of self by impacting selfworth and identity.

The AV feels undermining, making participants doubt their abilities, creating a sense they are a failure and undeserving. This is likely linked to the AV providing a coping mechanism; those doubting themselves being more reliant on the AV to solve problems and improve self-esteem.

Laura — "I'll get the instant response of like 'ah you're never going to be able to do that', or like 'you're not going to succeed', 'why do you think you can do that?' or like 'this is going to fail'."

Many viewed the AV becoming so ingrained into sense of self that it develops into their identity, perceiving themselves to be nothing without the familiarity of the AV. Some recalled not remembering life without the AV so find it leaving a scary prospect.

Lisa – "it's [the voice] been with me for so long now I don't know any different. I don't know who I am any more. I don't know how to live without it."

Participants' further along in treatment and recovery were better able to recognise the AV as separate to themselves. Some specifically accredit CBT-E helping this separation and perceive this as beneficial in challenging the AV (see 'CBT-E helped to win the fight').

Katie - "I'm more aware and can distinguish when it-, when it's the voice rather than me, because before I used to just think I was just really, um, critical of myself and I've learnt that actually a lot of the time that wasn't me"

This category leads to some finding it difficult to consider life without the voice; seeing the voice as part of their identity means people find relinquishing it a daunting idea, impacting on their motivation to engage.

"The voice is my coping mechanism"

Despite being critical and impacting self-worth, participants recognised the AV continue to provide similar functions to when first recognised.

The AV provides a coping mechanism for mood control by reducing anxiety and stress levels, given the high co-occurrence of these emotions within this sample, it is understandable they desire coping strategies. This sense of control also applies to actions in daily life, providing a sense of purpose.

Laura - "I feel much more like in control of my emotions if I'm not eating because they're just not really there, I feel much more numb and I think that's what the voice tried to remind me of like you're going to cope better with life if you're not eating"

Florence – "Even though my life was kind of like in shambles it was like 'well if you just, you know, eat this salad your life will be together it will be fine"

Acting as a companion, the AV reduces individuals' sense of isolation, its presence replacing friendships and providing comfort when others are not.

Mia - "I felt like I didn't have anything in common with my friends anymore, I felt isolated from them and I didn't really enjoy spending time with them [...] Yeah. She just made me-, I suppose she gave me, like, a friend."

Considering life without the voice

The majority perceived life without the AV as a scary and intimidating notion, predominantly due to seeing the AV as their identity and feeling uncertain about who they would be without it.

Mia – "I still feel scared that she's going to go, um, you know. I don't know if, like-, she's sort of been my, sort of my identity for so long and now it's like-, it's hard to let her go and, um, give up that idea completely sort of thing."

Others recognised the AV providing a coping mechanism leaving them reliant on it, liking the sense of comfort and control it provided if required.

Becky - " I would be a little bit scared if it went completely because I feel like it keeps me in check and keeps me from, like, like, going out of control.

However, some wanted the AV to leave, anticipating being happier and identifying AV elimination as a key motivator for engaging with CBT-E and recovering.

Lily - " I definitely always wanted to be free of it, um, and, yeah, my main reason for recovery wasn't-, I didn't want to gain weight, er, and it was always, 'Oh, I just-, I want this voice to just disappear'"

Although participants tended towards either wanting the AV to stay or leave, this was rarely clear-cut. Those recognising they would be happier without were still scared to relinquish entirely a relationship providing coping mechanisms and sense of identity. Additionally, respondent validation identified the AV relationship fluctuating, and with it the desire for it to leave and motivation to engage with CBT-E.

The duration of the eating disorder appears to mediate this category. Interviews provided data on period of diagnosis. Theoretical sampling facilitated testing this hypothesis; preliminary questions being asked about length of diagnosis and perceptions of CBT-E success. Individuals were then sampled accordingly to explore this link. Those with their diagnosis for six or more years leaned towards wanting the voice to stay, those diagnosed for less than four years tended to want the voice to leave. This pattern was apparent across all participants. Based on previous categories, this suggests the longer people have experienced the AV, the more reliant they become on it as a coping mechanism, and the more it is ingrained within their identity.

Importantly for interaction with CBT-E, this category influences motivation to engage; those wanting the AV to leave being motivated to engage. Alternatively, those perceiving the AV to be part of their identity and functional being more resistant to engage in a therapy expecting behaviour change.

"It only became a fight when I fought against it"

This category explores consequences of challenging the AV rather than succumbing, participants had similar experiences regardless of AN duration.

Predominantly, the AV becomes increasingly hostile, defensive and powerful when defied, enforcing greater restriction to compensate. Many experienced this creating a battle against the AV, whereas obeying the voice resulted in the voice lessening and becoming kinder. Some personify the AV, describing it to feel threatened when challenged and thus defensive.

Amber - "By doing these things and going against it, it gets kind of stronger. And then I think- it's almost like especially the next day after, I guess if I've been out for a meal or something, the next day then I'll be a lot more kind of- like it will be on my mind and I'll be a lot more critical."

Lisa - "'Yeah, okay, I'll just do what you say,' because it is-, you know, the battle's gone then, the battle stops the minute you give into it. It's like-, you, you know, you get a little respite then if you're doing what it says, you know"

Importantly, participants describe CBT-E initially creating the same fight as described above.

CBT-E aims to change eating patterns and cognitions, thus implicitly challenging the AV,

making it more powerful.

CBT-E creates a target for the AV's battle, making it more determined, critical and threatened by possibly being made redundant. Some describe the AV's defensiveness undermining the therapist, commanding participants not to listen or creating doubt about trust. The AV is perceived as domineering and powerful, meaning participants are likely to listen to it, creating a barrier to CBT-E engagement.

Becky - "Um, I think it just, like, p*****d it off and was, like, 'Ugh, just f*** off.' Um, 'No, we're not going to try that, no, we're not going to do that.' Um, I think, um, maybe made it more, like, defensive, and more, more, 'See, [name], I told you, you can't trust anyone but me. They just want to make you fat.'"

Voice as a barrier to engagement

Regardless of the journey to therapy, all participants expressed the AV impacting their ability to engage in CBT-E.

The AV actively encouraged task disengagement due to it feeling threatened.

Hannah – "It very much wanted me to, like, quit therapy and stuff, like it would tell me just like, 'Oh, you're not-, you're not sick enough, like, um, all of these other people that need the service more than you do'"

As previously mentioned, the AV undermined therapist advice and encouraged participants not to trust them. The AV's familiarity, strength and power mean participants tend to listen to it over the therapist who is perceived as less dominant. Listening to the AV therefore undermines the CBT-E process.

Lisa - "Oh, definitely, because it completely undermined everything that she was trying to do. It was just far more-, it was far power-, more powerful than what, um, my therapist was"

Participants recognise the importance of honesty in CBT-E but feel prevented by the AV that encourages them to be dishonest so they can continue eating disordered behaviours. Some expressed a desire to be honest but felt unable due to the AV power and fear of the consequences; one individual epitomising this, describing the voice as a bully.

Becky — "There were so many times that I would look at her and want to say-, tell her stuff, but I couldn't because the voice was, like, strangling me and wouldn't let me say anything and I knew if I said anything then-, I said to her, 'It's like a bully and if you tell on a bully then it just gets worse.' So I, I said-, I would look at her and be

screaming at her through my eyes, but I would not, not be able to say what I wanted to say to her."

Despite all experiencing the AV as a barrier to CBT-E initially, some went on to find CBT-E helpful in challenging the AV.

Learning to cope without the voice

CBT-E helped to win the fight

This category depicts aspects of CBT-E perceived to help challenge and improve the AV, thus overcoming the initial fight.

Participants recognised value in CBT-E providing specific techniques offering a logic and rationale that equipped them in challenging the AV. Over the course of CBT-E, with repeated challenging, many experienced a reduction in the AV power and participants realised consequences were not as bad as threatened.

Lily - "As long as you just keep, keep challenging-, if you only challenge it once then it's just going to keep roaring at you, but her thing was that keep, keep challenging it, keep challenging it, do the same thing a billion times and by-, it, it-, sometimes it took me 60 times to put dressing on my salad before, er, the 60th time I realised, 'Oh, nothing's actually stopping me from doing this and I'm not thinking about compensating'"

Whereas dishonesty was perceived as a barrier to engagement, some participants recognised honesty leading to a shift in CBT-E progress and the development of the therapeutic relationship, though generally, participants were unsure what had helped allow this honesty.

Some experienced guilt about lying, others felt motivated to change and were plateauing

whilst being dishonest. Given the accounts in categories above, one could hypothesise that AV power and strength needed to reduce to allow this honesty, but this was not specifically explored.

Florence - "After that it was a case of where it's like I can be honest about this and I'm just going to open up about everything so like it was a more of a situation where it was just like, yeah it was just a more open relationship I think and that was good. I felt like a got more out of it then because if I was being honest, I could actually say what was bothering me"

Many perceived discussing the AV as helpful; those who did not discuss the AV felt a negative impact on the success of CBT-E. Discussing the voice allowed participants to challenge the AV, reduce its presence in sessions, separate the voice from self, be honest about its impact on engagement and feel understood. Often the therapist introduced this topic helping people feel their internal battle with the AV was recognised and understood.

Amy - "Um, I'd probably say it's quite helpful, 'cos that way she kind of understands what I'm kind of trying to fight against, if you understand what I mean. What is kind of, like, stopping me from doing what I need to."

CBT-E was perceived by many in facilitating separation of AV from self and identity, making it easier to challenge. This separation presumably allowed participants to consider life without the AV and recognise there was more to their identity.

Laura - "I think trying to separate it as a separate thing was helpful as well. I think that was [therapist] that used to speak to me about that because I used to find that I was very wrapped up in it and thought that it was me [...] whereas it's actually been more helpful seeing it as like a separate voice that I can, like you said like almost argue with or try and get away from."

This category demonstrates that CBT-E helps participants to change the power dynamic in their relationship with the AV. Techniques to manage the voice helped them to battle it, in turn reducing its strength. Separating the voice from self allowed participants to be less "wrapped up" in the AV being their identity. The therapist plays an important role in helping participants feel understood and able to be honest, in turn reducing the AV's power.

Extra therapeutic factors that challenged the voice

Additional factors outside CBT-E helped people feel able to fight the AV by meeting its positive functions in other ways, thereby reducing AV dependence and increasing ability to consider life without it.

Participants recognise the importance of a social network, reducing their sense of isolation and recognising the AV is not a true friend and reducing dependency on it.

Florence - "It was like my only friend or you know it was from a time when I was really lonely, now that I have real friends and I have a real life, it doesn't fit in anymore really and it doesn't offer that-I don't need that sense of validation or companionship from it because I have those from like real people so I think in that way it's just kind of gone away"

People also experienced a renewed sense of purpose in life and having new interests, adding meaning to their lives and depth to their identity, reducing reliance on the AV to provide this.

Mia - "Whereas now, um, like, me and, like, usually there's different hobbies and friends and things, so I feel like my life has more purpose, um, has some positive things in it. So I find that I don't maybe need her so much"

CBT-E had no impact on ability to fight the voice

Many participants contributing to 'CBT-E helped to win the fight' also contribute to this category, highlighting these are not dichotomous.

Several participants experienced CBT-E as generally unhelpful, putting this down to lack of motivation to engage, or difficulty meeting the initial starting criteria. Some alluded to the AV remaining domineering at this stage and therefore struggling to engage.

Lisa - "I think the factor was, um, myself, deep down. It was just I didn't want-, I didn't want to gain weight and anything that-, anything that was being put in front of me that was going to make me gain weight just wasn't-, it wasn't going to work. Um, and for me I think that was my mindset"

Others recognise specific aspects of CBT-E as unhelpful, even where they considered CBT-E overall as successful. Food diaries were highlighted as especially challenging, increasing the AV presence.

Hannah - "I had to write down everything I was eating and I found that it would, like, enable my eating disorder a bit, because it would add it all up for me and because I wouldn't write it out as I, I was going, I'd write it out at the end of the day, it was like, 'You ate this today and this and this and this and this.'"

Finally, some experienced CBT-E as superficial, not tackling core reasons for their eating disorder and AV.

Becky - "The roots of my eating disorder are more through, like, things that have happened in life, so I think I need to, like, talk those through and just tell someone

about what had happened and process that, like, verbally, whereas I, um, I don't think CBT-E covers that"

In discussing what could have helped CBT-E to facilitate challenging the AV, some wished it had been explicitly named or that this happened earlier to provide insight and normalisation into this experience.

Amber - "I didn't really know if it was kind of normal and if, like if it wasn't being talked about then I kind of wasn't sure if like I should be experiencing this."

Others would have liked to discuss and actively challenge the AV alongside the therapist when it interfered with therapy.

Laura - "I guess it's like exploring it and thinking about positive reinforcements and maybe kind of focusing on why you want to challenge it and stuff I guess and yeah being able to talk about that more"

"The recovery voice"

Some participants considered themselves in recovery and reflected on their experience of their current AV; generally perceived as still present but less powerful, allowing them to feel more able to challenge it. The AV was recognised as less prominent due to no longer serving the function it did previously, rendering it redundant in helping them cope.

Mia - "So I find that I don't maybe need her so much. Um, yeah, I find that I don't feel like I want to go back to needing her, because I don't want to go back to where I was."

DISCUSSION

Summary of the theory

This researched aimed to investigate whether individuals perceive an interaction between the AV and CBT-E. The findings indicate they do, with the AV impacting CBT-E engagement for two reasons. Firstly, the AV is perceived as helpful and part of identity, creating reluctance to engage in therapy that may result in the AV leaving. Secondly, the AV becomes more powerful at the start of CBT-E, undermining the therapist, leaving individuals battling with trust and pulled towards listening to the AV due to its familiarity and power.

Some overcome this barrier to engagement by challenging the AV alongside the therapist, reducing AV power. Also, extra-therapeutic factors can support changes in individuals' AV relationship, becoming less reliant on it as a coping mechanism and recognising there is more to their identity.

Those not experiencing CBT-E as positive attributed this to not discussing the AV in therapy, CBT-E being superficial, or personal lack of motivation to engage.

Pertinent throughout this theory, therefore, is the notion that AV power and identity are key to understanding CBT-E and AV interaction and individuals' ability to engage and recover. A finding echoed by Duncan et al. (2015) who identified reclamation of power and self as key to recovery from AN.

Impact of AV power

AV power has consistently been shown to increase and maintain severe eating pathology (Pugh & Waller, 2016, 2017) and AVs perceived as more powerful than self are associated with greater distress (Pugh & Waller, 2016). This finding is echoed in psychosis literature

(Birchwood et al., 2000) where those with psychosis are also more likely to comply with the voice when more powerful (Mawson et al., 2010). Such findings reflect the current research and indicate the importance of considering AV power during therapy.

Reducing AV power appears fundamental in individuals' experiences of CBT. Those in recovery reported that reductions in AV power allowed them to feel able to manage the AV, despite other characteristics remaining stable. This mirrors Hormoz et al. (2019) who identified AV power was the only characteristics to reduce throughout therapy. This suggests that therapy could focus on reducing AV power rather than its complete removal.

Repeatedly challenging the AV during CBT-E allowed participants to realise consequences were not as bad as the AV threatened. This notion of repeated exposure being effective in reducing the perceived threat of the AV is perhaps not surprising given the existent CBT literature on this technique. Repeated exposure to a feared situation is recognised within CBT protocols for anxiety (Steinglass et al., 2011) and within CBT-E for food avoidance (Fairburn, 2008) as a technique to reduce the fear associated with certain stimuli or situations. It appears that in a similar way, and in keeping with CBT principles, repeatedly challenging the AV reduces its power and perceived threat.

Importantly, given the difficulty in engaging this client group (Guarda, 2007), therapists standing alongside service users against the AV has been suggested as a therapeutic inroad in other AN research (Pugh, 2016). In the current research, therapists recognising the AV led to individuals feeling understood and able to discuss ways the AV impacted engagement. Feeling understood by the therapist, rather than just the AV, seems an important transition, with the therapist becoming a new ally. In turn this reduced the AV power, improving engagement with CBT-E. It is well understood within CBT literature that the therapeutic relationship plays

a vital role in how well individuals respond to treatment across disorders (Cummings et al., 2013; Evans-Jones et al., 2009; Heins et al., 2013), with some preliminary research recognising its role within CBT-E specifically (Accurso et al., 2015). The current research furthers this literature, recognising the importance of this relationship in engagement with CBT-E and reducing AV power.

Impact of relationship with the AV

Individuals perceiving their relationship with the AV as positive reported finding engagement with treatment hard, worrying that CBT-E would remove the AV and thus their identity and coping mechanism.

Other research recognises AN dominating individuals' sense of self and identity, leading to reluctance for it to leave (Highed & Fox, 2010; Williams et al., 2016), creating a barrier to recovery (Lamoureux & Bottorff., 2005). The current findings suggest that perhaps it is the AV part of AN people struggle to consider life without, as it becomes their identity and helpful companion thereby reducing motivation to engage.

Motivation levels are often low within AN, people expressing ambivalence about needing to change (Casanovas et al., 2007; Macdonald et al. 2012; Vitousek et al., 1998). The transtheoretical model (Prochaska & Velicer, 1997) considers individuals with ANs readiness to change, distinguishing four stages; precontemplation, contemplation, action and maintenance (Mander et al., 2013). Research indicates less than 50% of individuals with AN are in action stage at assessment for intervention (Blake et al., 1997) identifying the majority are not ready to change.

Casanovas et al. (2007) recognised levels of ambivalence in AN due to fear of relinquishing symptoms perceived as functional. This mirrors current findings which recognise the AV relationship creates a barrier to engagement and that key to CBT-E success was helping people cope without the AV by providing new coping mechanisms and separating the AV from sense of self. Extra-therapeutic factors were also found to be valuable in replacing the AV's functions. Duncan et al. (2015) reinforces these findings, identifying individuals' need for treatment to focus on reclaiming identity and ability to function without the AV.

Therefore, it may be possible to improve motivation levels by discussing at CBT-E outset the aim to reduce AV power and replace unhelpful coping mechanisms, rather than removing it.

Implications for interventions

Given the fundamental role the AV plays in CBT-E engagement, and the fact that current CBT-E protocols do not explicitly address the AV, adapting protocols to explore reducing AV power and increasing individuals' abilities to cope without it could improve CBT-E outcomes.

Reducing AV power

Therapists may help reduce this by recognising it in sessions and acting as an ally, so servicer users feel understood and more able to challenge the AV within this trusting relationship.

Therapists should work collaboratively to consider the most helpful ways to challenge the AV for that individual.

Developing this relationship is important, otherwise recovery from AN can be prolonged (Ramjan, 2003). AV power varies across individuals and subtypes of AN (Pugh & Waller, 2017), so treatment should be informed by formulation. The current findings identify that the AV

may obstruct honesty and is likely to undermine the therapist initially, so therapists should reference the AV even if service users feel unable to do so.

Changing the relationship

Separating the AV from self during CBT-E allowed separation from identity, increasing individuals' ability to challenge it. Highed and Fox (2010) argue separation can improve motivation to engage; the current research suggests that separation helps individuals to consider life without the AV, lessening reluctance to engage in a therapy that might be perceived as attempting to remove it.

Externalisation techniques have been recommended to assist this separation (Highed & Fox, 2010; Tierney & Fox, 2010, 2011; Williams et al., 2016), although some express concern professionals may disregard issues if they believe the AV, not the individual, is talking (Tierney & Fox, 2011). Others suggest individuals may take less responsibility for their actions if the AV is externalised (Pugh, 2016). Therefore, needing to ensure both parties understand the rationale for separating AV from self.

Emotion focused therapy uses empty chair techniques to actively externalise and challenge the inner critic (Brennan et al., 2015), so could be used to challenge the AV. Mountford and Waller (2006) externalise the restrictive mode as an animate object with therapist and service user working collaboratively to tackle it. CBT-E could incorporate similar techniques to challenge the AV.

Limitations

Only females were recruited, and ethnicity data was not gathered, therefore it is not possible to generalise findings to the wider AN population. Female experiences were the focus, as it

was in previous AV research and it was not considered within the scope of a doctoral thesis to explore differences in males' experiences. The researchers recognise the importance of future research exploring this area.

NHS services participants were recruited by clinicians if meeting inclusion criteria and considered suitable. This may bias results as it depends on a subjective judgement by clinicians meaning not all interested participants may have had the opportunity to take part.

Eight participants were recruited via Beat and therefore self-reported both diagnosis of AN and whether they received CBT-E so there could have been inaccuracies in these reports.

However, there was no reason to dispute these claims; recollection of CBT-E was discussed when checking inclusion criteria and during the interview to ensure descriptions met protocol and EDE-Q scores identified eating pathology across the sample.

Reflexivity

The lead researcher remained aware of her preconceptions throughout the research and bracketed these out using a reflective journal and memos. However, it may be that some of the lead researcher's expectations influenced the analysis and write up of the data. For example, based on her preconceptions it was expected that individuals would have some difficulty engaging with CBT-E. Given that this was one of the results, these finding should be considered within the context of the lead researchers experiences. Other researchers would have interpreted the data through a different lens and may have identified or labelled themes otherwise.

Additionally, the researcher is aware of the impact of language used throughout this paper. In particular describing individuals' difficulties as an eating disorder and referring to this as an

illness. The use of these terms is a reflection of the language used within other research in this area, the participants own expressions, and the terminology used within eating disorder services that the researcher has worked within. This language may not fit with other people's perceptions of the difficulties, and the researcher recognises this terminology is a reflection of their own experiences.

This reflexivity is in keeping with the social constructionist version of grounded theory used within this research. Charmaz (2014) recognises that researchers preconceptions interact with existing knowledge and influence data analysis. As such, the researcher recognises that their own experiences may have influenced the use of terminology throughout this paper.

Recommendations for further research

The therapeutic relationship is identified within current research as important in allowing honesty and challenging the AV. However, questions remain about what enables honesty and the choice to listen to the therapist over the AV. Further research concerning interaction between the AV and therapist would be beneficial in understanding how to overcome the AV not only in CBT-E but any treatment for AN.

This sample had relatively low levels of eating pathology, perhaps because only these individuals felt able to discuss the AV openly and honestly. Understanding experiences of those with more severe eating pathology could help inform earlier stages of CBT-E. This research may be challenging if individuals feel unable to discuss the AV honestly whilst it remains dominating.

CONCLUSION

This research highlights how the AV and CBT-E interact, both making the other more challenging and difficult. These findings argue that considering the AV during CBT-E treatment is fundamental in helping individuals feel understood and engaged within treatment.

Reducing the power of the AV, and helping individuals to develop a sense of self without it, are key to therapy engagement and recovery. Given the significance of the AV role, and the fact that CBT-E protocols do not currently address it, there is a need to make some adaptations to treatment delivery, which could improve outcomes of therapy.

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APPENDICES

Appendix 1 - Journal author guidelines

Please note: For the purposes of thesis submission, this paper has been prepared to the Doctorate in Clinical Psychology guidelines of 8000 words to ensure everything necessary could be demonstrated. This word limit does not include tables, figures, references or appendices. References have been prepared to be in line with the most up to date guidelines, Publication Manual of the American Psychological Association (7th Ed.).

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Articles should adhere to the stated word limit for the particular article type. The word limit excludes the abstract, reference list, tables and figures, but includes appendices.

Word limits for specific article types are as follows:

Research articles: 5000 words Qualitative papers: 6000 words Review papers: 6000 words Special Issue papers: 5000 words

In exceptional cases the Editor retains discretion to publish papers beyond this length where the clear and concise expression of the scientific content requires greater length (e.g., explanation of a new theory or a substantially new method). Authors must contact the Editor prior to submission in such a case.

Please refer to the separate guidelines for Registered Reports.

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Brief-Report COVID-19

Until the end of July 2020, the *Psychology and Psychotherapy: Theory, Research and Practice* are accepting brief-reports on the topic of Novel Coronavirus (COVID-19) in line with the journal's main aims and scope (outlined above). Brief reports should not exceed 2000 words and should have no more than two tables or figures. Abstracts can be either structured (according to standard journal guidance) or unstructured but should not exceed 200 words. Any papers that are over the word limits will be returned to the authors. Appendices are included in the word limit; however online supporting information is not included.

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Contributions must be typed in double spacing. All sheets must be numbered.

Cover letters are not mandatory; however, they may be supplied at the author's discretion.

They should be pasted into the 'Comments' box in Editorial Manager.

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The manuscript should be submitted in separate files: title page; main text file; figures/tables; supporting information.

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You may like to use <u>this template</u> for your title page. The title page should contain: A short informative title containing the major key words. The title should not contain abbreviations (see Wiley's best practice SEO tips);

A short running title of less than 40 characters;

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The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;

Abstract;

Keywords;

Data availability statement (see Data Sharing and Data Accessibility Policy);

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Authorship

Please refer to the journal's Authorship policy in the Editorial Policies and Ethical Considerations section for details on author listing eligibility. When entering the author names into Editorial Manager, the corresponding author will be asked to provide a CRediT contributor role to classify the role that each author played in creating the manuscript. Please see the **Project CRediT** website for a list of roles.

Abstract

Please provide an abstract of up to 250 words. Articles containing original scientific research should include the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use the headings: Purpose, Methods, Results, Conclusions.

Keywords

Please provide appropriate keywords.

Acknowledgments

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

All articles must include Practitioner Points – these are 2-4 bullet point with the heading 'Practitioner Points'. They should briefly and clearly outline the relevance of your research to professional practice. (The Practitioner Points should be submitted in a separate file.) Main Text File

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

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

Title

Main text

References

Tables and figures (each complete with title and footnotes)

Appendices (if relevant)

Supporting information should be supplied as separate files. Tables and figures can be included at the end of the main document or attached as separate files but they must be mentioned in the text.

As papers are double-blind peer reviewed, the main text file should not include any information that might identify the authors. Please do not mention the authors' names or affiliations and always refer to any previous work in the third person.

The journal uses British/US spelling; however, authors may submit using either option, as spelling of accepted papers is converted during the production process.

References

References should be prepared according to the *Publication Manual of the American Psychological Association* (6th edition). This means in text citations should follow the authordate method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper. Please note that for journal articles, issue numbers are not included unless each issue in the volume begins with page 1, and a DOI should be provided for all references where available.

For more information about APA referencing style, please refer to the <u>APA FAQ</u>. Reference examples follow:

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Beers, S. R., & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. *The American Journal of Psychiatry*, *159*, 483–486. doi: 10.1176/appi.ajp.159.3.483

Book

Bradley-Johnson, S. (1994). *Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school* (2nd ed.). Austin, TX: Pro-ed. *Internet Document*

Norton, R. (2006, November 4). How to train a cat to operate a light switch [Video file]. Retrieved from http://www.youtube.com/watch?v=Vja83KLQXZs

Tables

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

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Appendix 2 - PROSPERO registration confirmation email

13/05/2020 Email - Harriet Collie - Outlook

PROSPERO Registration message [168796]

CRD-REGISTER <irss505@york.ac.uk>

Tue 11/02/2020 15:51

To: Harriet Collie < CollieHF@cardiff.ac.uk>

Dear Mrs Collie,

Thank you for submitting details of your systematic review "Service users' experiences of cognitive behavioural therapy for anxiety disorders: a meta-synthesis" to the PROSPERO register. We are pleased to confirm that the record will be published on our website within the next hour.

Your registration number is: CRD42020168796

You are free to update the record at any time, all submitted changes will be displayed as the latest version with previous versions available to public view. Please also give brief details of the key changes in the Revision notes facility and remember to update your record when your review is published. You can log in to PROSPERO and access your records at <a href="https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.crd.york.ac.uk%2FPROSPERO&data=01%7C01%7Ccolliehf%40cardiff.ac.uk%7C3f697b8b72da4d9237cb08d7af0a33aa%7Cbdb74b3095684856bdbf06759778fcbc%7C1&sdata=XH9iYHqNb6NLxgWwRWUU3Q9ifKdCwqRtwBNvgOlVv7k%3D&reserved=0.

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Best wishes for the successful completion of your review.

Yours sincerely,

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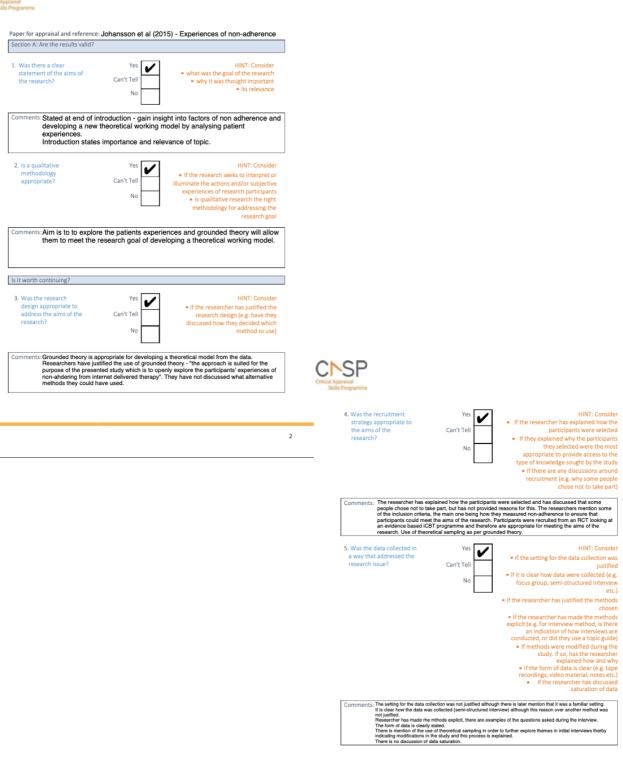
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1/2

Appendix 3 – Three example CASP checklists

Example CASP checklists completed by lead researcher







6. Has the relationship between researcher and participants been adequately considered?



HINT: Consider

- · If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data recruitment and choice of
- events during the study and whether they considered the implications of any changes in the research design

Comments: There is some recognition of the role of the relationship between the participant and the researcher. They consider who did the interviews and whether they were involved in the previous research and if this could have impacted responses. However, this is the only mention of this relationship being considered so I can't say whether this was adequate or not.

Section B: What are the results?

7. Have ethical issues been



HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained If the researcher has discussed issues
- raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
 - If approval has been sought from

Comments: Ethical approval was gained and participants provided informed consent before agreeing to take part in the research.



4

8. Was the data analysis



- If there is an in-depth description of the analysis process
 If thematic analysis is used. If so, is it clear
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis
- If sufficient data are presented to support
 - the findings

 To what extent contradictory data are
- taken into account

 Whether the researcher critically examined
 their own role, potential bias and influence
 during analysis and selection of data for

Comments: There is an indepth description of the analysis using grounded theory including an explanation for how the themes and final model were developed. However, there is limited explanation for how the raw data bull into these themes. Sufficient data is provided to support the findings, although there is limited discussion around any contradictory evidence. The researchers have considered their own role and have stated the use of more than analyst.

9. Is there a clear statement of findings?

- HINT: Consider whether
- If the findings are explicit
 If there is adequate discussion of the evidence both for and against the
- researcher's arguments

 If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more
- the original research question

The findings are made explicit and the researchers have somewhat considered their role. They have identified the use of more than one analyst and highlighted a lack of respondent validation. There is a discussion around how the findings sit within the expected findings from other research in the area. The findings are discussed in relation to the original research question.



Section C: Will the results help locally?

10. How valuable is the

HINT: Consider

If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
 If they identify new areas where research is necessary
 If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

nents: The discussion focuses on considering the contribution that the current study makes to exciting knowledge and understanding and whether the findings are in line with previous research. Additionally, it considers limitations and a number of areas for further research. However, there is no discussion around how generalisable the findings are to other populations. Also, the findings are only relevant to those who were non-adherent, can't make generalisations about everybodies experiences of CBT.



Paper for appraisal and reference: Mukherjee et al (2006) - adherence to treatment

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?



HINT: Consider · what was the goal of the research

why it was thought important
 its relevance

Comments: Provides a clear goal for research as well as a rationale for why this is important and how it develops upon other research in the area.

2. Is a qualitative appropriate?



HINT: Consider

. If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants methodology for addressing the research goal

Comments: The research goal is to better understand patients views which is something that grounded theory sets out to do.

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?



HINT: Consider • if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments: The researchers do not state their justification for the research design chosen, but it feels as though it was appropriate to address the aims of the research. This paper does not explicitly state the CBT protocol used, but the original paper explaining the trial that participants were taken from states it is evidence based but provides no reference for this.

4. Was the recruitment strategy appropriate to the aims of the research?



. If the researcher has explained how the

participants were selected • If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study

If there are any discussions around

recruitment (e.g. why some people chose not to take part)

Comments: The researchers explain how participants were selected as well as providing a rationale for why they chose participants who were below the poverty line, and why they samples from the sites that they did. Purposive sampling was used with a rationale for why. There are discussions around drop out rates of treatment and it states that people ented in to the research if they were

5. Was the data collected in a way that addressed the research issue?

Yes	
Can't Tell	
No	

HINT: Consider • If the setting for the data collection was iustified

 If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)

• If the researcher has justified the methods

chosen If the researcher has made the methods explicit (e.g., for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)

If methods were modified during the study. If so, has the researcher explained how and why

If the form of data is clear (e.g. tape recordings, video material, notes etc.)

If the researcher has discussed saturation of data

Comments: Yes. It is clear how the data was collected - interviews were audiotaped and transcribed. They describe how the interviews were conducted and the broad areas that the interview locused on. There is no clear justification for why interviews were used as the method of data collection. There is no discussion as to whether the methods were modified during the study.



between researcher and participants been adequately considered?



HINT: Consider · If the researcher critically examined their own role potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of

. How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

ts: There is no discussion in relation to the formulation of the research question. They identify that the interviewer has no previous relationships with the participant. But do say whether they consider this during sample recruitment and choice of location. There is no mention of events during the study or the

Section B: What are the results?

7. Have ethical issues been



nents: The paper states that consent forms have been approved by the review board, implying that the research has been reviewed by an ethics committee. The research explains that potential participants were contacted by phone to see if they were interested in the research, implying a discussion about the research took place. The researchers state that

HINT: Consider If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained

· If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)

If approval has been sought from

the ethics committee



If there is an in-depth description of the

If there is an in-depth description or the analysis process
If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
Whether the researcher explains how the

data presented were selected from the original sample to demonstrate the analysis

If sufficient data are presented to support the findings
To what extent contradictory data are

taken into account

Whether the researcher critically examined
their own role, potential bias and influence
during analysis and selection of data for

There is an indepth description of the analysis process including how themes were derived and that this was done by two people independently thereby considering their own role and potential bias during analysis. The researchers also highlight that the interviewers were not blind to the groups

HINT: Consider whether

If the findings are explicit If there is adequate discussion of the evidence both for and against the researcher's arguments
If the researcher's arguments
If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
If the findings are discussed in relation to

the original research question

5: The findings are explicit and discussed in relation to the orginal research question, although could be formatted more clearly. There is discussion around the different themes, there was no specific argument set out by the researcher. The researchers do discuss the credibility of their findings in

sufficiently rigorous?



Section C: Will the results help locally?

10. How valuable is the research?

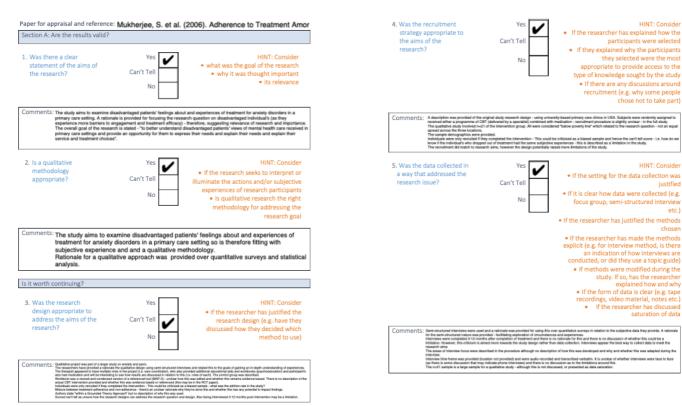
HINT: Consider If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant researchbased literature
 If they identify new areas where research

- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

intents: The researcher discusses the contribution this research makes to current literature and whether this is consistent with it or not. Additionally the research considers the clinical implications regarding interventions, staff and this particular client group and so has thought about the ways the research may be used. Additionally it has considered limitations and further areas for research.

Example CASP checklist completed by independent researcher





3



between researcher and participants been



HINT: Consider

- If the researcher critically examined their own role. potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of
- location
 How the researcher responded to events during the study and whether they considered the implications of any changes in the

Section B: What are the results?

7. Have ethical issues been



HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the
 - If approval has been sought from the ethics committee

4

informed consent was provided. The authors write "interviews were conducted after obtaining patients' signatures on the consent forms approved by the institutions' review boards' - implying ethical approval. Informed that interview details would not be passed to clinician's and interviewers were not involved in treatment.



sufficiently rigorous?



If there is an in-depth description of the

analysis process

If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data

 Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis

If sufficient data are presented to support

the findings

To what extent contradictory data are taken into account

 Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear staten of findings?



HINT: Consider whether

If the findings are explicit

If there is adequate discussion of the evidence both for and against the

evidence both for and against the researcher's arguments

If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)

If the findings are discussed in relation to the original research question



Section C: Will the results help locally?

10. How valuable is the research?

. If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-

based literature

- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments: The authors discuss the contribution that the paper makes in relation to the clinical implications (a. staff being sensitive to the barriers that are presented in low-income service users) and periodical registral difficulties which came out as a theme in the data. The importance of specificodisticities also is described as a contribution to relinized practice. The research contribution is also described as providing insights are qualitative research and the findings can inform future research. However, these contributions are presented within the limitations of the study (study design, difficulty in experient participations that CBT and medication, peneralisability, ents support received as would normally be accessed in clinical carel). There is no discussion of hours research operiunities and directions from the research. How individually define welltheigh and other concepts. There is a discussion of how their findings lock generalisability to other populations as it was a commissions campine that that plantine received additional apport.

Societ 0.5 for the contribution that the study makes, however the significant limitations in regards to lacking generalisability and the research design.

Appendix 4 - Stage 4 of meta-ethnography: determining how the studies are related

Tzavela et al. (2018)	Mukherjee et al.	McManus et al. (2010)	Halmetoja et	Burke et al. (2019)	Johansson et al.
	(2006)		al. (2014)		(2015)
Approaching the problem	Empowerment by	The relationship with the therapist	<u>Active</u>	<u>Helpful events</u>	<u>Perception of the</u>
Exploring the roots of the problem	<u>information</u>	Enabled openness and expertise increased trust	<u>approach</u>	Specific techniques	<u>treatment</u>
	Relief in		Needing to	developed insight	Extensive content,
Patients contribution to approaching the problem	understanding	Value of having a diagnosis and formulation	continue this		demands of reading
	disorder	To better understand difficulties	approach post	<u>Helpful impacts</u>	and writing
Therapist working collaboratively to reach			therapy	Supported and	capabilities, side
understanding	Sense of power	<u>Learned to interpret own experiences</u>		validated by	effects, lack of face-
	using skills and	differently through experiential work	<u>Passive</u>	interactions	to face contact
Easing in and opening up	techniques taught	Identifying avoidance and safety behaviours	<u>approach</u>		
Diminishing anxiety and increasing ease	in CBT		Symptoms	Able to manage anxiety	Patients situation
		Therapy was an emotional rollercoaster	becoming		Life factors, individual
Opening up: hesitant storytelling vs extensive	Dynamic iterative		worse when	Developed awareness	capability,
disclosure. Linked to getting to know the therapist	assessment of the	Difficulty changing long established habits	not remaining	and clarification	psychological
better.	intervention	Requirement of motivation	actively		vulnerabilities, need
	Assessing		involved post	Felt reassured by	for face-to-face
Building trust in and bonding	treatments	Transferring theory into practice	therapy	content	meetings, awareness
Developing a helping relationship	effectiveness	Challenges of generalising outside therapy			about the treatment
			<u>Experience</u>	Hindering events	
Actively cooperating	Barriers to	Relief from, and reappraisal of anxiety	and evaluation	Content not resonating	
, , ,	adherence	Reduction in symptoms	of treatment		
Making sense of panic	Logistical barriers	, ,	Aspects of CBT	Issues with course	
Making sense based on therapists explanation	involving tie and	More able to manage	that were	structure and time	
	travel	-	most helpful	commitments	
Jointly engaging in PD therapy vs awaiting relief		Greater acceptance of self and others	and most		
Jointly engaging with therapist and immersing self in			challenging	Hindering impacts	
therapy				Anxiety increased	
'				,	
Passive and hesitant expectations to be helped					
Believing in oneself vs relying on therapist					

Westra et al. (2010)	Button et al. (2019)	Khattra et al. (2017)	Kertes et al. (2011)	Morrison et al. (2017)	Macaulay et al. (2017)
The therapist surprised me	I dd the legwork myself	More adaptive	Experience of the therapist	Role of patient behaviour	In command of the
The therapist was	Expected to play a passive role in therapy but actually	interpersonal	Therapist characteristics	Own role within	worry train
collaborative and individuals	did more work than expected. Felt more in control of	relationships due	such as being non-	therapeutic process	From controlled by to
had the freedom to control	their anxiety and developed inner sense of	to therapy	judgemental, professional,		in control of anxiety.
things.	confidence		caring and encouraging.	Patient expectations	Unravelling the ball of
They were comfortable with		Positive shifts in		Expectations of role and of	worry. Externalising
the therapist, who was non-	Expecting rigidity and getting flexibility	the experience of	Therapist role as an	therapist	anxiety from self.
judgemental	Therapy was flexible and customised to individuals	<u>anxiety</u>	evocative guide that was		Relinquishing control
	needs more than expected. Process was driven by		collaborative and expected	Role of behaviour and	over the
The experience surprised me	participants.	Feeling a sense of	active engagement. Some	<u>affect</u>	uncontrollable. Being
Learnt to trust the process		<u>hopefulness</u>	experienced as directive.	Mirroring of behaviour and	assertive and setting
and overcome scepticisms.	I was sceptical about treatment, but it was effective	about changes		affect between service	boundaries.
Surprised by how helpful	Therapy was helpful. Moved from understanding	accomplished in	Experience of the therapy	user and therapist	
therapy was and that they did	something logically to believing it for themselves by	<u>therapy</u>	process		Experiencing myself
the work and felt comfortable.	doing things differently.		Client role was experienced	Patient comfort	in therapy in new
Didn't fit the stereotype of		<u>Therapists</u>	as either active or passive.	With therapist	<u>ways</u>
therapy.	My therapist was a pleasant surprise	positive role in	Disconfirmation of initial		Relating to myself in
	Developed an unexpected connection. Therapist was	facilitating shifts	negative expectations	Patient expression	new ways. Expanded
<u>I was disappointed</u>	an intuitive guide who was facilitative not a dictator.	<u>in therapy</u>	predominantly	Degree to which	emotional
External factors such as their				individuals expressed self	experience.
anxiety being too high or	Therapy provided a corrective experience	New intrapersonal	Experience of self	in CBT	Transformative
sessions too short for	Participants learnt they are not emotionally	and interpersonal	More able to manage		relationship with
disappointment in therapy	responsible and it's not their fault. Therapy provided	awareness	anxiety as well as	Therapist support and	therapist.
	a safe and comfortable outlet that meant people felt	<u>derived from</u>	interpersonal	<u>connection</u>	
<u>I trusted the process</u>	validated	<u>therapy</u>	improvements. Increased	Felt validated by therapist,	Oriented toward
Trusted therapy to help from			self-compassion. Decreased	felt connected and	<u>change</u>
the outset	Therapy was more structured than I expected	Learning helpful	levels of anxiety.	understood	Fed up and ready for
	Involved less talk and more action. Was goal focused.	CBT exercises and			change. Moved by
Therapy was what I thought it		tools to manage	Theory of therapy	Perceived intervention	the extent of change.
would be	Therapy didn't work for me in some ways	anxiety on an	Motivation key to success.	<u>strategies</u>	Confidence in
Confirmed positive		everyday basis	Specific helpful & unhelpful	Views on specific CBT	changes to come.
expectations			aspects of CBT techniques	techniques	

Appendix 5 – example of stage 5 of meta-ethnography: translating the studies into one another

Common concepts identified in stage 4	Tzavela et al. (2018) – 1st and 2 nd order interpretation	Mukherjee et al. (2006) – 1st and 2 nd order interpretation	McManus et al. (2010) – 1st and 2 nd order interpretation	Halmetoja et al. (2014) – 1st and 2 nd order interpretation
Making	Making sense of panic –	Empowerment by information	Value of having a diagnosis and	Did not endorse this theme
sense of	Making sense of panic, based on their therapists' explanation of	=	<u>formulation</u> – enabled people better	
anxiety	the problem's roots and maintenance. Heavily therapist	Many participants felt that	understand their difficulties, and	
disorder	mediated: most stressed therapist' role and mediation in their	information was empowering.	ultimately view themselves more	
	understanding of the mechanism of panic generation and	Participants experienced a	positively.	
	escalation.	sense of relief in	"I think it's really like opened my mind and	
	"she [therapist] explained, she made me understand something	understanding their disorder	it was really, really useful because first of	
	that I had not considered before: events/conditions themselves	and a sense of power when	all I realised that I wasn't the only oneI	
	do not necessarily generate stress"	using skills and techniques	didn't feel like I was not normal, this can	
		taught in CBT. The	happen to anyone"	
	By understanding how common the problem was they were	intervention reduced patients'		
	relieved, participants described a normalisation of fears.	sense of isolation.	Participants valued the formulation as	
	"He made me understand that I was not the only one [with this	"Just to know that I wasn't an	being a non-blaming explanation of how	
	problem] and that I should not feel like that I was going crazy"	isolated case, that it was a real	their difficulties had developed and were	
		diagnosis for which I could get	maintained.	
	Psychoeducation was evaluated by some as merely theoretical,	help. Without a diagnosis you	"We discussed were it might have come	
	widely available to the public, which minimised its personal	suffer in silence".	from and my kind of low self-esteem when	
	relevance.		I was an adolescent and things like	
	"This information was purely bibliographic, and I could have	A participant indicated that	thatand we jotted down a kind of flow	
	read it in a book"	the "workbookexplained the	diagram"	
		cycle of fear and I found that		
	The presentation of patient's personal formulation was	to be helpful not only for my	One person felt his experience of drawing	
	described as the "making sense" moment that was the most	panic but for other areas in	out the formulation had not felt like a	
	significant treatment moment.	my life"	collaborative venture and he struggled to	
	"This was a moment that I can pinpoint [as significant]. It was		understand or remember it.	
	about the process. [] I had understood the essence of my		"She just got a diagram out and said this is	
	problem and she was explaining what I could do to solve it"		a model of what's going on"	

Common concepts identified in stage 4	Burke et al. (2019) – 1st and 2 nd order interpretation	Johansson et al. (2015) – 1st and 2 nd order interpretation	Westra et al. (2010) – 1st and 2 nd order interpretation	Button et al. (2019) – 1st and 2 nd order interpretation
Making sense of anxiety disorder	Clarification, awareness, insight — developing awareness of how certain life experiences can influence anxiety; an insight into the recognition of their own anxiety, realizing the impact of their anxiety on their life and what they can do to control the anxiety they experience "It made me focus on my own situation and think about everything I had just read and how it related to me"	Did not endorse this theme	Did not endorse this theme	Understanding something logically to believing it for myself — unexpected benefits from doing things differently e.g. doing behavioural experiments "A lot of things I understood logicallybut talking about it and trying to apply ithelped me to move from understanding something logically, maybe even for someone else, but to start to believe that it should also apply to me" I made connections and understood why I worry — confirmations of expectations that therapy would provide insight into their worry "critically looking at yourself and recognising when you're doing it. That was something I had trouble doing before because I would just be anxious and have no idea why"

Common concepts identified in stage 4	Khattra et al. (2017) – 1st and 2 nd order interpretation	Kertes et al. (2011) – 1st and 2 nd order interpretation	Morrison et al. (2017) – 1st and 2 nd order interpretation	Macaulay et al. (2017) – 1st and 2 nd order interpretation
Making sense of anxiety disorder	New awareness about the nature of anxiety: from feeling stuck in a box to expanded perspectives — deriving a new perspective about the nature of anxiety by "bringing a new light" to it. Shift in viewing worry as unmanageable and overwhelming, came to see it as something they could learn to work with "the more we talked about what was that thought? Why did you think that way? I started seeing, oh okay, I can stop, look at it, slow it down, and try to reframe it"	Experience of self – described gaining increased agency, an improved perspective on anxiety, and increased awareness of the factors contributing to their anxiety. Also greater sense of being able to manage anxiety. "I realised that sometimes I set myself up to worry" Theory of therapy – Reduced sense of isolation though the realisation that others experience similar concerns, and attaining more awareness or increased clarity about one's concerns.	Did not endorse this theme	Unravelling the ball of worry - becoming aware of situations, relationships and core beliefs that underlie worry or trigger anxiety, which they were previously unaware of or had misunderstood. Being able to identify a distortion helped clients challenge thoughts and overall increase awareness helped clients to unravel the ball of worry "I know more clearly what my triggers are, what the contexts are that are going to make me think or feel a certain thing" Externalising anxiety from self - new understanding of the developmental roots of their anxiety, less self-blame and frustration, increased hope as a result of understanding and validation.
				Relinquishing control over the uncontrollable - increased awareness that their anxiety-related behaviours were efforts to control other people and situations.

Appendix 6 - Example of superordinate theme development

Concepts identified in stage 4	2 nd order interpretations	3 rd order interpretations (themes for synthesising)
MAKING SENSE OF PANIC: understanding anxiety,	a) people value gaining a new perspective on their	DEVELOPING INSIGHT: CBT helps individuals develop
recognising maintenance and roots of anxiety,	anxiety and understanding how it developed	insight into their anxiety, themselves and others. This
normalisation, developing new perspectives, relief in		seems to explain why individuals find the other aspects
understanding, non-blaming	b) this process is normalising as it allows people to	of CBT helpful, because they develop this insight.
	recognise that they are not alone and it could happen	
	to anyone	a) develop insight into anxiety: understand it better,
		feel validated and more able to manage it going
	c) having a formulation is non-blaming	forward
	d) developing understanding into anxiety must be a	b) developing insight into themselves: due to
	collaborative process	understanding their anxiety, people recognise that
		they are able to manage and control the anxiety.
	e) understanding anxiety also makes it more	People also recognise how critical they are of
	manageable	themselves and are able to develop some self-
OUTCOMES OF THERAPY: people notice change within	a) feel more able to manage their anxiety now that	compassion
themselves (increased self-efficacy, more in control of	they understand it, thus developing a confidence and	
anxiety, confidence in managing anxiety, self-	self-efficacy	c) developing insight into others: due to the
compassion) and in their relationships with others		therapeutic relationship differing to others, people
(increased assertiveness, recognising unhealthy	b) recognised the critical thoughts in mind and were	recognise that some of their interpersonal relationship
patterns).	able to use CBT to help them develop a sense of self-	are unhealthy. The relationship with the therapist
	compassion	implicitly challenges these, and sometimes they're
	a) the therapeutic relationship differs to ones they	explicitly challenged in therapy.
	have been involved with in the past and allows people	
	to recognise their unhealthy interpersonal patterns	
	b) these interpersonal patterns are challenged within	
	therapy	

Appendix 7 - Reflective journal extracts

Extract 1: Following first interview and transcription

"I'm a little worried that I'm unable to set aside my 'psychologist mode' and replace it with 'researcher mode'. I found it hard not to summarise and offer validation throughout the interview, especially when people are sharing such personal information. This is something I'm aware now that I hadn't considered beforehand and need to discuss in supervision in order to think about how I manage this in the future.

After John listened to the interview, he echoed my concerns about being too much of a psychologist, but also validated that it's normal. However, my summarising meant I sometimes ended up asking potentially leading questions, so this is definitely something I need to consider in future.

I'm wondering about my ability to 'bracket' off what I know from previous literature and knowledge of working in this area. I have the relevant skills from training to remain open minded and curious and I hope that this remains throughout the research interviews. Transcribing this interview was a helpful way of reflecting on this and recognising when I had maybe made assumptions about what she was meaning from the data. These assumptions will make it harder to analyse it and stay truly grounded to the theory. In future I need to recognise these assumptions and make sure I ask people to clarify if they have not explicitly stated it. I will ask myself 'do I know for a fact that is how they feel or am I casting my own judgements onto their experience?', hopefully this will help me manage my assumptions about the meaning of the data."

Extract 2: Following the fourth interview

"Time to pause data collection and reflect on the process so far. I need to alter my interview schedule; I'm spending the majority of time in the interview discussing the characteristics and relationship with the voice and not enough time considering the interaction with CBT-E when this is my research question.

Is it because I am really interested in the characteristics and relationship with the voice so ask too many prompts about this? Is it because participants get tired in the second part of the interview so start giving less full answers? Is it because the interview schedule doesn't have as many questions and prompts about the individuals' experiences of the AV and CBT-E?"

Extract 3: Following sixth interview

"This interview was the first one with someone who was not in her 20s and was much older than me. It made me aware of how the facts that I am a similar age to all the other participants so far may have influenced the information people felt comfortable sharing with me. It didn't feel during this interview that the content she was sharing was significantly different to what the other participants had shared but perhaps this would be hard to recognise. I wondered if me being the same age as the other participants was a help or a hindrance; maybe people felt I was easier to relate to and so were more open, or maybe people compared themselves to me and felt less able to be open with me. It will be interesting to note any differences when interpreting the data and if this seems to have influenced the interview content.

How does anybody have AN without the AV? Are they not the same thing? Is it just because I'm researching the AV that I feel like this? Perhaps nobody does experience AN without the AV but they just don't recognise it as the AV?"

Extract 4: Development of focused codes

"The process of focused coding feels quite exciting, it is the first time that the data is starting to come together, and I can imagine how the interviews are going to become a model.

However, I need to remain aware of my own preconceptions about the data and not let this influence it; having interviewed and transcribed participants I could easily make jumps from information I assumed during interview that was not actually in the data. You automatically make assumptions about what people mean during an interview based on their facial expressions or tone of voice that is not necessarily reflected in the transcripts.

I need to ensure I use constant comparison during the development of focused codes to ensure they are grounded within the data and I have sufficient quotes to back up any links I made."

Appendix 8 - Example memo

CBT-E creates the fight

Links to "only became a fight when I fought against it", this theme follows from that by describing how CBT-E creates this same fight. The underlying purpose of CBT-E is to help them recover by creating change in their eating patterns and cognitions. This therefore challenges the voice, even therapists do not explicitly discuss this in sessions, and so participants describe CBT-E making the voice worse, in the same way it gets worse when it is challenged in other ways.

Participants 1, 10, 2 and 3 report CBT-E creating something for the voice to fight against in that it provides a specific target for the voice to battle against. Participants perceive that CBT-E made the voice more determined.

Pt 1 - "I think it just gives it something to (pause) kind of fight against more [ok] umm (long pause), I don't know it's very, like it is very energy consuming and I just think (long pause). I don't know it just gives it more kind of reason to be (pause) critical about all the things that you're changing or are not doing or started doing that it wouldn't want you (pause) to be doing."

Pt 10 - "Um, nothing specific, no. I just think the whole-, the whole idea in general of the voice being challenged, um, didn't like it, because obviously the, the, the whole therapy is in the aim of getting me to recover and, and anorexia just doesn't want me to recover, it wants-, it wants to stay there, it wants to push everybody away and so everybody else that got involved, um, it, it, you know, it was just like every idea that was put forward, it, it challenged and it just seemed to grow in strength, um, and, and as the treatment went on it just did seem to get stronger, not weaker."

Pt 2 - "I think last year when I started to get more unwell it was almost like the anorexic voice saw CBT as something to like work against"

Pt 3 - "So kind of like the thing that's counteract- the thing that's fighting against CBT is the entirety of my eating disorder"

Participants 10, 11, 8 and 9 report specific characteristics of the voice getting worse and say it got stronger and more desperate. Participants 11 and 8 describe feeling as though this is specifically due to the voice feeling threatened and not wanting to be got rid of. This reasoning is the same as that provided by participants in 'it only became a fight when I fought against it'.

Pt 10 - "Um, I think if anything it made the voice even more determined-, Interviewer - Yeah.

Pt 10 - Um, because it, it was almost, like, defying, it was almost like, 'You're, you're trying your very hardest to undermine me here, but I'm not going to let that happen,' um, so I think if anything the voice got stronger and it became more determined to do what it wanted to do. So in that-, in that respect, yeah, it did have an impact, because I think it probably made it worse."

Pt 11 - "Er, I suppose the weighing, it felt like she was losing, um, it felt like she felt more out of control-,

Interviewer - Okay,

Pt 11 - Um, because I wasn't controlling that any more and she was getting more sort of erratic."

Pt 9 - "Er, yes, I think the, the main way that it changed is when I started treatment and, um, it almost went on the defensive-,

Interviewer - Okay.

Pt 9 - And it was like, 'Everyone's lying to you.'

Interviewer - Okay.

Pt 9 - 'Your therapist is trying to make you fat.'

Interviewer - Okay.

Pt 9 - And it changed-, it changed in that way and it almost got very desperate."

Pt 8 - "Um, I think it just, like, pissed it off and was, like, 'Ugh, just f*** off.' Um, 'No, we're not going to try that, no, we're not going to do that.' Um, I think, um, maybe made it more, like, defensive, and more, more, 'See, Vicky, I told you, you can't trust anyone but me. They just want to make you fat.' Um, so it tried to do that kind of thing."

Pt 8 - "Just because it knew that those were the tools and methods that were being implemented to get rid of it.

Interviewer - Okay.

Pt 8 - So then it would be, like, out of a job kind of thing."

Some participants identified specific techniques within their CBT-E treatment that appeared to trigger the voice more than other aspects; these include food diaries and introducing new foods.

Pt 12 - "I probably could have continued living with it for years and years and years, and then, yeah, as soon as I was given the meal plan, um, and I had to reintroduce different foods, as soon as I started gaining weight, um, it just amp-, yeah, amplified"

Pt 1 - "but I think then it kind of, when you kind of introduce a new food then it kinds of crops up again because then it' kinds of fighting back like you've added something else in that you shouldn't (pause) so then it's trying to stop you from doing that"

Pt 8 - "Um, I think, again, it would heighten with, um, yeah, like fear foods and challenges and that sort of more eating for social reason and enjoyment. Um, I think-, yeah, I think they were the main times."

Pt 2 - "Yeah, yeah I think definitely. Because it's almost like, obviously a lot of the CBT stuff is identifying where you're triggers are and what's holding you back (pause) and umm (pause) like with food diaries and stuff like that you're obviously then like highlighting how much you're eating in day and how you feel about it [mhm] and I think, for me, that then enabled the anorexic voice to be clearer because its like you have to think about it six times a day every day [ok] and then the voice I saying to you like (pause) 'look this is terrible' [laughter] [ok] like 'why have you done this?'"

This category seems to be an aspect of 'it only becomes a fight when you fight against it" (DIMENSION) because many of the comments are similar and the characteristics of the voice are the same whether it is challenged by CBT-E or any other way. Therefore, the difficulties participants face in the 'only a fight when you fight against it' theme are also going to be applicable to difficulties participants are facing during CBT-E.

Additionally, some participants in this theme identify that when the voice starts to attack the trust with the therapist when it becomes defensive and so I wonder how this links in with

conflict between the voice and the therapist, and whether this creates a barrier to engagement.

Appendix 9 - Ethical and Research & Development Approval

Research Ethics Committee approval letter



Gwasanaeth Moeseg Ymchwil Research Ethics Service



Wales REC 6 c/o Public Health Wales Building 1 Jobswell Road St David's Park SA31 3HR

Telephone : 01267 61 1164 E-mail : sue.byng@wales.nhs.uk Website : www.hra.nhs.uk

Dr John Fox South Wales Clinical Doctorate Programme, 11th Floor School of Psychology, Cardiff University Tower Building, 70 Park Place, Cardiff CF10 3AT

23 April 2019

Dear Dr Fox

Study title: The perceived impact of the anorexic voice on CBT-E

treatment outcomes

REC reference: 19/WA/0075
Protocol number: SPON 1713-18
IRAS project ID: 255395

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studvregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

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

Conditions of the favourable opinion

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

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

Health and Care Research Wales approval letter

Dr John Fox
South Wales Clinical Doctorate Programme, 11th
Floor
School of Psychology, Cardiff University
Tower Building, 70 Park Place, Cardiff
CF10 3AT

Dear Dr Fox

Study title:	The perceived impact of the anorexic voice on CBT-E treatment outcomes
IRAS project ID:	255395
Protocol number:	SPON 1713-18
REC reference:	19/WA/0075
Sponsor	Cardiff University

I am pleased to confirm that <u>HRA and Health and Care Research Wales (HCRW) Approval</u> has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see $\underline{\text{IRAS Help}}$ for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with

your non-NHS organisations to $\underline{\text{obtain local agreement}}$ in accordance with their procedures.

What are my notification responsibilities during the study?

The document "After Ethical Review – guidance for sponsors and investigators", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- · Notifying amendments
- · Notifying the end of the study

The <u>HRA website</u> also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is 255395. Please quote this on all correspondence.

Yours sincerely

Anne Gell

Email: Research-permissions@wales.nhs.uk

Copy to:	Mrs Helen Falconer	

Research & Development approval

RE: The perceived impact of the anorexic voice on CBT-E. Version 1 (7690)

Subject: The perceived impact of the anorexic voice on CBT-E. Version 1 (7690)

Dear Sponsor Representative,

Study title	The perceived impact of the anorexic voice on CBT-E. Version 1.	
R&D Local reference	19/JUN/7690	
IRAS reference	255395	

This email confirms that Cardiff and Vale UHB has the capacity and capability to deliver the above referenced study. We agree to start this study on a date to be agreed when you as sponsor give the green light to begin.

Please find attached the agreed Statement of Activities as confirmation.

Please note that the Principal Investigator, Debbie Woodward is responsible for:

- providing patients with localised participant information and consent documentation.

If you wish to discuss further, please do not hesitate to contact the R&D Office using the contact details below.

Sent on behalf of:

Professor Christopher Fegan
Cardiff and Vale UHB R&D Director
R&D Office, 2nd Floor TB2
University Hospital of Wales
Heath Park
Cardiff
CF14 4XW
CAV research.development@wales.nhs.uk

RE: The perceived impact of the anorexic voice on CBT-E. Version 1 (7690)



resgov Thu 18/07/2019 10:12

Dear Lee

Please accept this email as confirmation of Sponsor green light.

Kind regards

Helen

Research Governance Team Research and Innovation Services Cardiff University 7th Floor, McKenzie House 30-36 Newport Road Cardiff CF24 ODE

Email: resgov@cardiff.ac.uk

Tel: +44(0)29 2087 9277

Cardiff University is a registered charity

no. 1136855

Chris Shaw - Research Governance Coordinator Tîm Llywodraethu Ymchwil

Gwasanaethau Ymchwil ac Arloesi Prifysgol Caerdydd 7^{fed} Llawr, Tŷ McKenzie 30-36 Heol Casnewydd Caerdydd

CF24 ODE

Ffôn: +44(0)29 2087 9277

E-bost: resgov@cardiff.ac.uk

Mae Prifysgol Caerdydd yn elusen gofrestredig

rhif 1136855

Chris Shaw - Cydlynydd Llywodraethu

△ 5 % → …

Appendix 10 - Participant information sheet



The perceived impact of the anorexic voice on CBT-E treatment outcomes

PARTICIPANT INFORMATION SHEET

Introduction

You have been invited to take part in a research project that aims to explore your experiences of how the anorexic voice has impacted on your treatment for Anorexia Nervosa using CBT-E (enhanced cognitive behaviour therapy). Many people who have Anorexia Nervosa say they experience hearing an internal voice that comments on their eating patterns and behaviours. Some say this voice is hostile, while others say it can be their friend and helpful. We are interested in understanding people's experiences of this voice, and whether the voice has impacted on your treatment for Anorexia Nervosa. Effectively, we are interested to see whether the voice makes treatment easier or harder. Within this research, and other research into the area, this voice is referred to as the 'anorexic voice' but if you may have another name for it that

Please take the time to read this information sheet before you decide whether you would like to take part in the study. The following information outlines why the research is being carried out and what it will involve.

If you agree to take part in the research once you have read this information sheet, I will contact you to arrange a date for the interview. We will then go over this sheet again when we meet and can discuss any further queries or concerns before we proceed.

Thank you for taking the time to read this.

The researchers

My name is Harriet Collie and I am a Trainee Clinical Psychologist on the South Wales Doctorate Programme in Clinical Psychology. I am carrying out this study as part of my training. The research is being supervised by Dr John Fox (Clinical Psychologist, South Wales Doctoral

Participant information sheet - v7 - 11.04.2019

IRAS ID: 255395 Sponsorship ref :: SPON 1713-18

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Programme in Clinical Psychology) and Dr Debbie Woodward (Clinical Psychologist working in Cardiff & Vale University Health Board).

What is the purpose of the research?

This study aims to gain an understanding of peoples' experiences of the anorexic voice and the impact it has on their treatment using CBT-E. Research in the past has focused on the anorexic voice and CBT-E separately, but not looked at how they interact and impact on treatment outcomes. There is some anecdotal evidence that peoples' relationship with the voice changes through treatment, but there is no robust research looking at this in more detail. It is hoped that this study will provide a greater understanding of how therapists can use CBT-E to address the anorexic voice and improve treatment in the future.

Why have I been invited to take part in the study?

You have been invited to take part in the interview because you expressed an interest in being involved in the research. Presumably, this means you also have experiences of the anorexic voice and have had treatment for your Anorexia Nervosa using CBT-E at some point. Only your contact details (name, mobile number and address) have been passed onto myself, I do not hold any other confidential information about you.

What does taking part involve?

If you decide to take part in the research, I will contact you to arrange a date for the interview. On this date, you will first be asked to complete some questionnaires to gather some basic information about yourself. These questionnaires will be the Eating Disorder Examination Questionnaire (EDE-Q), Experience of Anorexic Voice (E.A.V.E) questionnaire, the Generalised Anxiety Disorder (GAD-7), and the Patient Health Questionnaire (PHQ-9). I will also ask for your age and BMI. This information is asked of all participants to gather some baseline information.

Following the completion of the questionnaires, you will be required to take part in an interview with myself where you will be asked a number of semi-structured questions about your experiences of the anorexic voice and your treatment using CBT-E. This interview will last approximately 60 minutes.

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During the interview, I will ask you some questions about what your experiences of having an anorexic voice have been like. We will discuss how your relationship with the voice has changed over time, whether the CBT-E had any impact on the voice, and whether the voice had any impact on your experience of CBT-E. We will also touch on other factors that have played a role in your treatment and/or recovery. You do not have to answer any questions that you do not want to. I will audio-record the interview so that I can type up exactly what was said during the interview in order to analyse the data afterwards.

After the interview, if there are any questions or concerns that you have regarding the research, these can be discussed together. I may contact you a few months after the interview so you can give me feedback about the themes from the interview, we would not have to meet again in person for this feedback. This feedback is also entirely voluntary if you would like to take part in the interview but not the feedback this is not a problem.

If you agree to take part, I will also ask for your GP details. Your GP will not be informed about your taking part in the research. I will only need to use these details if there are any safeguarding issues or concerns about risk during the interview (see below). If there are no concerns, these details will be destroyed following the interview.

Where will the interview take place?

The interview will take place in one of four locations; Global Link (an NHS site in Cardiff), The School of Psychology at Cardiff University, at your home, or via the telephone. Unfortunately, as the research is part of my doctorate and not funded, we will not be able to reimburse your travel and so if you agree to take part, we will discuss which of these locations is most convenient for vou.

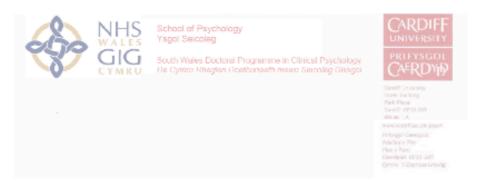
Do I have to take part?

Following reading this information sheet, you do not have to take part in the research if you decide not to. Even if you agree to take part, you may change your mind at any time and the interview will be terminated. You do not have to give a reason for withdrawing from the research. Participation is entirely voluntary and your decision will not affect the standard of care you are currently receiving.

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If you have any doubts about taking part in this research, then please feel free to ask questions and take all the time you need to consider it further.

Consent to take part in the study

If you decide that you would like to take part in the research, I will contact you to arrange a date for the interview to take place. On this day, we will go over this information sheet again and if you are still happy to take part will ask you to complete a consent form.

I will then ask you to complete the questionnaires before the interview takes place.

What will happen to my information?

After the interview, I will type out exactly what was said so that I can look in more detail about what we discussed. Following this, I will identify the themes that arose from the <u>interview</u>, and compare these themes with other participants. This way I can look at whether people have had similar experiences of the anorexic voice and CBT-E treatment, or whether there are differences. All transcripts of our conversation will remain anonymous, so your name and details will not be able to be connected with your interview record. All copies of the transcripts and audio recordings will be kept securely.

My supervisors (Dr John Fox and Dr Debbie Woodward) may read sections of the anonymised transcripts to ensure I am following the correct procedure for analysis. Any sections of the transcript included in the final version of my report will be anonymised.

Please see below for Cardiff University's policy on GDPR:

'Cardiff University is the Sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the Data Controller for this study. This means that we are responsible for looking after your information and using it properly. Cardiff University will keep identifiable information about you for 15 years after the study has finished. The legal basis we will rely upon to collect and store your information is public task.

Participant information sheet - v7 - 11.04.2019

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South Wales Doctoral Programme in Clinical Psychology



Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You are free to withdraw from the research at any time and it will not affect your standard care or treatment. If you choose to leave the study, we will need to keep any data you have provided up until the point you chose to leave the study and it may be included in the final analysis. As is the

case for all participants, you will not be identified in any publications or presentations about the

Cardiff & Vale University Health Board will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from Cardiff University and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Cardiff & Vale University Health Board will pass these details to Cardiff University along with the information collected from you. The only people in Cardiff University who will have access to information that identifies you will be people who need to contact you to for recruitment or audit the data collection process. Cardiff & Vale University Health Board will keep identifiable information about you from this study for 15 years after the study has finished.

You can find out more about how we use your information at https://www.cardiff.ac.uk/publicinformation/policies-and-procedures/data-protection

The University's Data Protection Officer can be contacted at: inforequest@cardiff.ac.uk'

Where will my data be stored?

Any personal identifiable data (e.g. contact details, consent form, and interview recordings) that you share when taking part in the research will be stored in a locked cabinet at Cardiff University.

Only I will be able to access this confidential data. None of this information will be stored for longer than it is required.

What are the possible disadvantages and risks of taking part?

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The interview involves asking you about your personal experiences of the anorexic voice and CBT-E. This may be an emotional and difficult experience for some people and could trigger some unwanted emotions. If at any time during the interview you feel as though you need to take a break, then please let me know and feel free to do so. You do not have to answer any questions that you don't want to. There will also be an opportunity to debrief and talk at the end of the interview. I will also provide you with an information sheet about support services you can contact should you require any further support.

The interview is not an opportunity to access services. If you would like some further support for your eating disorder you should contact your GP.

What are the potential benefits of taking part?

This research is a chance for your experiences to be heard and for these experiences to have a real impact on other peoples' treatment for anorexia nervosa. Despite the anorexic voice being common amongst people with anorexia nervosa, there are very few therapies that directly address this. The hope is that this research will be used to inform future psychological therapies and healthcare professionals in order to improve treatment for Anorexia Nervosa.

What if I have a concern or a complaint?

If you wish to make a complaint about any part of the research process these should be directed to the Chief Investigator, and academic supervisor. His contact details are as follows: Dr John Fox (Clinical Director). 11th Floor, School of Psychology, Tower Building, 70 Park Place, Cardiff, CF10 3AT. Telephone: 02920870582. John is responsible for dealing with any complaints and can re-direct to the Research Governance team if required.

Additionally, you can contact the Patient Advice and Liaison Service (PALS) who will be able to give you information about the NHS complaints procedure as well as how to get independent help if you want to make a complaint. You can find your nearest PALS office on the NHS website, or alternatively ask your GP surgery, hospital or phone NHS 111 for details of your nearest PALS service.

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Will my taking part in this study be kept confidential?

All of the information you provide to this study will remain confidential. The only time confidentiality may need to be broken is if you say something during the interview that I believe puts either yourself or someone else at risk. Where possible, I will discuss this with you first if I need to break confidentiality and inform your GP.

Who is monitoring this study?

This design for this study has been reviewed by the Research Ethics Committee and was approved on the 23.04.2019. The Research Ethics Committee is a process designed to protect your safety, dignity and rights. The study is also being monitored by my supervisors throughout to ensure the quality and safety of the research is being maintained.

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION!

Contact Details:

<u>Lead researcher</u> Harriet Collie (Trainee Clinical Psychologist) colliehf@cardiff.ac.uk 07771677703 (Mon-Fri 9am-5pm)

Chief Investigator
Dr John Fox (Clinical Psychologist)
South Wales Doctoral Programme in Clinical Psychology
Foxj10@cardiff.ac.uk
029 2087 0582

Principal Investigator
Dr Debbie Woodward (Clinical Psychologist)
Debbie.woodward@wales.nhs.uk
029 21832243

Participant information sheet - v7 - 11.04.2019

IRAS ID: 255395

Sponsorship ref SPON 1713-18

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Beat

13 August 2019 · 🔇

Some people with eating disorders experience an internal voice that comments on their eating patterns and behaviours which can make it harder to recover. Some people call this 'the Anorexic voice'. Harriet at Cardiff University is studying the relationship between the 'Anorexic voice' and the effectiveness of Enhanced Cognitive Behavioural Therapy (CBT-E). Click the link below to find out more information about who can take part and how to contact the researcher.



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BEATEATINGDISORDERS.ORG.UK

The perceived impact of the anorexic voice on CBT-E outcomes

Appendix 12 - Interview schedule with additional questions highlighted

- 1. Some people experience hearing a voice of their eating disorder. Is this relevant for you? Often people refer to this as the anorexic voice, do you have a name for it?
- 2. Can you tell me a little about what is your experience of the anorexic voice has been?

What sort of things does it comment on?

Does it ask you to do things? What sort of things?

Is it helpful?

Is it a friendly voice?

Is it your own voice or someone else's?

What gender does your voice have?

How loud is it?

Does it comment on any other aspects of your life?

When do you notice it the most?

How is it when you look in the mirror? When you're eating?

In what way do you engage with the voice?

What meaning do you make of that?

3. When did you first recall hearing the anorexic voice?

What was going on in your life then?

How would you describe the anorexic voice back then?

Why do you think that triggered the voice?

What do you think it means that the voice seems to be there in times of...?

4. Have the characteristics of the anorexic voice changed throughout your eating disorder? Has the strength of the voice changed?

Some people say that although it started off as friendly and praised them, it became more controlling and hostile as the eating disorder went on. Does that feel similar to your experience?

5. What would you say your relationship with the anorexic voice is like at the moment? Is it friendly or hostile?

Helpful or unhelpful? In what way is it unhelpful/helpful?

That's really interesting, can you tell me a bit about what that means about your relationship?

6. How do you respond to the voice?

Is it something you try and resist or allow to be there?

What helps you to manage the voice?

What would it be like if the voice wasn't there anymore?

7. What do you remember about your experience of CBT-E?

What happened in the sessions? For example, did you complete diaries, get weighed etc?

How many sessions did you have?

Did you complete all the sessions?

How long ago did you have CBT-E?

8. Did the anorexic voice have an impact on the success of CBT-E treatment? If so, how?

Did it make it difficult to engage?

Was the voice more dominant at certain times throughout the session? E.g. after being weighed

Can you provide a little more detail about that please?

Did you notice the voice being present during certain aspects of the CBT-E treatment? E.g. during monitoring (food diaries), when you started to increase your eating, trying new foods?

If the voice was present, what sort of things was it saying? In what ways did this have an impact on your ability to engage in the treatment?

If the voice wasn't present, why do you think this was? Was the voice ever present during treatment?

What does it mean to you that the voice was/wasn't present during these stages of treatment?

Did the voice have any impact on your relationship with the therapist?

9. Did CBT-E have any impact on the voice?

Did the voice stay the same or lessen as treatment went on?

If you feel that CBT-E did have an impact on the voice, which parts of treatment do you feel had the most impact? E.g. during monitoring, when you started to increase your eating, trying new foods, challenging your thought process?

How do you feel that these aspects of treatment impacted your voice?

If CBT-E helped you to challenge the voice, what was helpful? What was not helpful? If CBT-E did not have an impact, why do you think this is? Is there anything that would have been more helpful for impacting the voice?

What sense do you make of the fact that CBT-E did/did not have an impact on the voice?

10. Did your therapist acknowledge the voice or speak to you about the voice?

Were you directly asked about it or did you bring it up?

Why do you think this was?

Would you have liked them to bring it up if they didn't?

Do you think it was something about the characteristics of the therapist that meant it was/wasn't brought up?

11. What would have helped you from the therapist?

Is there anything the therapist could have done differently to address the voice?

- 12. Do you feel that the anorexic voice has a part to play in your recovery/treatment?

 Do you still experience the voice even now you are recovered?
- 13. What other factors have had a role to play in your recovery/treatment?
- 14. Is there something else you think I should know to better understand the relationship between CBT and the anorexic voice?
- 15. Do you have any questions for me?

Α	ppendix	13 -	Informed	consent	form

		CONSENT FORM				
		PARTICIPANT				
	Title of Project: The perceived impac Name of Researcher: Harriet Collie	ct of the anorexic voice	on CBT-E treatment outcomes			
Ple	ease initial all boxes you agree with:					
1.	I confirm that I have read and understan the above study. I have had the opportu and have had these answered satisfactor	unity to consider the info				
2.	I understand that my participation is volu without giving any reason, without my m					
3.	I understand that there were options about where the interview takes place (i.e. at an NHS site in Cardiff, at Cardiff University, at my home, or via the telephone). and these have been discussed with me.					
4.	I understand that participation in this res recorded. I understand that these record	·	_			
5.	I understand that some anonymised sections of the transcripts may be quoted within the final research report.					
6.	I understand that this research is not a way to access further support and know the appropriate channels to go down if I need more support.					
7.	I understand that what I discuss within the interview remains confidential. However, I understand that if I say anything that puts myself or anyone else at risk that confidentiality may have to be broken.					
8.	I understand that my information will be stored securely in a locked cabinet held at Cardiff University and the information I provide will be anonymised for use in the study.					
9.	I have been given information about the that I can use this if I have any concerns study.					
10.	. I agree to take part in the above study.					
_	Name of Participant	Date	Signature			
	(PLEASE PRINT)		-			

Na	me of Person Taking	Date	Signature				
	Consent						
	Consent to be contacted for data a	nalysis consultation					
	If you are interested, the researcher may contact you to ask for your opinion on the themes that emerge from the data. This is a way to check that the researcher has interpreted what you said in the interview correctly. This can be done via email or over the phone, it would not require us to meet in person. If you are interested in being involved in this process, please complete the form below and return to the researcher. Your participation in this is entirely voluntary and will not affect your standard of care.						
	I agree / I do not agree (please circ about themes that have emerged f		ontacted by the lead researcher				
	Full name:						
	Signature:						
	Date:						

GAD-7 Anxiety

Over the <u>last 2 weeks</u> , how often have you been bothered by the following problems? (Use """ to indicate your answer"	Not at all	Several days	More than half the days	Nearly every day
Feeling nervous, anxious or on edge	0	1	2	3
Not being able to stop or control worrying	0	1	2	3
Worrying too much about different things	0	1	2	3
Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
Becoming easily annoyed or irritable	0	1	2	3
Feeling afraid as if something awful might happen	0	1	2	3

	Column totals:	_ • -	_ • _ •	_
		= Tota	I Score	
If you checked off a	ny problems, how diffi	icult have these prob	lems made it for you	ı to
	care of things at home		•	
Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult	

From the Primary Care Evaluation of Mental Disorders Patient Health Questionnaire (PRIME-MD PHQ). The PHQ was developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues. For research information, contact Dr. Spitzer at rls8@columbia.edu. PRIME-MD® is a trademark of Pfizer Inc. Copyright® 1999 Pfizer Inc. All rights reserved. Reproduced with permission

PHQ-9 Depression

Over the <u>last 2 weeks</u> , how often have you been bothered by any of the following problems?			More than	Nearly
(Use "✔" to indicate your answer"	Not all	at Several days	half the days	
Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving .around a lot more than	•			2
usual	0	1	2	3
Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3
Column totals	_	· -·	+	

= Total Score ____

From the Primary Care Evaluation of Mental Disorders Patient Health Questionnaire (PRIME-MD PHQ). The PHQ was developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues. For research information, contact Dr. Spitzer at rls8@columbia.edu. PRIME-MD® is a trademark of Pfizer Inc. Copyright© 1999 Pfizer Inc. All rights reserved. Reproduced with permission



Eating Disorder examination questionnaire (EDE-Q 6.0)

Instructions: The following questions are concerned with the past four weeks (28 days) only. Please read each question carefully. Please answer all the questions. Thank you.

Questions 1 to 12: Please circle the appropriate number on the right. Remember that the questions only refer to the past four weeks (28 days) only.

	ON HOW MANY OF THE PAST 28 DAYS	NO DAYS	1-5 DAYS	6-12 DAYS	13-15 DAYS	16-22 DAYS	23-27 DAYS	EVERY DAY
1	Have you been deliberately trying to limit the amount of food you eat to influence your shape or weight (whether or not you have succeeded)?	0	1	2	3	4	5	6
2	Have you gone for long periods of time (8 waking hours or more) without eating anything at all in order to influence your shape or weight?	0	1	2	3	4	5	6
3	Have you tried to exclude from your diet any foods that you like in order to influence your shape or weight (whether or not you have succeeded)?	0	1	2	3	4	5	6
4	Have you tried to follow definite rules regarding your eating (for example, a calorie limit) in order to influence your shape or weight (whether or not you have succeeded)?	0	1	2	3	4	5	6
5	Have you had a definite desire to have an empty stomach with the aim of influencing your shape or weight?	0	1	2	3	4	5	6
6	Have you had a definite desire to have a totally fla t stomach?	0	1	2	3	4	5	6
7	Has thinking about food , eating or calories ,made it very difficult to concentrate on things you are interested in (for example, working, following a conversation, or reading)?	0	1	2	3	4	5	6
8	Has thinking about shape or weight made it very difficult to concentrate on things you are interested in (for example, working, following a conversation, or reading)?	0	1	2	3	4	5	6
9	Have you had a definite fear of losing control over eating?	0	1	2	3	4	5	6
10	Have you had a definite fear that you might gain weight?	0	1	2	3	4	5	6
11	Have you felt fat?	0	1	2	3	4	5	6
12	Have you had a strong desire to lose weight?	0	1	2	3	4	5	6

PAGE 1/3 PLEASE GO TO THE NEXT PAGE

EDE-Q 6.0

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Eating Disorder examination questionnaire (EDE-Q 6.0)

Questions 13-18: Please fill in the appropriate number in the boxes on the right. Remember that the questions only refer to th past four weeks (28 days).

Over the past four weeks (28 days)....

13	Over the past 28 days, how many times have you eaten what other people would regards as an unusually large amount of food (given the circumstances)?	
14	On how many of these times did you have a sense of having lost control over your eating (at the time you were eating)?	
15	Over the past 28 days, on how many DAYS have such episodes of overeating occurred (i.e. you have eaten an unusually large amount of food and have had a sense of loss of control at the time)?	
16	Over the past 28 days, how many times have you made yourself sick (vomit) as a means of controlling your shape or weight?	
17	Over the past 28 days, how many times have you taken laxatives as a means of controlling your shape or weight?	
18	Over the past 28 days, how many times have you exercised in a "driven" or "compulsive" way as a means of controlling your weight, shape or amount of fat, or to burn off calories?	

Questions 19 to 21: Please circle the appropriate number. <u>Please note that for these questions the term "binge eating" means</u> eating what others would regard as an unusually large amount of food for the circumstances, accompanied by a sense of having lost control over eating.

		NO DAYS	1-5 DAYS	6-12 DAYS	13-15 DAYS	16-22 DAYS	23-27 DAYS	EVERY DAY
19	Over the past 28 days, on how many days have you eaten in secret (ie, furtively)? Do not count episodes of binge eating.	0	1	2	3	4	5	6
		None of the TIMES	A FEW OF THE TIMES	LESS THAN HALF	HALF OF THE TIMES	MORE THAN HALF	Most of the TIME	EVERY TIME
20	On what proportion of the times that you have eaten have you felt guilty (felt that you've done wrong) because of its effect on your shape or weight? Do not count episodes of binge eating.	0	1	2	3	4	5	6
			Not at all	Sughter	Moderately		MARKEDLY	
21	Over the past 28 days, how concerned have you been about other people seeing you eat? Do not count episodes of binge eating.	0	1	2	3	4	5	6

PAGE 2/3 PLEASE GO TO THE NEXT PAGE

EDE-Q 6.0

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Eating Disorder examination questionnaire (EDE-Q 6.0)

Questions 22 to 28: Please circle the appropriate number on the right. Remember that the questions only refer to the past four weeks (28 days).

	ON HOW MANY OVER THE PAST 28 DAYS	NOT AT ALL	SLIGH	TLY	MODE	RATELY	MARKE	DLY
22	Has your weight influenced how you think about (judge) yourself as a person?	0	1	2	3	4	5	6
23	Has your shape influenced how you think about (judge) yourself as a person?	0	1	2	3	4	5	6
24	How much would it have upset you if you had been asked to weigh yourself once a week (no more, or less, often) for the next four weeks?	0	1	2	3	4	5	6
25	How dissatisfied have you been with your weight?	0	1	2	3	4	5	6
26	How dissatisfied have you been with your shape?	0	1	2	3	4	5	6
27	How uncomfortable have you felt seeing your body (for example, seeing your shape in the mirror, in a shop window reflection, while undressing or taking a bath or shower)?	0	1	2	3	4	5	6
28	How uncomfortable have you felt about others seeing your shape or figure (for example, in communal changing rooms, when swimming, or wearing tight clothes)?	0	1	2	3	4	5	6

what is your weight at present? (Please give your best estimat)e.j:			
What is your height? (Please give your best estimate.):				
If female: Over the past three to four months have you missed	any menstrual periods?:	YES 🔘	NO O	
	If so, how many?:			
Have you	a been taking the "pill"?:	YES 🔘	NO O	
PAGE 3/3	THANKYOU			
EDE-Q 6.0		© 2008 Christop	her G Fairburn and Sarah	Beglin

DEBRIEF FORM

PARTICIPANT

Title of Project: The perceived impact of the anorexic voice on CBT-E treatment outcomes Name of Researcher: Harriet Collie

Thank you for taking the time to participate in this research project, we really appreciate it.

The purpose of the research was to investigate individuals' experiences of the anorexic voice and their CBT-E treatment. Importantly, we wanted to know whether the anorexic voice impacted on your ability to engage with the CBT-E treatment. Additionally, we were interested to investigate whether CBT-E ever directly challenged the anorexic voice.

The interviews will now be transcribed and analysed by the researcher who will identify common themes between participants. These themes will then be gathered together to develop a model of how we can support people with anorexia nervosa in the future, and improve the treatment of anorexia nervosa.

We understand that some of the questions asked during the interview were of a sensitive nature. If you have anything you would like to discuss or have any questions, Harriet will be happy to answer these before you go.

If you require any further support below are some contact numbers for available helplines:

- BEAT 0808 801 0677
- Anorexia and Bulimia Care 03000 11 12 13 (option 2)
- Samaritans 116 123

If you would like any further support from services that you are not currently being supported by, you should contact your local GP.

Thank you again for participating in this research, we hope that you found it interesting.

Yours sincerely, Harriet Collie

Appendix 16 - Three extracts of transcribed interviews

Laura:

So, I was wondering if you could tell me a little bit about when you first recall hearing the voice?

Umm,I think, I think it was around when I was really young because I used to, like one of my earliest memories of like eating disordered behaviour was umm going, I used to go and have breakfast before my parents got up so I'd be already downstairs when they came down and I would put like one piece of cereal in my bowl and eat it and be like 'I just finished my breakfast I was up early'

Okay

And I can remember at that point having this sort of like 'that's what you need to do, this is going to make you a better person'

Okay

Umm 'this is going to make you feel better' like and I was that young as well.

Ok, so does it feel as though it's been there the whole time the anorexia has been there as well?

Yeah

Yeah?

Yeah cos like I can't remember not hearing that and feeling like yeah

Ok, and how would you describe the anorexic voice back then?

Umm, cos I think at that point I didn't even really know what anorexia was, like I didn't know what that was about. Umm so I think for me it was like a massively comforting thing and although it was coming from an like external sound in a way I think then and when I was younger it was-I didn't separate it as much so I thought it was like almost like my decision or like kind of, I don't know what I'm trying to say sorry my brain has gone a bit like (gestures)

No, no not at all

Umm yeah it was like, it seemed like a positive control in my life, or like a positive reinforcement of something and like an achievement

Okay

Like I definitely use to see it as more as like a positive achievement not to eat or to lose weight.

Ok, so does it feel as though the characteristics of the voice have changed over the time of the anorexia?

Yeah, I think so

Ok, in what ways have they changed?

Umm, yeah cos I think yeah back then it was definitely more like almost like, I definitely thought it would make be a better person if I listened to it. But yeah it was very much like goal orientated so it would be like umm 'you need to lose this many pounds in this amount of days' and if you can do that great, continue. Or like 'you need to only eat one hundred calories' like there were definitely very much kind of like goal posts and stuff

Okay

Whereas I think as I've got older and as I've had treatment I've broken out of some of those habits

Okay

So now it's more of like an attack on my self-esteem and my ambitions-

Okay

And things like that. Like it's, I feel less, I think I've managed to sort of like get out of the feeling of like needing to be at a certain weight or umm needing to eat a certain amount. It's still very much there like I still finding myself wanting to restrict and stuff but I've definitely opened up the amount of food I can eat and that I'm willing to eat. And even in the past it will have been like 'you can't eat in front of other people' umm' you can't go out for dinner' all of that sort of thing and I've broken a lot of those sort of habits now

Okay

So I think now it is definitely more like you'll feel better if you don't eat. I think it's more like I feel much more like in control of my emotions if I'm not eating

Okay

Because they're just not really there, I feel much more numb and I think that's what the voice tried to remind me of-

Okay

Like you're going to cope better with life if you're not eating-

Okay

Rather than you need to lose this certain amount of weight.

Ok, so it has changed from being goal directed to emotion focused?

Yeah

Yeah, ok. And does it feel as though the voice has been consistent from the age of nine until now, and it has been just there constantly, or have there been times when its peaked and troughed?

Umm I think it's always been there, I think as well it kind of, if I'm doing better with food, I was thinking about this earlier when you were saying about stuff about it being more all-encompassing, I think when I'm doing better in my recovery of anorexia it then takes a different direction again so like I also hear it in terms of like umm if its telling me not to eat something because it will make me feel better and I eat it, or umm I've gained weight and I'm kind of staying stable in my recovery and doing well with that, it will then start telling me to self-harm

Okay

Or umm kind of like intrusive more like suicidal thoughts-

Okay

Like 'well if you're not going to lose weight then you may as well just kill yourself'

Oh, okay

Kind of, those kind of thoughts. I think it- yeah if I'm doing better with food it then kind of tries to find another way to be negative or kind of like get another unhealthy coping mechanism

Okay

And then it's almost like, like when I used to have more of a pull on the self-harm, it would like almost be like 'see you've now hurt yourself it's, you've very visibly hurt yourself, wouldn't it have just been better if you had stopped eating?'.

Okay

So it kind of like still goes into the eating

Yeah

But yeah it's almost like ways to prove itself to be right, I guess?

Yeah

It is weird talking about it because it sounds like a weird like, but yeah.

Gemma:

So can you tell me about what you remember about your experience of CBT-E, please?

I remember it being a challenge, um, I've definitely on times hated it, because-, well, I was young, I suppose that didn't help, but being one on one, talking to someone in a room, um, I used to dread every single week.

Okay.

Um, and I think for the first few weeks and when I was being introduced to it, I didn't really think it was for me. I didn't think it was something that was going to help.

Okay. Why was that?

I didn't think talking to anyone was going to change how I felt-,

Okay.

Or, um, how I acted, and I guess I-, partly because of the anorexic voice, I didn't want to put my faith in another person, like, fixing things for me. I felt like they were just-, the voice would say, 'Oh, they're just trying to get you to eat more by telling you these things,' and would trick me into thinking that the therapy was just a way of making me put on weight quicker.

Okay.

So definitely for the first few weeks and stuff, it kind of felt a force-,

Okay.

Like it was something that I had to do because-,

Okay.

Certain people were telling you to do it and that I was just kind of going and coming away.

Okay.

I think I-, once I started accept maybe these things do apply to me and perhaps that would help, I put a little bit more confidence into it and then things like doing the-, actually doing the homework and stuff that I was set and starting to think about the different tools and tasks that, um, I was being told about, I did start to recognise more within myself.

Okay.

Like, I, um, I never would have classed myself as a perfectionist or having low self-esteem and stuff-,

Okay.

Until I started having CBT, because they kind of helped me recognise that in myself-,

Yeah.

Whereas I don't think I would have realised-,

Otherwise.

I think I always have been, I just hadn't realised.

Yeah, okay.

Um, and it's even-, it's kind of-, even with things like that I maybe recognise it in my parents and stuff as well.

Okay.

Like, in my family set-up, like, I could now sit and easily say to my mum, 'You tell me I'm a perfectionist, but you are as well.' Like it's-, yeah. It did open my eyes and-, into me as a person and my personality and stuff, I think, as well as, um, trying to help with the eating disorder.

Yeah, okay. And you mentioned there that initially you were-, it was a challenge-,

Yeah.

And then it kind of moved into you being more accepting that it applied to you.

Yeah.

I was just wondering if you can remember what kind of helped that shift.

Persevering with it, I suppose. Um, (TC: 00:40:00) I think-, because I've, I've had it in, like, different hospitals with different people, um, different, like, psychologists. I've had it with-, done it with, like, nurses and stuff as well, like, parts of it. Um, and I think that where I really recognise that it might have been making a difference was probably with one particular person, because I had a better connection with her.

Okay.

My first experience with it, um, was in an inpatient unit in XXXX, in CAMHS-,

Yeah.

And, um, it was with, like, the, the doctor or psycholo-, psychiatrist or whoever was in charge of my case at the time and I suppose I didn't feel like I connected with him very well-,

Okay.

Because he was-, he was very high up, he-, I would only see him for the appointments, obviously very well-trained and stuff-,

Yeah.

And it, it kind of-, at a young age and him being male, as bad as that sounds-,

No, it doesn't sound bad.

At, at the time I found it harder to open up to him.

Yeah, okay.

So because I wasn't opening up, I wasn't benefiting from it.

Okay. Okay.

Whereas then the time-, the first time that I really recognised it had started to work was with, she must have been more than a nurse, I can't remember what her title was, but it was just a bit more relaxed. Like, I felt like I could speak to her a little bit more. I felt like she understood me better-,

Okay.

We had more similarities. So I think because I felt more comfortable I took stuff on board more-,

Hannah:

How would you describe the tone of the voice?

Er, it's, it's quite critical and harsh. It's never, like, angry-sounding. It's almost like disappointed-sounding or, like, um, more in the neutral end, because if it was just shouting at me I'd probably be a bit more, like, 'I'm not going to do what you want.' So it's not-, it's never kind, but it's always been kind of like coaxing.

Okay.

Yeah, and it'll be like, 'Oh, it's for your own good. I'm being hard on you for your own good.'

Yeah.

So yeah, it's not critical as in, like, shouting at me, but in some ways it being a bit more neutral makes me more liable to listen to it, which isn't particularly helpful.

Okay, yeah.

(Inaudible 08.27).

Yeah. Yeah, yeah. Um, and I was just wondering if, um, it's-, if you describe it as your own voice or as somebody else's voice.

I would say it's my own.

Yeah.

But I, I have never experienced anything like someone else's voice in my head. Like, they're, they're just like my thoughts, so I would describe it as me, but, um, I think when I first started therapy, actually, I said it was someone else's-,

Okay.

When they asked me that question, because I didn't know that I could be so self-critical. I was like, 'It must be someone else. Like, I'm quite a nice person.' But, um, it is definitely-, it is definitely me, I think.

Okay. And you mentioned earlier about now you've started therapy you can separate it out as a voice from your thoughts.

Yeah.

And I was just wondering how you know what the difference is between the voice and it being your thoughts?

Er, it's entirely based on what it's saying-,

Okay.

And how much it says, because there is no kind of difference, like, between them, because it's just like-, it's just thoughts in your head. So I always found it quite difficult, um, but I would just base it off of-, if it's telling me to lose weight or to worry about my shape or to restrict my food it's probably (TC: 00:10:00) the anorexic voice.

Okay.

Um, and also if it's, like-, my, my normal, like, mindset I'm not grabbing things from everywhere and, like, evaluating them. And my mind isn't racing, like, the same way that it does.

Okay.

And it's not quite so overwhelming. So it-, I kind of base it on the content of what it's saying and also, like, the frequency of, like, when-, what it's trying to persuade me. Um, because, because, yeah, in, in normal life I'll just go and I'll make a decision and it's not like I'm basing off of so much evidence and it's just, like, throwing everything at me. So I can kind of tell, but nowadays it gets a bit more difficult, because things are a bit more nuanced, because when I was first in recovery I could just completely ignore it and be like, 'Okay, that's irrational.'

Yeah.

But sometimes, like, there's, there's-, some of the newer ones, because, like, society is a bit disordered, like, they are kind of true-,

Yeah.

And I struggle a bit with those. Like, things like-, um, if-, I don't know. Some people-, some people, like, compensate around if they've had, like, a meal out or something, and those ones are a bit harder to explain away because it seems-, it seems right in my head. Um, because I still-, I still think it, like, um, some of the things I don't think any more, but or, like, um, so I was talking about the ball. I'm like, 'I do want to look nice for it,' and, um, it's, it's the ones that are more, like, nuanced-,

Yeah, okay.

That are a bit more difficult and I'm still working on coaxing those apart.

Okay.

Um, because-, I don't know, like, my mum has quite a healthy relationship with food, but at one point she was getting a bit worried, because she was like, 'But you can't just eat whatever you want all the time and not gain weight,' and then-, and she's like, 'But when are, when are they going to start telling you to not eat, like, three meals and three snacks a day?' and stuff like that, because I'm like, 'Oh, maybe, maybe I shouldn't be doing it.'

Okay.

It's, it's mainly when I get feedback from others that, um, makes my thoughts, um-, it kind of backs them up-,

Okay.

That I then struggle to separate them from the eating disorder voice.

Okay.

So it's kind of-, it's kind of merging again a little bit.

Okay.

But, um, there are some things, like, if it's, like-, there are some things I can just tell-,

Yeah.

And I can get rid of it and be like, 'No. Don't.' There's a-, there's a couple of things.

That get a bit trickier.

Yeah.

Yeah, it's a bit-, yeah, the lines are a bit blurry by the sounds of it.

Mm, because it's like I struggle with the line between health and, like-, because I do want to be healthy-,

Yeah.

But, like, um, I don't know. I-, like, there's, like, keeping my mind healthy as well, so I don't necessarily always do the most subjectively healthy things. Like I go to a yoga class once a week or something, but, er, objectively it would be healthy to exercise more. So, so I'm always like, 'Maybe I should exercise a bit more,' but I-, it's, it's the things that I, I'm struggling with the line between disordered and healthy.

Yeah.

Um, because when, when I was in first year of uni I think I was, like, borderline, like, orthorexic, that I wouldn't eat anything-,

Okay.

That was, like, a refined carb or a refined sugar or a refined oil or pretty much anything like that, and I was like, 'Oh, I'm being so healthy,' and now I'll look back on that and compare my diet now to that and I was like, 'Oh, I was so healthy back then.' And I, I don't know, I find the line between healthy and disordered a bit blurred.

Yeah.

So it's the-, it's the, um, it's the thoughts that it tells me that kind of straddle that line that I struggle with.

Appendix 17 - Extracts of coded transcript

Laura:

Transcript	Initial codes	Focused codes	Conceptual
			category
Ok, and how would you describe the anorexic voice back then?			
the anorexic voice back then?			
Umm, cos I think at that point I			
didn't even really know what	Recalling anorexia unknown	Seeing voice as	"The voice is
anorexia was, like I didn't know		comforting	my coping
what that was about. Umm so I		_	mechanism"
think for me it was like a massively	Experiencing comfort		
comforting thing and although it			
was coming from an like external	Externalising voice		
sound in a way I think then and			
when I was younger it was- I didn't	Acknowledging difficulty	Expressing inability to	Impact of
separate it as much so I thought it was like almost like my decision or	separating voice from self	separation voice	voice on sense of self
like kind of, I don't know what I'm	Losing train of thought		Of Self
trying to say sorry my brain has	Losing train of thought		
gone a bit like (gestures)			
,			
No, no not at all			
Marian and Secure Blooks and	For entry the continue As	\/-:	#TI:-
Umm yeah it was like, it seemed like a positive control in my life, or	Experiencing voice to provide control	Voice creating sense of achievement	"The voice is
like a positive control in my life, of	Perceiving as achievement	achievement	my coping mechanism"
something and like an achievement	r creciving as acmevement		meenamsm
Okay			
Like I definitely use to see it as			
more as like a positive achievement	Viewing restriction		
not to eat or to lose weight.	positively		
G	,		
Ok, so does it feel as though the			
characteristics of the voice have			
changed over the time of the			
anorexia?			
Yeah, I think so			
,			
Ok, in what ways have they			
changed?			
Umm, yeah cos I think yeah back			
then it was definitely more like almost like, I definitely thought it	Recalling previous		
would make be a better person if I	experience		
Modia make he a herrer herzon II I	experience		L

Transcript	Initial codes	Focused codes	Conceptual
			category
listened to it. But yeah it was very	Associating voice with	Noticing relationship	Impact of
much like goal orientated so it	sense of self	between voice and	voice on sense
would be like umm 'you need to	Describing goal focused	self-worth	of self
lose this many pounds in this			
amount of days' and if you can do	Voice setting rules	Describing	Voice
that great, continue. Or like 'you		characteristics of the	characteristics
need to only eat one hundred	Pushing further	voice	fluctuating
calories' like there were definitely			over time
very much kind of like goal posts			
and stuff	Describing goal focused		

Gemma:

Transcript	Initial codes	Focused codes	Conceptual category
I remember it being a challenge, um, I've definitely on times hated it, because-, well, I was young, I suppose that didn't help, but being one on one, talking to someone in a room, um, I used to dread every single week. Okay.	Experiencing CBT-E as a challenge Recalling disliking CBT-E Viewing age as hinderance Describing individual therapy Experiencing 1:1 therapy as unpleasant	Finding CBT-E challenging	CBT-E had no impact on ability to fight the voice
Um, and I think for the first few weeks and when I was being introduced to it, I didn't really think it was for me. I didn't think it was something that was going to help.	Recognising initial resistance Anticipating CBT-E to be unhelpful	Finding CBT-E challenging	
Okay. Why was that? I didn't think talking to anyone was going to change how I felt-,	Viewing feelings and behaviours as unchangeable		
Okay.			
Or, um, how I acted, and I guess I-, partly because of the anorexic voice, I didn't want to put my faith in another person, like, fixing things for me. I felt like they were just-, the voice would say, 'Oh, they're just trying to get you to eat more by telling you these things,' and would trick me into thinking that the therapy was just a way of making me put on weight quicker.	Recognising role of AV Experiencing mistrust of others Resisting support Anticipating others intentions Recognising influence of voice Feeling tricked by voice Voice undermining role of therapy	Voice as a barrier to success Voice encouraging disengagement with CBT-E	Voice as a barrier to engagement

Hannah:

Transcript	Initial codes	Focused codes	Conceptual category
How would you describe the tone of the voice?			
Er, it's, it's quite critical and harsh. It's never, like, angry-sounding. It's almost like disappointed-sounding	Experiencing voice as critical	Describing hostile nature of voice	Characteristics of current voice
or, like, um, more in the neutral end, because if it was just shouting	Describing tone of voice		Volue
at me I'd probably be a bit more, like, 'I'm not going to do what you want.' So it's not-, it's never kind, but it's always been kind of like coaxing.	Anticipating defying if voice shouting Feeling coaxed by voice		
Okay.			
Yeah, and it'll be like, 'Oh, it's for your own good. I'm being hard on you for your own good.'	Experiencing voice to have best interests at heart	Describing characteristics of voice	
Yeah.			
So yeah, it's not critical as in, like, shouting at me, but in some ways it being a bit more neutral makes me more liable to listen to it, which isn't particularly helpful.	Clarifying voice not shouting Recognising succumbing to voice when neutral Acknowledging listening to voice as unhelpful		
Okay, yeah.			
(Inaudible 08.27).			
Yeah. Yeah, yeah. Um, and I was just wondering if, um, it's-, if you describe it as your own voice or as somebody else's voice.			
I would say it's my own.	Describing voice as own	Identifying internal voice	
Yeah.			
But I, I have never experienced anything like someone else's voice in my head. Like, they're, they're just like my thoughts, so I would	Clarifying voice is not another's Defining voice and thoughts as same		
describe it as me, but, um, I think when I first started therapy,	Recalling start of therapy		

actually, I said it was someone else's-,	Describing voice as someone else		
Okay.			
When they asked me that question, because I didn't know that I could be so self-critical. I was like, 'It must be someone else. Like, I'm quite a nice person.' But, um, it is definitely-, it is definitely me, I think.	Recalling unaware of own critical nature Perceiving voice to be someone else's initially Viewing voice as self now	Viewing voice as part of self	Impact of voice on sense of self