



School of Psychology

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A meta-synthesis of the lived experience of adolescents with type 1 diabetes, and an empirical study of the impact of ways of coping on power of the anorexic voice.

Thesis submitted in partial fulfilment of the requirement for

the degree of:

Doctorate of Clinical Psychology (DClinPsy)

South Wales Doctoral Programme in Clinical Psychology

Cardiff University

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21st July 2023.

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Acknowledgements.

I would like to firstly thank the individuals who kindly gave up their time to take part in my research and allowed me to explore a novel area within eating disorders. This study would not have been possible without their willingness to engage with their anorexic voice, and I wish all the participants the very best in their journeys moving forward.

I give thanks to my research supervisors, Dr Marc Williams and Professor John Fox for their support and expertise throughout this research project. A special mention to Sarah Radev for giving up her own precious research time to improve the reliability of mine!

I would also like to thank my clinical supervisors across the years, both on training and prior, who believed in me and helped me get to where I am today. To Cathy, who gave me the first chance I needed. Your support will never be forgotten.

This thesis would not have been possible without the support of the DCLin 2020 cohort. My colleagues, my friends... I will never forget the banter, memes and the numerous trips to the pub that got us through the DCLinPsy! We did it!

To Chris and everyone at Upside Down, thank you for giving me a space to fly high and get away from the stresses of research.

To my friends and family, I am eternally grateful for your love and support. Thank you for always being there for me and helping in any way you can. Thank you for buying me coffee and giving me hugs when I cried. Extra big thanks to my Dynamos, I love you girls so much!

Finally, to my mum, for always believing in me even when I did not believe in myself.

Thank you.

Preface.

Paper 1: Qualitative meta-synthesis.

Paper 1 is a qualitative systematic review of the literature regarding adolescents lived experience of Type 1 Diabetes Mellitus (T1DM). T1DM is a chronic health condition where the bodies natural ability to produce insulin is disrupted. Without insulin, blood glucose (sugar) is not metabolised and can build up within the blood stream, which can lead to life-threatening health complications. Diabetes is described as requiring management 24/7, 365 days a year and individuals effectively act as their pancreas. They must continually monitor their blood glucose levels and administer insulin throughout the day and in response to food and drink consumption. This is a substantial burden, and for adolescents, living with T1DM can be difficult to handle. Research has shown that adolescents with T1DM have worse metabolic control, increased hospital admissions and are less likely to attend appointments as they transition to adult services. Understanding the demands faced by adolescents with T1DM is vital if healthcare services want to provide the appropriate support to improve health outcomes for young people. Whilst there has been some exploration of the experiences of children and adults with T1DM, there is a gap in the literature for adolescents.

Several databases were systematically searched for qualitative papers that explored the lived experiences of adolescents with T1DM. In total 10 papers were identified for inclusion in this review, reflecting the experiences of over 200 adolescents across five different countries. Thematic synthesis was used to develop codes and themes within and across papers, which resulted in four over-arching themes: 1) Diabetes is exhausting and overwhelming, 2) Nothing is untouched by diabetes, 3) I will always be different because of diabetes and 4) Ways of coping with the burden of diabetes. Adolescents described feeling

distressed and overwhelmed by the burden of diabetes and the way it impacted every aspect of their life, from school to friendships and family life. T1DM made them stand out and feel different at a time where fitting in was extremely important. In order to cope with these difficult feelings, many adolescents avoided thinking about their diabetes, or disengaged from treatment altogether. Being able to accept diabetes as part of them helped to reduce feelings of distress, but this was a process that took place over time. The findings of this systematic review highlight the importance of healthcare services looking out for and asking adolescents about diabetes distress and supporting them to find adaptive ways of coping with the burden of management.

Paper 2: Empirical research study.

Paper 2 was concerned with exploring the impact of voice suppression on the power of the anorexic voice. The anorexic voice is a phenomenon described across eating disorders as a critical and powerful internal voice that comments on food, shape, and weight. Individuals with eating disorders have described how initially the voice starts out as encouraging and supportive, but over time it becomes more negative and hostile. What is not yet known is why the anorexic voice becomes more powerful over time. One possible mechanism is the use of metacognitive control strategies, which are ways of coping with thoughts and feelings that we experience. Some strategies, such as voice suppression, are less helpful as it actually increases the frequency of thoughts and levels of distress. Research has shown that voices perceived as malevolent are likely to be resisted and individuals with eating disorders are more likely to use control strategies like voice suppression. It may be that failure to suppress the anorexic voice leads to its increasing power over time.

This research study asked a group of participants with current experience of an anorexic voice to complete a series of questionnaires regarding their beliefs about their anorexic voice and to rate topographical features of it, such as its power, volume, frequency. Then, participants were asked to either suppress or accept the experience of their anorexic voice for a short period of time and to rate their anorexic voice again. The results were interesting and showed that engaging in thinking about the anorexic voice, whether through voice suppression or acceptance, increased its power. It was also found that the anorexic voice is perceived to be both benevolent and malevolent and individuals are simultaneously willing to engage with it and try to resist it. This has implications for therapy and may explain why recovery outcomes are so poor for individuals with eating disorders.

Paper 1: Systematic Review.

Feeling Different: A meta-synthesis of the lived experience of adolescents with Type 1 Diabetes.

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Word Count: 7957

This paper was prepared in accordance with the author guidelines for the British Journal of Health Psychology (see Appendix A). For the purposes of thesis submission, the DCLinPsy word limit of 8000 words has been used to ensure inclusion of relevant information. To support readability, figures and tables are embedded within the main body of the text.

Abstract.

Purpose.

Type 1 Diabetes Mellitus (T1DM) is a chronic health condition where ability to produce insulin to regulate blood sugars is affected. T1DM requires close monitoring and management in order to prevent life-threatening complications. Health outcomes for adolescents with T1DM are poor, with reduced treatment adherence and increased hospital admissions. This qualitative systematic review aimed to synthesise the lived experience of adolescents with T1DM to understand their needs and consider how to improve clinical practice to provide appropriate support.

Method.

Electronic databases (PsychInfo, Medline, Scopus, Web of Science, and Cinahl) were systematically searched to identify qualitative studies exploring the lived experience of adolescents with T1DM. The Critical Appraisal Skills Programme was used to assess the quality of the 10 included papers and thematic synthesis was utilised to develop analytic themes.

Results.

Four main themes were developed: 1) Diabetes is exhausting and overwhelming, 2) Nothing is untouched by diabetes, 3) I will always be different because of diabetes and 4) Ways of coping with the burden of diabetes.

Conclusions.

Adolescents with T1DM experienced significant amounts of distress from the burden of managing T1DM and struggle with feeling different from their peers as a result of their health condition. Many adolescents tried to cope by avoiding thinking about T1DM or disengaging from treatment altogether. Being able to accept diabetes as part of them helped to reduce feelings of difference and distress. Healthcare services should be proactively asking young people about their experiences of managing T1DM and consider the use of acceptance-based approaches.

Keywords: Meta-Synthesis; Type 1 Diabetes Mellitus; Lived Experience; Adolescents.

1. Introduction.

1.1. Diabetes: definition.

Diabetes Mellitus refers to a group of metabolic disorders characterised by high blood sugar (hyperglycaemia) resulting from dysfunction or destruction of pancreatic cells involved in the production, storage, and secretion of insulin (World Health Organisation [WHO], 2019). The most prevalent form is Type 2 Diabetes Mellitus (T2DM) which accounts for more than 90% of diabetes diagnoses. Causes of T2DM include poor diet and obesity and can usually be managed through lifestyle changes (Chatterjee et al., 2017). In contrast, whilst the exact pathology remains unclear, Type 1 Diabetes Mellitus (T1DM) results from an autoimmune response within the body that destroys pancreatic beta cells and can lead to complete insulin deficiency (Daneman, 2006). Normally, the pancreas secretes insulin throughout the day and in response to carbohydrate consumption to regulate blood sugar levels (Wilcox, 2005). In T1DM, as the body's ability to produce insulin is compromised, glucose (sugar) is not metabolised and builds up in the bloodstream. If untreated, rising blood sugar levels can lead to diabetic ketoacidosis which is life-threatening (Gibb et al., 2016). Long-term elevated blood sugars also increase the risk of cardiovascular disease and damage to eyes, kidneys, and nerves (Fowler, 2008).

To manage T1DM, individuals must replicate the functions of their pancreas by monitoring blood sugar levels and administering insulin manually throughout the day and in response to food and drink consumption (Carroll & Vittrup, 2020). Three-monthly blood tests are required to check glycated haemoglobin levels (HbA1c) which reflects average blood sugar levels (National Institute for Health and Care Excellence [NICE], 2015). High HbA1c suggests blood glucose is typically elevated and T1DM is not being well controlled.

1.2. Costs of type 1 diabetes.

Currently, an estimated 400,000 individuals within the UK have a diagnosis of T1DM (Hex et al., 2012). Poor management of T1DM has significant costs to health, wellbeing, and the economy. The Royal College of Paediatrics and Child Health (RCPCH, 2017) reported that nearly 10,000 children and adolescents were admitted to hospital over three years from diabetic complications. Adolescents are most at risk of hospital admission, with nearly 40% of all admissions occurring at age 10-14. In the UK, the cost of treating diabetes complications alone have been estimated to cost over £0.7 billion (Hex et al., 2012).

T1DM is described as a condition that “requires self-management 24/7, 365 days a year” (Diabetes UK, 2019, p. 10), which can be a significant burden to manage and negatively impact psychological wellbeing. Individuals with T1DM report elevated rates of anxiety (Buchberger et al., 2016), depression (Farooqi et al., 2022), and disordered eating (Goebel-Fabbri, 2009) compared to the general population. Poor mental health can make management of T1DM more difficult and can increase the risk of complications, resulting in hospital admissions (Stewart et al., 2005).

Many individuals with T1DM have found the emotional impact of living with diabetes was not accurately captured through existing diagnostic labels. This led to development of the concept of ‘diabetes distress’ (DD), defined as the negative affective experience arising from the daily burden of living with and managing diabetes (Skinner et al., 2019). Whilst this may include low mood, it is conceptually different from depression as it encompasses a range of emotional experiences including fear and worry (Fisher et al., 2014). Estimates suggest 20-30% of individuals with T1DM will experience DD, with greater risk of development at a younger age (Sturt et al., 2015). DD is negatively associated with self-management and self-

care behaviours which can lead to higher HbA1c levels (Powers et al., 2016). Additional diabetes-specific psychological difficulties include needle phobia (Cemeroglu et al., 2015), fear of low blood sugars (Driscoll et al., 2016) and intentional insulin restriction/omission to lose weight or prevent weight gain (Goddard & Oxlad, 2022).

1.3. Adolescence and type 1 diabetes.

Living with T1DM requires constantly attending to blood sugar levels and acting to manage them. This can be a substantial burden, and for adolescents, this occurs at a time of simultaneous biological, emotional, and social changes, particularly during puberty (Patton & Viner, 2007). Cognitive development continues in adolescence, but at different rates across the brain. Executive function, a set of processes including the ability to initiate, inhibit, monitor, and plan behaviour is considerably underdeveloped compared to other cognitive abilities, not reaching full maturation until adulthood (Ferguson et al., 2021). Poorer executive function processes are linked to increased risk-taking behaviours in adolescents (Pharo et al., 2011). Alongside these physical changes, many social transitions are happening. Developing one's identity and place in the world is a key developmental goal of adolescence (Erikson 1950, 1968) and adolescents seek independence by moving away from reliance on the family unit (McDonagh, 2000). The opinions of peers hold significant value, which can increase engagement in risky behaviours such as smoking, binge drinking, and dangerous driving (Andrews et al., 2020). Adolescence is also associated with onset of many mental health conditions including anorexia nervosa (Javaras et al., 2015), clinical depression (Shorey et al., 2021), and anxiety (Tiirikainen et al., 2019).

It is unsurprising then, considering the challenges of adolescence generally, that young people with a chronic health condition like T1DM, face substantial difficulties. HbA1c levels

rise considerably during puberty whilst treatment adherence declines, leading to poor glucose control and complications (Gale, 2005; Borus & Laffel, 2010). Research has found only 21% of older adolescents reached target HbA1c levels (Wood et al., 2013). This is concerning when longitudinal research has shown HbA1c levels in adolescence remained unchanged for a decade afterwards, leading to serious health complications (Bryden et al., 2003).

Adolescence is usually the period of increased responsibility for self-management of T1DM which can be a worry for both parents and the young person (Driscoll et al., 2016). On transition to adult services and sole responsibility for management, glycaemic control typically worsens, and healthcare appointment attendance reduces (Hanna & Woodward, 2013). It is evident that adolescence is a risky period for those with T1DM and is associated with poorer health outcomes. Understanding the needs of young people with T1DM is crucial to provide appropriate support during this time.

1.4. Lived experience of type 1 diabetes.

Currently, no systematic review has attempted to synthesise the lived experiences of adolescents with T1DM, with previous meta-syntheses focused on children (Rankin et al., 2017), adults (Due-Christensen et al., 2018), and parents (Kimbell et al., 2021). Children with T1DM described feeling frustrated with diabetes for disrupting and restricting them from living a 'normal' life. Feeling different from friends and experiences of bullying and mockery from others was common, resulting in many children keeping T1DM secret to avoid negative repercussions. The complexities of T1DM were hard to understand at a young age and many young children preferred to share treatment responsibility with their parents (Rankin et al., 2017).

Similar themes were reported by adults newly diagnosed with T1DM, who felt anger and resentment towards it for majorly disrupting their lives. They grieved the loss of their 'old pre-T1DM lives and considered their future forever changed (Due-Christensen et al., 2018). The experiences of using technology to manage T1DM were synthesised by Messer et al. (2018) and whilst some individuals felt continuous glucose monitors increased confidence and independence, many disliked its visibility that drew attention to them and made them stand out as different.

As discussed, the specific experiences of adolescents with T1DM reflect a significant gap within the field, especially when one considers the increased risk of poor health management and complications at this age. Some generalisations can be made from systematic reviews of adolescents with chronic illness (Shorey & Ng, 2020). Adolescents reported feeling sadness, anger, and depression at the realisation of life with an uncurable condition. They felt trapped by the constraints of daily treatment regimes and struggled with a lack of autonomy and privacy due to their condition. However, this may not capture the nuances and unique experiences of adolescents with T1DM and why they are at risk of such adverse outcomes.

1.5. Aims.

T1DM is a chronic health condition requiring continual management and can lead to life-threatening complications if poorly controlled. Health outcomes for adolescents with T1DM are poor, with reduced treatment adherence, worse metabolic control, and increased likelihood of hospital admissions. The mechanisms behind this are not yet understood and currently no research has attempted to synthesise the specific lived experiences of adolescents with T1DM. By understanding their specific experiences, healthcare services can

adapt their support to better meet young people’s needs and improve their physical and mental health. Therefore, this meta-synthesis aims to bring together qualitative research on the lived experience of adolescents with T1DM and through thematic synthesis, develop themes that provide insight into the impact of living with T1DM for young people and consider how clinical practice can be improved.

2. Method.

2.1. Data sources and search strategy.

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were adhered to throughout this systematic review (Page et al., 2021). Five databases (PsychInfo, Medline, Scopus, Web of Science, and Cinahl) were searched using a pre-determined search strategy, developed with research librarian support. The search was conducted in December 2022, focusing on four main concepts: i) type 1 diabetes mellitus, ii) adolescents, iii) lived experience and iv) qualitative studies. Boolean operators “OR” and “AND” were used to link search terms together. The full search strategies can be found in Appendix B.

2.2. Eligibility criteria and study selection.

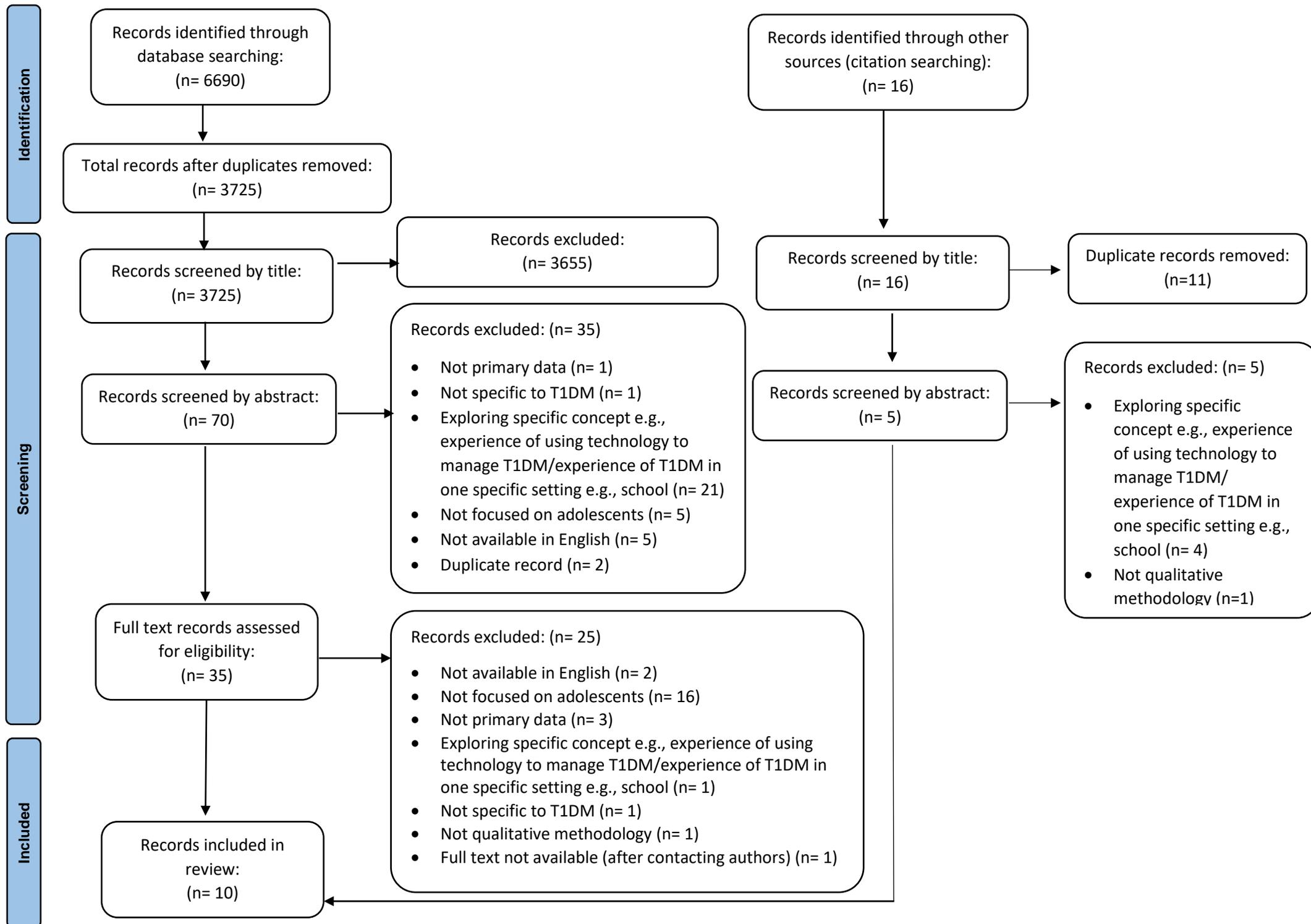
The Population, phenomenon of Interest and Context mnemonic (PICO; O’Connor et al., 2008) was used to develop the research question. The criteria and rationale for inclusion/exclusion are detailed in Table 1.

A third of papers that reached the stage of full-text reading were compared against inclusion/exclusion criteria by an independent researcher. Both researchers had an electronic spreadsheet containing the inclusion and exclusion criteria for the papers selected for review. Each researcher independently marked the paper against the inclusion and exclusion criteria to reach a decision of “include”, “exclude”, or “unsure”. Following this, the researchers met to compare and discuss their decisions. Any discrepancies on whether to include or exclude a paper were discussed and the papers were jointly reviewed and compared against the inclusion and exclusion criteria together until an agreement was reached. A Cohen’s kappa calculation of 0.75 indicated substantial agreement (McHugh, 2012). The PRISMA diagram below details the selection process of the 10 final papers.

Table 1. Inclusion and Exclusion criteria.

Criteria	Inclusion	Exclusion	Rationale
<i>Population</i>	<ul style="list-style-type: none"> • Adolescents (age 12-18 years). • Diagnosis of Type 1 Diabetes Mellitus (T1DM). 	<ul style="list-style-type: none"> • Children (age 11 and under). • Adults (19 years and older). • Diagnosis of Type 2 Diabetes. 	<ul style="list-style-type: none"> • Though there is considerable overlap in developmental stages, adolescence is defined as 12-18 years in order to rule out overlap with research with children (<12 years old) and adults (>18 years old) with T1DM (Rankin et al., 2017; Due-Christensen et al., 2018). • It is also important to note that age 18 is the typical age at which a young person finishes their transition to adult services (NICE, 2015).
<i>Phenomenon of Interest</i>	<ul style="list-style-type: none"> • Focus is on lived experience of T1DM. 	<ul style="list-style-type: none"> • Focus is on chronic conditions and not specific to T1DM. • Focus is on lived experience of other individuals than the adolescent, e.g., parent, healthcare professional. • Focus is on a <i>specific</i> concept, e.g., use of technology to manage T1DM/experience of T1DM in a specific setting e.g., school 	<ul style="list-style-type: none"> • This review aims to explore the overall lived experience of adolescents with T1DM. • Previous meta-syntheses have already explored perceptions of others, managing T1DM solely in school and the experiences of using technology.
<i>Context</i>	<ul style="list-style-type: none"> • Qualitative or mixed-method research design and analysis. • Papers written in English. • Studies reporting primary data published in peer-reviewed journal 	<ul style="list-style-type: none"> • Quantitative research design and analysis. 	<ul style="list-style-type: none"> • Qualitative research allows for thematic analysis. • No access to a translator for papers not available in English. • To ensure quality of studies.

Figure 1. PRISMA flow diagram.



2.3. Quality assessment.

The quality of the final 10 papers was appraised using the Critical Appraisal Skills Programme tool (CASP, 2018). The CASP was originally developed for use in healthcare research and is recommended for qualitative evidence synthesis (Noyes et al., 2019) to ensure interpretations drawn from the studies are reliable (Thomas & Harden, 2008).

The CASP uses 10 questions and related prompts that guides researchers to consider the appropriateness of the chosen methodology and design to answer the intended research question, the rigour of data collection and analysis process, and the value of the research in contributing to the wider evidence base. Questions are answered using a “yes”, “no” or “can’t tell” scale. The full set of CASP questions can be found in the table below.

Table 2. List of questions in the Critical Appraisal Skills Programme tool (CASP, 2018).

CASP Question Number	CASP Question
1	Was there a clear statement of the aims of the research?
2	Is qualitative methodology appropriate?
3	Was the research design appropriate to address the aims of the research?
4	Was the recruitment strategy appropriate to the aims of the research?
5	Was the data collected in a way that addressed the research issue?
6	Has the relationship between researcher and participant been adequately considered?
7	Have ethical issues been taken into consideration?
8	Was the data analysis sufficiently rigorous?
9	Is there a clear statement of findings?
10	How valuable is the research? <ul style="list-style-type: none">• Is there discussion of the contribution the study makes to existing knowledge or understanding• Are new areas where research is necessary identified?• Is there discussion of whether findings can be transferred to other populations?

The CASP is limited in that it does not provide a scoring system. NICE (2012) guidelines suggest quality of qualitative studies should be assessed on the proportion of checklist criteria fulfilled and the likelihood of altering conclusions (see Table 3 below). As recommended by Thomas and Harden (2008), no studies were excluded on the basis of quality.

Table 3. Guidelines for grading the quality of qualitative research as outlined by NICE (2012) guidelines.

Quality Score	Criteria
++	All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter.
+	Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter.
-	Few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter.

Similar to the process of paper inclusion, a selection of papers were subjected to quality appraisal against the same criteria by an independent researcher to improve inter-rater reliability. Both researchers had an electronic copy of the CASP which they independently rated the papers on, as well as the NICE (2012) guidelines for rating quality of qualitative research. After independent ratings, the researchers met to compare and discuss their ratings. Discrepancies were discussed and the CASP and quality rating for that paper was reviewed in full until a consensus was reached. Cohen’s kappa calculation of 0.78 indicated substantial agreement (McHugh, 2012) on quality appraisal between researchers and discrepancies were resolved through discussion to reach 100% agreement. Final quality appraisal scores can be found in the table below.

Table 4. Quality appraisal tool based on the CASP (2018)

✓ (Yes)	? (Can't tell)	X (No)
---------	----------------	--------

Article	CASP Question										Score	
	1	2	3	4	5	6	7	8	9	10		
Babler & Strickland (2015)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	Contributes to literature: ✓ Identified further areas of research: ✓ Considered generalisability: ✓	++
Burke & Dowling (2007)	✓	✓	?	✓	?	✓	✓	?	✓	✓	Contributes to literature: ✓ Identified further areas of research: X Considered generalisability: ✓	+
Carroll & Marrero (2006)	✓	✓	✓	✓	✓	X	✓	?	✓	✓	Contributes to literature: ✓ Identified further areas of research: X Considered generalisability: ✓	++
Commissariat et al. (2016)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓	Contributes to literature: ✓ Identified further areas of research: ✓ Considered generalisability: X	++
Dickinson & O'Reilly (2004)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓	Contributes to literature: ✓ Identified further areas of research: ✓ Considered generalisability: ✓	++

Joiner et al. (2020)	✓	✓	✓	✓	✓	✓	✓	✓	✓	Contributes to literature: ✓	++
										Identified further areas of research: X	
										Considered generalisability: X	
Kyngas & Barlow (1995)	✓	✓	✓	✓	✓	X	✓	✓	✓	Contributes to literature: ✓	++
										Identified further areas of research: X	
										Considered generalisability: ✓	
Pinar & Turan (2022)	✓	✓	✓	✓	?	X	✓	✓	✓	Contributes to literature: X	+
										Identified further areas of research: X	
										Considered generalisability: X	
Reitblat et al. (2016)	✓	✓	✓	✓	✓	?	✓	✓	✓	Contributes to literature: ✓	++
										Identified further areas of research: X	
										Considered generalisability: X	
Rising Holmström & Söderberg (2022)	✓	✓	✓	✓	✓	✓	✓	✓	✓	Contributes to literature: ✓	++
										Identified further areas of research: X	
										Considered generalisability: ✓	

2.4. Design.

Material from the primary studies was analysed using thematic synthesis (Thomas & Harden, 2008), in which meaningful patterns within and across studies relating to the research question are identified and thematically analysed (Braun & Clarke, 2006). Thematic synthesis is a useful method for meta-synthesis as it allows for description and interpretation of themes across studies and can be used with qualitative data varying in levels of detail and depth (Flemming et al., 2019).

Thematic synthesis (Thomas & Harden, 2008) follows three stages: 1) coding findings of primary studies, 2) organising codes to develop descriptive themes, and 3) development of analytic themes. Firstly, the researcher familiarised themselves with the included studies by reading and re-reading papers. Papers were coded using NVivo software and similarities and differences amongst codes were translated across studies. Descriptive themes were developed reflecting the findings of the studies. The final step involved going beyond simple description and exploring the meaning and implication of the themes, producing the final analytic themes. As suggested by Thomas and Harden (2008), findings were considered as all information included within the results and discussion sections of papers, including quotations and author interpretations. The inclusion of author interpretation is important as it prevents the meta-synthesis from simply becoming a secondary qualitative data analysis and allows for a richer understanding of the data which informs the new perspectives developed.

3. Results.

3.1. Study characteristics.

Included studies covered a variety of qualitative methodologies including grounded theory (n= 2), thematic analysis (n= 1), “qualitative analysis” (n= 3), “descriptive phenomenological approach” (n=1), phenomenological framework (n=1), content analysis (n=1) and hermeneutic approach (n=1). The experiences of 210 adolescents were explored across the 10 included studies. Over half of the relevant studies collected data from participants within the United States (n= 6), with data from participants in Ireland (n=1), Finland (n= 1), Sweden (n=1) and Turkey (n= 1) also included. Ethnicity of participants varied, with three studies reporting a Caucasian/white participant sample and three including a majority Hispanic and Latino population sample. Four studies did not report the ethnicity of their participants. The full characteristics of the included studies can be found in Table 5.

Table 5. Characteristics of studies included for synthesis.

Author	Location	Sample Size	Sample characteristics (age, sex/gender, race/ethnicity)	Method of data collection	Methodology	Aim
Babler & Strickland (2015)	United States	n= 11	Age 11-15 years (M=13.9) Girls (n=8) Boys (n=3) Caucasian (n=11)	15 interviews and 1 focus group.	Grounded theory (Glaser & Strauss, 2017).	To gain a greater understanding of adolescents' experiences living with diabetes and build a theoretical paradigm to inform interventional design.
Burke & Dowling (2007)	Ireland	n= 5	Age 13-18 years Sex/Gender not reported Ethnicity not reported	Unstructured recorded interviews.	'Descriptive Phenomenological Approach.' Colaizzi's (1978) seven procedural steps used for data analysis.	To describe the "essence" of living with diabetes in adolescence.
Carroll & Marrero (2006)	United States	n= 31	Age 13-18 years (M=14.9) Female (n=13) Male (n=18) White American (n=28) African America (n=3)	5 focus groups.	'Qualitative analysis'. Determining conceptual themes and developing thematic constructs.	To explore adolescents with T1DM perceptions of how having diabetes influences their perceptions of quality of life in general and their relationships with the 4 main social influences that contribute to both social development and their therapeutic lives: parents, peers, school, and their physician.

Commissariat et al. (2016)	United States	n= 40	Mean Age 16.5 years Female (n=19) Male (n=21) African-American/Black (n=7) Caucasian/White (n=11) Asian (n=1) Hispanic/Latino (n=21)	Guided interviews.	Thematic Analysis (Braun & Clarke, 2006).	The purpose of the current study was to explore adolescent personal and social identity development in relation to T1DM.
Dickinson & O'Reilly (2004)	United States	n= 10	Age 16-17 years Female (n=10) Caucasian (n=10)	Face to face unstructured interviews.	Van Manen's Phenomonological Framework (Van Manen, 2016).	The aim of the study was to make visible a comprehensive understanding of what it means for adolescent females to live with type 1 diabetes and to describe what that experience is like.
Joiner et al. (2020)	United States	n= 24	Age 12-19 years (M=15.4) Female (n=13) Male (n= 11) Latino (n=24)	Joint interviews with adolescents and parents.	'Qualitative descriptive approach & analysis'.	The purpose of this study was to explore the perceptions and experiences of Latino adolescents with T1DM and parents with LEP (Limited English Proficiency).
Kyngas & Barlow (1995)	Finland	n= 51	Age 13-17 years (M=15.1) Girls (n=23) Boys (n=28) Ethnicity not reported	Interviews.	Grounded Theory (Glaser & Strauss, 2017).	The purpose of this exploratory study was to examine the personal meaning and perceived impact of diabetes amongst adolescents aged between 13 and 17 years This qualitative data analysis was conducted to address the following questions (a) What is the meaning of diabetes for adolescents' (b) What impact does diabetes have on their lives'.

Pinar & Turan (2022)	Turkey	n= 19	Age 12-18 years Girls (n=14) Boys (n=5) Ethnicity not reported	Interviews.	Content Analysis.	This qualitative study of phenomenological type was conducted to determine how Type 1 diabetes affect the lives of adolescents.
Reitblat et al. (2016)	United States	n= 9	Age 12-17 years (M=13.7) Female (n=5) Male (n=4) Caucasian (n=6) Hispanic (n=1)	Interviews.	Qualitative analysis - Thorne's interpretive description technique (Thorne, 2008).	The purpose of this study was to describe the experience of Hispanic adolescents with T1DM from the perspective of adolescents and, secondarily, their diabetes clinicians.
Rising Holström & Söderberg (2022)	Sweden	n= 10	Age 13-18 years Female (n=7) Male (n=3) Ethnicity not reported	Open-ended qualitative interviews.	Hermeneutic approach inspired by Gadamer's philosophy (Fleming et al., 2003).	The aim of this study was to explore and elucidate the lived experiences of young people living with T1D in everyday life and school in Sweden.

3.2. Synthesised findings.

From the thematic analysis of the 10 included papers, four main themes were devised along with a number of sub-themes, as shown in Table 6. The four overarching themes were: 1) Diabetes is exhausting and overwhelming, 2) Nothing is untouched by diabetes, 3) I will always be different because of diabetes and 4) Ways of coping with the burden of diabetes. All themes were evidenced in at least 60% of the included papers. This suggested the themes were translatable across studies and relevant for inclusion in this meta-synthesis.

Table 6. Themes and sub-themes across included papers.

Author	Diabetes is exhausting	Nothing untouched by diabetes				Always different because of diabetes		Ways of coping	
		School	Friends	Autonomy/ Independence	Tied to parents	Responsibility	Feeling different	Practical versus emotional strategies	Acceptance
Babler & Strickland (2015)	✓		✓	✓	✓	✓	✓	✓	✓
Burke & Dowling (2007)	✓	✓	✓	✓	✓		✓	✓	✓
Carroll & Marrero (2006)	✓	✓	✓	✓	✓	✓	✓	✓	✓
Commissariat et al. (2016)	✓		✓	✓	✓	✓	✓	✓	✓
Dickinson & O'Reilly (2004)	✓	✓	✓	✓	✓	✓	✓	✓	✓
Joiner et al. (2020)	✓	✓	✓	✓	✓	✓	✓		✓
Kyngas & Barlow (1995)	✓			✓	✓		✓	✓	✓
Pinar & Turan (2022)	✓	✓	✓	✓	✓		✓	✓	✓
Reitblat et al. (2016)	✓	✓		✓	✓		✓	✓	✓
Rising Holström & Söderberg (2022)	✓	✓	✓	✓	✓	✓	✓	✓	✓

1) Diabetes is exhausting and overwhelming.

All 10 papers referenced battling the physical and emotional demands of life with diabetes. Adolescents described in detail the disruption it caused to their lives and the multiple, repeated stresses they felt every day.

Adolescents described the impact of living with an unrelenting and unavoidable treatment regime (Babler & Strickland, 2015, Burke & Dowling, 2007; Carroll & Marrero, 2006; Commissariat et al., 2016; Dickinson & O'Reilly, 2004; Joiner et al., 2020; Pinar & Turan, 2022; Reitblat et al., 2016; Rising Holström & Söderberg, 2022). Managing T1DM involved constant attendance to their blood sugars, watching and waiting for any changes. For some adolescents, this left them in a state of hypervigilance, always on the lookout for changes in their body or blood sugar levels. Adolescents felt tense, on edge, and were left feeling physically and mentally exhausted by the need to be constantly attuned to their body and prepared to act. Adolescents were required to plan for and act on every decision to eat, drink or be active to ensure their blood sugars were appropriately managed. They reflected on how the most normal activities of living were made more difficult and were frustrated by always having to accommodate for diabetes. For some, the freedom they felt they deserved as they grew older and witnessed their peers having, felt unobtainable due to the demands of T1DM.

"I need to check my blood, my sugar, I need to put in insulin. Just like all that, like I need to do that every day [sighs]. It really bothers me." (Joiner et al., 2020).

"Sometimes it is kind of hard, you just have those days where like it seems like everything is harder than it really is, basically when you have diabetes it's like you just want to give up." (Babler & Strickland, 2015).

Alongside the physical exhaustion from the daily demands of managing T1DM, adolescents described experiencing multiple negative emotions, resulting in feeling stressed and overwhelmed (Babler & Strickland, 2015; Burke & Dowling, 2007; Dickinson & O'Reilly, 2004; Joiner et al., 2020; Kyngas & Barlow, 1995; Pinar & Turan, 2022; Rising Holström & Söderberg, 2022). Some adolescents experienced fear at aspects of their treatment such as needle phobia, creating a significant barrier to treatment adherence and causing upset and anxiety multiple times a day. Others reported fear of hypoglycaemia (low blood sugar) and its consequences (passing out, even death) which drove some adolescents to maintain elevated blood glucose levels or over-correct. These compensatory behaviours not only maintain anxiety but also increase the risk of hyperglycaemic complications. Whilst some adolescents did not experience such high levels of fear, general worry about health and future complications was a common affective experience. Many adolescents described constant worry about ability to control their blood sugars and whether they could manage this in the future. Adolescents also worried T1DM would get in the way of being able to live a 'normal' life like their peers.

"This IS terrible, I do not know what will happen in the future. Diabetes is a real stress.

What kind of job will I get, what about my schooling and my health." (Kyngas & Barlow, 1995).

Many emotional responses to T1DM rose from a desire to minimise standing out from their peers and avoid drawing any unwanted comments or criticisms (Commissariat et al., 2016; Dickinson & O'Reilly, 2004; Joiner et al., 2020; Kyngas & Barlow, 1995, Pinar & Turan, 2022; Reitblat et al., 2016; Rising Holström & Söderberg, 2022). Adolescents reported feeling embarrassed about their treatment such as injecting insulin in public or around their peers.

For some this stemmed from previous experiences where others had questioned their actions or made stigmatising comments. The embarrassment and worry about other's reactions led some adolescents to not disclose their diabetes to avoid social judgements.

For some adolescents, T1DM was something they felt ashamed of. If their blood glucose levels were 'bad' then this was seen as a reflection of them as a person. Combined with fear of criticism or judgement from others, adolescents tried to keep T1DM a secret by not disclosing to others about their condition or administering treatments in private. Some adolescents tried to shield themselves from shame by disengaging from their diabetes management altogether, which was a common occurrence as noted in theme four.

"I don't tell them right away because I feel like they're going to look at me a certain way and think I'm special . . . needs." (Reitblat et al., 2016).

"I've been told so many times by adults, people I don't know at all, it's your own fault you got diabetes; you eat a lot of sweets.... At first, I just got sad, now I get angry..." (Rising Holström & Söderberg, 2022).

2) Nothing is untouched by diabetes.

Adolescents found it impossible to escape the impact of T1DM on all aspects of their life. Nothing was 'safe' from diabetes and adolescents were frustrated at the disruption to important parts of their life, such as autonomy and friendships.

Disrupted school experience.

T1DM significantly disrupted school experience with lessons missed due to feeling unwell or needing to administer insulin. For some adolescents, worry about missing lessons led to avoiding or delaying treatment at school. The opinions of and responses from classmates and peers at school had a big influence on ability to manage T1DM. Some adolescents worried others would think they were using T1DM as an excuse to miss lessons, which contributed to avoiding treatment. On the other hand, as discussed below, where peer relationships were supportive, adolescents felt more confident in managing their diabetes publicly in school (Carroll & Marrero, 2006; Joiner et al., 2020; Pinar & Turan, 2022; Rising Holström & Söderberg, 2022).

Supportive relationships with staff, as well as friends at school, were crucial. Positive relationships helped share the burden of diabetes care, whilst negative reactions made managing T1DM at school more difficult. Some adolescents described scrutiny and constant questioning from teachers about using phones to scan blood sugars or needing to leave early before lunch. Adolescents felt this reflected a lack of understanding about T1DM and often felt unsupported and uncared for at school. This was frustrating for adolescents who were treated differently by teachers and by friends, as discussed below (Burke & Dowling, 2007; Carroll & Marrero, 2006; Dickinson & O'Reilly, 2004; Joiner et al., 2020; Reitblat et al., 2016; Rising Holström & Söderberg, 2022).

“Sometimes when I'm in school, I go into internal conflict. Do I want to leave... the classroom? And then spend half an hour in the nurse's office when I can spend half an hour in the classroom.” (Joiner et al., 2020).

Changed peer relationships.

Many adolescents found that, despite initial reservations and fears about judgement and stigma, disclosing T1DM to friends was generally a positive experience (Babler & Strickland, 2015; Burke & Dowling, 2007; Carroll & Marrero, 2006; Commissariat et al., 2016; Dickinson & O'Reilly, 2004; Joiner et al., 2020; Pinar & Turan, 2022, Rising Holström & Söderberg, 2022). Many peers were accepting, understanding and open to learning about diabetes to support them. This allowed the adolescent to share some of the burden of managing T1DM with friends, who offered reminders to check blood sugars or supported them with treatment. This was particularly helpful at school when young people were more responsible for treatment in the absence of parents or staff support. Acceptance from friends made adolescents feel less alone and reduced a sense of difference from others, which was a prominent theme in this meta-synthesis.

“My friend told me, ‘Hey, you know, you have to take care of yourself, bro.’” (Joiner et al., 2020).

Other teenagers, however, reported negative changes in peer relationships following disclosure (Carroll & Marrero, 2006; Commissariat et al., 2016; Dickinson & O'Reilly, 2004; Pinar & Turan, 2022). Friends became over-bearing and over-involved in their diabetes, acting more like a parent than a friend. This frustrated adolescents who just wanted to be treated like any other teenager and increased a sense of difference between them and their peers. Other friends lacked understanding of diabetes and made ignorant or uninformed comments about T1DM, leading to feelings of shame about their health and feeling isolated from important people in their life.

“I swear it’s like I have 3 or 4 mothers, and they are all like, ‘Did you test yourself, you can’t eat that, that’s too much sugar.’ I’m like, ‘Oh my goodness. I left home to hang out with you guys to get away from my mom and you’re acting like her.’” (Commissariat et al., 2016).

Tethered to parents.

Relationships with parents and peers were markedly different. Whilst adolescents welcomed support from friends, many found this same help from parents to stifle their independence. T1DM tied them to their parents and often led to conflict (Babler & Strickland, 2015; Carroll & Marrero, 2006; Commissariat et al., 2016; Dickinson & O’Reilly, 2004; Joiner et al., 2020; Kyngas & Barlow, 1995; Pinar & Turan, 2022; Reitblat et al., 2016). Parents were described as over-concerned and over-protective and using ‘controlling’ and ‘intrusive’ behaviours such as constantly monitoring the adolescent and restricting their freedom. Some perceived this as a lack of trust from parents and resulted in resentment. Adolescents felt all their relationships, whether at school, with friends or with parents, were different to other teenagers at a time when fitting in was most important.

“They would probably like check [my blood glucose] every 5 minutes. . . . I wouldn’t leave their sight. . . . They would like probably check my sugar for me instead of like me doing it.” (Reitblat et al., 2016).

Some adolescents felt T1DM strengthened relationships with parents. They recognised their over-protection came from a place of care about their health, which

facilitated acceptance of their involvement. Diabetes was understood as impacting the whole family, not just the adolescent and by working together, the burden of T1DM could be shared (Burke & Dowling, 2007; Carroll & Marrero, 2006; Commissariat et al., 2016; Dickinson & O'Reilly, 2004; Joiner et al., 2020; Reitblat et al., 2016; Rising Holström & Söderberg, 2022).

“They have always been behind me and very supportive... All they really do is ask, though, they don't nag. They just want to make sure that I am doing what I am supposed to do.” (Carroll & Marrero, 2006).

Lack of independence and autonomy.

Adolescents perceived T1DM as preventing them from living a 'normal' teenage life by altering relationships with parents and friends and disrupting schooling (Babler & Strickland, 2015; Burke & Dowling, 2007; Carroll & Marrero, 2007; Dickinson & O'Reilly, 2004; Joiner et al., 2020; Kyngas & Barlow, 1995; Pinar & Turan, 2022; Reitblat et al., 2016; Rising Holström & Söderberg, 2022). Maintaining a healthy diet was difficult, particularly in the presence of peers where socialising often centred around food, and later on, alcohol. Adolescents felt their diets were restricted and experienced guilt at indulging in 'bad' foods for their diabetes. T1DM also hindered exercise and for some adolescents the effort involved in managing their blood sugars for this led to complete avoidance. Activities with friends were constantly evaluated against the costs to their diabetes, reducing opportunities for spontaneity. As adolescents aged, decisions regarding holidays, learning to drive, and even future careers was dictated by T1DM. At a time when young people were striving to develop autonomy, many felt T1DM left them with little agency over their lives.

“It's hard because at a party everyone's having fun. And I'm having fun too. But they're eating certain things... I know I can't be eating that constantly cause it's going to affect my blood sugars.” (Joiner et al., 2020).

3) I will always be different because of diabetes.

Feeling different from other teenagers was a recurrent theme throughout this meta-synthesis. Young people felt their teenage years were blighted by T1DM and did not have the same experiences as their peers (Babler & Strickland, 2015; Carroll & Marrero, 2006; Commissariat et al., 2016; Joiner et al., 2020; Kyngas & Barlow, 1995; Pinar & Turan, 2022; Rising Holström & Söderberg, 2022).

“My life is a prison, separated from other people's lives” (Kyngas & Barlow, 1995).

Increased pressures of responsibility.

T1DM brought increased responsibility that was not asked for and their peers did not have (Babler & Strickland, 2015; Carroll & Marrero, 2006; Commissariat et al., 2016; Dickinson & O'Reilly, 2004; Joiner et al., 2020; Reitblat et al., 2016; Rising Holström & Söderberg, 2022). The pressure to manage T1DM and avoid life-threatening complications was overwhelming for some adolescents. This led some to relinquish responsibility for management to parents, even if it reduced their independence. Other adolescents felt others in their lives such as teachers or friends did not understand and could not be relied upon and so took on sole responsibility. Many adolescents felt alone in carrying the weight of responsibility for their health at a young age, especially when their peers were not experiencing the same.

“I’m more mature about it because I realize I have to take care of myself and if I don’t, it’s not like it’s going to go away. It’s going to be there until there’s a cure, so I have to make sure I keep myself healthy.” (Commissariat et al., 2016).

Feeling different.

For young people with T1DM, as diabetes touched all parts of their life as described in theme two, their teenage years were felt to be completely different from others. The burden of responsibility for T1DM not always being well understood by others often increased feelings of isolation (Babler & Strickland, 2015; Burke & Dowling, 2007; Commissariat et al., 2016; Dickinson & O’Reilly, 2004; Joiner et al., 2020; Kyngas & Barlow, 1995; Pinar & Turan, 2022; Rising Holström & Söderberg, 2022). T1DM treatment is invasive, difficult to hide, and marked adolescents as visibly different. Even attempts to manage this discretely still made them stand out. Whether adolescents chose to formally disclose their T1DM or not, its visibility highlighted them as different from their peers.

Some young people found their whole identity was consumed by diabetes. All life choices were influenced by T1DM, regardless of their preferences or wishes. This further widened the gap between themselves and other adolescents who were exploring their interests and developing their individual identity (Carroll & Marrero, 2006; Dickinson & O’Reilly, 2004; Joiner et al., 2020; Kyngas & Barlow, 1995; Reitblat et al., 2016).

“I just feel different, and I feel like I have to do more than other people and that frustrates me a lot . . . So I feel like it’s extra weight and extra work and why do I have to do extra work?” (Commissariat et al., 2016).

4) Ways of coping with the burden of diabetes.

Practical versus emotional strategies.

Living with T1DM as a teenager was associated with many challenges and considerable stress. Strategies to cope with this were highly variable. Some relied on practical ways of coping such as implementing a strict routine, which improved adherence, blood sugar levels, and importantly, reduced disruption to daily life. However, for some adolescents, sticking to a rigid routine was difficult and further increased feelings of guilt and shame if this was broken (Commissariat et al., 2016; Pinar & Turan, 2022). Use of technology such as a continuous glucose monitor was helpful for many adolescents as it reduced the need to always be monitoring levels and allowed young people to be more independent in managing T1DM (Babler & Strickland, 2015; Dickinson & O'Reilly, 2004; Reitblat et al., 2016; Rising Holström & Söderberg, 2022).

“I've got a wireless CGM (continuous glucose meter) that I manage myself as well as a pump— it's so good, so much more freedom” (Rising Holström & Söderberg, 2022).

For some adolescents, the threat felt from trying to manage the demands of diabetes resulted in avoidance and disengagement from anything related to T1DM (Burke & Dowling, 2007; Carroll & Marrero, 2006; Commissariat et al., 2016; Dickinson & O'Reilly, 2004; Kyngas & Barlow, 1995). Delaying treatment, putting off or not checking blood sugars at all were common. These strategies were typically motivated by attempts to avoid feelings of embarrassment, shame, and worry attached to their diabetes. Some adolescents feared parental responses to blood sugar levels and avoided checking to prevent conflict or

punishment. Lying often functioned as a strategy to avoid questioning from parents and became a normal response over time.

“We gotta stop, you gotta go check yourself.” Nah, I’m just going to keep doing this, and then I’ll check myself [later].” (Commissariat et al., 2016).

A process of acceptance.

For many adolescents, the ability to cope with T1DM involved a process of acceptance (Babler & Strickland, 2015; Burke & Dowling, 2007; Carroll & Marrero, 2006; Commissariat et al., 2016; Dickinson & O’Reilly, 2004; Joiner et al., 2020; Kyngas & Barlow, 1995; Pinar & Turan, 2022; Reitblat et al., 2016; Rising Holström & Söderberg, 2022). This meant being able to accept T1DM as part of them but not their whole self, which reduced feeling different from peers. By accepting the presence of T1DM in their lives it helped lessen the struggle against it, which reduced feelings of stress and threat. T1DM became incorporated into their ‘normal’ life and young people felt better able to engage in their activities and relationships that mattered to them.

Acceptance was described as a journey and developed slowly over time. It didn’t always follow a linear path and there were times where acceptance was easier than others. When T1DM was seen as conflicting with important areas of their life, adolescents were more resistant to its presence. Acceptance was facilitated by relationships with peers who were non-judgemental and supportive of the impact of diabetes and what needs to be done to manage it. Acknowledging the young person as more than just their diabetes and drawing out common interests and experiences with other adolescents also helped reduce feelings of difference, making T1DM easier to accept.

“It [diabetes] is there, it will never go, but it is just how much you let it get to you is just the key to it, it never goes away it is always a part of you, until you just accept it, it is always just there.” (Babler & Strickland, 2015).

“I pay attention to it. But, after a while it is like when you are driving. You don't really concentrate on the driving because it becomes natural after a while. We don't have to concentrate on it [diabetes] anymore.” (Carroll & Marrero, 2006).

4. Discussion.

4.1. Aim of current systematic review.

This meta-synthesis aimed to explore the lived experience of adolescents with T1DM to improve understanding and consider implications for clinical practice, building upon previous research with children and adults. Ten qualitative papers were identified in this area and following the procedural steps outlined by Thomas and Harden (2008), four analytic themes were developed.

4.2. Meta-synthesis findings and relevance to wider literature.

The four themes were: 1) Diabetes is exhausting and overwhelming, 2) Nothing is untouched by diabetes, 3) I will always be different because of diabetes, and 4) Ways of coping with the burden of diabetes. Across themes, there were recurrent experiences of feeling different from peers due to T1DM and struggles to manage the impact of it on every aspect of their life. This may go some way to explaining why health outcomes for T1DM worsen during adolescence.

T1DM was associated with multiple negative affective experiences for young people, including embarrassment, fear, worry, and shame. The unrelenting demands of treatment and the disruptions it caused were frustrating and upsetting. These feelings built up over time with adolescents reporting a pervasive feeling of overwhelming stress at the “hell” of life with T1DM (Kyngas & Barlow, 1995). Though not explicitly named in the papers reviewed, these experiences reflect descriptions of diabetes distress. DD describes the negative affective experiences resulting from living with and managing T1DM (Polonsky et al., 1995). Alongside general distress, DD includes experiences of low mood, fear, and worry (Fisher et al., 2014). Fear and worry about their health and future are the most common reported sources of DD (Sturt et al., 2015). High DD is associated with greater likelihood of experiencing low mood in children and adolescents (Powers et al., 2016) and has been linked to higher HbA1c levels and poorer self-management in adults (Hessler et al., 2017). This can create a vicious cycle where poorly controlled blood sugars increase DD. Research by Hagger (2016) found experiences of DD in adolescents were exacerbated by conflict with parents including over-involvement in T1DM treatment. This corresponds with the findings of this meta-synthesis with many adolescents feeling frustrated and resentful towards parents involved in their T1DM care.

Some adolescents attempted to reduce DD through proactive problem-focused strategies such as implementing routines. Research has shown adaptive coping strategies such as problem-solving are related to lower HbA1c levels and improved quality of life in adolescents with T1DM (Jaser & White, 2011). A large proportion of adolescents, however, described disengagement coping strategies, distancing themselves from the source of stress (T1DM) or associated responses (negative emotions) to the stressor (Connor-Smith et al., 2000). Many adolescents put off or delayed checking their blood sugars, with some ignoring their diabetes needs altogether to prevent feelings of embarrassment, worry or shame.

Attempting to avoid or control negative emotional experiences is known as experiential avoidance (Hayes et al., 2004). Some young people also lied to others about their diabetes treatment to deflect expected criticism. The Shielding Against Shame model (Hughes & Golding, 2012) suggests individuals may lie, minimise situations, or blame others to protect against experiencing intolerable feelings of shame. While distancing oneself from T1DM through avoidance or lying may provide short-term relief from negative affective experiences, it can have significant health impacts. Maladaptive coping styles have been associated with poorer metabolic control in children (Grey et al., 1997) as well as depressive symptoms in adults with T1DM (Clarke & Goosen, 2009). These unhelpful coping styles may also explain why attendance at diabetes clinics significantly drops when adolescents transition to adult services (Hanna & Woodward, 2013) as they are not made to engage in their care by parents. DD and subsequent disengagement from T1DM and its treatment was a common thread throughout this meta-synthesis for adolescents and can have significant health consequences if not addressed.

Feeling different was a prevalent theme throughout this meta-synthesis and was magnified by the way that every aspect of adolescents' lives was impacted by T1DM. The unrelenting treatment regime disrupted their daily lives and drew attention to them and made them stand out. Many adolescents described changed relationships as a result of diabetes and were left feeling lonely and isolated as others did not truly understand their experience.

Adolescence is considered a critical period in which identity formation occurs and a search for purpose in life takes place (Erikson, 1968; Hill & Burrow, 2012). Each developmental stage is a time of vulnerability, but also potential growth if one can resolve the 'crisis' or conflict of that stage (Sokol, 2009). The developmental task of adolescence is seen as identity

development where, through social interactions, beliefs, values, and goals are established (Eccles & Roeser, 2011; Ragelienė, 2016). Adolescents that successfully resolve the “identity vs role confusion” crisis (Erikson, 1950) emerge with a stable sense of who they are and their place in the world, which provides purpose moving forward into adulthood (Sokol, 2009). However, young people who do not achieve this can be left questioning who they are as a person and how they fit into the world around them. T1DM and the sense of difference associated with it may hinder identity formation in adolescence.

Peers are a very important source of normative information guiding identity development (Hansen & Jessop, 2017). In particular, ‘fitting in’ with those at school is very important, as this is where adolescents spend the majority of their time (Eccles & Roeser, 2011). Research has shown adolescents who perceive themselves as not fitting in with peers at school try to cope in counterproductive ways (Crosnoe, 2011) such as internalising the reason for social exclusion. In the case of T1DM, this may mean blaming diabetes as the cause of feeling different and rejecting it as part of their identity, which is associated with poorer treatment adherence and worse glycaemic control (Oris et al., 2016).

In addition, the ‘fit’ between adolescents with T1DM and their social peers was widened by the “over-bearing and over-protective” involvement of their parents. Research has shown that families of adolescents with T1DM tend to become highly structured and controlled in response to the demands of diabetes, but this can come at the expense of development of independence for young people (Seiffge-Krenke, 1998). Seeking independence is a typical developmental goal for adolescents (Sanders, 2013) but T1DM was seen as inhibiting this for young people as they found themselves unable to make choices like their peers. This led to feelings of resentment and conflict with parents within this meta-synthesis, which has been linked to poorer treatment adherence and worse metabolic control

within the literature (Miller-Johnson et al., 1994). Research has suggested that better metabolic control in adolescence is not necessarily associated with functioning independently to manage T1DM, but with independence in decision making (Hanna & Guthrie, 2003). As reflected within this meta-synthesis, adolescents were accepting of parental involvement to share the burden of T1DM when they had autonomy to make this decision for themselves. This is supported by findings that young people with T1DM have better outcomes, including adherence, metabolic control, and reduced depression when their parents have a more collaborative approach (Wysocki et al., 2008). It is clear that T1DM can lead to dysfunctional family relationships, impacting on adolescents' development of independence and fitting in with peers. This may explain the disengagement from treatment and poorer metabolic outcomes for adolescents during this time and is a clear area for support from healthcare services.

Accepting diabetes as part of one's identity helped to reduce feelings of being different amongst adolescents in this meta-synthesis. Acceptance, defined as "recognizing the need to adapt to chronic illness while perceiving the ability to tolerate the unpredictable, uncontrollable nature of the disease and handle its averse consequences" (Evers et al., 2001, p. 1027), is related to better treatment adherence and improved quality of life (Jaser & White, 2011). It has also been linked to better emotional wellbeing including reduced anxiety, depression, and distress alongside improved functional outcomes in individuals with chronic illness (Casier et al., 2011; McCracken & Zhao-O'Brien, 2010). Similar reflections were captured within this meta-synthesis - accepting diabetes reduced the struggle against it and adolescents were better able to focus on other important areas in their lives.

There were many commonalities between the lived experience of adolescents with T1DM and those with chronic illness more generally (Shorey & Ng, 2020). Regardless of

specific diagnosis, perceiving illness as a burden and struggling to balance 'normal' teenage life with the demands of a health condition appear universal themes. This similarity across research may allow for generalisations and adaptations of effective interventions from other health conditions to T1DM. Experiences in childhood also continued into adolescence with both children and young people describing frustration at the disruption to daily life caused by T1DM (Rankin et al., 2017). Both reviews found that, whilst peer support could be positive, at times this was unhelpful for the young person, and they found themselves treated differently due to their health condition.

4.3. Implications for clinical practice.

Diabetes distress was evident in the lived experience of adolescents with T1DM. Adolescents described feelings of shame, fear, and embarrassment about living with a visible health condition that had a detrimental impact on their everyday lives. Many adolescents tried to cope with DD through distancing themselves from T1DM and its treatments in order to avoid these feelings. This may go some way to explaining why health outcomes, such as metabolic control, significantly worsen during adolescence. Considering the known negative impact DD can have on physical and emotional wellbeing (Hessler et al., 2017; Powers et al., 2016), it is of utmost importance that diabetes healthcare services are aware of the predominance of DD amongst adolescents and proactively assessing for it with the young people they support. This will allow for the appropriate support to be put in place for the young person to help them manage the physical and emotional demands of treatment at a challenging time of life for them. This is not a difficult change in healthcare practice and Diabetes UK (2019a) has outlined a "7 Areas" model to support healthcare professionals to work with DD. The full model can be found in Appendix D, but the important components are considered here.

Firstly, teams need to be aware that DD is common in adolescents and to assess using appropriate tools as part of standard practice. The Problem Areas in Diabetes Scale (PAID) is one such screening instrument with good psychometric properties and has been adapted for use with adolescents (Weissberg-Benchell & Antisdel-Lomaglio, 2011). Compassionately asking about young people's experiences of DD can help to normalise their feelings and reduce feelings of difference (Gonzalez et al., 2011; Balfe et al., 2013). The 7 Areas model also suggests pathways for supporting individuals with DD including providing advice or assisting with collaborative development of an action plan. Some adolescents may require support from another healthcare professional, such as a clinical psychologist with experience of working with health conditions (NICE, 2015). Healthcare teams should continue to follow up with the young person about their DD, understanding it may fluctuate with development as the pressures of adolescence change. Despite the simplicity of this model, many individuals with T1DM report that they are not asked about their feelings of living with diabetes (Diabetes UK, 2019b). This highlights the lack of awareness currently held about DD, which this meta-synthesis has shown to be widespread amongst adolescents and related to maladaptive ways of coping. Healthcare professionals should be continually holding in mind that the adolescents with T1DM they are supporting are likely to be experiencing DD and need to be assessing for it in order to provide appropriate care for both their physical health needs and emotional wellbeing.

Another implication of the current review is that non-adherence among adolescents with T1DM can be a reflection of emotional struggles. For many adolescents, the experience of shame, fear and worry were so toxic and overbearing that they tried to avoid these feelings by disengaging from thinking about T1DM or engaging in treatment. Therefore, healthcare professionals must be alert to the potential psychological and emotional underpinnings of

treatment non-adherence such as shame, worry, and avoidance rather than categorising adolescents as “difficult” or “challenging”. By holding an understanding that young people are simply trying to cope with high levels of distress through avoidance, it highlights the importance of services responding compassionately and empathetically to adolescents with T1DM. Experiencing criticism or punitive responses from healthcare professionals about their non-adherence to treatment may further compound feelings of shame and fear which could exacerbate attempts to reject T1DM, causing a vicious cycle. Healthcare professionals should continually hold in mind how a young person’s “non-adherence” might reflect unhelpful attempts to deal with distress and feeling different and should be helping young people to find more adaptive ways to cope rather than blaming or shaming them. Responding to distress with acceptance and empathy increases the likelihood of relational safety and that young people will feel more comfortable in discussing the difficulties they are experiencing in living with T1DM and help healthcare professionals to meet their needs.

Ways of managing experiential avoidance is also important for healthcare services. Acceptance and Commitment Therapy (ACT) suggests the counterpoint to avoidance is acceptance of uncomfortable feelings, thoughts, and sensations without trying to control or change them (Hayes et al., 2006). ACT has been shown to improve outcomes across several chronic health conditions (Lundgren et al., 2006; Nordin & Rorsman, 2012). Whilst the number of high-quality studies available are limited (Graham et al., 2016), there is some preliminary evidence that ACT can lead to improved glycaemic control and reduced anxiety for adolescents with T1DM (Alho et al., 2022). Kamody and colleagues (2017) also found T1DM adolescents who were high in psychological flexibility (the goal of ACT and includes ability to accept uncomfortable emotions) had lower levels of DD and reduced HbA1c levels. ACT has also been linked to reductions in shame and related distress (Luoma & Platt, 2015).

ACT may be a particularly feasible intervention for adolescents as discovering and working towards values are central to the model which corresponds to the developmental tasks of identity formation during this period (Hadlandsmyth et al., 2013). Use of acceptance-based approaches in diabetes healthcare services may help reduce emotional avoidance and associated unhelpful ways of coping, as well as improving physical health.

4.4. Strengths, limitations, and opportunities for future research.

Meta-synthesis is an approach dependent upon researcher interpretation and quality of included papers. Several processes were used to try and ensure methodological rigour, including adherence to PRISMA guidelines (Page et al., 2021) and an independent reviewer to improve inter-rater reliability of inclusion and exclusion criteria and quality appraisals. This systematic review also followed the procedural steps outlined by Thomas and Harden (2008) who explicitly describe the process from coding to developing analytic themes.

Several papers provided limited information on their chosen qualitative methodology and analysis, which may call into question the rigour of included studies. Only three acknowledged relationships between the researcher and participants; this lack of reflexivity leaves open the possibility of bias in interpretation. This was captured by quality appraisal using the CASP (2018) tool and NICE (2012) guidelines for systematic reviews. The majority were still considered to be of high quality, and all papers contributed to the analytic themes in some capacity. Removing the two papers of lower quality (Burke & Dowling, 2007; Pinar & Turan, 2022) was unlikely to have significantly altered the findings.

This meta-synthesis included 10 studies exploring the perceptions of over 200 adolescents with T1DM across five countries. Of those that reported ethnicity demographics, the majority of adolescents were white Caucasian with a smaller number of African-American

and Latino teenagers. There was little reference to the impact of cultural experiences in this systematic review and unique cultural nuances may have been lost due to the predominantly white Caucasian sample. Previous research has highlighted cultural differences in perceptions about taking insulin and managing T1DM across cultures (Rebolledo & Arellano, 2016). Further research may want to build on this meta-synthesis by exploring the lived experience of adolescents with T1DM in non-white and non-western cultures.

This systematic review was concerned with the experiences of adolescents, defined as ages 12-18. However, due to socioeconomic pressures, many transitions to adulthood are occurring at a much later date. Dependence on parents can continue well after 'traditional' adolescence ends and some research has suggested that need for support from parents may increase (Gillies et al., 2001). This has led to the term "emerging adulthood" to describe the developmental stage of 19-25 (Arnett, 2007). Individuals with T1DM in this stage have reported difficulties with identity development and wellbeing (Willemse et al., 2018), suggesting many of the struggles of adolescence may continue into later adult life. Considering the transition to adult services is a period of poor T1DM outcomes (Hanna & Woodward, 2013), future research may want to explore the experiences of emerging adults to better understand their needs and provide appropriate support.

4.5. Conclusion.

This systematic review synthesised the lived experience of adolescents with T1DM, which was marked by distress and feeling different. T1DM was a significant emotional burden that many adolescents tried to cope with by avoiding or disengaging from treatment. Accepting T1DM as part of oneself allowed for development of more helpful ways of coping. Healthcare professionals need to be aware of the distress adolescents may experience due to diabetes

and the ways in which they try to cope. Acceptance-based approaches may have a positive impact though further research is needed in this area. Finally, there is a need to explore the lived experience of adolescents in diverse cultures and in emerging adulthood in order to provide holistic support across the lifespan.

References.

- Alho, I., Lappalainen, P., Muotka, J., & Lappalainen, R. (2022). Acceptance and commitment therapy group intervention for adolescents with type 1 diabetes: A randomized controlled trial. *Journal of Contextual Behavioral Science*, 25, 153–161. <https://doi.org/10.1016/j.jcbs.2022.08.002>
- Andrews, J. R., Foulkes, L., Bone, J. K., & Blakemore, S. (2020). Amplified Concern for Social Risk in Adolescence: Development and Validation of a New Measure. *Brain Sciences*, 10(6), 397. <https://doi.org/10.3390/brainsci10060397>
- Arnett, J. J. (2007). Emerging Adulthood: What Is It, and What Is It Good For? *Child Development Perspectives*, 1(2), 68–73. <https://doi.org/10.1111/j.1750-8606.2007.00016.x>
- Babler, E., & Strickland, C. J. (2015). Normalizing: adolescent experiences living with type 1 diabetes. *The diabetes educator*, 41(3), 351-360. <https://doi.org/10.1177/0145721715579108>
- Balfe, M., Doyle, F., Smith, D., Sreenan, S., Brugha, R., Hevey, D., & Conroy, R. (2013). What's distressing about having type 1 diabetes? A qualitative study of young adults' perspectives. *BMC endocrine disorders*, 13, 1-14. <https://doi.org/10.1186/1472-6823-13-25>
- Borus, J., & Laffel, L. M. (2010). Adherence challenges in the management of type 1 diabetes in adolescents: prevention and intervention. *Current Opinion in Pediatrics*, 22(4), 405–411. <https://doi.org/10.1097/mop.0b013e32833a46a7>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>

- Bryden, K. S., Dunger, D. B., Mayou, R. A., Peveler, R. C., & Neil, H. A. W. (2003). Poor prognosis of young adults with type 1 diabetes: a longitudinal study. *Diabetes care, 26*(4), 1052-1057. <https://doi.org/10.2337/diacare.26.4.1052>
- Buchberger, B., Huppertz, H., Krabbe, L., Lux, B., Mattivi, J. T., & Siafarikas, A. (2016). Symptoms of depression and anxiety in youth with type 1 diabetes: A systematic review and meta-analysis. *Psychoneuroendocrinology, 70*, 70–84. <https://doi.org/10.1016/j.psyneuen.2016.04.019>
- Burke, H., & Dowling, M. (2007). Living with diabetes: Adolescents' perspectives. *Journal of Diabetes Nursing, 11*(3), 90-96. <https://link.gale.com/apps/doc/A163181826/AONE?u=anon~cb7fb6a2&sid=googleScholar&xid=3ed7dc95>
- Carroll, A. E., & Marrero, D. G. (2006). The Role of Significant Others in Adolescent Diabetes: A Qualitative Study. *The Diabetes Educator, 32*(2), 243–252. <https://doi.org/10.1177/0145721706286893>
- Carroll, N. C., & Vittrup, B. (2020). Type 1 Diabetes in Adolescence: Considerations for Mental Health Professionals. *Journal of Child and Adolescent Counseling, 6*(2), 137–148. <https://doi.org/10.1080/23727810.2020.1729010>
- Casier, A., Goubert, L., Theunis, M., Huse, D., De Baets, F., Matthys, D., & Crombez, G. (2011). Acceptance and Well-Being in Adolescents and Young Adults with Cystic Fibrosis: A Prospective Study. *Journal of Pediatric Psychology, 36*(4), 476–487. <https://doi.org/10.1093/jpepsy/jsq111>
- Cemeroglu, A. P., Can, A., Davis, A. T., Cemeroglu, O., Kleis, L., Daniel, M. S., Bustraan, J., & Koehler, T. J. (2015). Fear of Needles in Children With Type 1 Diabetes Mellitus on

- Multiple Daily Injections and Continuous Subcutaneous Insulin Infusion. *Endocrine Practice*, 21(1), 46–53. <https://doi.org/10.4158/ep14252.or>
- Chatterjee, S., Khunti, K., & Davies, M. J. (2017). Type 2 diabetes. *The Lancet*, 389(10085), 2239-2251. [https://doi.org/10.1016/S0140-6736\(17\)30058-2](https://doi.org/10.1016/S0140-6736(17)30058-2)
- Clarke, D., & Goosen, T. (2009). The mediating effects of coping strategies in the relationship between automatic negative thoughts and depression in a clinical sample of diabetes patients. *Personality and Individual Differences*, 46(4), 460–464. <https://doi.org/10.1016/j.paid.2008.11.014>
- Colaizzi, P. (1978). Psychological research as a phenomenologist views it. In: Valle, R. S. & King, M. (Eds.), *Existential Phenomenological Alternatives for Psychology* (pp. 48-71). Open University Press. <https://ci.nii.ac.jp/naid/10028127253>
- Commissariat, P. V., Kenowitz, J., Trast, J., Heptulla, R. A., & Gonzalez, J. S. (2016). Developing a Personal and Social Identity With Type 1 Diabetes During Adolescence. *Qualitative Health Research*, 26(5), 672–684. <https://doi.org/10.1177/1049732316628835>
- Connor-Smith, J. K., Compas, B. E., Wadsworth, M. E., Thomsen, A. H., & Saltzman, H. (2000). Responses to stress in adolescence: Measurement of coping and involuntary stress responses. *Journal of Consulting and Clinical Psychology*, 68(6), 976–992. <https://doi.org/10.1037/0022-006x.68.6.976>
- Critical Appraisal Skills Programme. (2018). *CASP Qualitative Checklist*. https://casp-uk.net/images/checklist/documents/CASP-Qualitative-Studies-Checklist/CASP-Qualitative-Checklist-2018_fillable_form.pdf

Crosnoe, R. (2011). *Fitting in, standing out: Navigating the social challenges of high school to get an education*. Cambridge University Press.

<https://doi.org/10.1017/CBO9780511793264>

Daneman, D. (2006). Type 1 diabetes. *The Lancet*, 367(9513), 847-858.

[https://doi.org/10.1016/S0140-6736\(06\)68341-4](https://doi.org/10.1016/S0140-6736(06)68341-4)

Diabetes UK. (2019). 7 As model – what is it and how does it work?

<https://www.diabetes.org.uk/professionals/resources/shared-practice/psychological-care/emotional-health-professionals-guide/7as>

Diabetes UK. (2019). *Too often missing: Making emotional and psychological support routine in diabetes care*. [https://www.diabetes.org.uk/resources-s3/2019-](https://www.diabetes.org.uk/resources-s3/2019-05/Full%20Report_Too%20Often%20Missing_Diabetes%20UK_May%202019.pdf)

[05/Full%20Report_Too%20Often%20Missing_Diabetes%20UK_May%202019.pdf](https://www.diabetes.org.uk/resources-s3/2019-05/Full%20Report_Too%20Often%20Missing_Diabetes%20UK_May%202019.pdf)

Dickinson, J. K., & O'Reilly, M. F. (2004). The Lived Experience of Adolescent Females With Type 1 Diabetes. *The Diabetes Educator*, 30(1), 99–107.

<https://doi.org/10.1177/014572170403000117>

Driscoll, K. A., Raymond, J. K., Naranjo, D., & Patton, S. R. (2016). Fear of Hypoglycemia in Children and Adolescents and Their Parents with Type 1 Diabetes. *Current Diabetes Reports*, 16(8). <https://doi.org/10.1007/s11892-016-0762-2>

<https://doi.org/10.1007/s11892-016-0762-2>

Due-Christensen, M., Zoffmann, V., Willaing, I., Hopkins, D., & Forbes, A. G. (2017). The Process of Adaptation Following a New Diagnosis of Type 1 Diabetes in Adulthood: A Meta-Synthesis. *Qualitative Health Research*, 28(2), 245–258.

<https://doi.org/10.1177/1049732317745100>

- Eccles, J. S., & Roeser, R. W. (2011). Schools as Developmental Contexts During Adolescence. *Journal of Research on Adolescence*, 21(1), 225–241. <https://doi.org/10.1111/j.1532-7795.2010.00725.x>
- Erikson, E. H. (1950). *Childhood and society*. WW Norton & Company.
- Erikson, E. H. (1968). *Identity youth and crisis*. WW Norton & Company.
- Evers, A. W. M., Kraaimaat, F. W., Van Lankveld, W., Jongen, P. J., Jacobs, J. W. G., & Bijlsma, J. W. J. (2001). Beyond unfavorable thinking: The Illness Cognition Questionnaire for chronic diseases. *Journal of Consulting and Clinical Psychology*, 69(6), 1026–1036. <https://doi.org/10.1037/0022-006x.69.6.1026>
- Farooqi, A., Gillies, C. L., Sathanapally, H., Abner, S. C., Seidu, S., Davies, M. J., Polonsky, W. H., & Khunti, K. (2022). A systematic review and meta-analysis to compare the prevalence of depression between people with and without Type 1 and Type 2 diabetes. *Primary Care Diabetes*, 16(1), 1–10. <https://doi.org/10.1016/j.pcd.2021.11.001>
- Ferguson, H. J., Brunsdon, V. E., & Bradford, E. E. (2021). The developmental trajectories of executive function from adolescence to old age. *Scientific Reports*, 11(1). <https://doi.org/10.1038/s41598-020-80866-1>
- Fisher, L., Gonzalez, J. S., & Polonsky, W. H. (2014). The confusing tale of depression and distress in patients with diabetes: a call for greater clarity and precision. *Diabetic Medicine*, 31(7), 764–772. <https://doi.org/10.1111/dme.12428>
- Fleming, V., Gaidys, U., & Robb, Y. (2003). Hermeneutic research in nursing: developing a Gadamerian-based research method. *Nursing Inquiry*, 10(2), 113–120. <https://doi.org/10.1046/j.1440-1800.2003.00163.x>

- Flemming, K., Booth, A., Garside, R., Tunçalp, Ö., & Noyes, J. (2019). Qualitative evidence synthesis for complex interventions and guideline development: clarification of the purpose, designs and relevant methods. *BMJ Global Health*, *4*(Suppl 1), e000882. <https://doi.org/10.1136/bmjgh-2018-000882>
- Fowler, M. (2008). Microvascular and Macrovascular Complications of Diabetes. *Clinical Diabetes*, *26*(2), 77–82. <https://doi.org/10.2337/diaclin.26.2.77>
- Gale, E. a. M. (2005). Type 1 diabetes in the young: the harvest of sorrow goes on. *Diabetologia*, *48*(8), 1435–1438. <https://doi.org/10.1007/s00125-005-1833-0>
- Gibb, F. W., Teoh, W. L., Graham, J. P., & Lockman, K. A. (2016). Risk of death following admission to a UK hospital with diabetic ketoacidosis. *Diabetologia*, *59*(10), 2082–2087. <https://doi.org/10.1007/s00125-016-4034-0>
- Gillies, V., McCarthy, J. R., & Holland, J. (2001). *Pulling together, pulling apart: the family lives of young people aged 16-18*. Family Policy Studies Centre / Joseph Rowntree Foundation. <http://oro.open.ac.uk/9020/>
- Glaser, B. G., & Strauss, A. L. (2017). *The discovery of grounded theory: Strategies for qualitative research*. Routledge.
- Goddard, G., & Oxlad, M. (2022). Insulin restriction or omission in Type 1 Diabetes Mellitus: a meta-synthesis of individuals' experiences of diabulimia. *Health Psychology Review*, *17*(2), 227–246. <https://doi.org/10.1080/17437199.2021.2025133>
- Goebel-Fabbri, A. (2009). Disturbed eating behaviors and eating disorders in type 1 diabetes: Clinical significance and treatment recommendations. *Current Diabetes Reports*, *9*(2), 133–139. <https://doi.org/10.1007/s11892-009-0023-8>

- Gonzalez, J. S., Fisher, L., & Polonsky, W. H. (2011). Depression in Diabetes: Have We Been Missing Something Important? *Diabetes Care*, *34*(1), 236–239.
<https://doi.org/10.2337/dc10-1970>
- Graham, C. D., Gouick, J., Krahé, C., & Gillanders, D. (2016). A systematic review of the use of Acceptance and Commitment Therapy (ACT) in chronic disease and long-term conditions. *Clinical Psychology Review*, *46*, 46–58.
<https://doi.org/10.1016/j.cpr.2016.04.009>
- Grey, M., Lipman, T. H., Cameron, M. M., & Thurber, F. W. (1997). Coping Behaviors at Diagnosis and in Adjustment One Year Later in Children With Diabetes. *Nursing Research*, *46*(6), 312–317. <https://doi.org/10.1097/00006199-199711000-00003>
- Hadlandsmyth, K., White, K. S., Nesin, A. E., & Greco, L. A. (2013). Proposing an Acceptance and Commitment Therapy intervention to promote improved diabetes management in adolescents: A treatment conceptualization. *International journal of behavioral consultation and therapy*, *7*(4), 12. <https://doi.org/10.1037/h0100960>
- Hagger, V., Speight, J., Sturt, J., & Skinner, T. (2016). Diabetes Distress Among Adolescents with Type 1 Diabetes: a Systematic Review. *Current Diabetes Reports*, *16*(1).
<https://doi.org/10.1007/s11892-015-0694-2>
- Hanna, K. M., & Guthrie, D. W. (2003). Adolescents' Behavioral Autonomy Related to Diabetes Management and Adolescent Activities/Rules. *The Diabetes Educator*, *29*(2), 283–291. <https://doi.org/10.1177/014572170302900219>
- Hanna, K. M., & Woodward, J. E. (2013). The Transition From Pediatric to Adult Diabetes Care Services. *Clinical Nurse Specialist*, *27*(3), 132–145.
<https://doi.org/10.1097/nur.0b013e31828c8372>

- Hansen, D. J., & Jessop, N. (2017). A Context for Self-Determination and Agency: Adolescent Developmental Theories. In *Springer eBooks* (pp. 27–46).
https://doi.org/10.1007/978-94-024-1042-6_3
- Hayes, S. J., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and Commitment Therapy: Model, processes and outcomes. *Behaviour Research and Therapy*, *44*(1), 1–25. <https://doi.org/10.1016/j.brat.2005.06.006>
- Hayes, S. C., Strosahl, K. D., Wilson, K. G., Bissett, R. T., Pistorello, J., Toarmino, D., Polusny, M. A., Dykstra, T. A., Batten, S. V., Bergan, J. J., Stewart, S. H., Zvolensky, M. J., Eifert, G. H., Bond, F. W., Forsyth, J. P., Karekla, M., & McCurry, S. M. (2004). Measuring experiential avoidance: A preliminary test of a working model. *Psychological Record*, *54*(4), 553–578. <https://doi.org/10.1007/bf03395492>
- Hessler, D., Fisher, L., Polonsky, W. H., Masharani, U., Strycker, L. A., Peters, A. L., Blumer, I., & Bowyer, V. (2017). Diabetes distress is linked with worsening diabetes management over time in adults with Type 1 diabetes. *Diabetic Medicine*, *34*(9), 1228–1234. <https://doi.org/10.1111/dme.13381>
- Hex, N., Bartlett, C. L. R., Wright, D., Taylor, M. J., & Varley, D. (2012). Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs. *Diabetic Medicine*, *29*(7), 855–862. <https://doi.org/10.1111/j.1464-5491.2012.03698.x>
- Hill, P. L., & Burrow, A. L. (2012). Viewing Purpose Through an Eriksonian Lens. *Identity*, *12*(1), 74–91. <https://doi.org/10.1080/15283488.2012.632394>
- Hughes, D., & Golding, K. S. (2012). *Creating loving attachments: Parenting with PACE to nurture confidence and security in the troubled child*. Jessica Kingsley Publishers.

- Jaser, S. S., & White, L. E. (2010). Coping and resilience in adolescents with type 1 diabetes. *Child Care Health and Development, 37*(3), 335–342. <https://doi.org/10.1111/j.1365-2214.2010.01184.x>
- Javaras, K. N., Runfola, C. D., Thornton, L. M., Agerbo, E., Birgegård, A., Norring, C., Ripke, S., Råstam, M., Larsson, H., Lichtenstein, P., & Bulik, C. M. (2015). Sex- and age-specific incidence of healthcare-register-recorded eating disorders in the complete swedish 1979-2001 birth cohort. *International Journal of Eating Disorders, 48*(8), 1070–1081. <https://doi.org/10.1002/eat.22467>
- Joiner, K. L., DeJonckheere, M., Whittemore, R., & Grey, M. (2020). Perceptions and experiences of living with type 1 diabetes among Latino adolescents and parents with limited English proficiency. *Research in Nursing & Health, 43*(3), 263–273. <https://doi.org/10.1002/nur.22019>
- Kamody, R. C., Berlin, K. S., Rybak, T. M., Klages, K. L., Banks, G. G., Ali, J. S., Alemzadeh, R., Ferry, R. J., & Thomas, A. (2017). Psychological Flexibility Among Youth with Type 1 Diabetes: Relating Patterns of Acceptance, Adherence, and Stress to Adaptation. *Behavioral Medicine, 44*(4), 271–279. <https://doi.org/10.1080/08964289.2017.1297290>
- Kimbell, B., Lawton, J., Boughton, C. K., Hovorka, R., & Rankin, D. (2021). Parents' experiences of caring for a young child with type 1 diabetes: a systematic review and synthesis of qualitative evidence. *BMC Pediatrics, 21*(1). <https://doi.org/10.1186/s12887-021-02569-4>
- Kyngas, H., & Barlow, J. (1995). Diabetes: an adolescent's perspective. *Journal of advanced nursing, 22*(5), 941-947. <https://doi.org/10.1111/j.1365-2648.1995.tb02646.x>

- Lundgren, T., Dahl, J., Melin, L., & Kies, B. (2006). Evaluation of Acceptance and Commitment Therapy for Drug Refractory Epilepsy: A Randomized Controlled Trial in South Africa-A Pilot Study. *Epilepsia*, *47*(12), 2173–2179.
<https://doi.org/10.1111/j.1528-1167.2006.00892.x>
- Luoma, J. B., & Platt, M. (2015). Shame, self-criticism, self-stigma, and compassion in Acceptance and Commitment Therapy. *Current Opinion in Psychology*, *2*, 97–101.
<https://doi.org/10.1016/j.copsyc.2014.12.016>
- McCracken, L. M., & Zhao-O'Brien, J. (2010). General psychological acceptance and chronic pain: There is more to accept than the pain itself. *European Journal of Pain*, *14*(2), 170–175. <https://doi.org/10.1016/j.ejpain.2009.03.004>
- McHugh, M. L. (2012). Interrater reliability: the kappa statistic. *Biochemia Medica*, 276–282.
<https://doi.org/10.11613/bm.2012.031>
- McDonagh, J. E. (2000). The adolescent challenge. *Nephrology Dialysis Transplantation*, *15*(11), 1761-1765. <https://doi.org/10.1093/ndt/15.11.1761>
- Messer, L. H., Johnson, R. E., Driscoll, K. A., & Jones, J. R. (2017). Best friend or spy: a qualitative meta-synthesis on the impact of continuous glucose monitoring on life with Type 1 diabetes. *Diabetic Medicine*, *35*(4), 409–418.
<https://doi.org/10.1111/dme.13568>
- Miller-Johnson, S., Emery, R. E., Marvin, R. S., Clarke, W., Lovinger, R., & Martin, M. (1994). Parent-child relationships and the management of insulin-dependent diabetes mellitus. *Journal of consulting and clinical psychology*, *62*(3), 603–610.
<https://doi.org/10.1037//0022-006x.62.3.603>

National Institute for Health and Care Excellence. (2012). *Process and methods [PMG4] Methods for the development of NICE public health guidance (third edition)*. NICE.
<https://www.nice.org.uk/process/pmg4/chapter/appendix-h-quality-appraisal-checklist-qualitative-studies#notes-on-the-use-of-the-qualitative-studies-checklist>

National Institute for Health and Care Excellence. (2015). *NICE guideline [NG17] Type 1 diabetes in adults: diagnosis and management*. NICE.
<https://www.nice.org.uk/guidance/ng17>

National Institute for Health and Care Excellence. (2015). *NICE guideline [NG18] Diabetes (type 1 and type 2) in children and young people: diagnosis and management*. NICE.
<https://www.nice.org.uk/guidance/ng18/>

Nordin, L., & Rorsman, I. (2012). Cognitive behavioural therapy in multiple sclerosis: A randomized controlled pilot study of acceptance and commitment therapy. *Journal of Rehabilitation Medicine, 44*(1), 87–90. <https://doi.org/10.2340/16501977-0898>

Noyes, J., Booth, A., Cargo, M., Flemming, K., Harden, A., Harris, J., ... & Thomas, J. (2019). Qualitative evidence. *Cochrane handbook for systematic reviews of interventions*, 525-545.

O'Connor, D., Green, S., & Higgins, J. P. (2008). Defining the review question and developing criteria for including studies. *Cochrane handbook for systematic reviews of interventions: Cochrane book series* (pp. 81-94).
<https://doi.org/10.1002/9780470712184.ch5>

Oris, L., Rassart, J., Prikken, S., Verschueren, M., Goubert, L., Moons, P., Berg, C. A., Weets, I., & Luyckx, K. (2016). Illness Identity in Adolescents and Emerging Adults With Type

- 1 Diabetes: Introducing the Illness Identity Questionnaire. *Diabetes Care*, 39(5), 757–763. <https://doi.org/10.2337/dc15-2559>
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T., Mulrow, C. D., Shamseer, L., Tetzlaff, J., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E., Mayo-Wilson, E., McDonald, S., . . . Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*, n71. <https://doi.org/10.1136/bmj.n71>
- Patton, G. C., & Viner, R. M. (2007). Pubertal transitions in health. *The Lancet*, 369(9567), 1130–1139. [https://doi.org/10.1016/s0140-6736\(07\)60366-3](https://doi.org/10.1016/s0140-6736(07)60366-3)
- Pharo, H., Sim, C., Graham, M., Gross, J., & Hayne, H. (2011). Risky business: Executive function, personality, and reckless behavior during adolescence and emerging adulthood. *Behavioral Neuroscience*, 125(6), 970–978. <https://doi.org/10.1037/a0025768>
- Pinar, B., & Turan, T. (2022). Living with Type 1 Diabetes: A Qualitative Study. *Turkiye Klinikleri Journal of Pediatrics*, 31(1). <https://doi.org/10.5336/pediatr.2020-80212>
- Polonsky, W. H., Anderson, B., EdD, Lohrer, P. A., Welch, G., Jacobson, A. M., Aponte, J. E., & Schwartz, C. E. (1995). Assessment of Diabetes-Related Distress. *Diabetes Care*, 18(6), 754–760. <https://doi.org/10.2337/diacare.18.6.754>
- Powers, M. A., Richter, S. N., Ackard, D. M., & Craft, C. M. (2016). Diabetes Distress Among Persons With Type 1 Diabetes. *The Diabetes Educator*, 43(1), 105–113. <https://doi.org/10.1177/0145721716680888>
- Ragelienė T. (2016). Links of Adolescents Identity Development and Relationship with Peers: A Systematic Literature Review. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 25(2), 97–105.

- Rankin, D. W. H., Harden, J., Jepson, R., & Lawton, J. (2017). Children's experiences of managing Type 1 diabetes in everyday life: a thematic synthesis of qualitative studies. *Diabetic Medicine*, *34*(8), 1050–1060. <https://doi.org/10.1111/dme.13362>
- Rebolledo, J. A., & Arellano, R. (2016). Cultural Differences and Considerations When Initiating Insulin. *Diabetes Spectrum*, *29*(3), 185–190. <https://doi.org/10.2337/diaspect.29.3.185>
- Reitblat, L., Whittemore, R., Weinzimer, S. A., Tamborlane, W. V., & Sadler, L. S. (2016). Life With Type 1 Diabetes: Views of Hispanic Adolescents and Their Clinicians. *The Diabetes educator*, *42*(4), 408–417. <https://doi.org/10.1177/0145721716647489>
- Rising Holmström, M. R., & Söderberg, S. (2021). The lived experiences of young people living with type 1 diabetes: A hermeneutic study. *Nursing Open*, *9*(6), 2878–2886. <https://doi.org/10.1002/nop2.995>
- Royal College of Paediatrics and Child Health. (2017). *National Paediatric Diabetes Audit 2016-17, Care Processes and Outcomes*. https://www.rcpch.ac.uk/sites/default/files/2018-07/npda_annual_report_2016_-_2017_april_2018_final_updated_3.pdf
- Sanders, R. (2013). Adolescent Psychosocial, Social, and Cognitive Development. *Pediatrics in Review*, *34*(8), 354–359. <https://doi.org/10.1542/pir.34-8-354>
- Seiffge-Krenke, I. (1998). The Highly Structured Climate in Families of Adolescents With Diabetes: Functional or Dysfunctional for Metabolic Control? *Journal of Pediatric Psychology*, *23*(5), 313–322. <https://doi.org/10.1093/jpepsy/23.5.313>

- Shorey, S., & Ng, E. D. (2020). The Lived Experiences of Children and Adolescents with Non-Communicable Disease: A Systematic Review of Qualitative Studies. *Journal of Pediatric Nursing, 51*, 75–84. <https://doi.org/10.1016/j.pedn.2019.12.013>
- Shorey, S., Ng, E. D., & Wong, C. (2021). Global prevalence of depression and elevated depressive symptoms among adolescents: A systematic review and meta-analysis. *British Journal of Clinical Psychology, 61*(2), 287–305. <https://doi.org/10.1111/bjc.12333>
- Skinner, T., Joensen, L. E., & Parkin, T. D. H. (2019). Twenty-five years of diabetes distress research. *Diabetic Medicine, 36*(12), 1415–1423. <https://doi.org/10.1111/dme.14157>
- Sokol, J. T. (2009). Identity development throughout the lifetime: An examination of Eriksonian theory. *Graduate journal of counseling psychology, 1*(2), 14.
- Stewart, S. M., Rao, U., Emslie, G. J., Klein, D. A., & White, P. C. (2005). Depressive Symptoms Predict Hospitalization for Adolescents With Type 1 Diabetes Mellitus. *Pediatrics, 115*(5), 1315–1319. <https://doi.org/10.1542/peds.2004-1717>
- Sturt, J., Dennick, K., Due-Christensen, M., & McCarthy, K. (2015). The Detection and Management of Diabetes Distress in People With Type 1 Diabetes. *Current Diabetes Reports, 15*(11). <https://doi.org/10.1007/s11892-015-0660-z>
- Thomas, J. D., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology, 8*(1), 1–10. <https://doi.org/10.1186/1471-2288-8-45>
- Thorne, S. (2010). *Interpretive description*. Left Coast Press
- Tiirikainen, K., Haravuori, H., Ranta, K., Kaltiala-Heino, R., & Marttunen, M. (2019). Psychometric properties of the 7-item Generalized Anxiety Disorder Scale (GAD-7) in

- a large representative sample of Finnish adolescents. *Psychiatry research*, 272, 30-35. <https://doi.org/10.1016/j.psychres.2018.12.004>
- Van Manen, M. (2016). *Researching lived experience: Human science for an action sensitive pedagogy*. Routledge.
- Weissberg-Benchell, J., & Antisdell-Lomaglio, J. (2011). Diabetes-specific emotional distress among adolescents: feasibility, reliability, and validity of the problem areas in diabetes-teen version. *Pediatric Diabetes*, 12(4pt1), 341–344. <https://doi.org/10.1111/j.1399-5448.2010.00720.x>
- Wilcox, G. (2005). Insulin and insulin resistance. *Clinical biochemist reviews*, 26(2), 19. <http://www.ncbi.nlm.nih.gov/pmc/articles/pmc1204764/>
- Willemsse, M., Deacon, E., & Segal, D. J. (2018). Life stories managing chronic illness: Young adults' lived experiences with type 1 diabetes. *Journal of Psychology in Africa*, 28(4), 336–339. <https://doi.org/10.1080/14330237.2018.1507328>
- Wood, J. R., Miller, K. M., Maahs, D. M., Beck, R. W., DiMeglio, L. A., Libman, I., Quinn, M., Tamborlane, W. V., & Woerner, S. L. (2013). Most Youth With Type 1 Diabetes in the T1D Exchange Clinic Registry Do Not Meet American Diabetes Association or International Society for Pediatric and Adolescent Diabetes Clinical Guidelines. *Diabetes Care*, 36(7), 2035–2037. <https://doi.org/10.2337/dc12-1959>
- World Health Organization. (2019). *Classification of diabetes mellitus*. <https://www.who.int/publications/i/item/classification-of-diabetes-mellitus>
- Wysocki, T., Nansel, T. R., Holmbeck, G. N., Chen, R., Laffel, L., Anderson, B. J., & Weissberg-Benchell, J. (2008). Collaborative Involvement of Primary and Secondary Caregivers:

Associations with Youths' Diabetes Outcomes. *Journal of Pediatric Psychology*, 34(8), 869–881. <https://doi.org/10.1093/jpepsy/jsn136>

Paper 2: Empirical paper.

The impact of ways of coping on the power of the anorexic voice.

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Word Count: 7,888

This paper was prepared in accordance with the author guidelines for the International Journal of Eating Disorders (see Appendix E). For the purposes of thesis submission, the DClinPsy word limit of 8000 words has been used to ensure inclusion of relevant information. To support readability, figures and tables are embedded within the main body of the text.

Abstract.

Objective.

The anorexic voice (AV) is a phenomenon reported across eating disorders where individuals report hearing a critical internal voice that comments upon food, weight, and shape. The AV has been described as changing over time, from supportive to hostile and powerful. The mechanism behind the change in power is not yet known. The cognitive model of auditory hallucinations suggests that malevolent voices are resisted and maladaptive strategies to control the voice, such as voice suppression, may lead to its increase in power. This study aimed to assess the impact of voice suppression on the power of the AV.

Method.

Thirty-two adults with current experience of an AV completed measures regarding beliefs about their AV. They were then randomised to an experimental condition where participants were asked to suppress or accept the experience of their AV for a short period of time. Power of the AV was rated before and after each trial.

Results.

The AV was perceived as both malevolent and benevolent, with individuals willing to engage with and resist it. Power of the AV significantly increased when participants engaged in thinking about it, with no significant difference between the voice suppression or acceptance groups.

Discussion.

The AV is simultaneously perceived as malevolent and benevolent, highlighting a complex relationship. The AV increased in power when it was accepted and suppressed which has implications for psychological interventions for eating disorders. Future research could consider how to alter the relationship with the AV to improve engagement with therapy and recovery outcomes.

Keywords: Eating Disorders; Anorexic Voice, Voice suppression, Power, Anorexia Nervosa.

1. Introduction

1.1. Eating disorders and the anorexic voice.

Eating disorders (EDs) are a group of syndromes characterised by disordered eating associated with beliefs about body weight, body shape, and eating (Grilo, 2006). There are many types of ED, with the most typical forms being Anorexia Nervosa (AN), Bulimia Nervosa (BN) and Binge Eating Disorder (BED) (Diagnostic and Statistical Manual of Mental Disorders, 5th Edition [DSM-5]; American Psychiatric Association, 2013). For individuals who do not meet the full diagnostic criteria for one of the specified EDs, but are experiencing significant eating related distress, the diagnosis of Other Specified Feeding or Eating Disorder (OSFED) may be given (Galmiche et al., 2019). Hay et al. (2017) estimated that over 20% of all EDs are classified as BED, with a further 19% as BN and 8% as AN. However, the most common diagnosis is OSFED, suggested to represent nearly half of all ED cases. This likely reflects the stringency of criteria for the main ED diagnoses (Fairburn & Cooper, 2011) as well as how commonplace disordered eating behaviours are in the general population.

Current figures suggest that the worldwide lifetime prevalence of any ED is 0.91% (Qian et al., 2021) although prevalence tends to be substantially higher in females than males. However, estimations of prevalence are varied and are complicated by changes to classifications of EDs alongside barriers that make receiving a diagnosis difficult. Individuals with lived experience have described a lack of understanding of EDs, and limited time and resources in primary care resulting in failures to identify and diagnose EDs (Johns et al., 2019). In addition, men and individuals from non-white communities are less likely to receive a

diagnosis of an ED (Sonneville & Lipson, 2018; Spratt et al., 2022). Therefore, prevalence rates may under-represent the true number of ED cases.

The consequences of EDs are severe. EDs are relatively rare compared to other mental health conditions and yet have the highest mortality rate of any psychiatric illness (Arcelus et al., 2011). Risk of death is greatest for sufferers of AN with an annual mortality rate nearly 12 times higher than in the general population (Sullivan, 1995). Approximately one in five deaths from AN are also attributed to suicide (Van Eeden et al., 2021). Recovery rates for EDs are also poor. Research suggests that less than half of individuals with a diagnosis of AN will achieve full recovery and a fifth of sufferers remain chronically ill (Van Hoeken & Hoek, 2020). A UK national eating disorder charity reported the experiences of individuals with EDs who described getting stuck in a recurring cycle of waiting, treatment, and recovery that took place over many years (Beat, 2015). This was found to cause significant impact on ability to engage in education and employment and reduced quality of life. The economic costs of EDs are also large. Beat (2015) reported that EDs in the UK cost the NHS approximately £4 billion with an additional £1 billion spent on private care. There are clear significant costs from EDs in terms of physical and psychological wellbeing and so enhancing treatment effectiveness is of the utmost importance.

Current recommended therapeutic treatment for EDs include cognitive behavioural therapy for eating disorders (CBT-E; Fairburn et al., 2009) as outlined in guidelines from the National Institute for Health and Care Excellence (NICE, 2017) and Matrics Cymru (National Psychological Therapies Management Committee, 2017). CBT-E focuses on the processes that maintain EDs (Murphy et al., 2010), including over-evaluation of weight and shape, dietary rules, and other condition-specific factors such as low self-esteem and perfectionism (Atwood & Friedman, 2020). Whilst CBT-E has shown some success in reducing core ED

psychopathology and behaviours, many randomised control trials did not prove it to be superior to other treatments such as Interpersonal Therapy (IPT; Atwood & Friedman, 2020). When one considers the poor recovery rates for EDs, this suggests that there may be other factors that hinder the efficacy of psychological interventions which requires further exploration.

Recently, arising out of work with individuals with lived experience of EDs, research interest has shifted towards understanding the phenomenon known as the ‘anorexic voice’ (AV). Many individuals report the experience of an internal voice that takes the form of “second or third-person commentary on actions and consequences relating to eating, weight and shape” (Pugh & Waller, 2016, p. 670). The AV is not considered to be a psychotic phenomenon as most individuals recognise that it comes from within them rather than being externally-generated (Pugh & Waller, 2016). Qualitative research into the lived experience of individuals with AN has provided insight into the AV (Higbed & Fox, 2010; Tierney & Fox, 2010). For many, the presence of the AV at first was comforting and offered ‘advice’ and ‘support’ (to engage in ED behaviours). The AV was even described as a ‘friend’. However, individuals described a transformation with their relationship with the voice, becoming ‘ensnared’ by it. The AV was perceived to become louder, more critical and controlling, and was seen as a powerful entity to obey at all costs. The AV has been likened to experiences of domestic violence – feeling trapped in a toxic and abusive relationship (Tierney & Fox, 2011). The dominance of the voice over an individual can become an obstacle for treatment and may partly explain the poor treatment outcomes for EDs (Tierney & Fox, 2010). Though much of the literature is based upon population samples of AN sufferers, the experience of an internal critical voice has been reported across ED subtypes including BN and atypical EDs (Broussard,

2005; Noordenbos et al., 2014). Therefore, within this paper, the term AV is used to refer to a critical internal voice experienced by sufferers of EDs.

1.2. Cognitive model of auditory hallucinations.

Much of the existing literature on the AV has drawn upon cognitive models of auditory hallucinations (Chadwick & Birchwood, 1994) to understand this phenomenon. The cognitive model of auditory hallucinations arose from the discovery that voice-hearing is not exclusive to clinical populations but experienced by many who do not require psychiatric care. Romme et al. (1992) reported a number of individuals who described hearing voices but experienced little distress and felt able to cope with the voice's presence. Since this research, it has been consistently demonstrated that the presence of a voice alone is not sufficient to result in distress (Lawrence et al., 2010).

In their cognitive model, Chadwick and Birchwood (1994) suggested that appraisals and beliefs the individual holds about the voice influences behavioural responses to the voice. Voices perceived as omnipotent (powerful) and malevolent (evil) are likely to be resisted (Birchwood et al., 2004). On the other hand, individuals are more likely to engage and comply with a voice that is perceived as benevolent (kind). A review by Mawson et al. (2010) found that voices appraised as omnipotent and malevolent were associated with higher levels of distress, anxiety, and depressed mood. The cognitive model of Chadwick and Birchwood (1994) and research from voice hearers (Sayer et al., 2000) is consistent with qualitative accounts of the AV (Pugh, 2016). At first onset, when the voice is perceived as friendly and supportive (benevolent), it is less distressing, and individuals are more receptive to engaging with it. Over time, as the AV becomes more hostile and powerful (malevolent and omnipotent), distress increases. Research has found that AVs appraised as powerful and/or

malevolent were associated with negative eating attitudes and cognitions, longer duration and severity of illness and increased use of compensatory behaviours (Pugh & Waller, 2016; 2017). It is clear that perceptions of the AV as critical, hostile, and powerful is associated with increased distress and may maintain EDs.

1.3. Metacognitive control strategies.

Research has suggested that voices perceived as omnipotent and malevolent are associated with attempts to resist, fight, or escape the voice (Gilbert et al., 2001). Romme et al. (1992) found voice hearers who felt unable to cope with their voice were more likely to engage in distraction coping strategies. Hill and colleagues (2012) found that clinical voice-hearers were more likely to endorse the belief that they 'need to control' voices compared to non-clinical voice-hearers. Actions taken to control mental events are referred to as metacognitive control strategies (Wells, 2000). It has been theorised that these control strategies arise from 'experiential avoidance' where individuals try to avoid negative internal experiences such as thoughts, feelings, and images (Hayes & Wilson, 1994). Some metacognitive control strategies are more maladaptive than others, such as thought suppression (Hayes et al., 2004). Research with thought suppression has found that despite aiming to push away and reduce uncomfortable thoughts, it actually leads to a short-term increase in the frequency of the thought (Marcks & Woods, 2005). Research exploring the impact of suppression of voices has also found this rebound effect (Badcock et al., 2011; Tully et al., 2017) along with subsequent increases in distress (Marcks & Woods, 2005).

Exploration of metacognitive control strategies in EDs has found that individuals with AN are more likely to endorse a need to control thoughts than non-eating disordered populations (Cooper et al., 2007). Greater need to control thoughts has also been found in

individuals with BN and OSFED compared to the general population and was associated with greater ED pathology (Olstad et al., 2015). Research has found that individuals with AN are more likely to engage in maladaptive metacognitive control strategies such as thought suppression compared to individuals without EDs (Woolrich et al., 2008). It appears that individuals with EDs have a greater tendency to suppress and resist unpleasant experiences such as the hostile and critical AV, and it is possible that this is a mechanism leading to increased frequency of the voice and distress. The failure to suppress the voice may also explain how perceived omnipotence of the voice grows over the course of EDs.

1.4. Aims of this research and hypotheses.

Research has demonstrated how the AV grows in power and malevolence over time leaving many individuals feeling entrapped and distressed by it (Tierney & Fox, 2010). Voices perceived as powerful and malevolent are associated with attempts to resist the voice whilst benevolent voices are engaged with. Research has demonstrated that individuals with EDs may be more likely to try and control the AV through strategies such as voice suppression, which have been shown to increase the frequency of the experience being suppressed as well as increasing distress (Badcock et al., 2011; Marcks & Woods, 2005). It is possible that unsuccessful attempts to suppress the critical and hostile AV leads individuals to feel powerless against the voice and thus increase its perceived power. As of yet, no research has directly tested this possibility.

The main aim of this study was to explore the impact of voice suppression on the perceived power of the AV. For the purposes of this study, the terms omnipotence and power may be used interchangeably. Both refer to perceiving the AV as dominant, powerful, and hard to ignore. If voice suppression is identified as a mechanism that contributes to the

dominant AV, then it provides a potential target for therapeutic interventions for EDs. Individuals with experience of an AV were asked to either suppress the voice or accept the experience of the voice for a brief period of time and topographical features of the AV (frequency, loudness, clarity, distress, and power) were measured before and after.

Hypothesis 1.

Perceptions of the AV as omnipotent will be positively correlated with perceptions of the AV as malevolent.

Hypothesis 2.

Perceptions of the AV as malevolent will be positively correlated with attempts to resist the AV.

Hypothesis 3.

Participants in the voice suppression condition will demonstrate a significantly greater increase in perceived power of the AV compared to those who are in the acceptance condition.

2. Method.

2.1. Design and analysis.

This experimental study utilised a two-way mixed ANOVA design to measure the interaction effect of participant condition (voice suppression, acceptance) x time (pre-intervention, post-intervention trial 1, post-intervention trial 2) on perceived power of the AV.

No prior research provided an effect size for estimating the required sample size. A medium effect size was selected as a conservative estimate. A G*Power analysis suggested that with standard conventions of an alpha error probability of 0.05 and power of 0.80, approximately 28 participants would be needed to identify a medium effect size.

2.2. Participants.

Participants were eligible to take part in the study if they were i) over the age of 18 and ii) had current experience of an AV. To recruit a more representative sample, no formal diagnosis of an ED was needed, only current experience of the AV.

Participant recruitment took place through social media advertisement, including Twitter, Instagram, Facebook, and Reddit. The recruitment strategy and poster can be found in the appendices. As research has suggested a high prevalence of EDs amongst student populations (Lipson & Sonnevile, 2017), undergraduate students at Cardiff University who met the eligibility criteria were offered the opportunity to take part. University students were awarded one course credit for completion of the screening survey (which took approximately 10 minutes) and an additional two credits for completion of the experimental study (which took approximately 20 minutes). Recruitment took place from December 2022 to May 2023.

A total of 234 participants responded to the initial screening survey. Forty-two participants were not currently experiencing an AV and thus not eligible to complete the screening survey. Seventy-two responses were incomplete and removed from further analysis. A total of 120 participants completed the screening survey in full and 84 consented to be contacted for part two by providing an email address.

Thirty-two participants continued and completed the experimental intervention study. These participants were randomised to either the voice suppression (n=17) or acceptance (n=15) experimental conditions. The participant sample ranged in age from 18-59 years, with an average age of 27 years (SD=11). The majority of participants were female (n=29), with one male and two non-binary individuals also taking part. Most participants were resident in the United Kingdom (n=25) but there were also participants from United States of America (n=4), Canada (n= 1), Kenya (n=1) and New Zealand (n=1). Participant occupation was varied though the majority were students (n=18). Other occupations included healthcare (n=5) and retail/service workers (n=4). Three participants classed themselves as unemployed due to disability. Fourteen participants reported that they were either currently receiving or had previously received support from ED services. Support included psychological therapy (n=14), medication (n=9) and dietetic support (n=6). Three participants reported having received inpatient treatment for their ED.

2.3. Measures.

A copy of all measures used in this study can be found in the appendices.

Eating Disorder Examination Questionnaire (EDE-Q; Fairburn & Beglin, 2008).

The EDE-Q is a self-report questionnaire that assesses symptoms and severity of EDs. It has been used across clinical and community settings (Mond et al., 2004). Research has

demonstrated acceptable internal consistency (Bardone-Cone & Agras, 2017), acceptable criterion validity as well as good concurrent validity (Mond et al., 2004). The EDE-Q can accurately discriminate individuals with EDs from those without (Aardoom et al., 2012).

The EDE-Q is comprised of 28 items that can be calculated to provide an overall score as well as comprising four subscales: restraint, eating concern, shape concern, and weight concern. Participants are asked to rate the frequency of ED-related behaviours and features over the last 28 days. Higher scores both globally and on subscales indicates greater ED pathology. The global score is calculated by taking the sum of all items and dividing by four (the number of subscales). Subscale scores are calculated by taking the sum of items in that subscale and dividing by the total number of items in that subscale. A global score of four or above is considered clinically significant for EDs (Carey et al., 2019).

Beliefs about Voices Questionnaire-Revised (BAVQ-R; Chadwick et al., 2000).

The BAVQ-R is a self-report questionnaire that measures beliefs, feelings, and responses to internal voices. The BAVQ-R has been shown to have good construct validity and is considered a useful tool for investigating the experience of hearing voices (Ratcliff et al., 2011). It is comprised of 35-items that separate into five subscales: three relating to beliefs about internal voices (omnipotence, malevolence, and benevolence) and two that describe emotional and behavioural responses to the voice (resistance and engagement). Participants are asked to rate each item on a 4-point Likert scale from 'disagree' to 'agree strongly'. A higher score indicates greater endorsement of the item (Chadwick et al., 2000). The BAVQ-R has been used previously in research exploring the AV (Aya et al., 2019). Following Pugh and Waller (2016), the BAVQ-R was adapted in this study by changing the term "voice" to "anorexic voice". No other changes were made to the questionnaire.

Topography of voices rating scale (TVRS; Hustig & Hafner, 1990).

The TVRS is a self-report questionnaire that asks participants to rate characteristics of the voice they hear across five domains: frequency, volume, clarity, distress, and power (Casstevens et al., 2012). The characteristics of the voice are rated across a 5-point Likert scale. A higher score on each item suggests a higher intensity of the associated characteristic (e.g., louder, more frequent, more powerful). As with the BAVQ-R, the term “voice” was adapted to “anorexic voice”.

2.4. Procedure.

2.4.1. Screening stage.

For participants recruited through social media, the screening survey was accessed by clicking the link embedded in the recruitment post or the QR code on the poster. Participants taking part through Cardiff University accessed the screening survey through the Experimental Management System (EMS). The screening survey was web-based and hosted on the Qualtrics survey platform. The first page provided information regarding the procedure, expected duration for completion, confidentiality and right to withdraw. Participants were instructed that by clicking the “next” button they consented to taking part in the screening study.

The first question acted as an eligibility screening tool. A description of the AV was provided, and participants were asked whether they were currently experiencing an AV. Participants that clicked “yes” were eligible to continue and complete the remainder of the screening survey. Participants that clicked “no” did not meet inclusion criteria for this research and were redirected to the end of the survey.

Those eligible to complete the remainder of the screening survey were asked to provide responses to the EDE-Q, BAVQ-R, and TVRS in turn. No forced responses were required though reminders were given if a question was left blank. Demographic information including age, gender, country of residence and experience of ED services was also asked for. The final question asked participants to provide an email address in order to be contacted about the second experimental part of the research.

2.4.2. Experimental intervention.

For participants who provided a contact email address, a standardised email was sent with an information sheet attached that explained the experimental study protocol (see Appendices). A link to sign up for a time slot was embedded in the email.

Participants were randomly assigned to either the voice suppression or acceptance condition using an online random number generator. Even numbers were allocated to the acceptance condition and odd numbers were allocated to the voice suppression condition. This number also served as a unique identification code to link them to their screening survey data. On the day of their selected time slot, participants received an email containing their identification code, experimental survey link, and Zoom link. The experimental survey was completed using the Qualtrics survey platform and Zoom was used to allow the researcher to explain the study protocol, gain consent and provide an individualised debrief at the end. On joining the Zoom link, once the researcher explained what participants would need to do, they were placed in a breakout room on their own to complete the study.

The first page of the experimental survey asked for their unique identifier code. Participants were then provided with information about the survey, their rights to confidentiality and ability to withdraw at any time without consequence. By clicking the

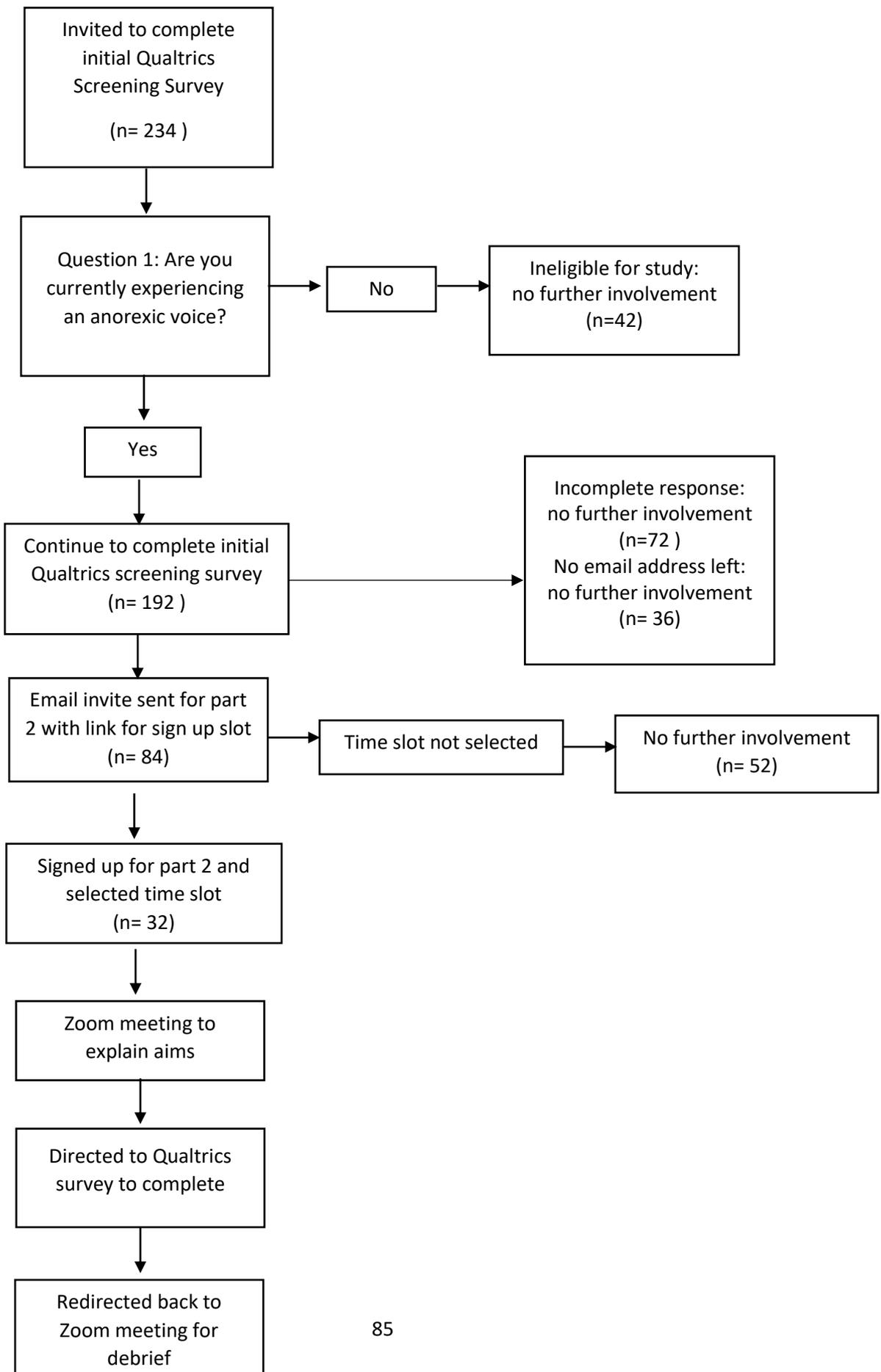
“next” button they consented to continue with the study. Participants were asked to complete the TVRS in respect to their AV over the last few minutes. They were then instructed to spend two minutes either suppressing or accepting the experience of their AV. Voice suppression and acceptance scripts were adapted from previous work in the area (Marcks & Woods, 2005; Salkovskis & Campbell, 1994; Harris, 2008). Audio and written instructions were provided – full scripts can be found in the appendices. Following this first trial, participants were asked to complete the TVRS again, before completing a second trial of voice suppression or acceptance and completing the TVRS for a third time. After each trial, participants were asked to rate how hard they tried to a) suppress the AV and b) accept the experience of it on a 10-point visual analogue scale. This served as a manipulation check and was adapted from previous experimental investigations of voice suppression and acceptance (Marcks & Woods, 2005). To minimise any potential negative impact of voice suppression, a mindfulness “leaves on a stream” video was embedded at the end of the survey for participants to watch prior to finishing the study.

On completion of the experimental survey, participants left their Zoom breakout room, and the researcher provided a 1:1 debrief explaining the aims of the study and answering any questions. A formal debrief form containing the aims of the study, signposting to support services, and researcher contact details were also emailed to participants after the study (see Appendix N). Figure 1. outlines the procedural steps of the study and participant numbers throughout the process.

2.5. Ethics.

This study was approved by Cardiff University School of Psychology Ethics Committee (approval code: EC.22.01.18.6502R, see Appendix O).

Figure 1. Flow diagram of procedural steps.



2.6. Sample characteristics.

The sample had a mean global EDE-Q score of 3.44 (SD= 1.23) in the acceptance condition and 4.05 (SD= 1.22) in the voice suppression condition. There was no statistical difference in EDE-Q scores between the two participant conditions, $t(30)= 1.457, p= .155$. These scores were in line with EDE-Q norms reported for clinical ED samples (Aardoom et al., 2012).

Scores on the BAVQ-R and TVRS for participants in both conditions are shown in Tables 1 and 2. Malevolence and benevolence ratings were in line with those found in previous research on the AV (Pugh & Waller, 2016).

The assumption of normality was assessed using visual inspection of Q-Q plots and Shapiro-Wilk test for normality. Data that was normally distributed was analysed using independent samples t-tests and data that was not normally distributed was analysed using Mann-Whitney's test. There was no statistical difference between the two participant conditions on any of subscale of the BAVQ-R; malevolence ($t(30)= .554, p= .584$), benevolence ($t(30)= .916; p=.367$), omnipotence ($t(30)= .574, p=.570$), resistance ($t(30)= .173, p= .864$), engagement, ($U= 89.00, p= .153$).

There were also no significant differences on any topographical feature of the AV between the two conditions: frequency ($t(30)= .545, p= .590$), loudness ($t(30)= .987, p= .332$), clarity ($t(30)= .124, p= .902$), distress ($t(30)= .445, p= .660$), power ($t(30)= .249, p= .805$).

Table 2. Average and standard deviation of scores on the Beliefs About Voices Questionnaire-Revised across the two groups at baseline screening.

BAVQ-R	Acceptance condition		Voice suppression condition	
	Mean	Standard Deviation	Mean	Standard Deviation
<i>Malevolence subscale</i>	7.9	4.5	8.8	4.5
<i>Benevolence subscale</i>	4.5	4.4	5.9	4.3
<i>Omnipotence subscale</i>	9.7	5.1	10.6	4.6
<i>Resistance subscale</i>	15.5	6.4	15.8	5.2
<i>Engagement subscale</i>	5.5	6.1	8.3	6.2

Table 3. Average and standard deviation of scores on the Topography of Voices Rating Scale across the two groups at baseline screening.

TVRS	Acceptance condition		Voice suppression condition	
	Mean	Standard Deviation	Mean	Standard Deviation
<i>Frequency</i>	3.7	0.7	3.8	0.9
<i>Volume</i>	3.2	1.0	3.5	0.9
<i>Clarity</i>	3.2	0.9	3.2	0.8
<i>Distress</i>	3.5	0.9	3.6	0.5
<i>Power</i>	3.3	1.0	3.2	1.0

3. Results.

3.2. Correlational analyses.

Pearson’s correlations were calculated to examine the relationship between beliefs and topographical features of the AV, as well as with ED severity. Pearson’s correlation has been demonstrated as sufficiently robust for analysis of ordinal data as captured in the TVRS (Murray, 2013).

As seen in Table 3, significant positive associations were found between ED severity, as measured by EDE-Q, and several features of the AV. Greater EDE-Q scores were significantly associated with greater omnipotence of the AV, but also with greater benevolence and

engagement ratings. There were significant positive correlations between EDE-Q scores and frequency, volume, clarity, and power of the AV.

3.2.1. Hypothesis 1.

Consistent with hypothesis one, perceptions of the AV as omnipotent was significantly positively correlated with malevolence. Interestingly, a similar association was found between omnipotence and perceiving the AV as benevolent.

3.2.2. Hypothesis 2.

In line with hypothesis two, greater malevolence of the AV was significantly positively correlated with resistance. In contrast, the benevolence subscale was significantly positively correlated with the engagement subscale. Perceiving the AV to be omnipotent was associated with both resistance and willingness to engage with it. There was not a significant correlation with resistance when power of the AV was measured using the TVRS.

Table 4. Relationship between eating disorder severity, beliefs about the anorexic voice and topographical features of the anorexic voice at baseline screening.

Pearson’s correlations for all study screening variables.

Variable	Correlated with											
	1	2	3	4	5	6	7	8	9	10	11	
1 EDE-Q	-											
2 BAVQ-R Malevolence	.297	-										
3 BAVQ-R Omnipotence	.640**	.628**	-									
4 BAVQ-R Benevolence	.359*	.084	.537**	-								
5 BAVQ-R Resistance	.183	.638**	.539**	.241	-							
6 BAVQ-R Engagement	.505**	.071	.537**	.851**	.121	-						
7 TVRS Frequency	.583**	.226	.552**	.531**	.163	.582**	-					
8 TVRS Volume	.635**	.115	.408*	.100	-.107	.295	.512**	-				
9 TVRS Clarity	.390*	.419*	.424*	.123	.209	.034	.190	.362*	-			
10 TVRS Distress	.203	.326	.375*	-.056	.242	-.113	.211	.427*	.563**	-		

11	TVRS Power	.604**	.372*	.730**	.437*	.276	.569**	.588**	.557**	.221	.128	-
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Note. * $p < 0.05$, ** $p > 0.01$ (two-tailed).

EDE-Q = Eating Disorder Examination – Questionnaire; BAVQ-R = Beliefs About Voices Questionnaire – Revised; TVRS = Topography of Voices Rating Scale

3.3. Experimental analyses.

3.3.1. Hypothesis 3.

3.3.1.1. Manipulation check.

Tables 5 and 6 show the average voice suppression and acceptance effort ratings for both participant conditions after the first and second intervention trials. After the first intervention trial, effort to suppress the AV was significantly higher in the voice suppression condition than acceptance condition, $t(30) = -.392$, $p < .001$, and efforts to accept the AV were significantly higher in the acceptance condition than voice suppression condition, $t(30) = 2.11$, $p = .043$. Within participants in the voice suppression condition, effort to suppress the AV was significantly greater than effort to accept it, $t(16) = 3.833$, $p = .001$. Amongst participants in the acceptance condition, acceptance effort ratings were higher than voice suppression effort ratings, but not significantly so ($t(14) = -1.95$, $p = .071$).

After the second intervention trial, voice suppression effort ratings were significantly greater in the voice suppression condition than acceptance condition, $t(30) = -7.546$, $p < .001$, and acceptance effort ratings were significantly higher in the acceptance condition than voice suppression condition, $t(30) = 2.949$, $p = .006$. For participants in the voice suppression condition, effort to suppress the AV was significantly greater than effort to accept the AV, $t(16) = 5.308$, $p < .001$. Within participants in the acceptance condition, effort to accept the AV was significantly greater than effort to suppress it, $t(14) = -.451$, $p < .001$. This suggests that

participants were engaging in the appropriate intervention (voice suppression or acceptance) as laid out by the instructions in the survey.

Table 5. Effort ratings of suppressing and accepting the anorexic voice for the two participant conditions after intervention trial one. Greater score indicates greater effort.

Effort ratings	Acceptance condition		Voice suppression condition	
	Mean	Standard Deviation	Mean	Standard Deviation
<i>Voice suppression Effort</i>	4.73	1.91	7.35	1.87
<i>Acceptance Effort</i>	6.27	1.62	4.65	2.65

Table 6. Effort ratings of suppressing and accepting the anorexic voice for the two participant conditions after intervention trial two. Greater score indicates greater effort.

Effort ratings	Acceptance condition		Voice suppression condition	
	Mean	Standard Deviation	Mean	Standard Deviation
<i>Voice suppression Effort</i>	3.73	1.83	8.12	1.45
<i>Acceptance Effort</i>	6.80	1.52	4.59	2.53

3.3.1.2. *Experimental intervention.*

A two-way mixed ANOVA was conducted to examine the effect of the experimental manipulation on power of the AV, with a between subjects factor of Condition (Voice suppression; Acceptance) and a repeated measures factor of Time (Pre-Intervention; Post-Intervention Trial 1; Post-Intervention Trial 2).

Examination of studentized residuals identified one outlier, with a value greater than ± 3 . To ensure this did not affect data analysis, ANOVA was run both with and without the outlier removed. No differences were found when the outlier was removed, therefore it was kept within the data set. Data was considered to be normally distributed through visual inspection of residuals using a Q-Q plot. There was some positive skew for power pre-

intervention, however ANOVA is typically considered robust against slight deviations from normality (Field, 2013). There was homogeneity of variance, as assessed by Levene's test ($p > .05$) and homogeneity of covariance was also established, as assessed by Box's test of equality of covariance matrices ($p = .855$). Mauchly's test of sphericity indicated the assumption of sphericity was met for the two-way interaction, $\chi^2(2) = .21, p = .900$.

The two-way mixed ANOVA revealed there was no statistically significant interaction between participant condition and time on power of the AV, $F(2, 60) = 1.53, p = .224$, partial $\eta^2 = .049$. The power of the AV was not significantly different between those asked to suppress or accept it, $F(1, 30) = .005, p = .946$, partial $\eta^2 = .000$. Figure 2 shows the changes in power of the AV for both conditions across the intervention trials.

There was a significant main effect of time on power of the AV, $F(2, 60) = 6.40, p = .003$, partial $\eta^2 = .176$. Post hoc analysis with a Bonferroni adjustment showed that power of the AV increased significantly ($p = .005$) from pre-intervention ($M = 2.16, SD = 1.01$) to post-trial 1 ($M = 2.84, SD = 1.02$), with a small and non-significant decrease in power after trial 2 ($M = 2.56, SD = .91, p = .517$). This suggests that both the voice suppression and acceptance groups had a short-term increase in power of the AV after trial 1.

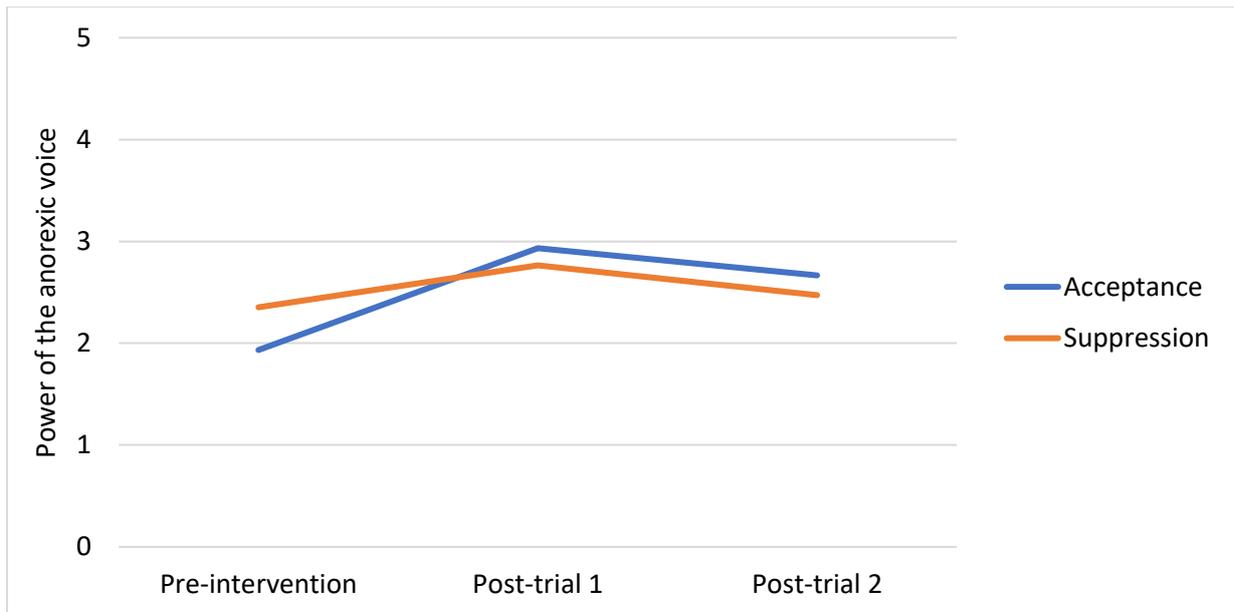


Figure 2. Power of the anorexic voice for the two participant conditions before and after experimental intervention.

3.4. Exploratory analyses.

Exploratory analyses were carried out to examine the impact of voice suppression and acceptance on frequency of the AV and distress associated with the AV.

3.4.1. Frequency of the anorexic voice.

A two-way mixed ANOVA was used to measure changes in the frequency of the AV. Inspection of residuals showed there were no outliers and normality was assumed through visual inspection of Q-Q plots. Assumptions were met for homogeneity of variance ($p > .05$), equality of covariances ($p = .876$), and sphericity ($\chi^2(2) = 1.016, p = .602$).

There was a statistically significant interaction between time and participant condition on frequency of the AV, $F(2, 60) = 4.3, p = .018, \text{partial } \eta^2 = .125$. In the acceptance condition, there was a statistically significant effect of time on frequency of the AV, $F(2, 28) = 13.778, p < .001, \text{partial } \eta^2 = .496$. Pairwise comparisons showed that frequency of the AV significantly

increased ($p < .001$) after the first trial of acceptance ($M = 3.80$, $SD = .94$) from pre-intervention ($M = 2.33$, $SD = 1.11$), but not after the second trial of acceptance ($p = .080$). For participants in the voice suppression condition, frequency of the AV did not significantly change between any of the trials, $F(2, 32) = 1.526$, $p = .233$, partial $\eta^2 = .087$. Simple main effects also showed that frequency of the AV was not significantly different between the voice suppression and acceptance conditions at any time point throughout the study, ($F(1, 30) = 1.942$, $p = .174$, partial $\eta^2 = .061$; $F(1, 30) = 1.916$, $p = .176$, partial $\eta^2 = 0.60$; $F(1, 30) = .173$, $p = .680$, partial $\eta^2 = .006$). Figure 3 shows the impact on frequency of the AV.

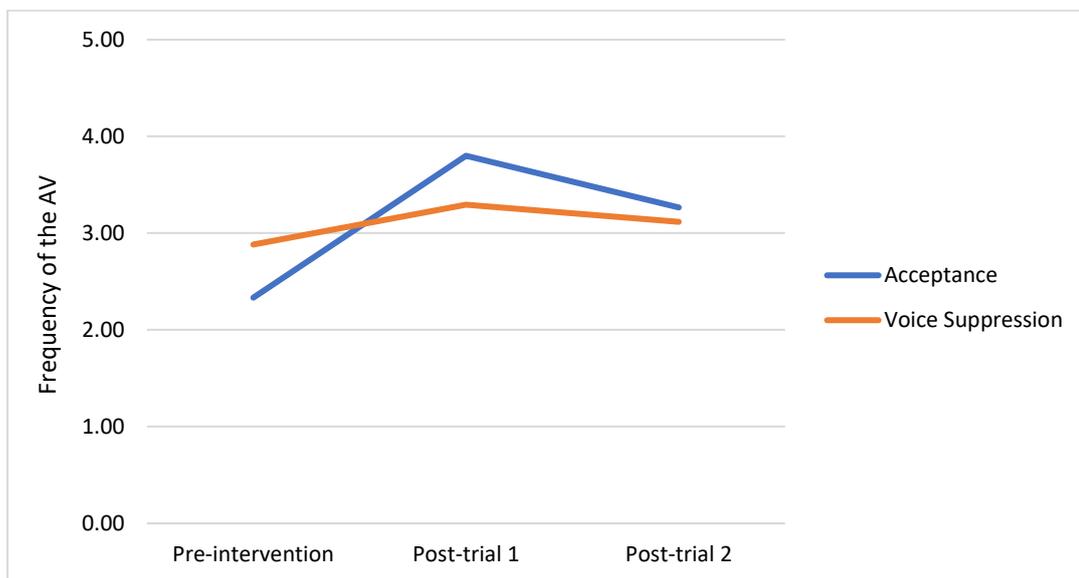


Figure 3. Frequency of the anorexic voice for the two participant conditions before and after experimental intervention.

3.4.2. Distress caused by the anorexic voice.

Inspection of studentized residuals showed there were no outliers with a value greater than ± 3 . Visual inspection of Q-Q plots suggested normal distribution, with some negative skew, though ANOVA is considered robust against minor deviations in normality. There was homogeneity of variances as assessed by Levene's test ($p > .05$), however Box's test of equality

of covariance matrices was significant at $p = .007$. Tabachnick and Fidell (2012) suggest that when there is not equality of covariances, caution should be taken when interpreting significant differences whilst non-significant effects can generally be trusted. Sphericity was assumed through Mauchly's test of sphericity, $\chi^2(2) = .528, p = .768$.

A two-way mixed ANOVA found no significant interaction between time and participant condition for distress related to the AV, $F(2, 60) = 1.351, p = .267, \text{partial } \eta^2 = .043$. There were no significant changes in distress from the AV across the three time points of the study, $F(2, 60) = 1.779, p = .178, \text{partial } \eta^2 = .056$, and no significant differences in levels of distress from the AV between the voice suppression or acceptance conditions, $F(1, 30) = .101, p = .753, \text{partial } \eta^2 = .003$.

4. Discussion.

4.1. Aims of the study.

The current study was interested in the impact of metacognitive control strategies on the power of the AV. Individuals were asked to either suppress or accept the experience of their AV for a brief period of time. Topographical features of the AV, including power, were measured before and after two trials of the intervention. It was hypothesised that 1) there would be a positive association between beliefs that the AV was omnipotent and malevolent, 2) perceiving the AV to be malevolent would be associated with attempts to resist the voice, and 3) power of the AV would be greater after voice suppression than acceptance. There was support for the first two hypotheses – omnipotence and malevolence were significantly positively correlated, and malevolence was associated with greater resistance on the

subscales of the BAVQ-R. However, omnipotence of the AV was also associated with benevolence and willingness to engage with it, which was an unexpected finding.

Hypothesis three was not supported; there was no significant interaction between participant condition x time. Power of the AV increased when participants engaged with it, whether that was through voice suppression or acceptance. These findings and the implications for clinical practice and future research are discussed in more detail below.

4.2. Hypothesis 1 and 2.

Correlations between screening variables revealed interesting relationships between appraisals of the AV. As predicted in hypothesis one, beliefs that the AV was powerful, as measured by the omnipotence subscale of the BAVQ-R, and evil (malevolent) were positively correlated, as well as being associated with greater resistance. Greater omnipotence of the AV was also associated with greater volume, clarity, distress, and the AV occurring more frequently.

Hypothesis two was also supported, as perceptions of the AV as malevolent was associated with greater resistance towards it, in line with predictions from the cognitive model of auditory hallucinations (Chadwick & Birchwood, 1994). These findings correspond with qualitative accounts of the AV as a powerful entity that is loud, critical, and controlling (Higbed & Fox, 2010; Tierney & Fox, 2010) and replicates findings with voice hearers that appraisals of voices influence attempts to cope with it (Gilbert et al., 2001).

Interestingly, omnipotence of the AV was also associated with perceptions of the AV as benevolent and willingness to engage with it. This suggests that the relationship with the

AV is more complex than classifying it as either a solely malevolent or kind entity. While the AV may be perceived as powerful, its intentions might be seen either as kind and helpful, leading to engagement with it, or as hostile, leading to resistance. Holding these contrasting perceptions of the AV at the same time was highlighted in a qualitative study that explored the impact of the AV on cognitive behavioural therapy (Collie et al., 2020). The AV developed as a result of offering some positive functions for the individual, such as reducing loneliness or improving self-esteem. Whilst the AV was described as growing increasingly more critical over time, often the positive functions of the AV remained, and individuals reported feeling attached to it despite also experiencing distress from it. The experience of feeling trapped by the AV and yet unwilling to let it go is a double bind found in previous ED research (Espíndola & Blay, 2009). A meta-ethnography by Eaton (2019) likened the ED to a life jacket that provides a sense of safety and security even when recognising its destructiveness and distress. This metaphor may also reflect the attachment to the AV. Appraisals of the AV as powerful and both malevolent and benevolent, leading to attempts to both resist and engage with the voice, may explain why individuals struggle to let go of their AV even when it is felt to be hostile and overpowering. It is clear that the AV is a unique phenomenon from other auditory hallucinations and rather than changing in a linear fashion from benevolent to malevolent, it is comprised of elements of both, that may fluctuate in their dominance over time. It should be noted that this study only examined general relationships between characteristics of the AV and was not able to tease apart specific associations between variables for individuals at different stages of their journey with their ED, which could be an area for future research.

It should be noted that there was not a significant association between resistance and power (measured using the TVRS). The TVRS uses a single Likert item to measure power of the AV as well as other topographical features and was therefore used as a measure to track

changes in perceptions of the AV at different stages of the experiment. However, single item scales have been subject to scrutiny for lack of internal consistency and difficulties in capturing the complexity of a psychological construct in one statement (Allen et al., 2022). It is possible the TVRS is a less robust measure of power and therefore may explain the lack of significant association with resistance, which did exist when measured with the BAVQ-R. Future research exploring AV power may want to consider the use of more rigorous measurement scales, such as the Voice Power Differential Scale (VPDS; Birchwood et al., 2000) which uses seven self-report items to measure the power and dominance of voices and has good internal reliability (Birchwood et al., 2018; Ratcliff et al., 2011).

4.3. Hypothesis 3.

There was no significant interaction effect of participant condition x time on power of the AV, thus hypothesis three can be rejected. Post hoc analyses indicated that power of the AV significantly increased from baseline after the first intervention trial, regardless of whether participants suppressed or accepted the experience of it. There was no significant change after the second intervention trial with power remaining relatively stable. These results suggest that engaging with the AV, regardless of what metacognitive control strategy is used, increases its perceived power. Whilst research has suggested that individuals with EDs are more likely to try and suppress negative internal experiences such as the AV, this did not impact power of the AV any differently than trying to accept the experience of it. This is a novel finding and has important implications for clinical practice.

It is not likely that the lack of an expected interaction effect was due to methodological issues. Although the experiment was conducted online and participants were provided with audio and written instructions to suppress or accept the AV, the manipulation checks built

into the experimental study indicated that the participants did follow these instructions. The manipulation checks were adapted from previous experimental research by Marcks and Woods (2005) who did find a significant effect from their intervention. While it is possible that responses were influenced by demand characteristics, this was somewhat controlled for by the use of a within-subjects design where participants were blind to the other condition. Furthermore, participants were randomised to their conditions and no significant differences existed between the two groups at baseline, which adds to the rigour of the design.

The finding that engaging with the AV in any way, whether by suppressing or accepting it, results in an increase in power has implications for clinical practice. It is well documented that recovery rates for EDs are poor and disengagement and drop-out from therapy is high (Mahon, 2000). An evaluation of patient pathways within two adult ED services in the UK found only half the number of individuals who entered treatment completed it (Waller et al., 2009). Motivation to change for individuals with EDs is often low, with many reporting feeling ambivalent about committing to recovery (Macdonald et al., 2012). The findings of the present study could make sense of this: if the perceived power of a malevolent AV increases when individuals are asked to think about it, talking therapies may lead individuals to feel more trapped by the AV. On the other hand, if benevolent qualities are made more powerful, individuals may want to continue engaging with it, which might hinder psychological therapy. Whilst current recommended therapeutic interventions such as CBT-E do not directly address the AV, they do ask the individual to address and change disordered behaviours, which is likely to involve thinking about the AV and may therefore increase its power. Qualitative research has described how the AV became a barrier to engaging in CBT, encouraging dishonesty and disengagement (Collie et al., 2020).

Working with individuals to change their relationship with the AV in order to minimise its power prior to starting formal therapy may be an important first step in reducing therapy drop out and improving recovery outcomes. Whilst the AV is still a relatively unexplored phenomenon beyond qualitative accounts of the experience, some initial research has started to explore adapting existing interventions to consider the AV. Hibbs and colleagues (2021) developed a brief six-session emotion-focused therapy (EFT) intervention that was modified to work with the AV. This involved the use of two-chair dialogue to externalise the AV and support individuals to establish boundaries against it and soften its impact. The use of chairwork with the AV has some preliminary support from single case reports (Dolhanty & Greenberg, 2009). Thematic analysis of qualitative responses described positive changes in individuals relationship with their AV. Participants felt their responses to the AV had changed, along with feeling more motivated to change as a result of the brief intervention. Some preliminary research with voice dialogue (Chua et al., 2022), which is another technique that supports better awareness and separation from the AV, has reported similar findings; participants felt they had a better understanding of their AV and could stand up to it more, as well as feeling more motivated and optimistic about recovery. Further research exploring the impact of emotion-focused therapeutic approaches is ongoing within the UK, with a multisite feasibility trial of Specialist Psychotherapy with Emotion for Anorexia in progress (Oldershaw et al., 2022). This research aims to focus on emotional experiences in AN that may be maintaining eating difficulties, including feelings of a lost sense of identity (Oldershaw et al., 2019) and incorporates EFT-techniques such as chairwork to enable “parts of the self to communicate” (Oldershaw et al., 2022, p. 4). It would be of interest to see through the qualitative outcomes of this research whether there is any positive impact on the AV, as demonstrated in the aforementioned brief interventions on chairwork and voice dialogue.

It is interesting that these techniques that involve discourse with the AV positively affected relationships with the voice whilst engaging with the AV through voice suppression and acceptance in this study increased its perceived power. Chairwork and voice dialogue creates psychological distance from the AV by reconceptualising it as a different part of them through the use of externalisation. Acceptance on the other hand, encourages individuals to sit with the AV without judgement, not getting caught up in trying to argue with it or push it away. The use of externalisation techniques to help separate the AV from the person as shown in chairwork and voice dialogue, may be important in reducing the AV's perceived power. It should also be recognised that this research study used a very brief acceptance-based intervention (approximately two minutes) compared to the hour-long sessions by Chua et al. (2022) and Hibbs et al. (2021). Power of the AV did stabilise by the second intervention trial, so it would have been of interest to assess the impact on power over a longer duration. More intensive studies of acceptance, through randomised control trials of acceptance and commitment therapy, have found positive impact on ED symptomatology (Onnink et al., 2022). Therefore, it would be of interest to further explore both the impact of chairwork/voice dialogue on the AV, but also more intensive acceptance-based interventions.

4.4. Exploratory analyses.

In this study there was no impact of voice suppression on either the frequency of or distress arising from the AV. Trying to control the AV by pushing it away did not produce the expected rebound effect in frequency that has been demonstrated with cognitions and other voices in the literature (Badcock et al., 2011; Marcks & Woods, 2005). This lack of rebound effect does

suggest that the AV may be a distinct phenomenon from other auditory hallucinations as already suggested by the unique appraisals of the AV.

That acceptance led to an increase in frequency of the AV, but no increase in distress may make sense in the context of appraisals of it as benevolent. If the AV is considered a kind, helpful or supportive entity, that one wants to engage with, then it makes sense in this research that an increase in its frequency was not distressing. Some parallels can be made to the experiences of auditory hallucinations in other populations, where 'clinical' and non-clinical' voice hearers are typically distinguished by distress levels. Typically, high distress levels resulting from a voice leads to contact with mental health services and classifications as a clinical voice hearer as well as a diagnostic label (Taylor & Murray, 2012). Research by Andrew, Gray and Snowden (2008) found differences between clinical and non-clinical voice hearers included appraisals of the voice as malevolent or benevolent. If the AV continues to retain some of its positive functions over time, which contributes to appraisals of it as at least partly benevolent, it makes sense that its increased presence and power is not distressing.

Furthermore, the lack of distress may be linked to a sense of pride in one's ED, as has been shown in the literature (Faija et al., 2017). Some individuals described feeling proud of their willpower and ability to restrict and lose weight, often in comparison to others who were not capable of this. Over time this pride became more toxic and pathological in nature, where individuals felt consumed by their ED yet still experienced a sense of empowerment and positive feelings from extremely disordered behaviours. If the AV is advocating for restrictive/compensatory behaviours that lead to a sense of pride for the individual, then it makes sense that some individuals may be accepting of its presence and not always distressed by it. It is clear from this current study that the AV is multifaceted, and can be appraised as

malevolent and benevolent at the same time, in differing amounts and fluctuating across the course of the ED.

4.5. Strengths and Limitations.

When considering the results of this research, that engaging with the AV increases its perceived power, it may in part be explained by the large attrition rate and therefore self-selecting sample. From the 84 participants who fully completed the screening survey and consented to be contacted for follow-up, only 32 continued to complete the experimental intervention. When participants were contacted about the experimental stage, they were informed that they would be asked to think about their AV and to only sign up if they felt able to manage that, particularly as the study was taking part online. Therefore, participants who signed up for this research were likely those who a) were motivated to engage in thinking about the AV and b) felt able to manage distress that arose from it. It could be possible this influenced some of the findings of this study such as little impact on distress as these participants already had suitable coping strategies in place. However, in order to ensure this research met appropriate ethical standards and to minimise any potential harm, it was important that participants knew they would be asked to think about the AV prior to signing up for the experimental study. Thus, the risk of a self-selecting sample was unavoidable.

Whilst the participant sample reflected a wide age range, it was predominantly female, white, and western, which may impact generalisability of these findings. It is well documented that other cultures often hold different meanings of hearing voices, often with a spiritual context (Luhmann et al., 2015) rather than being pathologized as typically found in white western countries. Future research would do well to explore the experience of the AV and appraisals of it amongst individuals from other cultures and genders.

A strength of this research study comes from the methodological design, which was supported by manipulation checks. This study demonstrated the feasibility of carrying out an experimental voice suppression and acceptance intervention online using Qualtrics and Zoom, whilst retaining many features of an in-person study such as individualised debrief. Furthermore, the sample size was sufficient to detect a medium sized effect, and randomisation of participants helped to rule out the influence of extraneous variables such as ED severity. Whilst the findings of this study did not ultimately support hypothesis three, there can be confidence that this was not a result of methodological limitations.

This study could be further improved through a more intensive design. This study compared two intervention groups, who were asked to engage with their AV through voice suppression or acceptance. It would be of interest to compare this against a no intervention control group, who are simply asked to do nothing for two minutes and examine the impact on the AV. This would allow greater understanding of how engaging with the AV influences its power and other topographical features. In addition, this research study was a brief, time-limited intervention consisting of two trials that involved two minutes of voice suppression or acceptance. As shown in the results, power of the AV increased significantly after the first trial but showed a small non-significant decrease after trial 2. This possibly suggests that the impact on power is short-lived and had further trials taken place, may have shown a continued decrease. Future research should consider additional trials in order to measure the duration of changes to power of the AV. Increasing the length of trials may also allow for exploration of the intensity of power of the AV, for example, does the AV become more powerful when engaging with it for a greater period of time. These adaptations would allow for greater understanding of the AV and thus improve clinical practice.

4.6. Conclusion.

This experimental study was interested in the impact of voice suppression on the power of the AV. Firstly, the study highlighted a complex relationship amongst appraisals of the AV, with it being perceived as powerful, benevolent, and malevolent alongside desires to engage with it and resist it. Secondly, the findings demonstrated that thinking about the AV, through voice suppression or acceptance, increased its perceived power. This did not result in any changes in distress. This has important clinical implications as thinking about the AV increases its perceived power, which becomes a barrier to engagement and may explain the high therapy drop-out rates for EDs. Preliminary research has begun to explore how to change the relationship with the AV as a precursor to therapy and future research should continue this in order to better understand the AV and hopefully improve outcomes for people with EDs.

References.

- Aardoom, J. J., Dingemans, A. E., Op't Landt, M. C. S., & Van Furth, E. F. (2012). Norms and discriminative validity of the Eating Disorder Examination Questionnaire (EDE-Q). *Eating behaviors*, 13(4), 305-309. <https://doi.org/10.1016/j.eatbeh.2012.09.002>
- Allen, M. S., Iliescu, D., & Greiff, S. (2022). Single item measures in psychological science: A call to action [Editorial]. *European Journal of Psychological Assessment*, 38(1), 1–5. <https://doi.org/10.1027/1015-5759/a000699>
- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders*, 5th Edition: DSM-5 (5th ed). American Psychiatric Publishing. <https://doi.org/10.1176/appi.books.9780890425596>
- Andrew, E. M., Gray, N. S., & Snowden, R. J. (2008). The relationship between trauma and beliefs about hearing voices: a study of psychiatric and non-psychiatric voice hearers. *Psychological Medicine*, 38(10), 1409–1417. <https://doi.org/10.1017/s003329170700253x>
- Arcelus, J., Mitchell, A. J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders: a meta-analysis of 36 studies. *Archives of general psychiatry*, 68(7), 724-731. <https://doi.org/10.1001/archgenpsychiatry.2011.74>
- Atwood, M. E., & Friedman, A. (2020). A systematic review of enhanced cognitive behavioral therapy (CBT-E) for eating disorders. *International Journal of Eating Disorders*, 53(3), 311-330. <https://doi.org/10.1002/eat.23206>

- Aya, V., Ulusoy, K., & Cardi, V. (2019). A systematic review of the 'eating disorder voice' experience. *International Review of Psychiatry*, 31(4), 347-366.
<https://doi.org/10.1080/09540261.2019.1593112>
- Badcock, J. C., Paulik, G., & Maybery, M. T. (2011). The role of emotion regulation in auditory hallucinations. *Psychiatry Research-neuroimaging*, 185(3), 303–308.
<https://doi.org/10.1016/j.psychres.2010.07.011>
- Beat. (2015). *The cost of eating disorders; social, health and economic impacts*.
https://www.basw.co.uk/system/files/resources/basw_104500-2_0.pdf
- Birchwood, M., Dunn, G., Meaden, A., TARRIER, N., Lewis, S., Wykes, T., Davies, L., Michail, M., & Peters, E. (2018). The COMMAND trial of cognitive therapy to prevent harmful compliance with command hallucinations: Predictors of outcome and mediators of change. *Psychological Medicine*, 48(12), 1966-1974.
<https://doi.org/10.1017/S0033291717003488>
- Birchwood, M., Gilbert, P., Gilbert, J. C., Trower, P., Meaden, A., Hay, J. R., Murray, E. J., & Miles, J. N. V. (2004). Interpersonal and role-related schema influence the relationship with the dominant 'voice' in schizophrenia: a comparison of three models. *Psychological Medicine*, 34(8), 1571–1580.
<https://doi.org/10.1017/s0033291704002636>
- Birchwood, M., Meaden, A., Trower, P., Gilbert, P., & Plaistow, J. (2000). The power and omnipotence of voices: subordination and entrapment by voices and significant others. *Psychological Medicine*, 30(2), 337–344.
<https://doi.org/10.1017/s0033291799001828>

- Broussard, B. B. (2005). Women's experiences of bulimia nervosa. *Journal of Advanced Nursing*, 49(1), 43-50. <https://doi.org/10.1111/j.1365-2648.2004.03262.x>
- Carey, M., Kupeli, N., Knight, R., Troop, N. A., Jenkinson, P. M., & Preston, C. (2019). Eating Disorder Examination Questionnaire (EDE-Q): Norms and psychometric properties in UK females and males. *Psychological Assessment*, 31(7), 839-85. <https://doi.org/10.1037/pas0000703>
- Casstevens, W., Coker, J., & Sanders, T. (2012). Mentored Self-Help: A Promising Approach to Exploring Voices. *Ethical Human Psychology and Psychiatry*, 14, 110-124. <https://doi.org/10.1891/1559-4343.14.2.110>
- Chadwick, P., & Birchwood, M. (1994). The omnipotence of voices: A cognitive approach to auditory hallucinations. *The British Journal of Psychiatry*, 164(2), 190-201. <https://doi.org/10.1192/bjp.164.2.190>
- Chadwick, P., Lees, S. H., & Birchwood, M. (2000). The revised Beliefs About Voices Questionnaire (BAVQ-R). *British Journal of Psychiatry*, 177(3), 229-232. <https://doi.org/10.1192/bjp.177.3.229>
- Chua, N., Serpell, L., Burnett-Stuart, S., & Pugh, M. (2022). Interviewing anorexia: How do individuals given a diagnosis of anorexia nervosa experience Voice Dialogue with their eating disorder voice? A qualitative analysis. *Clinical psychology & psychotherapy*, 29(2), 600-610. <https://doi.org/10.1002/cpp.2652>
- Collie, H., Fox, J., & Woodward, D. (2020). *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*. (Doctoral dissertation). <https://orca.cardiff.ac.uk/id/eprint/134991/2/HCollie%20Thesis%20for%20ORCA.pdf>

- Cooper, M. J., Grocutt, E., Deepak, K., & Bailey, E. (2007). Metacognition in anorexia nervosa, dieting and non-dieting controls: A preliminary investigation. *British journal of clinical psychology, 46*(1), 113-117. <https://doi.org/10.1348/014466506X115245>
- Dolhanty, J., & Greenberg, L. S. (2009). Emotion-focused therapy in a case of anorexia nervosa. *Clinical Psychology & Psychotherapy, 16*(4), 336–382. <https://doi.org/10.1002/cpp.624>
- Eaton, C. M. (2019). Eating Disorder Recovery: A Metaethnography. *Journal of the American Psychiatric Nurses Association, 26*(4), 373–388. <https://doi.org/10.1177/1078390319849106>
- Espíndola, C. R., & Blay, S. L. (2009). Anorexia Nervosa’s Meaning to Patients: A Qualitative Synthesis. *Psychopathology, 42*(2), 69–80. <https://doi.org/10.1159/000203339>
- Faija, C. L., Tierney, S., Gooding, P. A., Peters, S., & Fox, J. R. (2017). The role of pride in women with anorexia nervosa: A grounded theory study. *Psychology and Psychotherapy: Theory, Research and Practice, 90*(4), 567-585. <https://doi.org/10.1111/papt.12125>
- Fairburn, C. G., & Beglin, S. J. (2008). Eating Disorder Examination Questionnaire (EDE-Q 6.0). In C. G. Fairburn (Ed.), *Cognitive behavior therapy and eating disorders* (pp. 309–313). Guilford Press.
- Fairburn, C. G., Cooper, Z., Doll, H. A., O'Connor, M. E., Bohn, K., Hawker, D. M., Wales, J. A., & Palmer, R. L. (2009). Transdiagnostic cognitive-behavioral therapy for patients with eating disorders: a two-site trial with 60-week follow-up. *The American journal of psychiatry, 166*(3), 311–319. <https://doi.org/10.1176/appi.ajp.2008.08040608>

Fairburn, C. G., & Cooper, Z. (2011). Eating disorders, DSM–5 and clinical reality. *The British journal of psychiatry*, 198(1), 8-10. <https://doi.org/10.1192/bjp.bp.110.083881>

Field, A. (2013). *Discovering statistics using IBM SPSS statistics*. Sage.

Galmiche, M., Déchelotte, P., Lambert, G., & Tavalacci, M. P. (2019). Prevalence of eating disorders over the 2000–2018 period: a systematic literature review. *The American journal of clinical nutrition*, 109(5), 1402-1413. <https://doi.org/10.1093/ajcn/nqy342>

Gilbert, P., Birchwood, M., Gilbert, J., Trower, P., Hay, J., Murray, B., ... & Miles, J. N. V. (2001). An exploration of evolved mental mechanisms for dominant and subordinate behaviour in relation to auditory hallucinations in schizophrenia and critical thoughts in depression. *Psychological medicine*, 31(6), 1117-1127.

<https://doi.org/10.1017/s0033291701004093>

Grilo, C. M. (2006). *Eating and weight disorders*. Psychology Press.

Harris, R. (2008). *Acceptance and Commitment Therapy (ACT) Introductory Workshop Handout*. http://www.actmindfully.com.au/upimages/2008_Introductory_ACT_Workshop_Handout_-_Russ_Harris.pdf

Hay, P., Mitchison, D., Collado, A. E. L., González-Chica, D. A., Stocks, N., & Touyz, S. (2017). Burden and health-related quality of life of eating disorders, including Avoidant/Restrictive Food Intake Disorder (ARFID), in the Australian population. *Journal of eating disorders*, 5(1), 1-10. <https://doi.org/10.1186/s40337-017-0149-z>

Hayes, S. C., & Wilson, K. G. (1994). Acceptance and commitment therapy: Altering the verbal support for experiential avoidance. *The Behavior Analyst*, 17(2), 289-303. <https://doi.org/10.1007/BF03392677>

- Hayes, S. C., Strosahl, K., Wilson, K. G., Bissett, R. T., Pistorello, J., Toarmino, D., ... & McCurry, S. M. (2004). Measuring experiential avoidance: A preliminary test of a working model. *The psychological record, 54*, 553-578.
<https://doi.org/10.1007/BF03395492>
- Hibbs, R., Pugh, M., & Fox, J. (2021). Applying emotion-focused therapy to work with the “anorexic voice” within anorexia nervosa: A brief intervention. *Journal of Psychotherapy Integration, 31*(4), 327–347. <https://doi.org/10.1037/int0000252>
- Higbed, L., & Fox, J. R. (2010). Illness perceptions in anorexia nervosa: A qualitative investigation. *British Journal of Clinical Psychology, 49*(3), 307-325.
<https://doi.org/10.1348/014466509X454598>
- Hill, K., Varese, F., Jackson, M., & Linden, D. E. (2012). The relationship between metacognitive beliefs, auditory hallucinations, and hallucination-related distress in clinical and non-clinical voice-hearers. *British journal of clinical psychology, 51*(4), 434-447. <https://doi.org/10.1111/j.2044-8260.2012.02039.x>
- Hustig, H., & Hafner, R. J. (1990). Persistent Auditory Hallucinations and Their Relationship to Delusions and Mood. *Journal of Nervous and Mental Disease, 178*(4), 264–267.
<https://doi.org/10.1097/00005053-199004000-00009>
- Johns, G., Taylor, B., John, A., & Tan, J. (2019). Current eating disorder healthcare services—the perspectives and experiences of individuals with eating disorders, their families and health professionals: systematic review and thematic synthesis. *BJPsych Open, 5*(4), e59. <https://doi.org/10.1192/bjo.2019.48>

- Lawrence, C., Jones, J., & Cooper, M. (2010). Hearing voices in a non-psychiatric population. *Behavioural and cognitive psychotherapy*, 38(3), 363-373.
<https://doi.org/10.1017/s1352465810000172>
- Lipson, S. K., & Sonnevile, K. R. (2017). Eating disorder symptoms among undergraduate and graduate students at 12 U.S. colleges and universities. *Eating Behaviors*, 24, 81–88. <https://doi.org/10.1016/j.eatbeh.2016.12.003>
- Luhrmann, T. M., Padmavati, R., Tharoor, H., & Osei, A. (2015). Hearing Voices in Different Cultures: A Social Kindling Hypothesis. *Topics in Cognitive Science*, 7(4), 646–663.
<https://doi.org/10.1111/tops.12158>
- Macdonald, P., Hibbs, R., Corfield, F., & Treasure, J. (2012). The use of motivational interviewing in eating disorders: a systematic review. *Psychiatry Research-neuroimaging*, 200(1), 1–11. <https://doi.org/10.1016/j.psychres.2012.05.013>
- Mahon, J. (2000). Dropping Out from Psychological Treatment for Eating Disorders: What are the Issues? *European Eating Disorders Review*, 8(3), 198–216.
[https://doi.org/10.1002/\(sici\)1099-0968\(200005\)8:3](https://doi.org/10.1002/(sici)1099-0968(200005)8:3)
- Marcks, B. A., & Woods, D. W. (2005). A comparison of thought voice suppression to an acceptance-based technique in the management of personal intrusive thoughts: A controlled evaluation. *Behaviour research and therapy*, 43(4), 433-445.
<https://doi.org/10.1016/j.brat.2004.03.005>
- Mawson, A., Cohen, K., & Berry, K. (2010). Reviewing evidence for the cognitive model of auditory hallucinations: The relationship between cognitive voice appraisals and distress during psychosis. *Clinical psychology review*, 30(2), 248-258.
<https://doi.org/10.1016/j.cpr.2009.11.006>

- Mond, J. M., Hay, P. J., Rodgers, B., Owen, C., & Beumont, P. J. V. (2004). Validity of the Eating Disorder Examination Questionnaire (EDE-Q) in screening for eating disorders in community samples. *Behaviour research and therapy*, 42(5), 551-567.
[https://doi.org/10.1016/S0005-7967\(03\)00161-X](https://doi.org/10.1016/S0005-7967(03)00161-X)
- Murphy, R., Straebl, S., Cooper, Z., & Fairburn, C. G. (2010). Cognitive behavioral therapy for eating disorders. *Psychiatric Clinics*, 33(3), 611-627.
<https://doi.org/10.1016/j.psc.2010.04.004>
- Murray, J. (2013). Likert data: what to use, parametric or non-parametric?. *International Journal of Business and Social Science*, 4(11).
- National Institute for Health and Care Excellence. (2017). *NICE guideline [NG69] Eating Disorders: Recognition and Treatment*. NICE.
<https://www.nice.org.uk/guidance/ng69>
- National Psychological Therapies Management Committee. (2017). *Matrics Cymru: Evidence Tables*. Public Health Wales. <https://phw.nhs.wales/services-and-teams/improvement-cymru/our-work/mental-health/psychological-therapies/resources-psychological-therapies/evidence-tables-evidence-tables-matrics-cymru/>
- Noordenbos, G., Aliakbari, N., & Campbell, R. (2014). The relationship among critical inner voices, low self-esteem, and self-criticism in eating disorders. *Eating disorders*, 22(4), 337-351. <https://doi.org/10.1080/10640266.2014.898983>
- Oldershaw, A., Lavender, T., Basra, R., & Startup, H. (2022). SPEAKS study: study protocol of a multisite feasibility trial of the Specialist Psychotherapy with Emotion for Anorexia in Kent and Sussex (SPEAKS) intervention for outpatients with anorexia nervosa or

otherwise specified feeding and eating disorders, anorexia nervosa type. *BMJ open*, 12(2), e050350. doi: 10.1136/bmjopen-2021-050350

Oldershaw, A., Startup, H., & Lavender, T. (2019). Anorexia nervosa and a lost emotional self: a psychological formulation of the development, maintenance, and treatment of anorexia nervosa. *Frontiers in psychology*, 10, 219.
<https://doi.org/10.3389/fpsyg.2019.00219>

Olstad, S., Solem, S., Hjemdal, O., & Hagen, R. (2015). Metacognition in eating disorders: Comparison of women with eating disorders, self-reported history of eating disorders or psychiatric problems, and healthy controls. *Eating behaviors*, 16, 17-22.
<https://doi.org/10.1016/j.eatbeh.2014.10.019>

Onnink, C. M., Konstantinidou, Y., Moskovich, A. A., Karekla, M. K., & Merwin, R. M. (2022). Acceptance and commitment therapy (ACT) for eating disorders: A systematic review of intervention studies and call to action. *Journal of Contextual Behavioral Science*. 26, 11-28. <https://doi.org/10.1016/j.icbs.2022.08.005>

Pugh, M. (2016). The internal 'anorexic voice': a feature or fallacy of eating disorders?. *Advances in Eating Disorders*, 4(1), 75-83.
<https://doi.org/10.1080/21662630.2015.1116017>

Pugh, M., & Waller, G. (2016). The anorexic voice and severity of eating pathology in anorexia nervosa. *International Journal of Eating Disorders*, 49(6), 622-625.
<https://doi.org/10.1002/eat.22499>

Pugh, M., & Waller, G. (2017). Understanding the 'anorexic voice' in anorexia nervosa. *Clinical psychology & psychotherapy*, 24(3), 670-676.
<https://doi.org/10.1002/cpp.2034>

- Qian, J., Wu, Y., Liu, F., Zhu, Y., Jin, H., Zhang, H., ... & Yu, D. (2021). An update on the prevalence of eating disorders in the general population: a systematic review and meta-analysis. *Eating and Weight Disorders-Studies on Anorexia, Bulimia and Obesity*, 27, 1-14. <https://doi.org/10.1007/s40519-021-01162-z>
- Ratcliff, K., Farhall, J., & Shawyer, F. (2011). Auditory hallucinations: a review of assessment tools. *Clinical Psychology & Psychotherapy*, 18(6), 524-534. <https://doi.org/10.1002/cpp.729>
- Romme, M. A. J., Honig, A., Noorthoorn, E. O., & Escher, A. D. M. A. C. (1992). Coping with hearing voices: An emancipatory approach. *The British Journal of Psychiatry*, 161(1), 99-103. <https://doi.org/10.1192/bjp.161.1.99>
- Salkovskis, P. M., & Campbell, P. S. (1994). Thought voice suppression induces intrusion in naturally occurring negative intrusive thoughts. *Behaviour Research and Therapy*, 32(1), 1-8. [https://doi.org/10.1016/0005-7967\(94\)90077-9](https://doi.org/10.1016/0005-7967(94)90077-9)
- Sayer, J., Ritter, S., & Gournay, K. (2000). Beliefs about voices and their effects on coping strategies. *Journal of Advanced Nursing*, 31(5), 1199-1205. <https://doi.org/10.1046/j.1365-2648.2000.01375.x>
- Sonneville, K. R., & Lipson, S. K. (2018). Disparities in eating disorder diagnosis and treatment according to weight status, race/ethnicity, socioeconomic background, and sex among college students. *International Journal of Eating Disorders*, 51(6), 518-526. <https://doi.org/10.1002/eat.22846>
- Spratt, C. J., MacKenzie Myles, L. A., & Merlo, E. M. (2022). Eating Disorders in Men: A Comprehensive Summary. *Journal of Mind and Medical Sciences*, 9(2), 249-254. <https://doi.org/10.22543/2392-7674.1362>

- Sullivan, P. F. (1995). Mortality in anorexia nervosa. *American Journal of Psychiatry*, *152*(7), 1073-1074. <https://doi.org/10.1176/ajp.152.7.1073>
- Tabachnick, B. G., & Fidell, L. S. (2012). *Using multivariate statistics* (6th ed.). Allyn & Bacon.
- Taylor, G., & Murray, C. (2012). A qualitative investigation into non-clinical voice hearing: what factors may protect against distress? *Mental Health, Religion & Culture*, *15*(4), 373–388. <https://doi.org/10.1080/13674676.2011.577411>
- Tierney, S., & Fox, J. R. (2010). Living with the anorexic voice: A thematic analysis. *Psychology and psychotherapy: theory, research and practice*, *83*(3), 243-254. <https://doi.org/10.1348/147608309X480172>
- Tierney, S., & Fox, J. R. (2011). Trapped in a toxic relationship: Comparing the views of women living with anorexia nervosa to those experiencing domestic violence. *Journal of Gender Studies*, *20*(01), 31-41. <https://doi.org/10.1080/09589236.2011.542018>
- Tully, S., Wells, A., & Morrison, A. P. (2017). Attentional avoidance increases voice hearing in an analogue task in people with psychosis: An experimental study. *Psychiatry Research-neuroimaging*, *257*, 186–192. <https://doi.org/10.1016/j.psychres.2017.07.052>
- Van Eeden, A. E., van Hoeken, D., & Hoek, H. W. (2021). Incidence, prevalence and mortality of anorexia nervosa and bulimia nervosa. *Current opinion in psychiatry*, *34*(6), 515. <https://doi.org/10.1097%2FYCO.0000000000000739>
- Van Hoeken, D., & Hoek, H. W. (2020). Review of the burden of eating disorders: mortality, disability, costs, quality of life, and family burden. *Current Opinion in Psychiatry*, *33*(6), 521. <https://doi.org/10.1097/yco.0000000000000641>

Waller, G., Schmidt, U., Treasure, J., Murray, K. S., Aleyana, J., Emanuelli, F., Crockett, J., & Yeomans, M. (2009). Problems across care pathways in specialist adult eating disorder services. *Psychiatric Bulletin*, 33(1), 26–29.

<https://doi.org/10.1192/pb.bp.107.018325>

Wells, A. (2000). *Emotional disorders and metacognition: Innovative cognitive therapy*. John Wiley & Sons Ltd.

Woolrich, R. A., Cooper, M. J., & Turner, H. M. (2008). Metacognition in patients with anorexia nervosa, dieting and non-dieting women: A preliminary study. *European Eating Disorders Review: The Professional Journal of the Eating Disorders Association*, 16(1), 11-20. <https://doi.org/10.1002/erv.802>

Appendices.

Appendix A. Author guidelines for submission to the British Journal of Health Psychology.

AIMS AND SCOPE

The British Journal of Health Psychology publishes original research on all aspects of psychology related to health, health-related behaviour and illness across the lifespan including:

experimental and clinical research on aetiology

management of acute and chronic illness

responses to ill-health

health-related behaviour change and maintenance

screening and medical procedures

psychosocial mediators and moderators of health-related behaviours

influence of emotion on health and health-related behaviours

psychosocial processes relevant to disease outcomes

psychological interventions in health and disease

emotional and behavioural responses to ill health, screening and medical procedures

psychological aspects of prevention

Papers must make a clear potential contribution to health psychology theory, knowledge and/or practice and employ rigorous research design and methodology.

We do not typically publish cross-sectional studies or those using only student populations unless there is a strong rationale for doing so.

Papers describing intervention development (without also presenting an analysis of the outcomes of the intervention) will usually only be considered if they make a contribution to health psychology theory, knowledge and/or practice beyond the specific intervention context.

3. MANUSCRIPT CATEGORIES

The types of paper invited are:

papers reporting original empirical investigations, using quantitative, qualitative or mixed methods;

theoretical papers which report analyses of theories in health psychology;

review papers, which should provide systematic overviews, evaluations and interpretations of research in a given field of health psychology (narrative reviews will only be considered for editorials or important theoretical discourses);

methodological papers dealing with methodological issues of particular relevance to health psychology;

we particularly welcome papers reporting effectiveness (for example, Randomised Controlled Trials) and process evaluations of interventions in clinical and non-clinical populations.

Authors who are interested in submitting papers that do not fit into these categories are advised to contact the editors who would be very happy to discuss the potential submission.

Papers describing quantitative research (including reviews with quantitative analyses) should be no more than 5000 words (excluding the abstract, reference list, tables and figures). Papers describing qualitative or mixed methods research (including reviews with qualitative analyses) should be no more than 6000 words (including quotes, whether in the text or in tables, but excluding the abstract, tables, figures and references). 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.

All systematic reviews must be pre-registered and an anonymous link to the pre-registration must be provided in the main document, so that it is available to reviewers. Systematic reviews without pre-registration details will be returned to the authors at submission.

Please refer to the separate guidelines for **Registered Reports**.

4. PREPARING THE SUBMISSION **Free Format Submission**

British Journal of Health Psychology now offers free format submission for a simplified and streamlined submission process.

Before you submit, you will need:

Your manuscript: this can be a single file including text, figures, and tables, or separate files – whichever you prefer (if you do submit separate files, we encourage you to also include your figures within the main document to make it easier for editors and reviewers to read your manuscript, but this is not compulsory). All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers. If your manuscript is difficult to read, the editorial office may send it back to you for revision.

The title page of the manuscript, including a data availability statement and your co-author details with affiliations. (*Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.*) You may like to use [this template](#) for your title page.

Parts of the Manuscript

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

Title Page

You may like to use **this template** 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;

The full names of the authors;

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](#));

Acknowledgments.

Author Contributions

For all articles, the journal mandates the CRediT (Contribution Roles Taxonomy)—more information is available on our [Author Services](#) site.

Abstract

For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. As the abstract is often the most widely visible part of your paper, it is important that it conveys succinctly all the most important features of your study. You can save words by writing short, direct sentences. Helpful hints about writing the conclusions to abstracts can be found [here](#).

Keywords

Please provide appropriate keywords.

Acknowledgements

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.

Statement of Contribution

All authors are required to provide a clear summary of 'what is already known on this subject?' and 'what does this study add?'. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each.

Main Text File

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

Manuscripts can be uploaded either as a single document (containing the main text, tables and figures), or with figures and tables provided as separate files. Should your manuscript reach revision stage, figures and tables must be provided as separate files. The main manuscript file can be submitted in Microsoft Word (.doc or .docx) or LaTeX (.tex) format.

Your main document file should include:

A short informative title containing the major key words. The title should not contain abbreviations;

Acknowledgments;

Abstract structured (intro/methods/results/conclusion);

Up to seven keywords;

Main body: formatted as introduction, materials & methods, results, discussion, conclusion;

References;

Tables (each table complete with title and footnotes);

Figure legends: Legends should be supplied as a complete list in the text. Figures should be uploaded as separate files (see below)

Statement of Contribution.

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.

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 spelling; however, authors may submit using either option, as spelling of accepted papers is converted during the production process.

References

This journal uses APA reference style; as the journal offers Free Format submission, however, this is for information only and you do not need to format the references in your article. This will instead be taken care of by the typesetter.

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.

Figures

Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted.

[Click here](#) for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

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

Supporting Information

Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc.

[Click here](#) for Wiley’s FAQs on supporting information.

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

General Style Points

For guidelines on editorial style, please consult the **[APA Publication Manual](#)** published by the American Psychological Association. The following points provide general advice on formatting and style.

Language: Authors must avoid the use of sexist or any other discriminatory language.

Abbreviations: In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.

Units of measurement: Measurements should be given in SI or SI-derived units. Visit the [Bureau International des Poids et Mesures \(BIPM\) website](#) for more information about SI units.

Effect size: In normal circumstances, effect size should be incorporated.

Numbers: numbers under 10 are spelt out, except for: measurements with a unit

Research Reporting Guidelines

Accurate and complete reporting enables readers to fully appraise research, replicate it, and use it. Authors are encouraged to adhere to recognised research reporting standards. The EQUATOR Network collects more than 370 reporting guidelines for many study types, including for:

Randomised trials: [CONSORT](#)

Systematic reviews: [PRISMA](#)

Interventions: [TIDieR](#)

We encourage authors to adhere to the APA Style Journal Article Reporting Standards for:

Manuscripts that report primary qualitative research

Manuscripts that report the collection and integration of qualitative and quantitative data

Manuscripts that report new data collections regardless of research design

We also encourage authors to refer to and follow guidelines from:

Future of Research Communications and e-Scholarship (FORCE11)

The Gold Standard Publication Checklist from Hooijmans and colleagues

FAIRsharing website

Conflict of Interest

The journal requires that all authors disclose any potential sources of conflict of interest. Any interest or relationship, financial or otherwise that might be perceived as influencing an author's objectivity is considered a potential source of conflict of interest. These must be disclosed when directly relevant or directly related to the work that the authors describe in their manuscript. Potential sources of conflict of interest include, but are not limited to: patent or stock ownership, membership of a company board of directors, membership of an advisory board or committee for a company, and consultancy for or receipt of speaker's fees from a company. The existence of a conflict of interest does not preclude publication. If the authors have no conflict of interest to declare, they must also state this at submission. It is the responsibility of the corresponding author to review this policy with all authors and collectively to disclose with the submission ALL pertinent commercial and other relationships.

Funding

Authors should list all funding sources in the Acknowledgments section. Authors are responsible for the accuracy of their funder designation. If in doubt, please check the Open Funder Registry for the correct nomenclature: <https://www.crossref.org/services/funder-registry/>

Authorship

All listed authors should have contributed to the manuscript substantially and have agreed to the final submitted version. Authorship is defined by the criteria set out in the APA Publication Manual:

"Individuals should only take authorship credit for work they have actually performed or to which they have substantially contributed (APA Ethics Code Standard 8.12a, Publication Credit). Authorship encompasses, therefore, not only those who do the actual writing but also those who have made substantial scientific contributions to a study. Substantial professional contributions may include formulating the problem or hypothesis, structuring the experimental design, organizing and conducting the statistical analysis, interpreting the results, or writing a major portion of the paper. Those who so contribute are listed in the byline." (p.18)

Data Sharing and Data Accessibility Policy

The *British Journal of Health Psychology* recognizes the many benefits of archiving data for scientific progress. Archived data provides an indispensable resource for the scientific community, making possible future replications and secondary analyses, in addition to the importance of verifying the dependability of published research findings.

The journal expects that where possible all data supporting the results in papers published are archived in an appropriate public archive offering open access and guaranteed preservation. The archived data must allow each result in the published paper to be recreated and the analyses reported in the paper to be replicated in full to support the conclusions made. Authors are welcome to archive more than this, but not less.

All papers need to be supported by a data archiving statement and the data set must be cited in the Methods section. Where relevant, the paper must include a link to the repository in order that the statement can be published.

It is not necessary to make data publicly available at the point of submission, but an active link must be included in the final accepted manuscript. For authors who have pre-registered studies, please use the Registered Report link in the Author Guidelines.

In some cases, despite the authors' best efforts, some or all data or materials cannot be shared for legal or ethical reasons, including issues of author consent, third party rights, institutional or national regulations or laws, or the nature of data gathered. In such cases, authors must inform the editors at the time of submission. It is understood that in some cases access will be provided under restrictions to protect confidential or proprietary information. Editors may grant exceptions to data access requirements provided authors explain the restrictions on the data set and how they preclude public access, and, if possible, describe the steps others should follow to gain access to the data.

If the authors cannot or do not intend to make the data publicly available, a statement to this effect, along with the reasons that the data is not shared, must be included in the manuscript.

Finally, if submitting authors have any questions about the data sharing policy, please access the [FAQs](#) for additional detail.

Publication Ethics

Authors are reminded that the *British Journal of Health Psychology* adheres to the ethics of scientific publication as detailed in the **Ethical principles of psychologists and code of conduct** (American Psychological Association, 2010). The Journal generally conforms to the Uniform Requirements for Manuscripts of the International Committee of Medical Journal Editors (**ICJME**) and is also a member and subscribes to the principles of the Committee on Publication Ethics (**COPE**). Authors must ensure that all research meets these ethical guidelines and affirm that the research has received permission from a stated Research Ethics Committee (REC) or Institutional Review Board (IRB), including adherence to the legal requirements of the study country.

Appendix B. Search Strategies.

Search strategy for PsychInfo (413 results) and Medline (1093 results).

1

Diabetes Mellitus/

2

diabetes mellitus.tw.

3

type 1 diabet*.tw.

4

type one diabet*.tw.

5

diabetes type 1.tw.

6

diabetes type one.tw.

7

1 or 2 or 3 or 4 or 5 or 6

8

adolescen*.tw.

9

teen*.tw.

10

child*.tw.

11

young person.tw.

12

young people.tw.

13

cyp.tw.

14

8 or 9 or 10 or 11 or 12 or 13

15

"Experiences (Events)"/

16

"Life Experiences"/

17
lived experience*.tw.

18
belief*.tw.

19
attitude*.tw.

20
quality of life.tw.

21
perspective*.tw.

22
identity.tw.

23
perception.tw.

24
15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23

25
(Interpretative phenomenological analysis or grounded theory or thematic analysis or content analysis or phenomenological approach or constructivist epistemological framework or semi-structured or semistructured or unstructured or informal or indepth or indepth or face-to-face or structured or guide* or interview* or discussion* or questionnaire* or focus group or qualitative or ethnograph* or field work or fieldwork or key informant).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

26
exp qualitative methods/

27
25 or 26

28
7 and 14 and 24 and 27

Search strategy for Scopus (1443 results).

(TITLE-ABS ("diabetes mellitus" OR "type 1 diabet*" OR "type one diabet*" OR "diabetes type 1" OR "diabetes type one") AND TITLE-ABS (adolescen* OR teen* OR child* OR "young person" OR "young people" OR cyp) AND TITLE-ABS-KEY ("lived experience*" OR belief* OR attitude* OR "quality of life" OR perspective* OR identity OR perception*) AND TITLE-ABS ("Interpretative phenomenological analysis" OR "grounded theory" OR "thematic analysis" OR "content analysis" OR "phenomenological approach" OR "constructivist epistemological framework" OR "semi-structured" OR semistructured OR unstructured OR informal OR indepth OR "face-to-face" OR structured OR guide* OR interview* OR discussion* OR questionnaire* OR "focus group" OR qualitative OR ethnograph* OR "field work" OR fieldwork OR "key informant"))

Search strategy for Cinahl (2142 results).

("diabetes mellitus" OR "type 1 diabet*" OR "type one diabet*" OR "diabetes type 1" OR "diabetes type one") AND (adolescen* OR teen* OR child* OR "young person" OR "young people" OR cyp) AND ("lived experience*" OR belief* OR attitude* OR "quality of life" OR perspective* OR identity OR perception*) AND ("Interpretative phenomenological analysis" OR "grounded theory" OR "thematic analysis" OR "content analysis" OR "phenomenological approach" OR "constructivist epistemological framework" OR "semi-structured" OR semistructured OR unstructured OR informal OR indepth OR "face-to-face" OR structured OR guide* OR interview* OR discussion* OR questionnaire* OR "focus group" OR qualitative OR ethnograph* OR "field work" OR fieldwork OR "key informant")

Search strategy for Web of Science (1599 results).

(TS=("diabetes mellitus" OR "type 1 diabet*" OR "type one diabet*" OR "diabetes type 1" OR "diabetes type one") AND TS=(adolescen* OR teen* OR child* OR "young person" OR "young people" OR cyp) AND TS=("lived experience*" OR belief* OR attitude* OR "quality of life" OR perspective* OR identity OR perception*) AND TS=("Interpretative phenomenological analysis" OR "grounded theory" OR "thematic analysis" OR "content analysis" OR "phenomenological approach" OR "constructivist epistemological framework" OR "semi-structured" OR semistructured OR unstructured OR informal OR indepth OR "face-to-face" OR structured OR guide* OR interview* OR discussion* OR questionnaire* OR "focus group" OR qualitative OR ethnograph* OR "field work" OR fieldwork OR "key informant"))

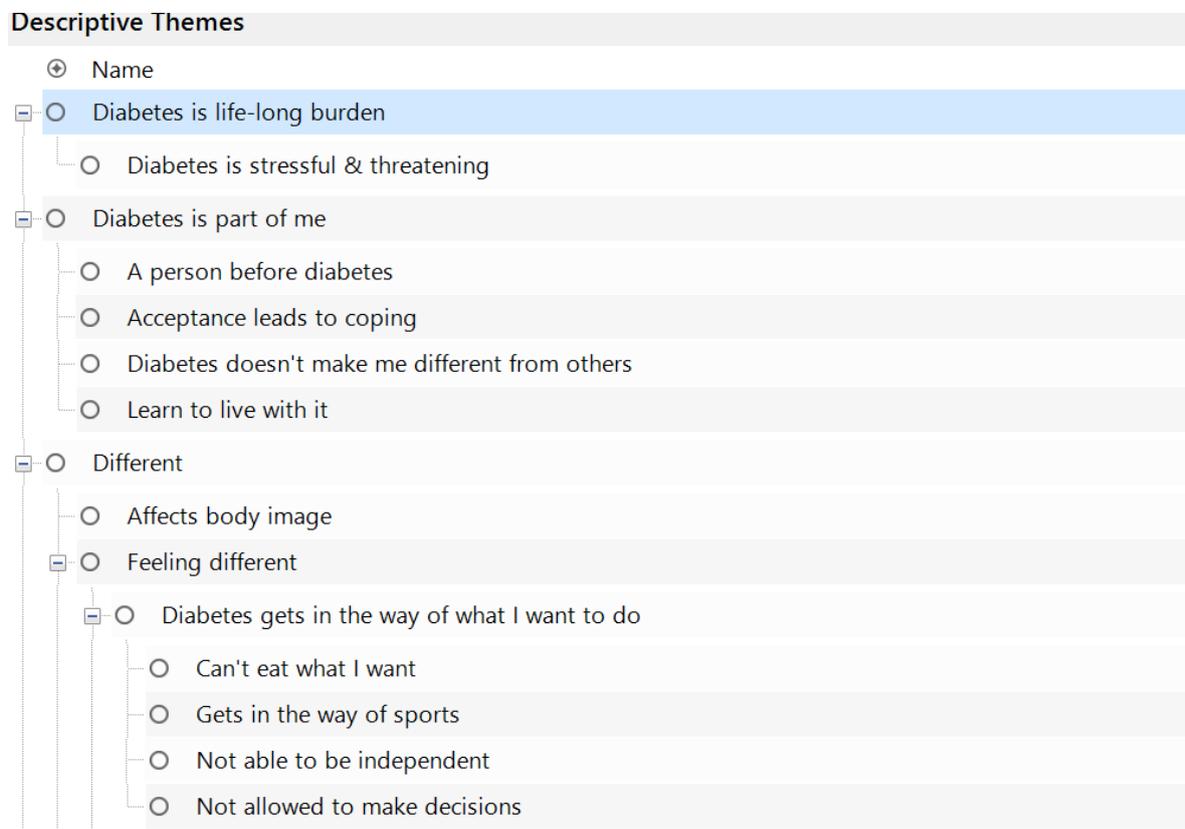
Appendix C. Example of coding and thematic analysis process using NVivo software.

Examples of initial codes.

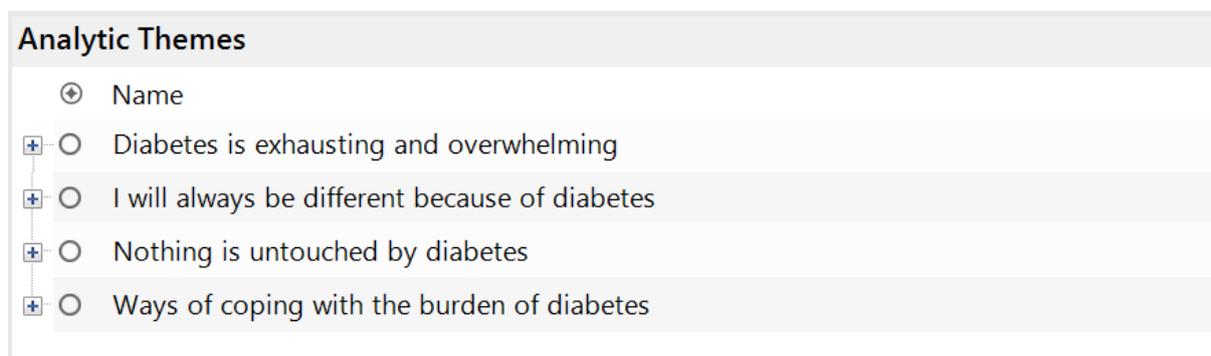
Initial codes		Search Project	
Name	Files	References	
<input type="radio"/> Diabetes becomes natural	3	3	
<input type="radio"/> Diabetes causes depression	1	1	
<input type="radio"/> Diabetes changed life	1	2	
<input type="radio"/> Diabetes controls me	3	4	
<input type="radio"/> Diabetes doesn't bother me	3	6	
<input type="radio"/> Diabetes doesn't define me	1	2	
<input type="radio"/> Diabetes doesn't make me different from others	3	3	
<input type="radio"/> Diabetes gets in the way of what I want to do	8	16	
<input type="radio"/> Diabetes has shaped identity	2	3	
<input type="radio"/> Diabetes is a burden	3	7	
<input type="radio"/> Diabetes is a life=long burden	5	8	
<input type="radio"/> diabetes is a prison	1	1	
<input type="radio"/> diabetes is a public social illness	1	1	
<input type="radio"/> Diabetes is part of me	4	8	
<input type="radio"/> Diabetes is stressful	4	7	
<input type="radio"/> Diabetes is threatening	3	4	
<input type="radio"/> Diabetes is time-consuming	1	1	
<input type="radio"/> Diabetes makes me stand out	2	2	
<input type="radio"/> Diagnosis difficult to accept at first	3	6	
<input type="radio"/> Diagnosis=Death	1	1	
JH 275 Items			

Initial codes		Search Project	
Name	Files	References	
<input type="radio"/> Other peers don't understand	2	2	
<input type="radio"/> Other's dont understand what is involved	1	1	
<input type="radio"/> Others overreact	2	2	
<input type="radio"/> Others think taking drugs	1	1	
<input type="radio"/> Parent involvement important	3	3	
<input type="radio"/> Parental involvement feels like lack of trust to manage diabetes	4	6	
<input type="radio"/> Parental lack of knowledge is frustrating	1	3	
<input type="radio"/> Parental over-protection stops me being a normal teenager	2	3	
<input type="radio"/> Parents are over-concerned and over-protective	5	13	
<input type="radio"/> Parents care	1	1	
<input type="radio"/> Parents need to trust children	1	2	
<input type="radio"/> Parents over-protection=care	2	3	
<input type="radio"/> Parents try to take burden off adolescents	2	2	
<input type="radio"/> Patients and aparents need support to manage transition to independence	2	2	
<input type="radio"/> Peer mentors	1	1	
<input type="radio"/> Peer understanding helps with management	3	5	
<input type="radio"/> People ask lots of questions	4	4	
<input type="radio"/> Permanent change	1	1	
<input type="radio"/> Positive professional relationships	1	1	
<input type="radio"/> Prevent medical crisis	1	1	
JH 275 Items			

Example of development of descriptive themes.



Example of development of analytic themes.



Analytic Themes

⊕ Name

☐ ○ Diabetes is exhausting and overwhelming

☐ ○ Feelings about treatment

○ Embarrassed about treatment

○ Fear of treatment

○ Indifference just as bad as fear

☐ ○ Shame

○ Stigma

☐ ○ Worry

○ Worry about blood sugar

○ Worry about complications

○ Worry about the future

☐ ○ Unrelenting daily treatment regime

☐ ○ Treatment leads to hypervigilance

☐ ○ Acting

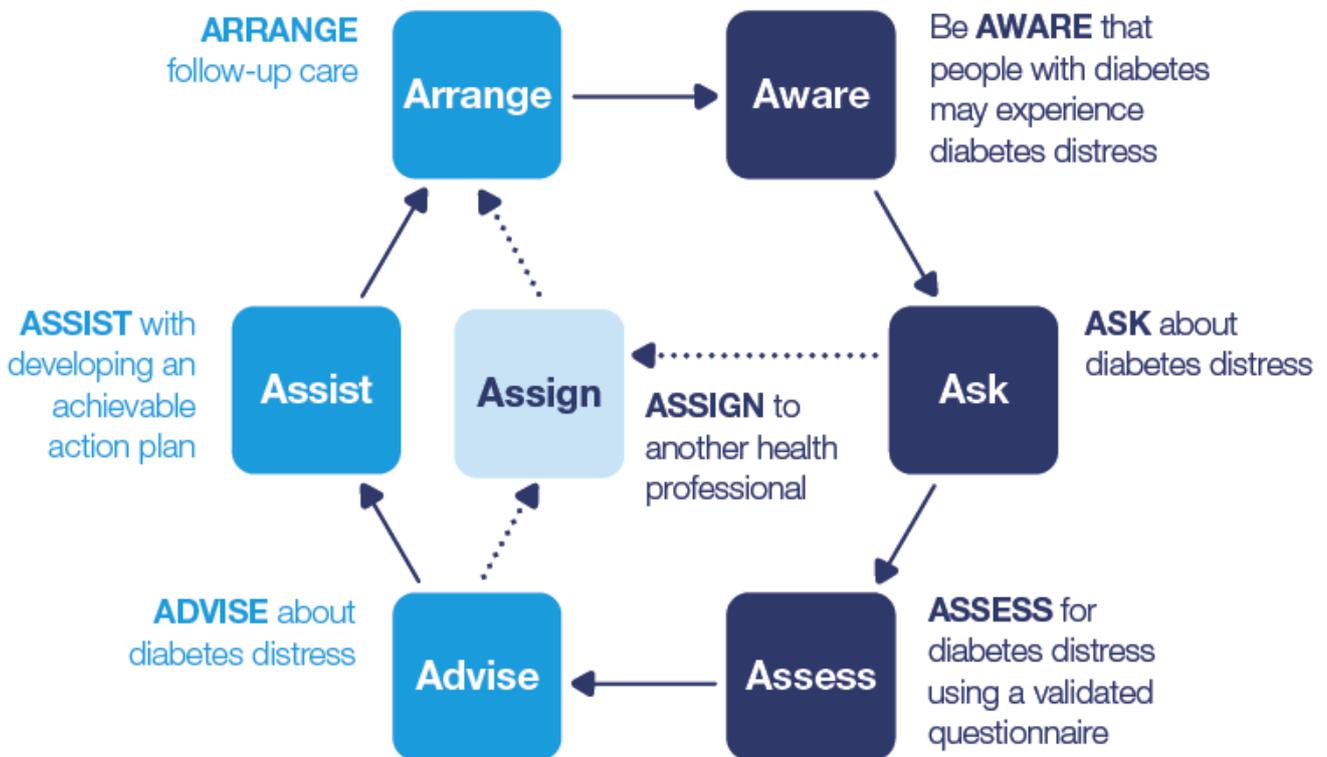
○ Calculator

○ Constantly have to stop what I'm doing

○ Managing diabetes

○ Strict routine

Appendix D. 7 Area's model (Diabetes UK, 2019).



Appendix E. Author guidelines for International Journal of Eating Disorders.

DETAILED MANUSCRIPT PREPARATION GUIDANCE

Title Page

The Title Page of the manuscript should comprise:

- A brief informative title containing the major keywords. The title should not contain abbreviations (see [Wiley's best practice SEO tips](#)).
- All co-author details, including affiliation and email address.
- Up to ten keywords.
- If published already as a preprint, a link to the preprint server.
- An author contributions statement that succinctly indicates how each author contributed to the piece of work, using the [CRediT "Contributor Roles Taxonomy"](#). Author contributions are also required within the submission form of both original and revised submissions.
- Any applicable statements relating to our ethics and integrity policies, such as:
 - data, materials and code availability statement
 - funding statement or other acknowledgements of support
 - conflict of interest disclosure
 - permission to reproduce material from other sources

Abstract

The Abstract provides a succinct summary of the article content. The recommended format and word limit vary by **article type**.

Structured abstracts have a recommended maximum of 250 words and should be organized into: **Objective**: state the primary purpose of the article, or major question addressed in the study. **Method**: indicate the sources of data, give brief overview of methodology, or, if it is a review article, how the literature was searched and articles were selected for discussion. For research-based articles, briefly note study design, how participants were selected, and major study measures. If your data are based on a preregistered study, provide the preregistration number or link. **Results**: summarize the key findings. **Discussion**: indicate main clinical, theoretical, or research applications/implications.

Main Text File

The main text file should be in MS Word and include the following content and recommended formatting:

- Main body, formatted as Introduction, Method, Results, and Discussion, as recommended by the International Committee of Medical Journal Editors (ICMJE) (**J. Pharmacol. Pharmacother. 2010, 1, 42-58**). Exceptions to these formatting recommendations include Commentaries, Forum articles, and Perspective articles.

- A Public Significance statement (< 70 words) that explains why this research is important and is written in plain English for a general, educated public.
- Figure titles should be supplied as a complete list in the text.

References

Please refer to **article types** regarding the number of permissible references.

This journal offers Free Format submission and authors may submit using their preferred referencing style, as long as consistency is applied throughout the manuscript.

The typesetter will apply the American Psychological Association reference style on manuscripts accepted for publication. If authors wish, they may review **reference style guidelines** prior to submission.

Tables

Tables should include a descriptive title and, if needed, footnotes defining abbreviations and any other information critical to interpreting the data shown.

Figures

Figures should have legends (and if needed, notes) that succinctly describe the information being displayed. Figures should be uploaded in the highest resolution possible.

Supporting Information

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

Authors should mention the Supporting Information in the text of the main article to provide context for the reader and highlight where and how the supplemental material contributes to the article. View **Wiley's FAQs** on Supporting Information.

Supporting (supplemental) information should be submitted in separate files.

If accepted for publication, Supporting Information is hosted online together with the article and appears without editing or typesetting.

Note: Authors are encouraged to utilize publicly available data repository for data, scripts, or other artefacts used to generate the analyses presented in the paper; in such cases, authors should include a reference to the location of the material in the Method section (rather than in Supporting Information).

Additional Guidance Regarding Manuscript Preparation

The IJED reaches a global audience. Authors are encouraged to consider the implications of their research for populations, settings, or policies beyond those applicable to their own local circumstances.

For studies involving human participants, to aid comprehensive and consistent reporting across regions/countries and cultures, the IJED provides **Demographic Characteristics Reporting Guidelines**.

Authors for whom English is not their first language are encouraged to seek assistance from a native or fluent English speaker to proofread the manuscript prior to submission.

Footnotes to the text are not allowed and any such material should be incorporated into the text as parenthetical matter.

Terminology. Authors should refrain from using terms that are stigmatizing, discriminatory, or ambiguous. The journal rejects stand-alone nouns that refer to individuals by their diagnosis or condition (e.g., "anorexics," "obese," "diabetics," etc.), race and ethnicity identification (e.g., "Whites," "Hispanics," etc.), or presumed disadvantaged status ("minorities"). "Participants" should be used in place of "subjects." For further explanation and examples, see "*Speaking of that: Terms to avoid or reconsider in the eating disorders field*" (DOI: [10.1002/eat.22528](https://doi.org/10.1002/eat.22528).)

Abbreviations: Only abbreviate terms if they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter, use the abbreviation only.

Units of measurement: Please use the International System of Units. Access www.bipm.fr for more information.

Numbers under 10 should be spelt out, except for: measurements with a unit (8 mmol/L); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).

Trade Names: Chemical substances or drugs should be referred to by the generic name only, not by trade names. For proprietary drugs, the proprietary name and the name and location of the manufacturer should be added in parentheses.

DO YOU EXPERIENCE AN "ANOREXIC VOICE"?

We are looking for people to take part in a **research study** looking at **WAYS OF COPING WITH THE ANOREXIC VOICE**

WHAT IS THE ANOREXIC VOICE?

The anorexic voice is described as a voice that commentates on your food, shape, and weight but feels different to your own thoughts about yourself.

WHAT DOES THE STUDY INVOLVE?

WHO CAN TAKE PART?

- Anyone who currently experiences an anorexic voice
- Aged 18 or over
- You do not need to have a formal diagnosis of an eating disorder

There are two parts to this study.

Part 1 will involve filling out online questionnaires about attitudes to food, weight, and about the anorexic voice.

The researcher will contact you if you are eligible for part 2 of the study.

Part 2 involves thinking about and working with your anorexic voice. It will be completed virtually over Zoom with the researcher.

HOW DO I TAKE PART?

Scan the QR code on the poster, OR use the following link to complete PART 1 of the study.

https://cardiffunipsych.eu.qualtrics.com/jfe/form/SV_2fuszCv2OuszczPQ



This study has been approved by Cardiff University Ethics Committee. For more information about the study, please contact holtj2@cardiff.ac.uk



Appendix G. Social Media Recruitment Posts.

Twitter Recruitment Post.

“looking for #participants to take part in #research on #eatingdisorders - if you have an #anorexicvoice we are interested in your ways of coping! please see poster for more information & click here to participate in part 1 - https://cardiffunipsych.eu.qualtrics.com/jfe/form/SV_2fuszCv2OuszcpQ”

Instagram Recruitment Post.

“looking for #participants to take part in #eatingdisorder #research - if you have an #anorexic voice we are interested in your ways of #coping - please see poster for more information & access part 1 on this link - https://cardiffunipsych.eu.qualtrics.com/jfe/form/SV_2fuszCv2OuszcpQ

#eatingdisorders #anorexia #anorexiarecovery #edrecovery #eatingdisorderrecovery #precovery #recovery #edresearch #anorexiaresearch #psychology #clinicalpsychology #psychologyresearch”

Reddit Recruitment Post.

“I am a trainee clinical psychologist undertaking a doctorate in clinical psychology at Cardiff University. As part of this I am undertaking a large-scale research project. I am passionate about improving understanding and interventions for eating disorders.

I AM LOOKING FOR PARTICIPANTS FOR MY TWO-PART STUDY ON THE WAYS OF COPING WITH THE ANOREXIC VOICE.

What is the anorexic voice?

Many individuals with experience of eating disorders have described a phenomenon now described as the “anorexic voice”. It is reported as a voice that commentates on food, shape, and weight and is considered as being different from one’s own thoughts about themselves. Many people have described how the anorexic voice often started out as supporting and encouraging but very quickly became critical, demeaning and demanding. This voice can be very hard to ignore and reason with and many individuals describe feeling trapped by it.

Can I take part in this research?

Anyone **over the age of 18** who currently experiences what we described as the anorexic voice is eligible to take part in this study. You **do not need a formal diagnosis of anorexia or any other eating disorder in order to take part.**

If you experience hearing voices not related to food, shape or weight, or in addition to the anorexic voice, you are unfortunately not eligible to take part in this study.

What will this study involve?

There are two parts to this study.

Part 1, accessed through the below link, is part of our screening process. You will be asked to complete some questionnaires online, taking approximately 5-10 minutes of your time.

Part 2 will take place at a later date if you pass screening. The researchers will contact you if eligible. The second part will be completed over Zoom where you will be asked to complete some tasks on the survey platform Qualtrics. This survey is hosted over Zoom so that the researcher can be on hand for any questions and to provide an individualised debrief at the end of the study, to mimic conditions of completing a research study in person.

What if I change my mind about taking part?

If you are uncomfortable at any point throughout the study or begin to experience distress, you have the right to withdraw at any time during the study, without providing a reason for doing so and without any repercussions.

Your participation is voluntary, and you can change your mind at any time during the study. You can exit the study by clicking the [x] button and selecting "leave now". You will be unable to return to the study at a later time.

Will my information be confidential?

The information you provide in this research study will be held confidentially. No-one other than the lead researcher will know you have provided specific information. Data will be anonymised and kept on a password protected server for up to 7 years once the study is completed. Once your data is anonymised you will not be able to withdraw your responses once you have submitted them.

What will happen with the results?

The results from this research will be written up and submitted as part of the qualification for a Doctorate in Clinical Psychology at Cardiff University. The findings will also be prepared for publication in a scientific journal.

Who has approved this research?

This project has been approved by Cardiff University School of Psychology Ethics Committee. The lead researcher will be supervised by two clinical psychologists throughout to ensure best practice.

IF YOU ARE INTERESTED IN PARTICIPATING: PLEASE CLICK THE LINK FOR PART 1.

https://cardiffunipsych.eu.qualtrics.com/jfe/form/SV_2fuszCv2OuszcpQ ”

Appendix H. *Eating Disorder Examination Questionnaire (EDE-Q; Fairburn et al., 2008).*



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 flat 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



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 the 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 regard 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. Please note that for these questions the term "binge eating" means 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	SLIGHTLY	MODERATELY		MARKEDELY	
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



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	SLIGHTLY			MODERATELY		MARKEDLY	
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 estimate.):

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

If so, how many?:

Have you been taking the "pill"?: YES NO

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THANK YOU

Appendix I. Beliefs about Voices Questionnaire-Revised (BAVQ-R; Chadwick et al., 2000).

Please read each statement and tick the box which best describes the way you have been feeling in the past week.

Item	Disagree	Unsure	Slightly Agree	Strongly Agree
1. My anorexic voice is punishing me for something I have done	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My anorexic voice wants to help me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. My anorexic voice is very powerful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. My anorexic voice is persecuting me for no good reason	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. My anorexic voice wants to protect me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. My anorexic voice seems to know everything about me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. My anorexic voice is evil	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. My anorexic voice is helping to keep me sane	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. My anorexic voice makes me do things I really don't want to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. My anorexic voice wants to harm me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. My anorexic voice is helping me to develop my special powers or abilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I cannot control my anorexic voice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. My anorexic voice wants me to do bad things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. My anorexic voice is helping me to achieve my goals in life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. My anorexic voice will harm me if I disobey or resist it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

16. My anorexic voice is trying to corrupt or destroy me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I am grateful for my anorexic voice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. My anorexic voice rules my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. My anorexic voice reassures me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. My anorexic voice frightens me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. My anorexic voice makes me happy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. My anorexic voice makes me feel down	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. My anorexic voice makes me feel angry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. My anorexic voice makes me feel calm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. My anorexic voice makes me feel anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. My anorexic voice makes me feel confident	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. I tell my anorexic voice to leave me alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. I try and take my mind off my anorexic voice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. I try and stop my anorexic voice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. I do things to prevent my anorexic voice talking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. I am reluctant to obey my anorexic voice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. I listen to my anorexic voice because I want to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. I willingly follow what my anorexic voice tells me to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. I have done things to start to get in contact with my anorexic voice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. I seek the advice of my anorexic voice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix J. Topography of voices rating scale (TVRS; Hustig & Hafner, 1990).

Over the last few days my anorexic voice has been:

Absent (I have not heard it at all) <input type="checkbox"/>	Fairy infrequent (I have heard it several times this week but not every day) <input type="checkbox"/>	Average (I have heard it once a day) <input type="checkbox"/>	Fairly frequent (I have heard it several times a day but not every hour) <input type="checkbox"/>	Very frequent (I have heard it every hour) <input type="checkbox"/>
---	--	--	--	--

Very quiet <input type="checkbox"/>	Fairy quiet <input type="checkbox"/>	Average <input type="checkbox"/>	Fairly loud <input type="checkbox"/>	Very loud <input type="checkbox"/>
--	---	---	---	---

Very mumbled <input type="checkbox"/>	Fairy mumbled <input type="checkbox"/>	Average <input type="checkbox"/>	Fairly clear <input type="checkbox"/>	Very clear <input type="checkbox"/>
--	---	---	--	--

Very comforting <input type="checkbox"/>	Fairy comforting <input type="checkbox"/>	Neutral <input type="checkbox"/>	Fairly distressing <input type="checkbox"/>	Very distressing <input type="checkbox"/>
---	--	---	--	--

Very easy to ignore <input type="checkbox"/>	Slightly distracting <input type="checkbox"/>	Fairly distracting <input type="checkbox"/>	Very distracting <input type="checkbox"/>	Compelling me to obey them <input type="checkbox"/>
---	--	--	--	--

Appendix K. Recruitment follow-up email.

“Dear participant,

You recently completed part 1 of the research study “*The impact of ways of coping with the anorexic voice*”. Your time spent doing this is very much appreciated.

I am pleased to inform you that you are eligible for part 2 of this research study.

The information sheet with full details of what part 2 involves is attached to this email.

A brief overview is provided below:

- Part 2 will take approximately 15-20 minutes of your time.
- Part 2 will involve thinking about and working with your anorexic voice. Please do not participate if you are not comfortable with this.
- Part 2 will take place using Zoom and the Qualtrics survey platform.
- *You can keep your camera and microphone off and use the chat function to communicate if you would prefer anonymity.*
- The researcher will introduce themselves on Zoom and explain the procedure, like doing an experiment in person. You will then be placed in a breakout room on your own to complete the Qualtrics study. You can turn your microphone and camera off to complete this – so it will be like you are alone in a room. The Qualtrics study will provide all the instructions you need.
- The researcher will then provide a 1:1 debrief over Zoom explaining the aims of the study and answering any questions once you have finished the survey.
- The researcher will be on hand at all times to answer any questions.

If you would like to take part in part 2 of this research study, please use the link below to access the Doodle calendar to book a time slot. Please be aware that time slots are based on GMT (United Kingdom)

<https://doodle.com/bp/jordanholt/research-study---anorexic-voice-part-2>

You will receive an email before your chosen time slot with a Zoom link and the study link.

If none of the time slots are suitable but you would like to take part, please reply by email with dates and times that are suitable for you.

I would like to thank you again for your commitment to participating in this research.

Jordan Holt

Trainee Clinical Psychologist”

Appendix L. *Participant Information sheet.*

School of Psychology
Ysgol Seicoleg

South Wales Doctoral Programme in Clinical Psychology
De Cymru Rhaglen Doethuriaeth mewn Seicoleg Glinigol



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Wales UK
www.psych.cf.ac.uk
Prifysgol Caerdydd
Adelad y Tŵr
70 Plas y Parc
Caerdydd CF10 3AT
Cymru Y Deyrnas Unedig

Participant Information Sheet

“The impact of different ways of coping with the experience of the anorexic voice”

This research study is interested in the experience of the anorexic voice and the way in which we think about it. Research into the anorexic voice is currently limited despite individuals with lived experience describing the dominant impact it can have.

It is hoped this research will help us better understand the relationship with the anorexic voice and identify strategies to manage it in a way that will improve therapeutic approaches and recovery rates for people with eating disorders.

What is the anorexic voice?

Many individuals with experience of eating disorders have described a phenomenon now described as the “anorexic voice”. It is reported as a voice that commentates on food, shape, and weight and is considered as being different from one’s own thoughts about themselves. Many people have described how the anorexic voice often started out as supporting and encouraging but very quickly became critical, demeaning and demanding. This voice can be very hard to ignore and reason with and many individuals describe feeling trapped by it.

Please note: you do not have to have a diagnosis of anorexia or another eating disorder to take part in this study. If you currently identify with the experience of the anorexic voice described above, then you are eligible to take part in this study.

Can I take part in this research?

Anyone over the age of 18 who currently experiences what we described as the anorexic voice is eligible to take part in this study. You do not need a formal diagnosis of anorexia or any other eating disorder in order to take part.

If you experience hearing voices not related to food, shape or weight, or in addition to the anorexic voice, you are unfortunately not eligible to take part in this study.

What will this study involve?

Once you have read this information sheet, you will be asked if you would like to take part in this research. A consent form will need to be completed in order to participate in this research.

There are two parts to this study. First you will be asked to complete some questionnaires using Qualtrics. This is part of our screening process. If you are eligible for the second part of the study, you will be contacted by the researchers for part two.

The research study will be completed wholly online, using the Qualtrics platform and Zoom. Ensure before you start that you are in a quiet and private space, free from distractions. You will be asked to listen to audio clips through the speakers of your computer device, or you may require headphones.

It is estimated this study will take 20 minutes in total to complete. On Zoom, you will be placed in a breakout room to complete the study. This means the researcher will be on hand throughout the whole experiment in case you have any questions.

This research experiment will ask you to think about and work with your anorexic voice for a small period of time, approximately 10 minutes in total.

You will receive training in how to do this and will also be asked to answer some questions at the beginning and end of the study.

Following this study there will be a debrief with the researcher. The debrief will explain the aim of the study and answer any questions you might have.

What if I change my mind about taking part?

If you are uncomfortable at any point throughout the study or begin to experience distress, you have the right to withdraw at any time during the study, without providing a reason for doing so and without any repercussions.

Your participation is voluntary and you can change your mind at any time during the study. You can exit the study by clicking the [x] button and selecting "leave now". You will be unable to return to the study at a later time.

If you withdraw from the study, the researcher will make contact by phone. This is only to check to provide debriefing information and you will not be asked to complete the study or to provide reasons for withdrawing.

Will my information be confidential?

The information you provide in this research study will be held confidentially. No-one other than the lead researcher (Jordan Holt, Trainee Clinical Psychologist) will know you have provided specific information. Data will be anonymised and kept on a password protected server for up to 7 years once the study is completed. Once your data is anonymised you will not be able to withdraw your responses once you have submitted them.

What happens if I feel distressed during the research study?

This research experiment will ask you to think about and work with your anorexic voice, so we only recommend that you continue with participation if you feel confident in being able to manage this. A 1:1 debrief with the researcher will happen following the research experiment where you will have the opportunity to discuss any aspect of the study.

What will happen with the results?

The results from this research will be written up and submitted as part of the qualification for a Doctorate in Clinical Psychology at Cardiff University. The findings will also be prepared for publication in a scientific journal.

Who has approved this research?

This project has been approved by Cardiff University School of Psychology Ethics Committee. The lead researcher will be supervised by two clinical psychologists throughout to ensure best practice.

Researcher contact details:

Project Lead

Jordan Holt,
Trainee Clinical Psychologist,
11th Floor,
School of Psychology,
Tower Building,
70 Park Place,
Cardiff University,
Cardiff,
CF10 3AT
(02920) 870582

Academic Supervisors

Professor John Fox and Dr Marc Williams
11th Floor,
School of Psychology,
Tower Building,
70 Park Place,
Cardiff University,
Cardiff,
CF10 3AT
(02920) 870582

Who do I contact if I have concerns about this research?

The University of Cardiff's School of Psychology Research Ethics Committee

School of Psychology
Tower Building,
70 Park Place,
Cardiff University
Cardiff,
CF10 3AT
(02920) 870360
Email: psychethics@cardiff.ac.uk
<http://psych.cf.ac.uk/aboutus/ethics.html>

Thank you for taking the time to read this information.

Appendix M. *Voice suppression and Acceptance Scripts.*

Voice suppression script (adapted from Marcks & Woods, 2005; Salkovskis & Campbell, 1994)

“Please sit comfortably, somewhere that is quiet and private.

I am asking you to spend the next two minutes suppressing the anorexic voice.

I will provide some more instructions on how to do this.

I will speak again when your time is up.

For the next two minutes I am going to ask you to not acknowledge the anorexic voice.

It is very important that you try as hard as you can to suppress the anorexic voice.

If you hear it, I want you to push it away, to resist listening to it.

Try not to focus on the voice or what it is saying.

Please, to the best of your ability, do not listen to the anorexic voice until I tell you otherwise.

It is important that you try your hardest to push away the anorexic voice for the full two minutes.

Your two minutes are over.

Please press the next button and answer the following questions.”

Acceptance script (adapted from Harris, 2008).

“Please sit comfortably, somewhere that is quiet and private.

I am asking you to spend the next two minutes accepting the experience of the anorexic voice.

I will provide some more instructions on how to do this.

I will speak again when your time is up.

For the next two minutes, when the anorexic voice makes itself known, I am asking you to simply notice its presence, without judging it.

I am not asking you to agree with what it is saying or to argue with it.

Simply notice that the anorexic voice is present.

You don’t have to like the voice or approve of it, but simply allow it to be there.

Notice that it might get louder or quieter and might come and go.

Changing or getting rid of the voice is not the goal.

Simply make room for the anorexic voice and allow it to be where it is.

It is important that you try your hardest to do this for the full two minutes.

Your two minutes are over.

Please press the next button and answer the following questions.”

Appendix N. *Participant Debrief sheet.*

School of Psychology
Ysgol Seicoleg

South Wales Doctoral Programme in Clinical Psychology
De Cymru Rhaglen Doethuriaeth mewn Seicoleg Glinigol



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Cymru Y Deyrnas Unedig

Participant Debrief Form

“The impact of different ways of coping with the experience of the anorexic voice”

Thank you for taking part in this research study.

The aim of this study was to look at the impact of suppressing the anorexic voice and how that may lead to changes in how powerful the voice is perceived to be.

This study asked participants to either suppress their anorexic voice for a short period of time, or to accept the experience of it.

Research has shown that when we try and suppress thoughts in attempts to get rid of them, it actually results in the opposite – a rebound effect where the frequency of these thoughts increases. Previous studies with individuals who hear voices have found a similar effect of voice suppression in terms of a short-term increase in frequency of the voice. Voice suppression is a type of metacognitive control strategy, that is, a way of interacting with our thoughts. Some strategies (acceptance) may at times be more helpful than others (voice suppression). It has been shown that individuals with disordered eating are more likely to use *unhelpful* metacognitive control strategies such as voice suppression.

As well as frequency of the voice, we were also interested in how powerful the voice was perceived to be following voice suppression. Research has suggested that voice-related distress depends on things like how powerful the voice is perceived to be rather than simply just the presence of a voice. We also know from accounts of people with eating disorders, that somewhere along the line the anorexic voice shifts from being perceived as supportive to negative and critical.

This study was interested in whether attempts to suppress the anorexic voice may explain the increase in things like perceived power of the voice described by many individuals with eating disorders. To do this we asked some participants to suppress their anorexic voice for a short time and compared ratings of features of the voice before and after. We also asked some participants to do the opposite and accept the experience of their anorexic voice.

We hope that if voice suppression is found to impact on the perceived power of the anorexic voice, we may be able to think about targeting this therapeutically. Supporting individuals to use more helpful metacognitive control strategies may reduce the power of the anorexic voice and hopefully improve recovery rates.

We hope this information provides some rationale for what we asked you to do. Please be reassured that research has shown any increases in frequency of the voice are **temporary and disappear quickly**.

If you are feeling distressed by working with your anorexic voice, please note the following services provide free support to individuals with eating disorders or who are struggling with their mental health.

- **BEAT – Eating Disorders**

<https://www.beateatingdisorders.org.uk>

Helpline: **0808 801 0677**

Helplines are open 365 days a year from 9am–8pm during the week, and 4pm–8pm on weekends and bank holidays.

- **C.A.L.L. Helpline (Wales)**

<https://www.callhelpline.org.uk/>

Helpline: **0800 132 737**

The helpline is open 24/7 and offers confidential listening and support services.

- **Samaritans**

<https://www.samaritans.org>

Helpline: **116 123**

Email: jo@samaritans.org

Helpline is open 24/7, 365 days a year.

- If you are a university student, there are student services available to support you with your mental health. These can usually be found through your university intranet or portal. If you are a **Cardiff University** student, you can contact Student Health and Wellbeing on the following:
 - Email: studentconnect@cardiff.ac.uk
 - Telephone: 029 2251 8888
- In case of continuing levels of distress following this study, please contact your GP for additional support.

If you have any further questions or concerns, please contact the lead researcher or academic supervisors through the details provided below.

Thank you for taking the time to take part in this research. Your contribution is highly valued and appreciated.

Project Lead

Jordan Holt,
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Appendix O. Ethical approval.

Ethics Feedback - EC.22.01.18.6502R



psychethics [REDACTED]
17/03/2022 15:02



To: [REDACTED]

Dear [REDACTED]

The Ethics Committee has considered your revised PG project proposal: The impact of different ways of coping with the experience of the anorexic voice. (EC.22.01.18.6502R).

Your project proposal has received a **Favourable Opinion** based on the information described in the proforma and supporting documentation.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met:

- You must retain a copy of this decision letter with your Research records.
- Please note that if any changes are made to the above project then you must notify the Ethics Committee.
- Please use the EC reference number on all future correspondence.
- The Committee must be informed of any unexpected ethical issues or unexpected adverse events that arise during the research project.
- The Committee must be informed when your research project has ended. This notification should be made to psychethics@cardiff.ac.uk within three months of research project completion.

The Committee reminds you that it is your responsibility to conduct your research project to the highest ethical standards and to keep all ethical issues arising from your research project under regular review.

You are expected to comply with Cardiff University's policies, procedures and guidance at all times, including, but not limited to, its Policy on the Ethical Conduct of Research involving Human Participants, Human Material or Human Data and our Research Integrity and Governance Code of Practice.

Kind regards,

[REDACTED]

School of Psychology Research Ethics Committee

[REDACTED]