Children and Young People's Experience of Avoidant/Restrictive Food Intake Disorder

Rebecca Doleman

A thesis submitted in partial fulfilment of the requirements
of the University of East London for the degree of
Professional Doctorate in Clinical Psychology

May 2022

ACKNOWLEDGEMENTS

Firstly, to Claire, thank you for all your support, from my initial doctorate interview to my final thesis feedback session. Your knowledge on ARFID and the profession has been invaluable. I thank you for keeping me calm throughout my whole doctorate.

To my parents, Kim and Nick, thank you for limitless support, love and encouragement. You raised me to believe I could do anything I put my mind to.

Martin, my husband to be, thank you for all the cups of tea, loaves of bread and washing up. You have always been my number one cheerleader. I promise there will be much less proof reading and no more degrees!

Roanna, my best friend, and sister. Thank you for always being interested in my career and being there when I need distracting. I hope I make you proud.

My ‘BS’ women. There is no way I could have done this without you. Thank you for teaching me how to be compassionate, smart and human.

Finally, to all the children and young people who took part. You all are so brave, thoughtful and inspiring. I cannot thank you enough.

ABSTRACT

Background

ARFID is a relatively new diagnosis. ARFID is understood to cause an inability to consume enough food to meet nutritional and energy needs leading to harmful effects on those impacted as well as their families. Currently there is a lack of research on what it is like to live with ARFID as a child or young person and there is no national guidance on intervention.

Aims

This study aims to explore the impacts of ARFID on children and young people and how they understand, cope, and make sense of the eating disorder.

Methods

Qualitative data were gathered through online, semi-structured interviews with eight children and young people aged between 10-17. The sample included five young people with ARFID and three who did not have a formal diagnosis but who were experiencing difficulties with eating in line with the criteria. The data was analysed using reflective thematic analysis from a critical realist position.

Results

Four main themes and twelve related subthemes were developed from the data. The four main themes were: the challenge of being in my body; ARFID shrinks my life; no one understands so how do I; and how I get by.

Conclusions

The findings provide a novel insight into the experience of living with ARFID as a child or young person. The young people spoke about the impacts of ARFID on their bodies, experiencing unpleasant sensations and emotions and seeing food as a threat. The impacts of ARFID were far reaching, affecting school, hobbies and their social lives. Most of the adults around them, including professionals, did not appear to understand ARFID. It was common to experience invalidating comments from others, leading to shame. The young people made some attempts to make sense of their experience, but avoidance and indifference to thinking about ARFID was found. To cope, the young people tightly controlled their food and found support from certain individuals. The findings should inform families, schools and clinicians leading to better child-centred care.

TABLE OF CONTENTS

LIST OF ACRONYMS

ADHD: Attention-Deficit Hyperactivity Disorder
AN: Anorexia Nervosa
APA: American Psychology Association
ARFID: Avoidant Restrictive Food Intake Disorder
ASD: Autism Spectrum Disorder
BN: Bulimia Nervosa
BPS: British Psychological Society
CAMHS: Child and Adolescent Mental Health Service
CBT: Cognitive Behavioural Therapy
CYP: Child(ren) or Young Person/People
DSM: Diagnostic and Statistical Manual
ED: Eating Disorder
HCP: Healthcare Professional
MDT: Multidisciplinary Team
NG tube: Nasogastric Tube
NHS: National Health Service
RCT: Randomised Control Trial
TA: Thematic Analysis
WHO: World Health Organisation

1. INTRODUCTION

1.1. Overview

This chapter provides an overview of the current understanding of Avoidant Restrictive Food Intake Disorder (ARFID). It covers the history of ARFID, the causes, current treatments, and professional opinions on the diagnosis. It details a review of the literature on ARFID in childhood and adolescence, highlighting the lack of research in the area. It then goes on to provide scoping reviews and a critique of literature in neighbouring areas of fussy eating and EDs. The chapter will conclude with an outline of the gaps in the current literature and a summary of the study aims and research questions.

1.2. Avoidant Restrictive Food Intake Disorder

The NHS website describes ARFID as ‘when someone avoids certain foods, limits how much they eat or does both’ and when beliefs about weight or body shape are not present as reasons why (NHS, 2021). More precisely, the DSM-5 states that ARFID is understood to be a difficulty in feeding or eating often caused by a lack of interest in eating, concerns around negative consequences of eating or an aversion to the sensory characteristics of food. The disturbance to eating will lead to an inability to take in enough food to meet nutritional and energy needs resulting in one or more of the following consequences: significant weight loss, impaired growth in children, nutritional deficiency, marked interference with psychosocial functioning or dependence on enteral feeding or oral supplements. For the diagnosis to be given the difficulty must not be explained by a concern around weight gain, lack of access to food or any other physical explanation requiring medical attention. Additionally, the behaviours around food need to not be better explained by other mental health difficulties (APA, 2013).

1.2.1. Literature Review

An initial literature review was done to identify all articles covering an experiential or qualitative account of eating and feeding problems directly related to Avoidant Restrictive Food Intake Disorder (ARFID) in children. In order to carry out a comprehensive literature search electronic databases were searched following scoping review guidance (Arksey & O'Malley, 2005). The databases (CINAHL; APA PsycArticles; APA PsycInfo; Academic Search Complete; Pudmed) were searched using the terms 'ARFID' or 'avoidant restrictive food intake disorder' or 'selective eating disorder' and 'child' or 'youth' or 'adolescents' or 'children' and 'experiences' or 'perceptions' or 'attitudes' or 'views' or 'feelings' or 'qualitative' or 'perspective'. This search produced 125 papers after the removal of non-English and duplicated papers.

A scoping review as a method of literature search was selected as it is more suitable for a broader topic area than a systematic review and can be useful in identifying research gaps (Arksey & O'Malley, 2005). From the initial searches supplementary searching strategies such as back chaining, forward chaining and checking other work by relevant authors were employed to gather a comprehensive list of sources.

Papers that were relevant to ARFID in childhood were screened initially by reading their titles and abstracts. At the time of the literature review none of the papers portrayed the experience of living with ARFID as a child. Because of the lack of literature on the child's perspective two further scoping reviews were completed in neighbouring research fields: eating disorders and fussy/picky eating. The full details of these searches are detailed later in the chapter. All papers that were still relevant to ARFID in childhood were read to gain a comprehensive overview of the area.

1.2.2. History of ARFID

The diagnosis of ARFID is relatively new and was introduced in the DSM-5 (APA, 2013) in 2013 to capture a large group of people who previously may not have met criteria for other EDs or would have been given residual diagnosis (e.g. ‘not otherwise specified’). The aim was to join up differing, yet related presentations in early childhood and adolescence/adulthood to create a lifespan diagnosis. One of the motivations for introducing ARFID as a new diagnosis was the hope that a more coherent grouping of these characteristics would lead to improved evidence-based practice (Al-Adawi et al., 2013; Bryant-Waugh, 2020c). Individuals who were previously excluded from classification were experiencing significant difficulties around eating but the motivations to restrict food were not related to concerns around body shape (Kreipe & Palomaki, 2012; Mammel & Ornstein, 2017). They also often required complex multidisciplinary input with medical, dietetic and psychological interventions (Norris et al., 2016). Today evidence is demonstrating that the desired effect from the development of the diagnosis has been achieved as there is a reduction in the number of people who are receiving a ‘not otherwise specified diagnosis’ (Fisher et al., 2015; Ornstein et al., 2013).

1.2.3. Diagnosis and Symptomology

As summarised above the DSM-5 (APA, 2013) states four criteria or areas in which an eating disturbance can have significant impact. Only one of the four must be met for the diagnosis to be given. The Radcliffe ARFID Workgroup (an international MDT working group) met to give clarity in how ARFID is defined (Eddy et al., 2019). The explanations of how each criterion is measured clinically and examples of how they present are detailed below.

1.2.3.1. Significant weight loss (or failure to achieve expected weight gain or faltering growth in children). This criterion is measured through a BMI of less than 18.5 in adults or for children sitting within or below the 5th percentile for weight and height. Other clinical indicators for low weight are also used depending on the severity of illness through clinical judgement (Eddy et al., 2019). Significant weight loss is the most common reason for diagnosis (Cooney et al., 2018) with Norris and colleagues (2021) finding that the majority of new referrals will present with low weight. It is known that children with ARFID are more likely to see more medical specialists before starting psychological intervention than people with other EDs, thus weight loss or restricted growth will often be a reason why children will initially seek support (Strand et al., 2019).

Direct research on the impact of malnutrition due to ARFID has not been published. However, through longitudinal studies in developing countries, research has demonstrated the far-reaching negative impacts of being severely underweight for prolonged periods in childhood. Some of these include; poor school outcomes (Walton & Allen, 2011); poor global physical health (Torpy et al., 2004); impaired cognitive abilities and the development of motor skills. (Victora et al., 2008). Similarly within AN research the link between low weight and increased mortality is established (Franko et al., 2013).

1.2.3.2. Significant nutritional deficiency. Depending on a team's access to resources, nutritional deficiencies will be established through blood work or the analysis of food diaries by dieticians (Eddy et al., 2019). Eating 10 or fewer foods monthly may indicate nutritional deficiency (K. Williams et al., 2015). The detrimental impact of food restriction due to ARFID can lead to inadequate vitamin and mineral intake. This can cause major health issues such as scurvy, rickets, anaemia and in extreme cases blindness (Harrison et al., 2019; Sharp & Stubbs, 2019).

1.2.3.3. Dependence on enteral feeding or oral nutritional supplements. To fulfil this criterion an individual must be using nutritional supplements or tube feeding for more than 50% of their daily calorie intake. Cohort studies have found that around a quarter of children diagnosed needed hospitalisation as a part of the treatment (Norris et al., 2021) and 17% are dependent upon tube feeding (K. Williams et al., 2015).

1.2.3.4. Marked interference with psychosocial functioning. This criterion is measured using clinical assessment and judgement by looking at how food restriction can impair an individual's ability to live their life, for example by attending school and maintaining relationships. Current literature disagrees on how likely professionals are to diagnose using the presence of this criterion alone (Cooney et al., 2018; Eddy et al., 2019). The challenges and adaptations with eating and mealtimes can lead to strains on peer and family relationships, often negatively impacting on psychosocial outcomes (Krom et al., 2019). Quantitative research has examined the impact of ARFID on psychosocial functioning through measures and questionnaires. The links between ARFID and: anxiety (i.e. Gonçalves et al., 2019); low mood (i.e. Norris et al., 2021); and school functioning (i.e. Krom et al., 2019) have been recognised. To date no qualitative research has explored the impact of ARFID on day-to-day functioning.

An individual with ARFID could present with any number of the above criteria which can lead to significant variability in presentations and a large range of associated consequences. For example, a typical physical presentation of a child with ARFID could be small and underweight, with a lack of interest in food. However, a diagnosis would still be given to an individual who is over typical weight and is only consuming a handful of 'safe' highly calorific foods who needs to take nutritional supplements to meet dietary requirements. This heterogeneousness leads to challenges associated with identifying individuals for diagnosis and brings up questions around the appropriateness of the diagnosis (Bryant-Waugh, 2020c; Sharp & Stubbs, 2019).

1.2.4. The Diagnosis of ARFID

The utility and validity of the diagnosis of ARFID has been debated in the field. Quantitative evidence, through latent class analyses have established separate groups of restrictive eating (concerned with body image and not) which supports the diagnostic differentiation between AN (and BN) and ARFID (Pinhas et al., 2017; Schmidt et al., 2018). Further support for the diagnosis comes from reduction of the amount of people given 'not otherwise specified' labels which it is hoped will lead to the development of diagnosis specific treatment guidance (Fisher et al., 2015; Ornstein et al., 2013). Conversely, others have vocalised that the diagnosis is acting as an umbrella, attempting to catch various presentations affecting different and non-overlapping groups of people. The 'catch-all' position of the diagnosis could explain some of the difficulties in the recognition and assessment faced by professionals mentioned below. There has been a resulting call for different subtypes of the diagnosis to be recognised so assessment, formulation and treatment guidance can be tailored for different presentations (Sharp & Stubbs, 2019). This is strongly echoed by Strand and colleagues (2019) who state that the construct validity for ARFID is poor, explaining that diagnosis was originally created from a heterogenous group of presentations which had only two things in common: they did not fit into other eating or feeding disorder diagnoses and had detrimental food restriction. They argue that ARFID therefore should not be understood as a distinct clinical entity. They also support a stronger emphasis on the three identified sub-domains and a further clarification of the boundaries of ARFID to increase the validity of the diagnosis. The three sub-domains of lack of interest in food, sensory sensitivity, and fear of aversive consequences of eating are gaining support in the research literature and are likely to be better conceptualised in the future (Bryant-Waugh, 2020c; Strand et al., 2019).

1.2.5. Prevalence

Despite the diagnosis existing for almost ten years, the prevalence rates of ARFID in children are still widely unknown. Estimates suggest that it may affect around 5-15% of school aged children (Gonçalves et al., 2019; Norris et al., 2016). Research in America has found that ARFID diagnoses make up around 20% of cases in CYP ED services (Fisher et al., 2015; Nicely et al., 2014) and affects 7% of children in a general paediatric hospital in Europe (Schöffel et al., 2021). Some research suggests it may be as common as AN and BN (Kurz et al., 2015).

As mentioned above, ARFID is a heterogenous diagnosis so generalisations about who it affects are difficult to make. However, it appears that ARFID is more common in young adolescents and children and seen less in older children and adults. Stark gender differences are generally not reported making it distinctive from the female bias seen in other ED presentations (Gonçalves et al., 2019; Keery et al., 2019; Norris et al., 2016). Norris et al., (2021) points out that published cohort studies are small and highlight huge variability in findings, indicating more research needs to be done to truly understand what ARFID looks like.

1.2.6. Causes

ARFID is an umbrella diagnosis capturing a wide range of experiences and difficulties which means that there is a lot of variability in the factors which can lead to the restriction of food (Bryant-Waugh, 2020c). Little research has been done into the risk factors of developing ARFID and although research from fussy eating can be drawn upon, it cannot be uncritically transferred across due to the differences between ARFID and fussy eating. It is generally accepted that a combination of biological, psychological and social mechanisms will play a role (Coglan & Otasowie, 2019a; Eddy et al., 2019; Micali & Cooper-Vince, 2020).

1.2.6.1. Biological mechanisms. Thomas and colleagues (2017) put forward biology as a major contributor in ARFID with a three-dimensional model of neurobiology, in which sensory perception, homeostatic appetite, and a sensitive flight/fight response can put someone at risk of developing ARFID.

Heightened sensitivity to the taste, smell, sight and textures of food are commonly reported by those with ARFID (Norris et al., 2021; Pilato, 2021). Thomas and colleagues (2017) state that this can be understood by biological differences in the processing of the senses rather than simply a lack of experience with disliked foods. Evidence to support this theory comes with ‘picky’ children being more likely to taste bitter substances, such as 6-n-propylthiouracil, and those with supertasting abilities were more likely to be of reduced height than their peers (Golding et al., 2009).

Lack of appetite or having little interest in food is another common experience of people with ARFID and can often be apparent since birth or early childhood (Dovey et al., 2019; Strand et al., 2019). This can be linked to deficits in the appetite stimulating hormones and differences in the activation of appetite-regulating centres in the brain (Micali & Cooper-Vince, 2020; Thomas et al., 2017). Research comparing women with ARFID, AN and healthy controls found differences in appetite-regulating hormones between those with ARFID and AN and those without EDs (Becker et al., 2021).

Finally, neurobiological differences in reactivity of the threat response can be used to explain a heightened fear of the aversive consequences of eating such as choking, gastrointestinal pain or vomiting. Norris and colleagues (2021) found that around 40% of the CYP with ARFID attending eating clinics had presented with long established problems around food which had been made acute by a recent triggering event. Thomas and colleagues explain that a predisposed sensitive threat system (i.e. the amygdala, anterior cingulate, and ventral prefrontal cortex) could predate a traumatic food event (e.g. choking) and make it more likely for an individual to become fearful of food, leading to a restriction of their eating (2017). However, the recognised link between trauma and the sympathetic nervous system makes it harder to establish biological causation (van der Kolk, 1994). Further research investigating the neurobiology of people with ARFID is due to be published in 2022 (Micali & Cooper-Vince, 2020).

1.2.6.2. Comorbidity with physical health. The DSM-5 states that an ARFID diagnosis cannot be given if other medical or psychological factors better explain the restriction of food (APA, 2013). Nonetheless CYP with ARFID are more likely to have other medical conditions such as genetic differences, food allergies, cerebral palsy, and gastrointestinal tract diseases than CYP with other EDs (Eddy et al., 2015; Fisher et al., 2014). Reasonably, Micali and Cooper-Vince (2020) argue that physical health conditions which are associated with abdominal discomfort are more likely to put children at risk of developing ARFID through conditioned food aversion. Additionally, CYP prior to a diagnosis do not often present at ED services but instead seek consultation with professionals like primary care providers, gastroenterologist and paediatricians etc. It will often be the case that medical tests are encouraged to rule out any biological grounds for food restriction (such as celiac disease, Crohn’s disease or allergies), meaning that even for children without comorbid health difficulties, they may have spent a lot of time visiting doctors, hospitals and undergoing intrusive medical investigations (Eddy et al., 2019). Once again potentially pairing eating and food behaviours with unpleasant experiences. Lastly, the impacts of having a restricted diet can cause gastro-intestinal issues (Feillet et al., 2019) suggesting that the symptoms of ARFID can actually create or exacerbate physical health difficulties leading to more aversive associations with food, and furthering the want to restrict food.

1.2.6.3. Psychological mechanisms. Various psychological processes have been recognised to play a role in the onset and maintenance of ARFID. Namely, as mentioned above, increased anxiety about the consequences of eating plays a role in many people's experience of ARFID (Strand et al., 2019). This raised anxiety, alongside a sensory sensitivity of food and a sensory sensitivity of internal biological feedback (noticing gagging, bloating, stomach movements etc.) can lead to a cognitive hyperawareness of the experience of eating (Zucker et al., 2019). Cognitive behavioural theory within anxiety disorders understands that a bias in attention will make it more likely that negative sensations or texture/taste will be noticed and once they are, the significance will also be distorted (Harvey et al., 2004). This suggest that individuals with ARFID can be stuck in a cycle of worrying about the aversive experiences of eating, being hypervigilant, noticing something in their body and experiencing resulting anxiety.

Zucker and colleagues (2019) explain how classical or operant conditioning can cause food restriction by the paring of the behaviour of eating and unwanted bodily sensations. Simply, if a CYP learns that eating is associated with something unpleasant it is not surprising that they might want to avoid or reduce their eating (Pavlov, 1957). Future avoidance can then act as a psychological reinforcer as avoiding eating is paired with a sense of relief and a reduction of anxiety. Psychological differences in response to disgust, arousal levels and cognitive inflexibility have also been put forward as contributing factors (Eddy et al., 2019; Micali & Cooper-Vince, 2020).

1.2.6.4. Neurodiversity and ARFID. The ARFID population has higher numbers of people with neurodevelopmental conditions such as ASD and

ADHD (Coglan & Otasowie, 2019a; Inoue et al., 2021). This link is not surprising given that children with ASD are more likely to have problems with eating and feeding (Martins et al., 2008) and children with ADHD are more likely have more disruptive eating behaviours at meal times (Ptacek et al., 2014). The sensory sensitivities which are very common for people with ASD and differences in interoceptive abilities to notice hunger will also be contributing factors for the association between ARFID and ASD (Coglan & Otasowie, 2019a).

1.2.6.5. Social. A child and their eating behaviours do not exist in isolation and so contributory biological and psychological factors are best understood within the social context in which the CYP lives. Research into fussy eating has focused upon the impact of family (specifically parents) but wider socio-political factors are largely underexplored or ignored in current literature (Micali & Cooper-Vince, 2020). How parents feed their children and parental mental health have both been found to impact on CYP eating behaviours. Parental frustration and repeatedly offering preferred foods after food refusal have been found to contribute to children's feeding problems (Mitchell et al., 2013). Similarly, parents of children with feeding and eating disorders are more likely to report feeling stressed and are more likely to use punishment to change behaviour (Martin et al., 2013). Higher levels of parental anxiety which understandably can arise from having a child who is struggling or refusing to eat will impact on a child's anxiety, which as mentioned above can exacerbate food restriction. Furthermore, parents with EDs or ED traits may model food restriction or avoidance making it more likely for their child to develop ARFID (Micali & Cooper-Vince, 2020). Most research on ARFID has been conducted in the global North. Solely focusing on parents as instigators of eating difficulties is reductionist by assuming western and middle-class norms. It does into take in account multiple and differing caregivers and the other environments that children spend a lot of time in like day care or school. Food and mealtimes are highly social events and are often closely tied to an individual's family, culture and identity. The current literature and understanding of the causes has not explored significant wider socio-cultural influences on eating behaviours.

1.2.7. Treatments

Currently the UK has no national guidance for the assessment and treatment of ARFID (National Institute for Health and Care Excellence, 2017). Furthermore, there are no well-established treatments for ARFID and no large scale studies or RCTs have looked at the effectiveness of different treatments (Bourne et al., 2020; Eddy et al., 2019). However, professionals and teams have experience in treating and managing ARFID, informed by practice-based evidence acquired from working with individuals with eating difficulties which predate the coining of the diagnosis (Sharp & Stubbs, 2019). The challenges of developing specific treatment guidance for ARFID are due to the recency of the diagnosis and the heterogeneity of the presentation (Bryant-Waugh, 2020d).

A review of treatments in 2020 (Shimshoni & Lebowitz, 2020) found that the current empirical evidence for interventions for ARFID in children is primarily made up of case reports and pilot RCTs. Recent papers have demonstrated the effectiveness of different interventions (often based upon treatments for other EDs or anxiety disorders) in small n studies. Examples of psychologically informed interventions include acceptance-based interoceptive treatments (Zucker et al., 2019), interventions based upon CBT (e.g. Dumont et al., 2019; Ornstein et al., 2017; Thomas et al., 2020) and family-based work (Bryant-Waugh, 2013; Dolman et al., 2021; Lock et al., 2018). MDT interventions which include CBT, family-based therapy, and adjunctive pharmacological interventions are common approaches in both inpatient and outpatient settings (Bourne et al., 2020).

Looking forward, the field needs robust evaluation methodologies like RCTs to understand the effectiveness of different approaches. However, a one-size-fits all approach and generic national guidance to AFRID will prove inadequate due to variability of presentations within AFRID (Ornstein et al., 2017). Bryant-Waugh suggests a ‘modular’ approach with standardised treatment options which can be used for reliably researched presentations is the most useful step-forward for professionals and services users (Bryant-

Waugh, 2020d). She has put forward a 10-step evidence informed framework for 2-17-year-olds with ARFID. The framework, rather than being a specific therapy, outlines a way of working. It endorses psycho-behavioural, dietetic and medical inputs with an emphasis on MDT working and family discussions. It also encourages joined up working with schools and other systems around the child. The framework is being trialled for effectiveness and is hoped that it will become evidence based and used as national guidance (Bryant-Waugh et al., 2021).

1.2.8. Professional Opinion

Recent publications on ARFID have explored the barriers that professionals face with the assessment and treatment of ARFID. Harrison (2021) looked at primary HCP's views on identifying, referring and working with ARFID in paediatric health settings in England through an online survey. A TA of the responses to the question around current barriers to effective diagnosis and treatment of ARFID found two themes: the lack of awareness and systemic factors. These themes more specifically mentioned the lack of understanding in the difference between fussy eating and ARFID and a paucity of specific training. Various participants also highlighted the lack of care pathways leading to children falling between the cracks of services and noticing the need for MDT working. The survey found that almost 70% of the HCPs asked said that they did not feel confident in identifying children with ARFID, with many saying that they were not sure how to refer children for appropriate treatment. This study, although only considering a region of England, highlights the lack of guidance on ARFID for HCPs. It is worrying that many primary HCPs do not feel confident in assessing for ARFID or signposting on when many people with ARFID will initially present to a GP or primary care provider for help (Eddy et al., 2019).

Similar views have been found in North America from qualitative research with professionals working with children with ARFID. Interviewees, who were made up of mental health professionals, occupational therapists, dieticians and doctors, reported not knowing where to find resources to inform treatments and felt ill-equipped to assess and treat ARFID. Just over half of the professionals said they had provided treatment for ARFID without any training. They spoke about feeling torn between providing interventions without adequate training versus offering no treatment which could potentially lead to medical complications and even death (Magel et al., 2021). Likewise, a survey with paediatric HCPs, found that in general, there was low confidence in the clinical management of ARFID, and ambiguity in clinicians' judgments around giving diagnoses of ARFID. Very few of the participants responded that they felt confident in working with ARFID, including those who had worked with children with ARFID in the past. Most worryingly, 15% professionals delivering regular care for EDs said that they were not familiar with the diagnosis of ARFID (Coelho et al., 2021).

The above studies highlight the concerns of professionals and their want for clear professional guidance, with top-down care pathways and training to increase knowledge and confidence. Harrison (2021) points out that the lack of awareness amongst professionals is concerning and it is likely that the NICE guidance for EDs is not being met for those with ARFID. Further qualitative research with specialist ED teams, parents/carers and individuals with ARFID would help to develop a rounded view of the barriers to diagnosis and treatments for all stakeholders. This could help to inform training and the creation of national and local services which are clearly needed in the NHS.

In summary, ARFID is a reasonably new diagnosis which was created to bring together those experiencing challenges with feeding or eating but did not meet criteria for other EDs (Fisher et al., 2015). It can impact people in many different ways but will always lead to a restriction or avoidance of food which leads to negative changes to people’s day-to-day lives (APA, 2013). These impacts are varied and include effects such as weight loss, interruption of schooling and even blindness (Cooney et al., 2018; R. Harrison et al., 2019; Krom et al., 2019). The usefulness of the diagnosis is currently being debated, with calls for a recognition of the three subsets of the presentation (lack of interest in food, sensory sensitivity, and fear of aversive consequences) to be formally recognised (Strand et al., 2019). The current understanding of the causes of ARFID are a combination of biological, psychological and social factors and existing treatments reflect this, often employing MDT working to provide medical, dietetic and psychological interventions (Eddy et al., 2019; Micali & Cooper-Vince, 2020). However, professionals working with people with ED do not feel confident working with ARFID and no national guidance exists (e.g. Harrison, 2021). At the time of writing no qualitative papers were found detailing lived experience ARFID meaning that research is missing the voice of CYP with ARFID.

1.3. Qualitative Research

Recently, the significance and utility of qualitative research to help inform healthcare has been better acknowledged (Wolstenholme et al., 2020). Likewise in the world of psychology, more researchers are choosing to conduct qualitative research, arguably drawn in by the rich human encounter (Barker et al., 2016). Information gathered from qualitative research can provide valuable insights into the ways people conceptualise health and give answers to questions posed by those commissioning, developing and providing treatment interventions (Chafe, 2017). Recently, WHO has commented that qualitative studies are vital for complex health decision making as they help to understand the values and needs of stakeholders (Langlois et al., 2018).

Peterson and others (2016) agree with this idea within the ED field, proposing a three-legged stool of evidence-based practice involving research, clinical experience, and patient perspectives for best treatment practice. They also state that service user viewpoints are often ignored, leading to poorer clinical outcomes (Peterson et al., 2016). Bryant-Waugh (2020) has spoken to the need of carefully listening to individuals and family members of those affected by ARFID. She highlights the lack of qualitative research in ARFID and how gathering a better understanding of the experience of those affected could enhance the quality of care.

As mentioned above, there is no peer reviewed published qualitative research on CYP's experience of ARFID. Nevertheless, Bradbury (2020) in a book chapter, informally explored her conversations in clinical practice with CYP who have a diagnosis of ARFID. From her clinical experience Bradbury has found that children with ARFID can often struggle to communicate their experiences making it difficult to understand the diagnosis from a child's viewpoint. Consequently, she was motivated to explore this further through informal conversations with CYP aged 6-16.

Her conversations were not analysed but she noted some common themes. She found that the experiences of these CYP were often very individual and many struggled to describe what it was like for them. Ambivalence around changing their eating behaviours was common, yet some older CYP shared that they wanted to be 'normal' and fit in with their peers. The CYP spoke about mealtimes causing conflict with their parents, but many did not seem to be motivated by the link between food and health to change their behaviour. Predictably, the CYP spoke about tasks around trying new foods as extremely anxiety provoking. However, some spoke about the value of achieving goals in the clinic. Salient points around the impact of ARFID on peer interactions were made by many children and how this can negatively impact their social lives. Finally, many children spoke about feeling different about their eating behaviours to those around them. The feeling of being misunderstood was common for the CYP. In addition, some felt that they were not bothered by their eating habits and felt frustrated by being asked to change.

Bradbury concluded from her informal research that centring future research around the views of the CYP is crucial in informing new practice. This could lead to better engagement with interventions and a more positive, empowering and validating experience for CYP (Bradbury, 2020).

Due to the lack of qualitative research which explores the impact of ARFID on a CYP's life, two scoping reviews were done in neighbouring fields. The two research areas selected were eating disorders and fussy/picky eating which attempted to capture some of the comparable experiences of living with ARFID. Eating disorders as a field of interest related to this research was chosen due to the overlap with experiences such as weight loss, medical and psychological intervention and living with a mental health diagnosis. Fussy/picky eating was chosen to gather more information about having a difficult relationship with some types of food and the social implications which may come with that. It is important to note that fussy/picky eating does not have a standardised definition within the literature and is most commonly described to be a rejection of foods leading to an inadequate variety or quantity of foods being eaten (Trofholz et al., 2017). This definition is conceptually very broad and therefore the research on fussy/picky eating captures a spectrum of experiences from people who have a mild dislike of some foods, to those living with a presentation comparable to ARFID.

The two reviews generated small bodies of research on the experiences of CYP in fussy/picky eating and ED. Both additional scoping reviews were carried out with the guidance set out by (Arksey & O'Malley, 2005).

1.3.1. Qualitative Research in Fussy Eating

Firstly, a scoping review on the experience of children and fussy eating was undertaken. The databases (CINAHL; APA PsycArticles; APA PsycInfo; Academic Search Complete) were searched using the terms 'fussy eating or picky eating' and 'children or adolescents or youth or child or teenager' and 'experiences or perceptions or attitudes or views or feelings'. Papers were also sought through back-chaining, forward-chaining and checking other work by relevant authors. At the time this produced 92 papers after the removal of non-English and duplicated papers. Once the abstracts were read for relevance, five papers were deemed suitable for inclusion. One paper on the experience of fussy eating of adults, one paper which did not have fussy eaters as the target population and one unpublished thesis were included due to the paucity of relevant literature and as they were deemed to have valuable findings. The findings of the relevant papers are detailed below.

Wolstenholme, Hennessy & Heary, (2020) conducted a systematic review of qualitative studies on families' experiences of having children who are fussy eaters. It was found that the majority of existing studies focused on pre-school children and no papers were found which had a primary focus on fussy eating behaviours from the child's perspective. Therefore, they recommend that there needs to be more research including the children's own perspectives (especially in adolescence) and fathers.

Fox and colleagues (2018) interviewed adults who were picky eaters and only consumed a very limited diet. Recruitment was conducted by advertising on an online support group for picky eaters. They used semi-structured interviews to gather information which included questions on participant's food preferences, the impact of their food restriction on various areas of their lives, and their views on help and recovery. The two main themes which were drawn from the data were: *the construction of food*, *barriers and motivators of change*. The *construction of food* theme was broken down into sub-themes which explored how participants understood and related to food including how food can be either safe or hazardous. Some participants went as far as describing unliked food as no longer a food item in their minds. The *barriers and motivators to change* theme encompassed both ideas, that participants wanted to change their eating habits yet acknowledged the reasons why this was a challenge. Sub-themes included, *health*, *social motivators*, *lack of faith in professionals* and *fear of change*.

The authors concluded that some of the barriers to change are a result of lack of efficacy around change which could be an avenue to explore in treatment. The study provides useful and novel insight into the experiences of living with food restriction as an adult. However, as the sample did not have diagnoses of ARFID, differences between picky eaters and those with a confirmed diagnosis may differ significantly. Additionally, all participants were part of the same online support group which may mean that they shared a common desire for support and similar conceptualisation of their difficulties. Therefore, wider research which includes those with ARFID diagnoses is indicated to expand on the points raised in the paper.

In the US Santiago and colleagues (2019) used focus groups with parents and children (aged 6-11) to hear about the barriers and enablers to eating fruit and vegetables. They found that children knew that eating fruit and vegetables was important and was linked to being healthy. They also shared a belief their parents had an influence on how much they ate, stating that rewards and encouragements were helpful as well as seeing their parents eating fruit and vegetables. Barriers they discussed included disliking the taste, preferences on how the fruit and vegetables were prepared and having access to choice. The conclusions from the study highlighted the significance of parental behaviour (encouragement and modelling) on food choice in children, despite children having some autonomy of their own eating behaviours and highlight how these cognitions can be used to inform interventions on healthier eating. However, the study was not specifically looking at children who were fussy eaters and the barriers and enablers may not apply to those who have more complex relationships with food.

Thompson and colleagues (2015) used alternative methods to gather data with CYP (aged 14 to 22) or their families who were identified by their parents as picky eaters. The authors chose to use photo-elicitation methods and go-along interviews which took place in food settings and included other people like colleagues and family members. During the interviews, both the researcher and the participants ate together. Participants were also accompanied on a routine food shopping trip. Results were analysed with TA and found that personal accounts of fussy eating matched those described in the literature. All participants spoke about having strong likes and dislikes to food with emotional reactions to foods they did not like. Carbohydrates were much preferred over fruits and vegetables and the sensory experience of food was highlighted to be very important for the individuals. For some, their identity as a fussy eater was seen as embarrassing and disempowering, but for others it was not problematic, and in some cases even positive. However, the sample did not include those with a clinical diagnosis of restrictive eating which limits the depth of its knowledge. Additionally, only four of the nine individuals were the primary participants suggesting that their experiences were described and shaped through perspectives of their families. Using photo food diaries and go-along interviews show innovative ways of gathering rich data.

Sixteen families in Ireland with children (aged 7-10) who were identified as picky eaters by their parents were interview by Wolstenholme (2020). TA was chosen for the data analysis and three main themes were found which are outlined below. The first theme: *typical individual differences or bad behaviour* found that CYP perceived fussy eating as negative whilst acknowledging a dislike of some foods was a typical experience. The CYP spoke about fear, unfamiliarity and negative experiences of trying new foods, or being asked to eat those they do not like. The second theme established was: *different motivations, goals and mealtime emotions.* The sensory elements of foods were commonly used as the reason for rejecting food. Some CYP spoke about being motivated to eat disliked foods for health reasons, yet few had external motivations to eat through rewards. It was found that the CYP were aware of the discrepancy between child/parent mealtime goals and understood that their parents had negative emotions around fussy eating. The final theme: *dealing with dislikes* highlighted the techniques the CYP used at mealtimes. Some of the strategies included, picking off unliked food, stating that they are full, throwing food away or asking for preferred food. Finally, the CYP spoke about the strategies their parents used to make them eat disliked food. The perceived acceptability and effectiveness of these strategies varied across the children. In general, it was found that the children believed the strategies to be more effective if they were in line with their own motivations.

Wolstenholme concluded that CYP with picky eating showed that they had agency around their food choices and had views on what is helpful at mealtimes, discrete from their parents. She states that future research investigating the potential differences in children who have ARFID is indicated (Wolstenholme, 2020).

In summary, there is a small amount of literature on the experiences surrounding fussy eating. The literature explores why people who are fussy eaters find some food unappealing. Highly processed foods and carbohydrates are seen to be preferable with fruits and vegetables being more likely to be problematic (Fox et al., 2018; Thompson et al., 2015; Wolstenholme, 2020). Across the studies participants spoke of understanding the health benefits of eating better but that the knowledge did not necessarily translate to changes in eating behaviours. The research on CYP also shines light onto the perceived barriers and enablers to changing eating habits and the impact of parents. Two studies point out that children seem to have at least some autonomy in their eating behaviours but are also aware of the influence of their parents (Santiago et al., 2019; Wolstenholme, 2020). Thompson's (2015) study is the only paper which looks into the impact of fussy eating on people's lives and explores the meaning of being a fussy eater. The body of research is generally more focused on beliefs around food and what things would help to reduce fussy eating. The literature could be expanded by gaining a richer understanding of the lived experience of having different eating behaviours. Many concepts, namely ideas of why food is unappealing, and perceived barriers and enablers to changing eating habits could be transferred across into ARFID. However, this literature will not be capturing medical experiences such as frequent doctor's appointments, hospital stays and NG tube feeding which are experienced by some people with ARFID. Similarly, it may also be missing the stories of those who have been dangerously underweight or have gone through a traumatic incident with food.

1.3.2. Young People and their Experience of EDs

To capture and understand the views of those who may have had more medicalised experiences with eating, a second additional scoping review was carried out looking at qualitative research on children with EDs. The databases (CINAHL; APA PsycArticles; APA PsycInfo; Academic Search Complete) were searched using the terms 'eating disorders' and 'children or adolescents or youth or child or teenager' and 'qualitative research or qualitative study or qualitative methods or interview'. Due to an initial high number of papers, a subject index term, ’eating disorders’ was used, and all papers older than 20 years were removed to narrow the search. Papers were also sought through back-chaining, forward-chaining and checking other work by relevant authors. At the time this produced 184 papers after the removal of non-English and duplicated papers. Once abstracts were read for relevancy, ten papers which investigated the experience of CYP with EDs in the UK were suitable for inclusion. Five of these papers explored the experience of receiving treatment with the remaining five looking into views on recovery, onset of difficulties, identity and compulsory treatment. The details of the ten papers follow below.

Colton and Pistrang (2004) spoke to CYP about their experiences of being on an inpatient unit whilst receiving treatment for AN. They used a discovery-oriented, phenomenological approach to get a richer understanding of the experience of the unit. Nineteen female participants aged between 12 to 17 years were interviewed. The interviews focused on areas such as what had been helpful and unhelpful; how they felt about being with others; and their experience of anorexia itself. The main themes found were: *what is this illness that I have*; *do I want to get well*; *being with others*: *support vs distress*; *being an individual vs just another anorexic*; and *collaborating in treatment vs being treated*. One of the main topics all the participants spoke about was the conflict between wanting to get better versus ‘keeping’ the anorexia. The interviews also highlighted how important it was to the young people that the treatment helped with a holistic recovery rather than a sole focus on weight gain as an outcome. The authors went on to make recommendations for treatment such as including broadening treatment goals to include psychological needs. They concluded that research into AN has often neglected the views of those receiving treatment.

Adolescents’ experiences of recovery after undergoing family-based therapies were explored by Nilsen and colleagues (2020). Thirty-seven adolescents with AN were interviewed, all of whom had been on an inpatient treatment programme and had received family-based treatments. Their mean age was 15.8. Individual interviews covered questions around different stages of their admission. From the data the authors came up with a superordinate theme: *recovery is a long and winding journey*, and three main themes: *realising you have a problem*; *being involved in important relationships*; and *giving treatment a real chance*. The main conclusions were that the CYP felt that their own responsibility, motivation, and self-determination were very important factors in recovery. Therefore, that clinicians should take into account the CYP's preferences in recovery to improve clinical care.

Similarly, Tierney (2008) spoke to 10 teenagers who had attended an inpatient unit for AN or BN/AN and asked them to reflect on their experiences of treatment. Common themes in the interviews included: feeling that it was difficult to initially access appropriate care; that professionals only reacted to physical changes of an ED; and ignoring emotional and behavioural difficulties. They also found that it was felt that the unit focused too much on weight gain and not enough effort went into changing psychological process associated with AN. Specific qualities in HCPs such as being easy to deceive and insensitive to distress were mentioned as being difficult for the teenagers to cope with. The CYP also spoke about the importance of seeking help from alternative places such as family members or support groups. Finally, all but one of the teenagers referred to the treatment as 'life saving' yet discussed how they were still left with problems with food. Some also mentioned ongoing difficulties with poor self-esteem and worries around socialising. The authors conclude that the important findings from the study indicate that many people with AN can 'eat their way out of the hospital' but interventions fail to offer psychological support around ED thoughts and fail to address secondary negative outcomes associated with AN such as the impact on one's social life.

Furthermore, Offord and colleagues (2006) interviewed seven 16-23 year olds to explore their views regarding the inpatient treatment they received for AN. The research highlighted how much the young women felt disconnected from the outside world as an inpatient, leading to feelings that their lives were put on hold and a sense of isolation. They also spoke about how they felt they were not treated as individuals and that standardised treatments and sweeping generalisations about EDs were common. Many reported that there was an emphasis on weight gain, with psychological recovery being overlooked. However, some experienced the treatment as holistic and that it focused on wider issues such as self-esteem. Similarly, a theme which was present in all accounts was the idea of *control versus collaboration*. Many spoke about the initial relief of a lack of control over the food they were given. However, some of the CYP spoke about additional controls over non-eating behaviours to be too restrictive and lead to feelings of powerlessness and inadequacy. Understandably, the idea that feeling involved in their own care decisions and working collaboratively with the staff teams were important for the CYP. Finally, ideas around peer relationships were discussed, both inside and outside of the inpatient unit. Overall, valuable information in relation to service provision was gathered from the study especially when considering practices which may have led to a reduction in well-being.

Bohrer and colleagues (2020) explored the definitions of recovery in EDs from comments on forums on the social media website Reddit[1]. The data was taken from a six-month timeframe of comments on recovery focused sub-reddits. 505 comments were included in the final analysis, which was made up of 294 individual commenters. The data was the analysed through TA. The themes that were identified were *recovery as a process* and *psychosocial factors. Recovery as a process* meant that it was common for people to speak about their recovery as a non-linear journey which was not like anyone else's recovery. Psychosocial factors such as feeling happier, eating more and being able to enjoy social interactions were also commented on in detail. The authors emphasised that the findings back-up the idea that current interventions for EDs which focus on removing symptoms, do not consider the complex and very individual nature of ED recovery. The findings also suggest a move away from a binary model of

---

[1] Demographics of the sample were unknown so may capture child and adult views across the world.

illness and recovery to a process-focused approach to healthcare in ED. They recommend that service users should be included in planning and implementing future research. As the comments on these sites are unbiased in terms of any research effect, gathering information in this way means that richer accounts of lived experience of EDs can be collected. Nevertheless, due to the nature of the data the authors were unable to establish the demographics of the commenters and therefore cannot make sense of the themes specifically in relation to groups of people or specific ED diagnosis.

To explore AN and personal identity, Tan and colleagues (2003) interviewed 10 CYP aged 13-23 with AN. It was found that AN was an important part of their identity which had implications for recovery and leaving treatment as it was felt that they would be losing a part of themselves. The authors state that these concepts should be kept in mind when assessing for consent for treatment as personal identity could be a barrier to engagement.

Comparably Rich (2006) interviewed seven girls with AN aged 11-17 to understand the ways in which they managed the complexities of the presentation of an anorexic identity. The CYP spoke about feeling that those around them held a limiting, medicalised view of AN with a focus on the physical attributes such as weight. And that these ideas of AN left them feeling isolated and pathologised and wanting to turn to others with AN for support and comfort. They also spoke about ways they could gain a sense of control over their identities by tricking inpatient staff and being a ‘better anorexic’ which was often associated with empowerment. The findings add explanations to popularity of ‘pro-ana’ websites by highlighting how conceptualisations of AN by professionals and those around the individual are limiting and unhelpful. This research recognises the complex narratives of EDs which have to be navigated for those living with difficulties with food.

Tan and colleagues (2010) used qualitative interviewing to explore CYP’s view on the compulsory treatment of AN. Twenty-nine young women were interviewed aged between 15-26. It was found that many of the young woman were not against compulsory treatments when the situation was life threatening as they felt that consent to treatment could be problematic due to AN compromising decision-making. There were differing opinions on the acceptability of using compulsory treatments at early stages of AN. Interestingly, the young women felt that trust within relationships either with family members or professionals was very important, and that some of the negative impacts of losing control and autonomy in treatment was mitigated by having trust for those making the decisions. The study highlights how professionals showing compassion and care can help to lessen some of the ethical challenges which come with inpatient treatment for AN. The research helps to provide a voice to those who have often been stripped of any say or power over their day-to-day lives. However, the results need to be taken in context and not used as evidence to push for further compulsory treatments in EDs.

Finally, Koruth and colleagues (2012) used grounded theory to make sense of CYP's views of their onset of AN. Participants were aged 13-17, attending a CAMHS service and were interviewed individually. The authors took three main themes from the interviews: *overwhelming emotions* and *awareness of anorexia* and how these two experiences combined to impact on *interpersonal interactions*. The young people spoke about how these changed over time with a better understanding of how they were feeling and an increased awareness of AN. The authors suggest that helping CYP with AN to acknowledge and label their emotions may facilitate their ability understand their AN, leading to better engagement with interventions.

In summary, most of the literature capturing CYP's views in the field of EDs focuses on how they have experienced inpatient treatment, with recovery and identity also being explored. The studies highlight that holistic treatment is very important and that CYP feel that professionals are too focused on weight gain (e.g. Bohrer et al., 2020; Colton & Pistrang, 2004). References to the importance of peer support and compassionate care indicate how relationships are prioritised for this group of young people (e.g. Rich, 2006; Tierney, 2008). The literature also highlights the complex relationship that CYP have with their ED identity and the dynamic nature of their awareness of their difficulties (e.g. Koruth et al., 2012; Tan et al., 2010). The results from these studies can help professionals to consider how to better engage CYP with treatments.

Nonetheless, the body of literature can be criticised for only capturing a select group of participants. There is a surprising lack of research capturing the voices of younger adolescents with ED especially as the onset of symptoms often occurs in teenage years (Richmond et al., 2020). Most of the studies' (with the exception of Bohrer et al., 2020) participants were mainly white, female with a diagnosis of AN and aged 13 or above. This does not fully represent CYP with ED and further research would be useful to see if the experiences documented are more universal. Equally, some of the studies were completed retrospectively and only included those who had recovered. This means that the accounts of treatment may have become better balanced over time and did not capture the experiences of those who were finding treatment unhelpful. It would be valuable to hear the accounts of CYP in current treatment to capture fresh experiences of treatment for EDs and to include perspectives of outpatient interventions.

Information gathered from CYP's experiences of other EDs (albeit mainly AN) can be used tentatively to inform knowledge on ARFID. The experiences of CYP receiving ED treatments and describing a dynamic relationship with engagement may be similar to CYP receiving treatment for ARFID (Bradbury, 2020). Similarly, the ideas of holistic recovery and an emphasis on psychological well-being being important for CYP is likely to also be true for CYP with ARFID. Qualitative research on CYP views of ARFID treatments are missing from the literature and would help to confirm the similarities and differences seen across EDs. Importantly, the complex relationships with perceived identity and peer support may not be similar for those with ARFID. This is because there is not a well-established social discourse around ARFID and due to the prevalence of the diagnosis (and differences in symptomatology) online support groups or group treatment programmes do not exist in the same way. Further research could explore

CYP's relationships with their identity with ARFID and how they seek support away from professionals.

1.4. Rationale

ARFID is arguably not a well-known or well-understood eating disorder both by the general public and professionals (Coelho et al., 2021). Currently there is no national guidance for assessing and treating ARFID and due to the umbrella-like nature of the diagnosis it is hard to grasp what a 'typical' presentation of ARFID is (Eddy et al., 2019; National Institute for Health and Care Excellence, 2017). In neighbouring fields, qualitative research is being used to gather richer understandings of those experiencing mental and physical health difficulties with the hope of improving care (Peterson et al., 2016). Interviews with CYP with AN have highlighted some of the barriers to engaging with treatment (Tan et al., 2003) and their views on compulsory treatments (Tan et al., 2010). It has also been used to further understand the relationship to food for fussy eaters (Fox et al., 2018), CYP awareness of their eating behaviours and the impact of parents on change (Wolstenholme, 2020). However, current research is missing the voice of CYP living with ARFID. In conducting research which gathers the voices of CYP, the findings can inform interventions to become empowering and effective for the CYP (Bradbury, 2020). It is hoped that by collecting and listening to voices of those living with ARFID a richer research grounding will be provided within a much speculated and under-researched area.

1.5. Personal Reflexivity

My personal relationship with food is positive. I find cooking, feeding others and eating as a way to be creative and curious, show my love and experience joy. Despite recently restricting my diet to vegan food, for environmental and ethical reasons, I do not identify as a fussy eater and have never experienced a dislike or an avoidance of food. My attitude to food was very different from one of my siblings growing up who experienced challenges with food comparable to the features of ARFID. His avoidance and fear of food frequently impacted events in my childhood. I believe that the stark contrast of our experiences around food piqued a curiosity within me about eating behaviours and my interest in psychology in general. As an assistant psychologist I worked with families who had children with diagnoses of ASD. In this role I came across children who were struggling with food, not dissimilar to my brother, and I enjoyed seeing positive changes take place with the team's support and a huge amount of effort and bravery from the children and their families. More recently, through training at the University of East London, I have become more aware of issues of power and have spent time considering who has a voice in society. Generally children in our culture are overlooked and this is especially true for those with a mental health diagnosis whose voices are further marginalised (Greder et al., 2004). I believe that it is these experiences which have drawn me to conduct this research. Through doing this research I hope to gain some shared understanding of what is like to live with a difficult relationship with food, and with this new knowledge shape how we, as psychologists, seek to help.

1.6. Aims

As very little research has been conducted previously this study aims to explore the impact and experience of living with a diagnosis of ARFID as a CYP.

1.7. Clinical Relevance

This research aims to inform services working with CYP with ARFID, leading to idiosyncratic formulations and intervention plans. As indicated above, it has been stated that the field of ARFID requires more much research and this would be best done collaboratively with those with lived experience (Bryant-Waugh, 2020a).

1.8. Research Questions

-What is the impact of ARFID on a child/young person?
-How do children/young people understand, make sense and cope with ARFID?

2. METHODS

2.1. Overview

This chapter considers the epistemological and ontological positioning of the research. The research design, procedure, and approach to analysis will be covered. Ethical considerations with regards to CYP and researcher reflexivity will also be discussed.

2.2. Epistemological Considerations

When undertaking research, it is crucial to clarify one’s epistemological positioning. This enables a better understanding of the assumptions and intentions behind the gathered knowledge and helps to inform the choice of methodology (Braun & Clarke, 2006; Harper, 2011).

This research was undertaken through a lens of critical realism. A critical realist position is ontologically realist yet believes that our access to knowledge is shaped by subjective experience (Willig, 2012). Critical realism proposes that an absolute truth does exist but it can never accurately be found due the truth being mediated via socio-cultural meanings (Greenwood, 1994; Pilgrim & Bentall, 1999). It also differentiates between the observable and the unobservable, believing that there are underlying structures at play which cannot necessarily be measured or discovered (Willig, 2012).

A critical realist positioning was selected for the research as it felt important to recognise that physical symptoms associated with ARFID exist as a truth for CYP and their families, but that their experiences of these are contextualised by wider influences. This means that the research can seek to understand some ‘truths’ about living with ARFID, whilst acknowledging the impact of things such as diagnosis, social norms and unobservable mental and biological processes. The easily measurable symptoms such as poor weight gain and nutritional deficiency are taken to be an observable truth from a critical realist position. Additionally, critical realism allows for an understanding that the way CYP, families and professionals interact with and conceptualise the symptoms of ARFID will be heavily influenced by society, cultural experiences and prior knowledge. Furthermore, this positioning enables unobservable mechanisms behind the reasons for avoidance and restriction of food to be acknowledged.

2.2.1. Aims of the Research

When choosing a philosophical positioning the aims of the research were also considered. If the aims were to uncover reasons behind the causes of ARFID then a realist quantitative approach would have been chosen. Equally, because the project seeks to make some generalisations about the experiences of living with ARFID a purely relativist or social constructionist approach would not have been appropriate as this positioning states that knowledge cannot be abstracted and only exists within its context. The project's intentions are to provide deeper insight into the experiences of having AFRID as a CYP, with the hope to inform families, schools, and professionals to increase awareness and understanding, which sits within a critical realist framework (Harper, 2011).

2.2.2. Research with Children

Generally, personhood is synonymous with adulthood meaning that CYP are disenfranchised and not thought to have rational capacity and thought in the same way that adults do. This means that the knowledge gained from CYP can often be dismissed as inaccurate and unreliable (Hendrick, 2008; Woodhead & Faulkner, 2008). A critical realist approach helps to take knowledge from children as truth whilst also acknowledging the impact socialisation has on children's reality.

2.2.3. Qualitative Research Method Selection

As mentioned in the introduction, a qualitative approach was selected in order to capture rich meanings of the experiences of living with ARFID as a CYP which is suited to a critical realist positioning (Harper, 2011). Reflexive Thematic Analysis was chosen as the framework to analyse the data. Due to the lack of qualitative research on ARFID, TA was chosen to allow the research to remain broad. Grounded theory or interpretative phenomenological analysis both could have been selected but would have limited the research questions to either explore social processes or phenomenological experiences (Braun & Clarke, 2021a). Additionally, TA can be a method which seeks to understand reality as a truth or to disentangle the construction of reality, meaning that it can be used when holding a critical realist stance (Braun & Clarke, 2006).

2.2.4. Reflexive Thematic Analysis

Reflexive TA is an approach to data analysis which acknowledges the impact of subjectivity and the positioning of the researcher on the research and encourages an inquisitive and transparent approach to writing-up and conducting research. This approach fits with a critical realist epistemological positioning that understands that multiple realities exist (Braun & Clarke, 2021a). Reflexive TA entails the researcher to consider and name their: history, culture, values, and assumptions, all of which will impact on how the research is carried out and analysed (Braun & Clarke, 2021b). For the project I took a reflexive approach, considering the reasons why I was motivated to do the research (see 1.6.); my relationship with food; my history of interactions with children; my history and relationship with qualitative research and my political assumptions. Throughout the research I kept a reflexive log to help me to explicitly consider my values, biases and assumptions and how they were impacting on the research and my interpretation of the data. Please see Appendix A for an example of a reflexive log entry.

2.3. Design

The research design was qualitative study, with individual, semi-structured interviews used to address the research questions. The conversations with the CYP for data collection could have been done in different ways. A focus group for the current research could have been a suitable research design.

Focus groups are useful in eliciting information from CYP by helping to reduce the power imbalance between adult researcher and child participants as they are supported by peers (Adler et al., 2019). However, due to anticipated difficulties with recruiting within a small target population and confidentiality considerations, individual interviews were preferred. Individual interviews enable richer conversations about private and potentially shameful topics (Symon & Cassell, 2012). A semi-structured format for questioning was selected due to the exploratory nature of the research and to allow for flexibility for age and ability adjustments (Williamson, 2013).

2.4. Participants

2.4.1 Inclusion Criteria

2.4.1.1. Aged 10-17. A large age range was chosen to maximise the niche target population and recruit enough participants. The lower age limit was chosen from clinical experience of CYP being at an age to engage and it is roughly in line with Piaget's formal operational stage of development, meaning that the CYP should be able to grasp abstract concepts and hypothesise about their experiences (Piaget, 1971). Seventeen was chosen as the upper limit to capture the experience of CYP services and schooling which typically end at age 18.

2.4.1.2. A diagnosis of ARFID or diagnosis would be highly likely considering the criteria documented in the DSM-5. Having ARFID or an ARFID like presentation was a requirement for the study. As mentioned above the criteria also included those with similar difficulties, yet had not been given a formal diagnosis to help with recruitment.

2.4.1.3. ARFID being their main difficulty (this can be alongside ASD and ADHD). As the purpose of this study was to explore the experience of ARFID any bigger issues would potentially influence the findings. Many CYP have both ASD or ADHD and ARFID so this was not eliminated.[2]

---

[2] In line with the DSM-5 criteria, for all the CYP with ASD/ADHD the severity of their eating difficulties exceeded that routinely associated with ASD/ADHD and warranted additional clinical attention.

2.4.1.4. Currently living in the UK. Speaking to CYP in the UK meant that their experiences would reflect the processes and treatments available on the NHS which is important when considering the epistemological position that the data should be considered within its social, political and cultural context.

2.4.1.5. Can engage in questions about ARFID/their life for at least 20 minutes over video call. The study's design was a semi-structured interview, so a requirement of the study was to be able to engage in the interview process.

2.4.2. Exclusion Criteria

2.4.2.1. Young people with eating difficulties which can be better explained by another diagnosis. To ensure that the difficulties fit within the diagnosis of ARFID as determined by the DSM-5.

2.4.2.2. Young people who have been engaging in self-harm behaviours in the last 6 months. Excluding CYP who had been self-harming was to prevent the interview causing any considerable distress as recommended by the ethics panel.

2.4.2.3. Young people who would need lots of support to be able to answer the questions independently. As above, a requirement of the study was to be able to engage in the interview process.

2.4.2.4. Young people who are currently experiencing other significant mental health difficulties which may mean the interview could cause considerable distress. As above, to protect the CYP from harm and eliminate other difficulties which would potentially influence the findings as recommended by the ethics panel. Additional significant mental health difficulties may have also meant that CYP may not meet the criteria for ARFID due to other presenting emotional factors which impact on eating difficulties.

2.4.3. Recruitment

The recruitment posters (Appendix B) were shared on various ARFID Facebook support groups. They were also posted on Twitter and Instagram using various ARFID and eating disorder hashtags and shared by local autism charities and Facebook groups. It was advertised that the CYP would receive a £5 voucher as a gesture of thanks for taking part.

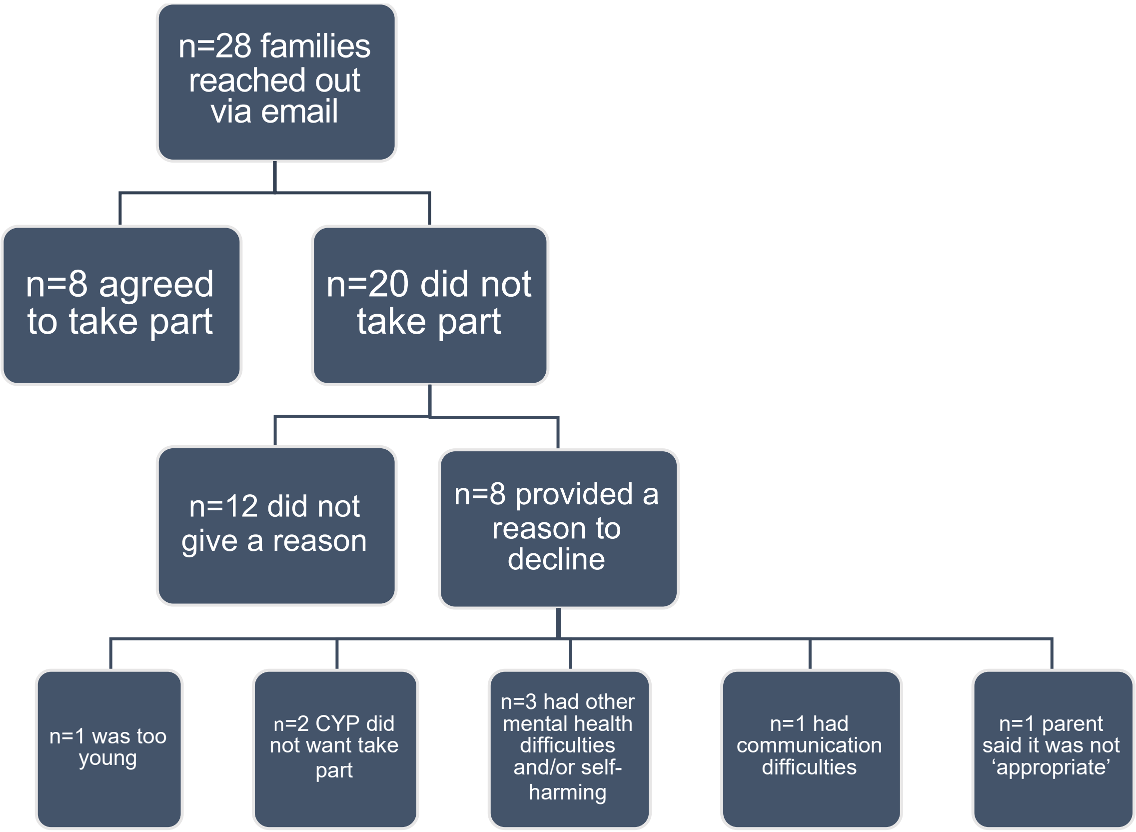
Initially data collection began with an age range of 10-16 and a formal diagnosis of ARFID required to take part. After three months of recruitment and discussions with my supervisor the criteria were expanded to include 17-year-olds and those who would meet the DSM-5 guidance for diagnosis but had not been provided with an official diagnosis. This was due to small numbers of families being eligible and feedback on social media that a formal diagnosis was hard to acquire. The appropriate changes were made to the recruitment posters, information sheets and debrief sheets which were all approved through ethical amendment procedures.

2.4.4. Sample

A total of 28 people contacted me via email asking for more information on the project, of which 8 families took part. Please see Figure 1 for the breakdown of people interested in the project.

Figure 1

Flow Chart of Potential Participants



2.4.5. Final Sample

Due to the relatively small population pool, individual demographics will not be listed to protect anonymity. However, the general demographics of the group have been shared to contextualise the findings. All eight of the CYP described themselves as White British, with one CYP adding that they were also Jewish. Five of the sample had an ARFID diagnosis and three did not, but matched criteria listed by the DSM-5 and personally identified with the diagnosis. For those given a diagnosis the professionals delivering the diagnoses were: a CAMHS psychologist (n=1), private psychologists (n=2), a community paediatrician (n=1) and psychologist within local specialist ASD team (n=1). Half of the sample had a co-morbid diagnosis of ASD (with one CYP with ASD and ADHD) and one CYP had been given additional diagnoses of anxiety and depression. All but two of the CYP had been given some treatment for their eating difficulties. Treatments included CBT (n=3), MDT input in an ED clinic with NG feeding (n=1), hospitalisation (n=1), food exposure work (n=3), and ASD informed psychological input (n=1). All the

CYP were invited to come up with a pseudonym to protect their identity and below are the names they chose. Each of the CYP with their aliases, genders, ages and whether they did the interview individually or with their parents are listed below.

Table 1

Participant Demographics

Name	Gender	Age Range	Interview format
Alice	female	15-17	Independently
Anne	female	13-15	Mainly independently
Demigamer	male	10-12	With mother
Ella	female	13-15	Independently
Evie	female	13-15	With mother
John	male	10-12	Mainly independently
Lily	female	15-17	Independently
Lucy	female	15-17	Independently

2.5. Materials

2.5.1. Interview Schedule

The initial draft questions for the interview schedule were informed predominantly by the themes highlighted by Bradbury (2020), the literature reviews on both EDs and fussy eating, and in-depth conversations with my supervisor who has experience of working with CYP with ARFID. After the consultation process, detailed below, the final proforma was put together (Appendix C).

2.6. Procedure

2.6.1. Consultation

Three experts by experience were consulted at the planning stage of the research. One consultant was an adult who had lived with an ARFID presentation in her childhood (Sarah), and the other two were boys aged 12 and 11 who have been given a diagnosis of ARFID and had been treated in a specialist ED team (Ben and Ryan). After the initial ideas for the study were formed and the research proposal was approved by the university, I firstly spoke with Sarah. Her contact details were provided by the clinical supervisor and an email inviting her to consult on the project was sent out. She was asked to review the interview schedule, draft information and de-brief sheets. Over an online conversation, Sarah shared that for her, feelings of shame and embarrassment associated with her eating difficulties were one of the hardest things to deal with. Together we added the following question to the schedule: "who knows about your difficulties?" and included prompts around telling friends to elicit conversations around levels of embarrassment. It also made me more mindful of how to sensitively ask questions, holding in mind that the CYP may be talking about things they have not previously shared. To make this safer for my participants, I considered the importance of reminding my participants of the confidentially and anonymity of the study and how to construe unconditional positive regard during the interviews (Rogers, 1957).

Finally, Sarah shared that she felt all the interview questions were appropriate and relevant. She additionally put forward her opinion on the images of food on my draft recruitment poster, stating that as a child she would be put off taking part as she 'no way would have eaten pizza' and would have felt that the poster could have construed a lack of understanding about ARFID. At the time I did not make changes to the poster as I was waiting to hear the opinion of my CYP experts.

I then had an online meeting with Ben to get his views on the poster, CYP information sheet, debrief and interview schedule. He shared that some of my graphics were 'babyish' and 'boring' and agreed with Sarah that images of food were not appropriate. I made relevant changes to the documents for the project. Ben gave feedback on the interview schedule. He thought it was important to ask about young people's understanding of ARFID and it could be interesting to hear what language other young people use. I added these as initial questions. Ben also emphasised that the questions around what makes eating easier and harder were very important. He also suggested some extra prompts around the impact of ARFID (school trips and cooking in school). Ben felt that when asking about the impact on family, allowing CYP to have privacy from their parents was a good idea.

For my final stage of consultation, I conducted a pilot online interview with Ryan using my amended interview schedule. Ryan gave positive feedback on the process and found that the questions were relevant and not too emotionally challenging. He did not have any other suggestions for other areas to explore and thought the interview had covered a wide range of areas. I found doing a pilot interview helped me to become more familiar with the questions and prompts, the recording and transcription functions and reminded me to check for demographics. The initial consultation helped to ensure that the research remained relevant to its population and that the voices of the CYP with ARFID remained integral. The time limitations of the project meant that the research was unable to follow full participatory action research guidelines (Balcazar et al., 2004). The consultants were given a voucher for payment of their time.

2.6.2. Screening

Once a parent or CYP aged 16 or over asked for more information to take part in the study, the appropriate information sheets and inclusion and exclusion criteria were sent via email (see Appendices D and E). Parents (or CYP aged over 16) were asked to send back the consent and assent forms (see Appendix F) prior to booking in a time slot for interview. CYP (or their parents depending on age) who did not have a formal diagnosis were asked to detail their restriction and avoidance of food over email. At the start of the interview, questions based upon the Short ARFID Screen-self (SAS-S) or the Short ARFID Screen–parents/carers (SAS-P) (Bryant-Waugh, 2020b) depending on the CYP's age and ability were asked to determine the likelihood of a diagnosis being given. All three CYP who were interested in taking part without a diagnosis were experiencing difficulties with eating that were in line with an ARFID diagnosis and so were included in the final sample.

2.6.3. The Interviews

Once the consent and assent forms were signed, a time slot on Teams was offered to each CYP and their parents. I also offered a separate 'get to know me' session to some of the CYP to help with rapport building but this was not required for any family. The interviews were conducted over video call on Microsoft Teams and lasted between 30-60 minutes.

The interviews started with me asking the CYP about something unrelated to ARFID to break the ice (e.g. school or commenting on something in their environment). A brief introduction was then used to build rapport and collect demographic information which included age, gender, ethnicity, and history around ARFID diagnosis and treatment. The interview schedule asked questions around the impact of ARFID on day-to-day life, mental and physical health, and relationships. It also explored if the CYP had shared their difficulties with others and the things they find help and hinder their eating. The format of the interview differed for each CYP depending on their age, level of communication and neurodiversity. I adapted my questioning style using practice-based evidence of working with CYP. Finally, I invited each CYP to come up with a 'message of hope' to the other young people taking part, which anonymously was shared with each CYP after the write up was complete (Appendix H). This was collected so that I was able to offer something (alongside a voucher) in return for their time. At the end of the interview I left time for any questions, to cover the contents of the debrief sheet. Shortly after the interviews I sent the appropriate debrief sheets (Appendix G) to the CYP and parents via email.

2.6.4. Research with Children

When conducting psychological research, the power difference between researcher and subject needs to be considered and attempts need to be made to diffuse the imbalance. This can be made even more of a challenge when doing research with CYP as children will rightfully position adults as having power over them. With this in mind, as suggested by Mayall (2008), I acknowledged the power difference with all the CYP in age appropriate ways (e.g. speaking about how grown-ups and professionals can be 'rubbish' at listening to children). I also made it clear that I was a researcher who wanted to hear their views and opinions and not a doctor or psychologist who is interested in changing their behaviours with food. The CYP were given autonomy over the choice of the presence of their parents. Literature argues both the positive and negatives of having parents present in interviews with CYP. Parents can over-ride the child's contribution or divert conversations but can also enable conversation and increase CYP confidence (Mayall, 2008). The information sheets made it clear that the presence of a parent during the interview was at the CYP's discretion. Some CYP did the interviews alone, some had their mothers present for some of the interviews and some had their mothers present for the entirety. Please see Table 1 for a full breakdown of parental input during the interviews.

2.7. Data Analysis

2.7.1. Inclusion and Exclusion of Data

Careful decisions around the use of data from parents during the interviews were made. It was important to balance capturing rich data provided by the mothers yet sticking to narratives from the CYP's own perspective. All the CYP who had parental support also had a diagnosis of ASD so the mothers' input helped to amplify the CYP voices who may have been less easily able to communicate their perspectives (Mayall, 2008). ASD can be associated with memory differences (D. L. Williams et al., 2006) and challenges with recognising own emotions (D. Williams, 2010). The mothers who supported the interviews mentioned similar difficulties around recall during the interviews. Therefore, data from parents was included if it prompted conversations with the CYP or expanded on a point that the CYP had raised. Information around things that happened to the CYP which they had forgotten was also included. Parts of conversation which were purely the perspective of the parents or had little do to do with the experience of their CYP were not included in the analysis.

2.7.2. Approach to Analysis

Data was analysed using inductive TA. This process was selected owing to the fact that there is little research in this area and it felt important for the analysis to provide a rich description of the data set as a whole. In doing so, the predominant and important themes from all the CYP were acknowledged. This is the recommended approach for analysing viewpoints on new areas (Braun & Clarke, 2006). The process of data analysis outlined by Braun and Clark (2006) was used.

2.7.1.1. Familiarizing yourself with your data. Conducting the interviews, writing the transcripts, and then re-reading the data was used as familiarisation of the data set. During interviewing I started to hear similar experiences being talked about by the CYP and initial ideas of themes and commonalities were forming in my mind. Discussions of these and ideas for coding were done with my supervisor at various points throughout my recruitment and data gathering stage.

2.7.1.2. Generating initial codes. I approached coding with a goal to capture a rich description of the data set as a whole. Codes were both latent and semantic depending on the points raised by the CYP. I did this manually, using a pen and a highlighter on the printed transcripts (see Appendix J). After each interview I then recorded all the codes and relevant page number(s) onto an Excel spreadsheet, which helped me to see a development of ideas across and within the interviews. This technique produced a large amount of codes from each script which is recommended in the guidance (Braun & Clarke, 2021b). After I had coded all the transcripts, I looked at the codes and grouped them into topics to check for crossover and fine-tuned the names of codes. I then went back over each script and adjusted codes. After the second coding I re-examined my codes (see Appendix K), with some being merged and some separated out to enable a set of code which represented the diversity in the data set yet was a manageable amount to work with (Braun & Clarke, 2021b). See Appendix A for a reflective log entry related to coding.

2.7.1.3. Developing Themes. After coding three transcripts I started to jot down rough themes which were coming up frequently within and throughout the scripts, or points which felt striking and fundamental for the CYP. After I had finished coding, all codes were written onto post-it notes and were placed into topic areas. This sorting occurred until they were placed into coherent themes (see Appendix L for photo representation).

2.7.1.4. Reviewing Themes. Once the initial themes were developed, the data set was looked over again to check that the themes were an accurate representation, and six themes were selected (see Appendix M for an initial version of themes). After a meeting with my supervisor, we considered the breadth versus the depth of the themes. At this point I reviewed the themes and to see if any could be collapsed together, enabling a more coherent narrative with more space to discuss each theme. After looking at the codes and draft themes again, the final four themes were finalised and recorded (see Appendix N for how each theme, subtheme and codes are captured in the data set).

2.8. Ethics

2.8.1. Ethical Approval

Ethical approval was granted from the University's board of ethics. Amendments were made and approved on two occasions, once to make changes to the materials and interview schedule following the consultation and once to expand the inclusion criteria to help recruitment. Details of the ethics process are documented from Appendices O through to R.

2.8.2. Informed Consent

Children aged 16 and above can provide consent to take part in psychological research studies but are encouraged to inform their parents/carers that they are participating (Oates et al., 2021). Therefore, for the CYP aged 10-16 informed consent was sought from parents, with the CYP giving their assent prior to commencing the interview. The information sheets (Appendix E) were given to the parents and CYP outlining the full details of the study. The information sheets made it clear that participation was voluntary, and that the interview could be paused or stopped at any point without consequences. The sheets also outlined that the interviews would be recorded, the withdrawal processes and the anonymous publication of their data. Parents and CYP were asked to sign the consent and assent forms prior to booking a slot for an interview. At the start of each interview, I checked with each CYP that their parents had spoken to them about the purpose of the call and clarified that consent had been given. Following the interview, parents and CYP were given the debrief sheets (Appendix G) which signposted to services if further support was needed after the interview. The information provided on the debrief sheets was informed by BPS guidance (Oates et al., 2021).

2.8.3. Anonymity and Confidentiality

The CYP were invited to provide aliases for the purposes of the write up to protect their identity. At the point of transcription, all other identifying information was removed from the interviews. It was made clear to the CYP that confidentiality could have been broken to seek help around risk issues, but this was not required. At the end of the study all the names and contact details of the participants were deleted. All quotes used in write-up were anonymised and the confidentiality of the families was always upheld.

2.8.4. Data Protection

Interviews took place over Microsoft Teams using the inbuilt recording and transcribing software which stores the files on a secure password protected cloud drive. The automatic transcriptions were checked for accuracy against the recordings and all identifying information removed. The recordings were then deleted. The consent, assent and demographic forms were stored on the University's password protected cloud drive and separate to the anonymised transcripts.

2.8.5. Protection of Vulnerable Participants

As the CYP were aged under 18 and were experiencing distress around eating they were deemed vulnerable (BPS, 2014). As specified by ethics panel, I as the researcher possessed an extended DBS check, CYP could choose to have their parents present in the interview and check-ins about more sensitive topics were conducted. The impact of being underweight and having a lack of energy on cognitive functioning was also held in mind (Coglan & Otasowie, 2019b). At the start of the interviews the CYP were reminded about the option to skip questions and take breaks if needed. All CYP were given age-appropriate de-brief sheets and information on how to seek help if needed after the interview. I also normalised feelings of tiredness or negative emotions immediately after the interview and encouraged the CYP to engage in a pleasant and relaxing task. I received no feedback that the CYP had found the interviews distressing and heard that some had found it enjoyable and empowering.

2.8.6. Research with CYP

As well as following the BPS code of human research ethics (Oates et al., 2021) Alderson's ethical guidance for research with CYP commissioned by Barnardos, was consulted (Alderson, 1995; Alderson & Morrow, 2004). The guidance includes topics which overlap with the BPS code (privacy and confidentially, informed consent, costs and benefits and selection) and poses further questions around the wider impact of the research on CYP. How the additional topics in the guidance were considered are detailed below.

2.8.6.1. The purpose of the research. The aim of the research was to help inform stakeholders of CYP with ARFID with the hope to improve understanding and inform care and treatments for CYP.

2.8.6.2. Funding. Research with CYP should only be funded by agencies which avoid harm to CYP. As the research was a requirement of the Clinical Psychology Doctoral Training the research was funded by the NHS, which is not associated with unethical practices or policies impacting CYP (Department of Health and Social Care, 2021).

2.8.6.3. Dissemination. It is hoped that an abbreviated write up of the research project will be accepted for publication. Also, the findings will be presented in an online presentation to all CYP and families who took part. An easy read summary and CYP friendly social media graphics will be made from the conclusions. The families who took part will also receive a copy of the ‘messages of hope’ shared by the CYP.

2.8.6.4. Impact on Children. Locally, the conclusions of the study will help ED services to be more informed. More widely, the findings could impact children by encouraging further qualitative research to be conducted on CYP with complex mental and physical health issues.

2.8.6.5. Consultation. CYP should be invited for their input on research involving them as much as possible. CYP have been consulted on the aims, procedure and scope of the research. They were also paid for their time.

3. RESULTS

3.1. Overview

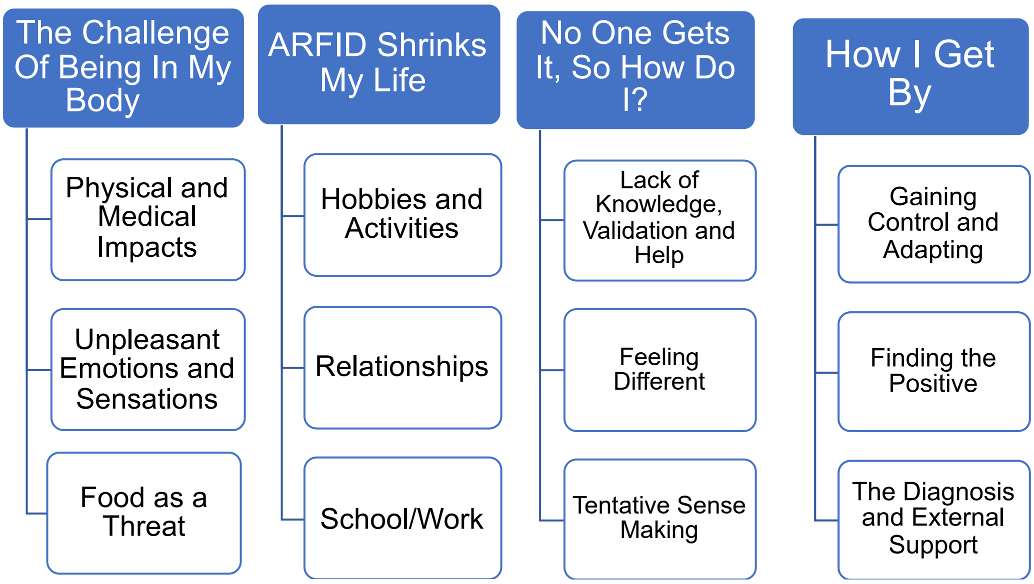
This chapter presents the research findings from the analysis of the interview data. It summaries the final sample and presents 4 main themes elucidated with quotes from the CYP.

3.2. Themes

Four themes are discussed below with reference to excerpts from the interviews. In the quotes, brief interjections, pauses and repetitions have been removed to improve readability. An overview of the four themes are detailed in the thematic map.

Figure 2

Thematic Map



3.2.1. Theme 1: The Challenge of Being in my Body

A salient theme from the CYP was the embodiment of living with ARFID. It was felt that the CYP were often describing that their body could be an unsafe place with powerful, intrusive sensations related to both the causes and consequences of ARFID being commonly experienced. Additionally, it was felt that conversations around mental distress had a physical focus with descriptions of things such as ‘panic attacks’ and ‘heart palpations’. The physical impacts of ARFID on their bodies including attending medical appointments with tests and procedures were also a prominent theme. Similarly, throughout the interviews, food was seen as a source of embodied stress and fear implying that it was seen as a threat to their bodies. Food was emphasised as being very significant in the CYP lives, with many speaking about the minutiae of food indicating they were hyperaware of its physical properties. The CYP shared their negative experiences with food and eating, highlighting the small range of their diets and the importance of food being predictable to reduce the aversive consequences of eating.

Alice was able to speak about the physical implications of not eating enough food has on her body:

> “I just feel like as the day goes on, I can feel like the life being sucked out of me 'cause I'm so tired and I can just feel my body starting to ache and starting to be tired and just be done with the day.” Alice.

For Anne, thinking about some foods produced a whole-body reaction:

> “Some things it just makes me really uncomfortable. Like milk. I hate milk. I can't…cheese… *visible shiver* I just get nervous and uncomfortable trying new things.” Anne.

For Ella the ARFID could lead to strong emotional reactions which she described as ‘meltdowns’:

> “On a bad day, I can have a meltdown caused by my autism, a panic attack and an anxiety attack because I feel like I'm missing out or because I just want to be able to eat and I'm desperate.” Ella

3.2.1.1. Subtheme: Physical and medical impacts. The effects of ARFID on the CYP’s health were varied, with some not mentioning many negative consequences. However, some experienced and spoke about a significant toll on their bodies. Lack of growth and/or issues with weight were raised as consequences of ARFID for some. Many CYP had experienced medical intervention.

Many of the CYP described a reality of attending doctors’ appointments.

> “I missed practically all of primary four and all of primary five and all of that was between doctors and hospital appointments” Alice

> “Eating disorder services saw me when I was about 13 and they did say to me if you lose anymore weight, we will put you in hospital.” Lucy

Lily and Alice both had shared experiences of undergoing tests and procedures.

> “I ended up being hospitalized and it was for about five days I think. And obviously they did blood tests, did an ultrasound on my stomach. And they were just kind of monitoring my eating.” Lily

> “I hate doctors now because whenever I go they just poke and prod (you)” Alice

For some, their medical experiences were traumatic.

> Evie spoke about having her NG tube changed: Evie: “I don’t like them.” Mum: “There was one tube change in the early days where a nurse came to do it, who wasn't very good at it, and she caused an horrendous nosebleed. And then it all got…she got in a bit of a state and the nurse herself started to cry and get really upset and 'cause that made Evie worse. I think it has had quite a negative impact.”

> Lily went on to describe how she found being hospitalised: “I found it really scary because obviously I didn't know what was going to happen. I didn't know how long I was going to be there for. I did not know what they were going to do…so I was like ahhh!” Lily

The physical impacts of having a restrictive diet were conveyed. Many of the CYP spoke about how the ARFID had impacted on their weight or growth, indicating how ARFID affected their bodies.

> “I know that I'm very, very petite and I don't think that the eating disorder has helped with that.” Lucy

> “I'd say it's impeding him thriving in growth. Obviously he's lost weight since September, I think 5 kilos since September” Mother of Demigamer

Comments around feeling ill and tired were a shared experience.

> “It just makes me tired all the time.” Evie

> “You become very, very like tired and you can't really function. And particularly recovering from the operations as well has been quite difficult because you need more food for your body to heal. So yeah, I think that's been difficult.” Lucy

Having little or no energy was another associated consequence.

> “I'm really excited to do sports and I don't have enough energy to do it.” Demigamer

> “We were still having to push her in a buggy, a child's pushchair if we went anywhere because she was too heavy to carry, but she just couldn't walk. Suddenly her legs would just give up and she would almost collapse.” Mum of Evie

> “It impacts on my life because it obviously effects my energy. I don't have much energy, sometimes to do stuff.” Lily

Some felt ARFID had negatively impacted on their appearance.

> “I obviously don't eat enough to like, to fuel me so by the end of the day I just look like I'm risen from the dead, I look terrible.” Alice

> “It's definitely impacted the way that I look, I think not to like a really unsafe extent that…yeah…I would like to be larger.” Lucy

3.2.1.2. Subtheme: Unpleasant emotions and sensations. Unwanted physical and mental processes were described by all the of CYP indicating that ARFID had led to emotional and physical distress in their bodies. The topic of visceral bodily sensations such as fullness and feeling nauseous were prominent in the conversations.

> “That is one of the biggest things that I avoid is, you know, any type of feeling full is scary to me.” Lucy

> “For some of the vegetables that I hate…sometimes I just gag” John

> “I would be chewing meat and like I physically couldn't swallow it and I had to spit it out 'cause it was making me feel sick.” Anne

For Alice she spoke about having fears around these unpleasant physical sensations.

> “I can't eat without a drink because I always overthink that I'm going to choke and then 'cause I'm thinking about it I would do it. Like I get stuck in my throat because I've thought about it so much I've like tricked myself into it.” Alice

Emotional distress resulting from ARFID was also felt in the bodies of the CYP.

> “I sort of go into rabbit holes of thinking. Why am I this way? Is it my fault? And I spiral and have a panic attack.” Ella

> For Alice when being faced with a fear food: “I can feel my whole body, like the shivers inside of it and my heart racing, and my legs start to go like jelly and everything” Alice

For those with ASD experiencing a severe emotional and physical reaction to food was not uncommon.

> Mum: “And then what else happens? Then you get really upset, don't you?” Demigamer: “Yeah.” Mum: “And then it can take quite a while to calm him down because of his autism and everything.” Demigamer

> “Someone put a sausage on my toast and I got very upset and then had to be taken outside because I was being very loud and was disturbing people.” Anne

*3.2.1.*3. *Subtheme: Food as a threat.* The unpleasant emotional and physical sensations were often closely tied to eating. It was very apparent that eating was a struggle for the CYP and that food led to numerous challenges every day. Food was often perceived as something to be wary of and many CYP spoke about being in a position where they were unable to eat for various reasons. Food could often cause an assault on the senses. Many shared that they missed meals or did not eat for extended periods of time.

> “And (the psychologist) agreed with my mum that it would be best for me to spend some time in hospital because it had got to a point when I hadn't eaten in a few days.” Lily

> “While I was at sixth form it was like an hour to have lunch… that’s not long enough, so I wouldn't have any lunch either, so I go like 8 hours without having any food” Lucy

Eating was also seen as chore.

> “I can't with ARIFD. I can't eat for enjoyment. I can only eat because I have to.” Ella

Even when the CYP felt they wanted to eat, many also faced challenges.

> “We even washed the whole punnet and she was like she couldn't eat it. This is when she's hungry and she's like, I want to eat them” Mother of Anne.

It was a common experience to be in situations where they did not like any of the food options available to them.

> “I haven't had any of the school food yet…some of the food there just doesn't look very nice.” John

All the CYP spoke about their relationship with food as an object. Food was seen to be something that needed to be paid particular attention. This was especially true with its smell, texture and taste, indicating once again the strong bodily experience of eating with ARFID.

> “Like part of me wanted to eat, but I physically couldn't like, even the smell of food was repulsive.” Lily

> “Taste’s a bit more tricky because if it has a really strong taste like it tends to…You know like sometimes you can still taste afterwards and it tends to like linger which I find really difficult because it kind of for me like mimics…like it makes you feel sick or it just mimics sort of tastes of when you’ve been sick, so that's much harder”. Lucy

> “I'm very hypersensitive and have very strong senses and they think that that accelerates the difficulty that I have with food and texture and smell.” Ella

Inspecting or checking small details of food was common practice for some CYP.

> For John he struggled with different textures. “You’re trying to figure out what they are, you eat them and see if you like them then, if you don't, then you have to like, get all of it out and just put it somewhere else.” John

> “We got a bag (of popcorn) and it had black bits in it, and it smelt weird. And the black bits, they weren't like burnt bits. They were all like on the popcorn and it wasn’t burnt. It was just weird” Anne

Even food that was not going to be consumed by them was seen as threatening to some CYP.

> “Jacket potatoes were one of my worst fear foods, I sometimes even struggle to say it on bad days, but it's really bad.” Ella

> “I can't even be in the house for my mum's cooking mince cause I can't stand the smell of it. If my dad’s eating it, I’ll eat in a different room or like build a massive wall so I can't even see his plate”. Alice

Like Alice, a strong reaction to disliked foods could lead to difficulties being around others when they were eating.

> Ella was reflecting on the impact on mealtimes at home: “They (her sisters) will eat something else, and if that happens to one of my fear foods, they will eat before me or after me. But if they've eaten before me, we have to clear around the entire area or I have to eat somewhere else because I feel like I can't eat there.” Ella

> When asked about what it is like to be around other’s eating Demigamer said: “Sometimes alright, sometimes sick”.

Due to the threatening nature of food, it was clear that the predictability and consistency of food was very important for the CYP. All the CYP spoke about preferring particular foods and eating in certain ways to reduce the potential threat of food. The CYP spoke about having a very small range of foods that they typically ate.

> “I would usually just eat chocolate buttons and cheese.” Evie

> “Whenever I came out from sports, I used to always to get a garlic bread.” Mum: “At one point it was the only food that he was eating.” Demigamer

Preferred food often needed to be a specific type or from a specific shop or brand.

> “We couldn't buy the milkybar buttons that she eats in France 'cause they have to be the exact same ones in exact same packet.” Mother of Evie.

> Mum: “The garlic breads got to be a Morrison’s garlic bread” Anne : “And the round one as well” Anne

Differences in preparing food and eating environments also made a difference to the tolerability of food.

> "If I was to be like oh tonight, my brothers cooking it there's no way I could actually psych myself up to eat it because someone different is cooking it." Alice

> "But if we took our bread and our cheese and our knife, and we went to her grandma's house and we made (a sandwich) with our food and exactly the same way and gave it to her there, she still wouldn't eat it. Even though it's exactly the same, but because she's not at home, she wouldn't eat it." Mum of Evie.

3.2.2. Theme 2: ARFID Shrinks my Life

With food and mealtimes being so central to life, the day-to-day impact of living with ARFID was significant. For the CYP, ARFID had impacted on multiple areas of their reality, often restricting what they could do, who they saw and their ability to learn in school. The causes of these constraints were due to the need to avoid food and/or due to a lack of energy. It was also felt that the lack of understanding around ARFID (expanded upon in theme 3) and living in a culture where food is closely tied to socialising impacted on the CYP's relationships. The CYP communicated a strong sense of missing out.

Lily speaks about how her lack of energy and worries around food choice get in the way of her life:

> "ARFID impacts on my life because obviously it affects my energy. I don't have much energy sometimes to do stuff…. If I want to go out with friends, I get really panicky because I don't know what food there might be or what the options will be so I don't go out because I don't know what food there's going to be." Lily

3.2.2.1. Subtheme: Hobbies and activities. Many of the CYP discussed how they were prevented from doing things that they enjoyed. Hobbies, especially sports were greatly impacted due to a lack of energy.

> “I used to do like gymnastics and dance but by the time I got to like, 14 the amount of food that I ate compared to the amount of activities didn't work, so I don't really do anything” Alice

> Mum: “swimming was hard last night for you wasn’t it?” Demigamer: “Yes. It makes it harder for me to do the sports.” Demigamer

Other enjoyable activities were also impacted.

> For Evie, she spoke about the impact of receiving her feeds. Evie : “I just want to like be doing my own thing.” Mum: “It means she has to sit still for a couple of hours and have the feeds. She might be in the middle of doing an activity or playing or doing something, and she doesn't want to be tied down for a couple of hours.” Evie

> “I couldn't really get out of bed like laying in bed all day. I didn't have the energy to like play with my dog or anything.” Lily

At the more severe end, some CYP spoke about the shrinking of their lives being so significant that at points there were not able leave their house.

> “It got to the point where I couldn't leave the house because the anxiety around food and around the eating was very bad” Lucy

> “I don't go out because I don't know what food there's going to be.” Lily

3.2§.2.2.Subtheme: Relationships. Many of the CYP reflected on how the ARFID had affected their families. Due to the social nature of food all the CYP spoke about how ARFID impacted their social lives. Some found it challenging to eat with friends meaning that the ability to socialise with peers was reduced.

> “I don't go to my friend’s house for tea or anything.” Alice

> “If I go out to lunch with my friends and they all have something off the menu and I have to go through ordering something completely different, which sounds like a first world problem, but it’s difficult”. Ella

Similarly everyday childhood experiences like birthdays and parties were often difficult to attend or host.

> “I do remember being six or seven and going to those birthday parties where you'd have the magician and not really eating much, having one or two finger sandwiches, and that was about it.” Ella.

> “Remember when Claire had a Pizza Hut Party? The girl that she was really good friends with had a birthday party and pretty much invited everybody in the class but didn't invite Evie. But it was because it was a Pizza Hut party and they just said we didn't see the point in inviting her because she wouldn't eat anything.” Mum of Evie

> “I never really had parties and stuff with my friends because they don't like the foods I like.” Alice

Understandably some of the CYP stated how they had noticed how the eating difficulties had impacted on their friendships.

> “I was taking forever to eat and I wasn't able to play with friends (at break in school)” Demigamer

> “And I had a lot of friends in high school who just didn't have the time of day to deal with it, so just stopped being friends with me.” Alice

The CYP were also aware the difficulties had impacted the lives of their family members too.

> “it's probably not great because if (my family) wanted to go somewhere but they didn't have anything I could eat, then they couldn't go there.” Anne

> “Like the holiday we went on in the summer. I'm aware that there were things (my family) wanted to do and they didn't do.” Lucy

Many of the CYP spoke about the strain that ARFID had put on their relationships with family members.

> “I think it also causes problems 'cause I don't eat with the rest of the family. And my poor mum she's amazing, but she does get, you know, completely, rightly does get quite frustrated at times.” Lucy

3.2.2.3. Subtheme: School and work. Almost all of the CYP spoke about the impact of ARFID on their schooling. For many they had to take periods of time off school or higher education.

> For Lucy, she spoke about having an operation unrelated to her eating and then dropping out of sixth form: “I had some major surgery in October. So that was the main reason why I got out of sixth form. But even without the major surgery, I probably would have had to have taken the year out anyway because the food intake was so rubbish.” Lucy

> For Lily, she had been signed off school and spoke about some of the reasons why: “I don't like eating in school. So usually most days I didn’t really eat and then I come home and I would just completely just go to sleep.” Lily

> "I didn't go to uni because of it. Because I don't think I would have ate without like without my mum reminding me that I need to eat." Alice

As well as impacting on attendance, for some ARFID meant that even when the CYP were in school that specific lessons had to be missed.

> "I would get really bad heart palpitations if I was doing any exercise. So I ended up having to be signed off doing PE at school." Lily

> "I have never been able take part in (food technology) lessons and it sucks because it's a double lesson so I had to sit in a room for two hours and like read." Ella

Due to poor food intake, some of the CYP had noticed an impact on their cognitive abilities and therefore their capacity to concentrate in class.

> "All I could do was focus on actually getting into sixth form and so I didn't really take anything in" Lucy

> "If I go into a lesson hungry because I haven't eaten lunch because the environment around me is stopping me from eating, I'm not going to be able to focus." Ella

3.2.3. Theme 3: No One Understands so How Do I.

This theme relates to the complex and unfamiliar nature ARFID and the subsequent influence on the conceptualisation ARFID for the CYP. It was apparent that all the CYP were aware of the lack of understanding and awareness of ARFID both in the general population, their families, and professionals around them. This lack of understanding impacted on CYP in two ways. Firstly, by leaving them feeling that ARFID was something 'odd' and something to be ashamed of. It was felt that for many of the CYP that their main challenges around ARFID were caused by a feeling that no one truly understands or listens. Secondly, it seemed that for the CYP, ARFID was complex and hard to understand. All the CYP had made some attempts at trying to make sense of ARFID, with many also appearing indifferent to thinking about various aspects of ARFID.

Ella sums up the experience of trying to understand ARFID for both herself and her family:

> “I think it's difficult for them (my family) not knowing how to help me because they don't know what I'm going through…And I think for my sisters as well, my younger sister is 7, so explaining it all to her…she doesn't quite understand. It was difficult and we're still learning. We all are including me.” Ella

Alice describes the difficult feelings around believing that no one will ever understand ARFID if her close family members cannot. She also indicates that ARFID creates difficult feelings linked to shame.

> “I don't really talk to my dad anymore because I think I found it really difficult that if my own dad didn't understand the whole situation then how was someone else going to understand it when he lived with me. I'm like well it just makes me feel so like embarrassed that my own family didn’t even always understand it.” Alice

Later on in the interview she spoke about how no one could understand her difficulties with eating:

> “I grew up going to so many doctors, I was referred from doctor to doctor. No one gave me an answer I tried dietary thing and under the sun and I've had like every test there could possibly be given and no one was ever able to say to me this is what's wrong. And then I think that just made me feel really misunderstood and because like not even doctors could be like ‘this is what's wrong with you’” Alice.

3.2.3.1. Subtheme: Lack of knowledge, validation and help. It was apparent that interactions with health professionals, school or other adults were often disappointing, and that help was not readily available. It was explained that finding professionals that understood and helped was a challenge. Even within the medical/psychological fields some found that awareness of ARFID was poor.

> "It was like it was really difficult like finding someone that knew what ARFID was and they hadn't just googled what ARFID was then just read the little short thing." Lily

> For Demigamer's mum she went to their GP when she found out what ARFID was and discovered that the GP was not familiar with ARFID: "we went straight to a GP and they just looked at us gone out." Mum of Demigamer

Trying to access the right support was described as a challenge which could be frustrating for the CYP. This has made it even harder for those without the formal diagnosis.

> "I would just like more people to know about the inaccessibility of help that there is. Help is difficult to get and big names like *name of national centre* whilst yes they do have experts. My ARFID is not going to go away in the four years I spend waiting for those experts to help me. It's only going to get worse." Ella

> "I wish there was more help." Evie

> For Lucy she felt that a diagnosis would mean better access to help. "It would just be, you know, something in order to access the right support…We haven't been able to access any counselling on the NHS at all." Lucy

Even after accessing help, many felt that it had not really resolved symptoms of ARFID.

> “We've tried therapy. We had 25 sessions of therapy for CBT therapy. It worked to a degree to where we got him…sort of trying a food a week but he never liked anything.” Mum of Demigamer

> For Lily, she felt sessions with a psychologist were not helpful. “They're not very well educated on ARFID so the stuff they were saying to me it was like…they thought that I was like scared of food, which I'm not really scared of food. And they were like talking to me as if I was like terrified of food and I was like, it's not that…they just didn't understand.” Lily

> “When I started CAMHS I thought it would make me feel like physically better, But I did like a year of it and I don't actually feel any physically better, like I tried new foods and I did everything they asked me like I didn't argue against any of it. But, by the end of it, I feel physically worse than I ever have ‘cause I've put myself through that much that I just feel worse” Alice

Interactions with others around the difficulties with eating could often be invalidating.

> “An old friend, I told them and they're like oh people have bigger problems. You know, I have this and I'm depressed and I was like well, I'm sorry about that I just thought I'd tell you.” Lily

It was felt that others did not take the time to try and understand.

> “The people around they don't listen to me because they think that they as an adult, it’s always adults, they know better about something I've lived with for more than 10 years.” Ella

> “I find it such a stressful thing 'cause some people can be so judgey and it's just like they judge before even trying to like, understand the situation or like the person it is. And I think 'cause people can't see

> that there’s particularly a problem, they don't always believe that there is. So it just makes it quite difficult.” Alice

It was felt that public knowledge of ARFID was poor. Many have assumed that some of the CYP had AN.

> “I did an exchange… a German exchange and I struggled a lot with that. My exchange family were very concerned. They did think I was anorexic because my food intake was very, very little.” Lucy

Similarly to Alice above, many CYP expressed that their fathers were not good at understanding.

> “Particularly the boys, my dad and my brother, they're a bit like, come on like, you know. And I think it’s when you don't understand.” Lucy

> For John he was speaking about being pressured to eat “It’s happened once with daddy. It was happening once because he doesn't really understand the whole thing.” John

> “My mum has to tell my dad to calm down because, I remember, sometimes, when I wouldn’t eat my dad didn't know what to do and he would get really upset and angry and then he'd get a bit shouty” Lily

Some CYP had experienced distressing interactions with teachers at school.

> “The teachers didn't really give ARFID like a time of day. Like my home (economics) teacher put on that like supersize versus super skinny show and then he'd say that I would know what the super skinny person must be like. And I would probably eat the same amount and my whole class would look at me and he'd say openly in front of my whole class.” Alice

3.2.3.2. Subtheme: Feeling different. Perhaps due to the lack of awareness in the general population, all the CYP made reference to their realisation that their eating behaviours were different from the norm and they preferred to keep their difficulties private. Many CYP implied that they were feeling levels of shame associated with ARFID, indicating that the social mediated aspects of living with ARFID had led to a conceptualisation that ARFID was something to be ashamed of. Many expressed an acute awareness of what typical eating behaviour was like.

> “I did find it difficult sometimes because seeing all the people eat whatever food they want and not having any struggles. It was kind of like… hit…because it’s like oh, you know you realise how different you are” Lily

> “Eating should be easy, eating should be something that people do normally and it is something that lots of people would do normally.” Lucy

An awareness that other people thought their food behaviours were odd was common and many of the CYP experienced comments or reactions from strangers when out.

> “My parents order like a big meal and then, I’d order like a slice of cake, like I can see the people looking at me weirdly.” Alice

> Ella spoke about her experience at a cinema: “we ordered (a cheese board) with just the crackers and she told me, the lady there, ‘that that's very weird, I've never had that before, what are you eating?’ It was like urgh, It's tiring.” Ella

Many felt that they did not want to disclose ARFID to others.

> “My sister, she mentioned that at one point all I would eat was hot dogs…I don't want to be judged. I just got really mental that she told

> people, they really didn’t need to know that because that's none of their business.” Anne

> “I'm really reluctant to tell any of my friends.” Lucy

> “I just never ever really speak about like I don't even really talk about it with my mum….I don't offer up the information to anyone, really.” Alice

Some CYP made efforts to hide their eating behaviours. Evie and her mum mentioned that her calorie intake in school had reduced as she was hiding her food to avoid others noticing.

> Evie: “I was worried if they’d say something about what I am eating.”
> Mum: “She tries to hide what she has in a lunch box…and she sort of used to sneak her hand into the tub inside the lunch box, away from people, and just get one button out and quickly pop it in her mouth when nobody was looking.”

The CYP indicated further that they were aware that ARFID was unfamiliar and not common. Feeling isolated and alone was a shared experience.

> “I've had many countless nights crying over the fact that I’m different.” Alice

> “It's such an isolating thing sometimes… you scour the internet… you don't find anyone with this sort of thing.” Lucy

Finally, the CYP spoke about having to balance the social pressures of being polite whilst navigating mealtimes.

> “Some people make homemade stuff and if I don't like it some parts of it like, a pizza or something they’ve made…It's just awkward just to kind of start poking stuff off of it.” John

> “If someone is taking you out for a meal or they're paying for you or they're providing food. It's this real pressure” Lucy

3.2.3.3. Subtheme: Tentative sense making. The conceptualisation of ARFID for the CYP was diverse and complex. It felt that the ‘unknowness’ of ARFID either piqued curiosity or generated cognitive avoidance for the CYP. For many of the CYP they displayed both inquisitiveness and avoidance when considering ARFID during their interviews. Despite the variety seen in how the CYP made sense of ARFID, almost all the CYP characterised ARFID to be some of external force which prevented them from eating.

> “It's just that there’s always a voice telling me no.” John

> “It's something that is out of my control that stops me from eating what I want to eat” Ella

When asked about what ARFID was Evie explained it simply as:

> “It doesn’t let me try things.” Evie.

It was also common for ARFID to be described as problem in their lives.

> “I think it massively impacts my life.” Lucy

> “I think it is a problem, but it's not as big as other ones.” John

Lucy shared a desire to overcome her difficulties around eating:

“I want to recover and I want to tackle (the food related difficulties)” .Lucy

Being curious around the triggers for the eating difficulties indicated that the CYP had attempted to find meaning in their experiences. Some of the CYP shared they had spent time wondering why they had developed ARFID.

> “I always wonder about (the cause of my ARFID) 'cause no one in my family has any food issue any like health problems or anything like I'm totally by myself on it.” Alice

> “I did a lot of work with my…my counsellor about this to try and work out exactly where it started.” Lucy

The reasons and triggers that the CYP gave were varied and complex, once again indicating how ARFID can be difficult to conceptualise.

> For Ella she reflected on the causes of ARFID: “I thought about this a lot…this was the confusing part for me because when I was learning about it, I often saw (ARFID) is caused by trauma or something, and I haven't had a traumatic experience. And then I realised that at the age of five when I'm still learning about how food works, being forced to sit on a table with adults, mean adults, forced to eat foods I couldn't physically eat until I felt sick. So I think that I was traumatised from that and that could very well be the reason that I live with it today.” Ella

Despite some of the CYP taking time to consider ARFID, being unaware and/or unsure of the impacts of ARFID was also conveyed by the CYP. The CYP spoke about not knowing or not being able to express how they felt ARFID was impacting lives, indicating that ARFID was too complex or difficult to think about.

> Researcher: “What do you think ARFID might be doing to your body?”
> Demigamer: “I don't know. Not a clue.” Demigamer

> Researcher: “How much do you think it might impact on your feelings”
> Evie: “I’m not sure.” Evie

Some did not have language for ARFID.

> For John, when asked how he speaks about the eating difficulties at home. “I don’t really have a word.” John

It was felt that perhaps some of the CYP’s views on ARFID were discrepant to that of those around them, once again highlighting the complexities of developing a comprehensive understanding ARFID.

> “I'm seeing all these other people around me so worried about my health. It was kind of bit like oh, should I be worried?” Lily

> Demigamer was asked about arguments with parents around trying food. Demigamer: “I don't know”. Mum: “We have a lot… we're trying not to, but we have had a lot. We keep trying but it just gets frustrating at times. We do a lot don’t we?” Demigamer: “I don’t know.” Demigamer

It was felt that many of the CYP had underdeveloped theories around ARFID in their minds. Some CYP did not have responses when asked to broaden some of their thoughts around ARFID or could not make any further sense of their initial ideas.

> For Lily, she understood the ARFID to be a ‘wall’ but could not expand on why the ‘wall’ had developed, she explained: ‘It's just like…that looks nice, but I can't eat that. And it's like I don't know…It's just yeah, just don't know where it came from, but it's just that this wall is being like ‘you can't eat that’. Lily

> For Anne she was clear about the limits of her understanding of ARFID “I have like an idea of what it is but I'm not like ‘ARFID is like this, this, this and know everything about it. I don't know much.” Anne.

3.2.4. Theme 4: How I Get By

Even though all the CYP spoke at length about challenges, there was a sense that at some level they had found ways to cope, even if it meant their eating was not improving. All the CYP had an idea of what helped them to eat and handle the wider impacts of ARFID. The strategies for coping were varied but a strong theme of gaining control of their relationship with food was apparent. For some they had found positives from living with ARFID and times when the effects did not feel as bad when people in their lives were helpful. For many receiving a diagnosis helped them and those around them make better sense of the diagnosis and open up avenues for support.

> Ella was able to reflect on how she is able to stay resilient: “It's difficult to cope but I think building the relationship with myself and the idea that it is totally fine to be a bit different.” Ella

> Alice spoke about how ARFID had shaped her: “It’s made me quite strongminded like no one will ever be able to pressure me to do anything because I can stand my ground. And I think I cope because I don't know any different. At times I think it's a bad thing. But like 'cause, I've always had it, I don't hate it… like it doesn't bother me. I just kind of get on with it.” Alice.

3.2.4.1.Subtheme: Gaining control and adapting. Learning to live with ARFID often meant employing strategies which gave the CYP a sense of control over their food. This meant food was more predictable and manageable. One way of doing this was bringing their own food to places.

> Demigamer reflected on his mum bringing food into school.
> Demigamer: “It's easier now because I'm getting food which I like. I'm having chips and my mum puts in bread and butter.” Demigamer

> “Instead of me being able to eat any of the food there, we had to pack me a big bag full of crisps and sandwiches and things and give it to my teacher” Ella

> “I just pack my snack that I know I like.” John

Advanced planning helped to avoid challenges with eating.

> Evie and her mum reflected on going on holiday. Mum: “I had to buy camping fridges that we could plug in in the car and literally fill them up to the brim with supplies. Enough for two weeks to take with us.” Evie: “It was good for me because I was just eating like normal.” Evie

> For John, his meals were planned. “It's pretty much just a set thing of foods I’ll eat. One day we're going to have this and the next week, same day, we are going to have the same thing.” John

Almost all the CYP found that eating on their own was helpful sometimes because it reduced the pressure to eat, or they did not have to see others eating.

> “A lot of the time I find it easier, I just eat alone in my room because then I feel like no one is watching me and I can just kind of eat up on my own time.” Lily

> “I go off into a separate room….it makes it easier.” Evie

> “Sometimes, like if I'm eating something by myself then it is (easier)” John

Many of the CYP employed self-talk to help them to eat.

> “I tell myself I like the food. I actually can kind of psych myself up and be like, oh yeah, its chips for tea. If I think about it for long enough, I can convince myself that I'm excited to eat it.” Alice

> "…telling myself that it's OK and then maybe tomorrow I'll be able to eat better. And then it isn't my fault that I can't do this, makes me less angry at myself" Ella

> "I'll try to sit there and say to yourself, look, people have half an hour lunch breaks all the time and that's normal and you can eat in an hour and you'll feel fine afterwards." Lucy

3.2.4.2. Subtheme: Finding the positive. For all the CYP they had managed to either reflect on some of the positive things that had occurred due to the challenges associated with food or hold onto moments when things had felt easier. Having ARFID for some, had increased their psychological mindedness.

> Alice reflected on her work in a nursery with a child who would not eat: "He clearly didn't either feel comfortable to eat in nursery yet or he just didn't like the food. I would never force anyone to eat anything because I have been forced to eat stuff. So I would go get him other food and now he sits down and eats all the food with everyone." Alice

> "I've had a lot of time to learn about myself and the way that I deal with food. I think it does help you to understand yourself and your body a lot more like it's giving me an opportunity to really kind of understand how I work on a very like deep level." Lucy

Some CYP were able to embrace their differences. Ella spoke about her own relationship with ARFID:

> "I am building the relationship with myself and the idea that it is totally fine to be a bit different. I post on Instagram a little bit. Not very much about me and my struggles with it, but I do like to raise awareness. So I have made it known on separate occasions that I do live with ARFID." Ella

Others had seen an improvement in their health or eating.

> Demigamer: “I tried some chips”. Mum: “We've now got chips so a variety of chips or not just chip shop chips. He can eat French fries and the chips at school.” Demigamer

> “She got the NG tube and within a month I would say she was like a different child. It was unbelievable. The difference. She's suddenly shot up. She's taller than me. She is thriving academically. She's way above, you know, where she should be.” Mum of Evie

Times where the difficulties were not as apparent were also mentioned.

> “I seem to like cake, so it hasn't really affected birthdays I don’t think.” Lily

> “I don't have many friends’ houses that I go to, and if I do, they'll always make me something that I'll eat so it's not (tricky).” Anne

> “I’ve baked some cookies (at school). I like to make food.” Demigamer

3.2.4.3.Subtheme: The diagnosis and external support. Despite prevalent feelings of other people not understanding, all the CYP mentioned at least one person being supportive, helping to mitigate some of the challenges. It was often the case that receiving or discovering the diagnosis created a shift the CYP’s understanding of themselves and their difficulties. For many they found that the diagnosis helped those around them to understand them better. For those attending a specialist education provision school seemed to act as a buffer to some of the difficulties experienced by the other children.

> Anne: “I am in a special school and so a lot of the kids probably have similar things, so it's not really something that I think I'd be judged about.” Mum: “I think Anne’s experience is probably managed differently because of the environmental situation, the children have

> their own difficulties. The dinner ladies accommodate without question.” Anne

> Researcher: “So the people around you are quite understanding?” Evie: “Yes.” Mum: “(school) are very, very supportive of everybody and everybody is there for a reason. They all have their quirky little ways and habits, so they don't really bat an eyelid at a tube” Evie

Many found that certain friends had been good at accommodating or understanding.

> “Some of them like would really take it on board and like I would go to their houses routinely, but I will just have pizza or like chips or something or we’d get a takeaway or they mostly come to mine.” Alice

> “With best friends whose mothers have known me since I was about six, it's fine because they'll just know if I'm coming over to cook pasta and they're lovely.” Ella

Almost all spoke about their mums or wider family being supportive.

> “My parents of course are very understanding, as are my grandparents. And when we got the diagnosis and we let my family know they were all very accepting and very understanding and it was really lovely to receive sort of message saying we believe you.” Ella

> “My mum kind of got it because since I was a baby. She noticed that (I couldn’t eat). So she always said to all the doctors, for all the years that there is a problem with food” Alice

Receiving the diagnosis was welcomed by many of the CYP and their families.

> “When we became aware that a diagnosis might be in order, or that I had a diagnosis, that's when it sort of clicked in my head.” Ella

It also helped some CYP to feel less alone.

> When asked about how the diagnosis made him feel Demigamer said: “Better…. I know it’s just not me.” Demigamer

> “I just think it really helped me to be like oh actually that’s okay, like other people feel that way too.” Alice

The diagnosis also meant better access to help.

> “It was helpful because then I could come and get the treatment, I could like look for specialists that actually know about ARFID.” Lily

> “Because he's got an official diagnosis, this CCG locally is now stepping in to try and get him some funding.” Mum of Demigamer

4. DISCUSSION

4.1. Overview

This chapter considers the results of the analysis in relation to the two research questions. It will contextualise the novel findings with existing research and highlight the results which may have useful clinical implications. An evaluation, researcher reflexivity, the strengths and limitations of the study, and future research directions will also be discussed.

4.2. Introduction to Findings

Four main themes and twelve sub-themes were developed from the data set to answer the research questions:

1) What is the impact of ARFID on a child/young person?
2) How do children/young people understand, make sense and cope with ARFID?

4.3. Research Question 1: What is the impact of ARFID on a child/young person?

This is the first time that a qualitative study has investigated the impact of ARFID[3] on CYP. It was established that the negative impacts of ARFID were both internal (situated inside their bodies) and external (situated within their micro and macro systems). ARFID was found to negatively impact on how the CYP experienced being inside their own bodies, with the CYP frequently speaking about embodied difficulties. Some of these included: frequent medical appointments or procedures; feeling tired or ill; having no energy;

---

[3] ARFID in this chapter should be understood to mean those with an ARFID diagnosis and those who are highly likely to meet criteria and identify with the diagnosis, to help with readability.

being underweight or not growing; unpleasant digestive sensations; unwanted emotional reactions and unpleasant sensory stimulation. Food was viewed as an object of stress and anxiety which created day-to-day challenges with eating for the CYP. Unfortunately, the CYP found that people within their schools, families and healthcare systems did not always understand their experience of ARFID. Living with ARFID meant that the CYP felt othered and different from those around them. Because of this, it was found that both the physical impacts of having ARFID and feeling that no one else understood, led to restrictions on the CYP's lives. The limitations were far reaching and impacted the CYP in many different aspects of their childhood or adolescence including school and peer relationships. Below each of the themes related to research question one, will be discussed in relation to the existing literature and how they contribute to addressing the research question.

4.3.1. Theme 1: The challenge of being in my body

The lived experience of ARFID for the CYP was very physical. ARFID had meant that CYP's bodies were sometimes an unpleasant place to be. Medical appointments and tests were common for many of the CYP, sometimes being intrusive and distressing. Physical sensations such as hunger, disgust and nausea were prominent in the lives of the CYP, with emotional distress also being felt. The impact on mental health, although was present in the interviews was spoken about less than the physical impacts. Furthermore, the emotional impacts were often described more as sensations rather than thoughts. ARFID also led to feelings of exhaustion with a lack of energy to complete everyday tasks. The subtheme around food being a threat captured the impact of ARFID on a CYP's diet and eating behaviours. The CYP saw food as causing considerable distress and a threat to their bodies. Being hyperaware and sensitive to the properties of food was a collective experience. Mealtimes and eating were understandably difficult, often leading to a restriction of food intake. The food range consumed by the CYP was often limited and rigid indicating that avoidance of food was taking place.

This is the first study to explore the embodiment of ARFID. Attending frequent medical appointments is evidenced in quantitative research of ARFID (Strand et al., 2019). Equally, the literature within AN aligns with the idea that CYP can experience overwhelming emotions, although CYP with AN appear to experience a stronger emotional impact (Koruth et al., 2012). Moreover, it was interesting that a lack of energy or feeling poorly was a prominent feature for the CYP, as the literature on AN does not seem to reflect a comparable experience, despite also leading to restriction of food.

The intensity of the bodily sensations associated with eating could be somewhat explained through atypical introspection often found with individuals with ASD, as half the CYP had a diagnosis of ASD. Internal biological feedback for people with ASD can be hyper or hyposensitive meaning that sensations such as pain or sickness may be felt more strongly, or feelings such as hunger may be imperceptible (DuBois et al., 2016). Interestingly these differences in biological feedback could also being playing a role in the changes in eating behaviours in those without a diagnosis of ASD. There were no stark differences noted between the neurotypical and neurodiverse interviewees in their descriptions of intense bodily sensations (Khalsa et al., 2022).

The findings around food restriction are aligned with the DSM-5 (APA, 2013) criteria for ARFID and substantiates that avoiding and restricting food is a common experience for those with ARFID. Fox and colleagues (2018) similarly found that picky eaters saw food as hazardous. Experiencing hypervigilance towards a perceived threat is well understood within anxiety literature (Richards et al., 2014). It is also what some ARFID treatment programmes are based upon (Eddy et al., 2019). The sensitivity to the taste, smell and texture of food has also been found to be significant for picky eaters (Wolstenholme, 2020). However, viewing food as a threat does not appear in AN literature (Bezance & Holliday, 2013) suggesting a contrast between the two EDs. This is the first study to capture a rich description of what the sensitivity of food and eating looks and feels like for people with ARFID, providing insight into the daily challenges associated with eating.

Having a better understanding of the thoughts and behaviours associated with the inspection of food and the sensitivity of its sensory components could help to hone CBT interventions.

4.3.2. Theme 3: No One Understands so how do I

Theme three spans both research questions and will therefore be explained accordingly. This theme captures the unfamiliarity and complexity of ARFID for both the CYP and those around them, and how that has impacted on the experience of living with ARFID. Due to the general lack of awareness and understanding of ARFID, the CYP found ARFID to be an isolating and othering experience. It was usual for the CYP to experience invalidating comments from others, which sometimes led to feelings of shame. Some CYP felt unable to disclose that they had ARFID and many would conceal their eating behaviours. Many spoke about feeling that their fathers or wider family members were insensitive. Accessing appropriate help was hard, with many medical or psychological professionals demonstrating a lack of an awareness of ARFID.

Experiencing judgements from others and feeling different were mentioned as having significant impact, often preventing the CYP from engaging in activities with their friends or going out in public (see ARFID Shrinks my Life below). It appeared that without being misunderstood and othered, ARFID would be much less of a problem for the CYP. Within AN research it has been found that CYP receiving inpatient treatment felt that the interventions did not focus enough on the secondary effects of living with AN (Tierney, 2008). Interventions that help to alleviate distress caused by interactions from others, rather than solely focusing on changing their food behaviours may therefore be beneficial for CYP with ARFID.

The CYP experiencing barriers to help from professionals is backed up by research indicating that awareness and confidence with working with ARFID is low amongst professionals (e.g. Harrison, 2021) and the signs of ARFID can often be missed by primary healthcare providers (Cooney et al., 2018). Worryingly, some of the CYP had experienced traumatic incidents with teachers or doctors. It therefore may be valuable to place some interventions at a community level, to help increase understanding in school and primary care providers. This is the first study to demonstrate the impacts of living with an ED which is poorly understood by healthcare providers and schools.

4.3.3. Theme 2: ARFID Shrinks my Life

Due to the physical and social challenges discussed above, it was found that ARFID has a significant impact on preventing the CYP from participating in preferred activities; interfering with their schooling and was detrimental to their relationships with families and friends. In essence, ARFID got in the way of the CYP being typical children or teenagers.

The CYP spoke at length about issues with seeing friends when food was present. The impact on socialising is similar to the opinions of other CYP with ARFID (Bradbury, 2020) and is aligned with the suggestion that CYP with ARFID may face teasing within peer relationships (Bryant-Waugh, 2013). Likewise, it is comparable to some of the findings from AN literature (Koruth et al., 2012; Offord et al., 2006). The impact on school attendance and ability to properly engage in a complete school experience is noteworthy. In wider research on CYP with chronic illnesses have found similar widespread educational and socio-cultural impacts (e.g. for cystic fibrosis: Jamieson et al., 2014; for chronic fatigue: Parslow et al., 2017) suggesting that the felt disruption of life may be closer to that of a medical condition.

This study provides novel findings on why and how ARFID has a detrimental impact on the socio-cultural wellbeing of CYP. The findings highlight that additional interventions, to help reduce the negative impacts of ARFID, could be welcomed. Interventions which are systemic in nature and work with the systems around CYP could help to avoid the longer term effects of missing education (Gottfried, 2011) and being disenfranchised from peers.

4.4. Research Question 2: How do children/young people understand, make sense and cope with ARFID?

This study understood that for CYP, ARFID was challenging to make sense of. The CYP’s conceptualisation of ARFID was complex, diverse and often contradictory, made more difficult by the lack of understanding in their families, professionals and the public. However, a shared understanding that ARFID was a mental ‘block” which got in the way of eating was dominant. Many of the CYP also conceptualised that ARFID was something to be ashamed of and hidden. Some of the CYP had taken a curious approach to think about ARFID. For others, a sense of ambivalence or unawareness of ARFID was apparent.

To cope, attempts to gain back control of food was a common approach. Having individuals around them that understood and were willing to adapt also made living with ARFID easier. Receiving a diagnosis was also welcomed and often led to a better understanding of ARFID and could elicit help. Below each of the themes related to research question two will be discussed in relation to the existing literature and how they contribute to addressing the research question.

4.4.1. Theme 3: No One understands So How Do I

As mentioned above the CYP experienced that many of the adults around them did not have a good understanding of ARFID. This is consistent with other qualitative research on professionals indicating that knowledge on ARFID is modest (A. Harrison, 2021). Indeed, if medical/psychological professionals feel they struggle to have a good grasp of ARFID then it is not surprising that families and CYP have difficulty making sense of it. Despite this all the CYP, even those without a diagnosis, seemed to have some conceptualisation of what ARFID was, with many seeing it as a problem. However, there was a perceptible divide between the CYP, some of whom had spent time considering what ARFID was and why it had happened to them and others appearing indifferent. The ideas of indifference to ARFID or a discrepancy in beliefs to illness severity to those around them were important findings and are widely seen in CYP AN literature (e.g. Koruth et al., 2012; Tan et al., 2010). The differences seen between the CYP in their motivation to understand could be explained by their ages, ability levels the multifariousness of ARFID (Sharp & Stubbs, 2019).

A commonality found was the idea that ARFID was a mental block, sometimes described as a voice or a wall. The idea that ARFID is an external mechanism preventing individuals from eating, has parallels within the world of AN. It has been found that many individuals with AN personify their ED, frequently referring to it as ‘Ana’ (Pugh, 2016). However, distinctions need to be made as ‘Ana’ can be often seen as both positive and negative (S. Williams & Reid, 2012). Whereas for the CYP in this study, the external block was only described negatively. This finding may be useful in helping inform interventions which sit well within the CYP’s internal worlds. As they have already started to externalise ARFID, narrative therapy ideas which take this concept further may be helpful (e.g. Heins & Ritchie, 1985). This study considered the experience of having an ED which is less well-known perhaps leading to the CYP believing that ARFID was a shameful thing. Research indicates that feelings of embarrassment are experienced by picky eaters (Thompson et al., 2015). Likewise, literature within AN explores ideas of feeling isolated (Offord et al., 2006) and online support groups (Tierney, 2008), indicating that living with an ED can be isolating yet peer support can be valuable. This study adds to the understanding of AFRID by highlighting that the conceptualisation of ARFID is socially mediated. All the CYP said that they had never spoken to another CYP with ARFID meaning that ARFID can be a particularly isolating experience. Finding ways to connect CYP with ARFID could help to reduce feelings of shame or difference.

The concepts around ARFID being difficult to understand, leading to either curiosity or an avoidance of thinking about it are significant findings and could be helpful in understanding barriers to engagement with treatments. Research in AN literature draws parallels with the idea that integrating an ED into a personal identity for CYP is challenging, with professionals often holding a differing view (Rich, 2006). Indifference or ambivalence is also seen in AN (Koruth et al., 2012) and supports the conclusions from Bradbury's conversations with CYP (2021). Bradbury states that it is this lack of acknowledgement of difficulties which can lead to problems in motivation to make changes, acting as a barrier to treatment. Nonetheless, the current study found that none of the participants were completely dismissive of the impacts of ARFID and curiosity about ARFID was noted. The difference in findings could be related to the environments in which the CYP have been questioned. Bradbury's evidence was collected in a clinical setting where CYP may have felt pressurised to acknowledge difficulties and make changes to their eating behaviours. As a researcher, I may have been perceived as more neutral and less likely to engage in confrontation meaning that denial or resistance were less likely to be used by the CYP (Emmons & Rollnick, 2001). Choosing to focus on areas where the CYP are willing to consider the impacts of ARFID may be effective places to start interventions.

4.4.2. Theme 4: How I get by

Despite the challenges associated with ARFID, there was a sense that the CYP were able to adapt and find ways to navigate a food saturated world. To cope, the most common approach was making adaptations to food and eating behaviours to make mealtimes more predictable, which increased the sense of control for the CYP. Likewise, as a contrast to feelings of being misunderstood all the CYP had people in their lives who were supportive and validated their experiences which helped to build resilience in the CYP. Receiving a diagnosis (or discovering what ARFID was) was generally welcomed and was seen as beneficial. Finally, this study found that the CYP did not always experience ARFID as exclusively negative, with some finding moments where the effects were not as harmful and some expressing that ARFID had led to positive events in their lives. The findings from this theme highlight a spectrum of experiences of living with ARFID.

Finding positives from ARFID such as an increase in empathy or self-awareness, connection to parents and embracing difference were experienced by some of the CYP. CYP with AN have too been found to gain positives from living with an ED (Rich, 2006) and some fussy eaters view their identity in a positive light (Thompson et al., 2015). Similarly, for some, ARFID did not impact negatively in every area of their lives meaning that the enormity of ARFID felt different for each of the CYP. The differences described add weight to the idea that ARFID captures a wide variety of presentations within the diagnosis (Eddy et al., 2019). Some of the variety in experiences could also be due to the ages of the CYP. Some of the mothers shared that they felt that their CYP would be much more impacted once they had started to gain more independence, spent more time with peers and formed romantic relationships. These findings show that CYP with ARFID can hold a nuanced view of ARFID.

Advanced planning, eating alone, bringing own food to places and having autonomy over food choice were all examples of how the CYP made changes so that they could manage to eat in different situations. The finding is comparable to Wolstenholme (2020) who found that even young fussy eating CYP demonstrated agency around their food choices and knew what was most helpful. These coping mechanisms are closely tied to the concept that food is a threat and needs to be the same (considered in theme 1). The idea of sensory prediction developed within ASD literature could help to explain how having control over food can help to reduce anxiety around food. Sensory prediction is the theory that brains make guesses about incoming sensory information to help process the outside world in a more efficient way. However, a mismatch between the prediction and the actual incoming sensory feedback can lead to feelings of anxiety (Gaigg et al., 2019). If an individual experiences differences in sensory processing, commonly seen within ARFID (Thomas et al., 2017), then it is also likely that their sensory prediction will be affected too. This concept suggests that even the smallest changes in foods may be experienced as very different, leading to feelings of anxiety when eating. The need to take control of food and eat very similar foods as a way of coping is an attempt to make food more predictable and reduce these feelings of anxiety. Conceptualising the anxiety around food for those with ARFID in this way can help to understand how CYP with ARFID are making sense of their food and help to inform and modify food exposure interventions.

In contrast to other people who were invalidating or uninformed on ARFID, the CYP had individuals or systems in their lives who understood their difficulties and were helpful and accommodating. Specialist education schools were described as being very helpful in accommodating the CYP's mealtime needs as well as acting as a buffer to social marginalisation. Again, this finding adds weight to the idea that many of the difficult consequences of ARFID are socially moderated and that efforts may need to be made to intervene within the CYP's systems.

Having friends that understood and were willing to adjust their mealtimes helped to limit the impact on peer relationships and many described their mothers as being understanding and considerate at mealtimes. The importance of social support has been explored within adults with EDs (Linville et al., 2012) and CYP (Offord et al., 2006). This study highlights the significance of social support for CYP with ARFID. Workshops to help families (especially fathers) to understand could be indicated.

The process of receiving a diagnosis (or wanting to receive a diagnosis) was experienced as a generally positive experience. For many the diagnosis was validating, provided a reference point to make sense of their difficulties and generating avenues to help. This is the first study to collect viewpoints on the diagnosis of ARFID for those receiving the diagnosis. Interestingly the feeling that the diagnosis was too vast was not raised as an issue by any of the CYP, indicating a differing view from researchers (Strand et al., 2019) and clinicians (Eddy et al., 2019). The findings can be used to add evidence to the debate surrounding the diagnosis currently occurring in the published literature.

4.5. Evaluation of the Study

Evaluation techniques of qualitative research need to be implemented carefully, ensuring that they fit within the theoretical framework of the original research and are not holding onto concepts from positivist quantitative research (Braun & Clarke, 2021b; Morse, 2020). Tracy (2010) has helpfully put together eight key markers of quality in qualitative research which can be used across theoretical frameworks and methodologies. The key markers were consulted throughout the research process to attend to quality. How this study met each of the eight criteria are detailed below.

4.5.1 Worthy Topic

This study fulfils a gap in the literature (see 1.5) and is relevant due to the recency of the diagnosis of ARFID and current interest in qualitative research in healthcare (Langlois et al., 2018).

4.5.2 Rich Rigour

Rigour was achieved through completing the study over a two-and-a-half-year period; through the recruitment of a cross-section of CYP with ARFID, spanning age groups, genders, neurodiversity and geographical location; and a commitment to understanding and implementing quality TA with both the research and supervisor.

4.5.3. Sincerity

The process surrounding data analysis have been openly described including documentation of draft themes and notes. As recommended by Braun and Clark (2021b) a reflexive log was taken and researcher reflexivity has been frequently spoken to in the report.

4.5.4 Credibility

The results section details both latent and semantic themes from a multiplicity of CYP voices. It details a rich description of multiple aspects of the CYP lives and captures a diversity of experience.

4.5.5. Resonance

The research creates a narrative which describes an evocative representation of the lived experience of CYP with ARFID. The results will have transferable and meaningful findings to those living and working with ARFID.

4.5.6. Significant Contribution

The research provides novel insights into the experience of living with ARFID as a CYP meaning it has contributed to the research literature and helps to inform clinicians working with ARFID. It has added evidence to the theories underlying the causes of ARFID was well as highlighting areas where intervention may be most helpful.

4.5.7 Ethics

The study was in line with the BPS code of human research ethics (Oates et al., 2021) and Alderson's ethical guidance for research with CYP (Alderson & Morrow, 2004) with ethical approval sought from the university (see 2.8).

4.5.8 Meaningful Coherence

The study significantly answers its research questions and stays coherent to its aims and critical realist positioning. It manages to articulately draw together findings from picky eating and eating disorder literature filling in a research gap.

4.6. Strengths

4.6.1. Addresses a Gap in the Literature

The research has addressed a gap in the literature which has been called for by many in the field (Bradbury, 2020; Bryant-Waugh, 2020a; Wolstenholme et al., 2020). In doing so, it has provided a voice for CYP with ARFID who have repeatedly been overlooked. Moreover, it has conveyed novel ideas for intervention indicating its clinical significance.

4.6.2. Consultation

The study took time to consult with experts by experience at various levels of the research. This means an assessment of the appropriateness and comprehensibility of the research for the target population was made. This has ensured that the research has not ignored the voices of CYP with ARFID.

4.6.3. Heterogeneity of Sample and Inclusivity

The sample, although not diverse in terms of ethnicity, included a range of ages, genders, abilities, and neurodiversity. By enabling CYP who needed extra support from their mothers to take part, it meant that a wider range of perspectives were heard from. The sample therefore represents the strong correlation between neurodiversity and ARFID seen in the population (Mayes & Zickgraf, 2019) meaning that the results are not only limited to neurotypical or neurodiverse experiences of ARFID.

4.6.4. Dissemination

The anonymised 'messages of hope' provided by the CYP were collated and sent to the other participants once the transcription was completed (see Appendix H). The findings, once the write up is finalised, will be presented back to the participants in an age-appropriate way via an online presentation. A simple read summary of the project will also be circulated to the CYP and their families (see Appendix I for a draft outline). Infographics capturing the findings of the study will be posted on the Facebook groups and Instagram hashtags where the recruitment posters were originally advertised. It is planned for the research to be submitted to a journal to ensure a wide distribution of the results to increase awareness. Employing a variety of ways to disseminate the findings means that the CYP have been respected for their time and the research has been ethically used to improve the lives of CYP (Alderson & Morrow, 2004; Rosenthal, 2008).

4.7. Limitations

4.7.1. Whiteness of the Sample

Due to the lack of data on cohort studies in the UK, the ethnicities of CYP with ARFID is unknown (Micali & Cooper-Vince, 2020) yet it is clear that the final sample included in this study would not represent CYP with ARFID in the UK. All the CYP in this study were White British meaning that the findings may be biased towards white centric, and westernised ideas of the detrimental consequences and how ARFID is conceptualised (Singh et al., 2020). This is especially significant due to the close ties between culture and food. It will also be the case the CYP with ARFID and who belong to one or more minoritised identities will experience the impacts of ARFID more adversely due to intersectionality (Crenshaw, 1989).

4.7.2. Recruitment

The bulk of the CYP were recruited from online groups or pages for parents of CYP with ARFID, which may explain the homogenous sample. This may contextualise the findings to particular experiences of CYP with ARFID. For example, the support groups may be used by families of CYP at the more severe end of ARFID, or by parents who feel less well equipped to cope. The support groups may also be limited to families who have things in common like their education level or cultural experiences.

4.8. Researcher Reflexivity

As mentioned above self-reflexivity is a key component to considered and meaningful qualitative information gathering (Braun & Clarke, 2021b). The on-going use of reflective journaling helped to position the interpretations and conclusions that the research came to. Some of the factors that may have had the biggest influence on my interpretation of the data are detailed below.

I am soon to be a qualified clinical psychologist wanting to spend my career alleviating distress for CYP. However, I also believe that because of my political alignment (left-wing), the current landscape of an underfunded NHS, and the positioning of my doctorate training programme (critical social constructionist) I am becoming more sceptical of the usefulness of NHS services in their current format. These circumstances potentially have influenced how much weight I have given to the finding that many of the CYP have been misunderstood by systems. Moreover, that interventions could be best placed at a systemic level as well as working with the CYP on their eating behaviours.

Likewise, I was raised by a single mother with strong left wing, feminist leanings who was vocal about the rights of women and children. She was also a manager of our local preschool, which I spent a lot of time at after school. My adolescence was marked by a significant adverse event happening to a child in my life. I witnessed how adults around me helped or hindered the children with their understanding of and coping with the event. I believe that these experiences have given me a respect and appreciation of the viewpoints of CYP and a motivation to advocate for their rights. This, alongside my clinical experience of working with CYP helped me to hold an authentic curious and appreciative stance during the interviews (Cecchin, 1987) meaning that CYP felt genuinely listened to. This will have helped the collection of richer information from the CYP.

Understandably, I was saddened and frustrated hearing about how the CYP had been treated by others in their lives often leaving them feeling ‘odd’. I believe that the influence of my doctoral training with a particular focus on power, oppression and marginalisation, shaped the lens through which I viewed the data. I was drawn to the feelings of difference portrayed by the CYP and felt compelled to acknowledge these feelings as a subtheme. I found myself at times feeling responsible for alleviating distress but I found it useful to remind myself that the research would hopefully lead to concrete changes reducing the burden for many more CYP with ARFID.

4.9. Recommendations for Future Research

Due to the exploratory nature of the research, it has revealed many areas which could be further explored in future qualitative research. Notably, as the research focused on CYP aged 10-17, research looking at younger age groups and adults could help to understand the differences in impact and conceptualisation of ARFID across the lifespan. Evidence suggests that ARFID often starts in early childhood so research involving parents may help to capture a younger perspective (Cooke, 2020) and research with adults could examine whether the social and occupational impacts continue into adulthood. Similarly, research capturing the experiences of the those around the CYP, like siblings would build a richer understanding of the wider impacts and conceptualisations of ARFID. Research around stories of hope and evidence of people overcoming their difficulties would add to the literature.

The current literature is also missing the viewpoints of the acceptability and usefulness of ARFID interventions. This would be valuable to pursue due to the findings that many CYP found that seeking professional help was unsatisfactory. A study which gathers participants from an NHS sample may also help to capture a wider view of experience in terms of severity and cultural experience. As mentioned above, biases around clinicians acting as researchers would need to be held in mind when conducting research on treatment interventions.

Additionally, further cohort and longitudinal studies are needed to better understand who is developing ARFID, the reasons why it can occur and the longer-term trajectories of outcomes.

4.10. Implications for Clinical Practice

Various findings from this study will be able to inform clinical practice which have been detailed throughout the discussion. To summarise, the findings such as sensitivity to food and bodily sensations provides evidence to support current clinical practice and understanding (e.g. Dumont et al., 2019; Thomas et al., 2017; Zucker et al., 2019). Furthermore, the findings suggest that interventions should not only focus on eating behaviours but also help the CYP navigate the social and psychological implications of ARFID. These views are similar to CYP with AN and are starting to be seen in novel systems-based ARFID interventions (Bryant-Waugh, 2020b). The research adds weight to the idea that a large focus of the work should also be around creating safe and understanding systems around the child. Increasing knowledge and understanding in care givers, wider family and school may reduce the stressors on the CYP and perhaps give space for a change of eating to occur. Regular network meetings for CYP's systems would help to raise awareness of the challenges and help to create more consistent and comprehensive support.

Additionally, the findings establish that all the CYP have ways in which they cope with ARFID and make eating easier. Using interventions which fit well with how a CYP is already coping (e.g. externalising ARFID and employing positive self-talk may indicate narrative therapy) may be beneficial. Equally, the findings add weight to the idea that the experience of AFRID is idiosyncratic. Therefore it is indicated that clinicians should employ integrative, flexible, child-centred ways of working.

4.11. Implications at a Wider Level

The results of this study show that knowledge and understanding of ARFID is lacking within schools, mental and physical health teams, and the public. The findings substantiate the beliefs that ARFID is not well known or understood within different professional groups (e.g. Harrison, 2021). Training for primary care providers such as GPs and health visitors or for doctors working in gastrointestinal teams would mean that ARIFD could be picked up sooner and sign posting to appropriate services would increase. The research highlights a need for clear practice guidelines which could be aimed at and accessed by specialist, secondary and primary care services. This could help to reduce some of the feelings of difference and frustrations with the inaccessibility of help experienced by the CYP and their families. Due to the helpfulness of receiving the diagnosis, it would be useful for more provisions for CAMHS services to have the skills to diagnose and offer workshops or interventions. Equally importantly, schools need to be made aware of the psychological implications of living with ARFID so they are better equipped to make accommodations within school so the impact on learning is reduced. Finally, society level awareness campaigns from larger organisations like Beat or the National Autism Society could help the public to be more familiar with the signs of ARFID meaning that CYP with ARFID would feel less different.

4.12. Conclusion

The research provides a rich and complex insight into the experiences of CYP living with ARFID. As conveyed in current literature, ARFID is an umbrella diagnosis capturing an array of experiences associated with challenges with eating, meaning that the impact and conceptualisation of ARFID was diverse amongst the CYP. Nonetheless, some common and prominent themes were noted. The lived experience of ARFID was described as very physical, with intense bodily and emotional sensations and intrusive medical intervention. Food was experienced as a threat to their bodies with many CYP describing a hyperawareness to food. The impact of ARFID was widespread, effecting school, family, and peer relationships. Feelings of difference, shame and isolation were common due to a lack of understanding of ARFID. When trying to make sense of ARFID, curiosity and avoidance were both used. Yet, despite the challenges the CYP found ways to cope often by tightly controlling their food and receiving support from others. The findings provide useful insight into areas for clinical intervention and highlight the need for a much better understanding of ARFID at every level of a CYP's life.

REFERENCES

Adler, K., Salanterä, S., & Zumstein-Shaha, M. (2019). Focus group interviews in child, youth, and parent research: An integrative literature review. *International Journal of Qualitative Methods*, *18*, 1–15. https://doi.org/10.1177/1609406919887274

Al-Adawi, S., Bax, B., Bryant-Waugh, R., Claudino, A. M., Hay, P., Monteleone, P., Norring, C., Pike, K. M., Pilon, D. J., Herscovici, C. R., Reed, G. M., Rydelius, P.-A., Sharan, P., Thiels, C., Treasure, J., & Uher, R. (2013). Revision of ICD – status update on feeding and eating disorders. *Advances in Eating Disorders*, *1*(1), 10–20. https://doi.org/10.1080/21662630.2013.742971

Alderson, P. (1995). *Listening to Children: Children, Ethics and Social Research*. Barnardo's.

Alderson, P., & Morrow, V. (2004). *Ethics, Social Research and Consulting with Children and Young People* (2nd edition). Barnardo's.

American Psychiatric Association. (2013). *DSM-5: Diagnostic and statistical manual of mental illness (fifth ed.)*. American Psychia-try Publishing. https://www.appi.org/Diagnostic_and_Statistical_Manual_of_Mental_Disorders_DSM-5_Fifth_Edition

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, *8*(1), 19–32. https://doi.org/10.1080/1364557032000119616

Balcazar, F. E., Taylor, R. R., Kielhofner, G. W., Tamley, K., Benziger, T., Carlin, N., & Johnson, S. (2004). Participatory action research:

General principles and a study with a chronic health condition. In *Participatory community research: Theories and methods in action* (pp. 17–35). American Psychological Association. https://doi.org/10.1037/10726-001

Barker, C., Pistrang, N., & Elliott, R. (2016). *Research methods in clinical psychology: An introduction for students and practitioners (3rd ed.)*. Blackwell. https://doi.org/10.1002/9781119154082

Becker, K. R., Mancuso, C., Dreier, M. J., Asanza, E., Breithaupt, L., Slattery, M., Plessow, F., Micali, N., Thomas, J. J., Eddy, K. T., Misra, M., & Lawson, E. A. (2021). Ghrelin and PYY in low-weight females with avoidant/restrictive food intake disorder compared to anorexia nervosa and healthy controls. *Psychoneuroendocrinology*, *129*, 105243. https://doi.org/10.1016/j.psyneuen.2021.105243

Bezance, J., & Holliday, J. (2013). Adolescents with Anorexia Nervosa Have Their Say: A Review of Qualitative Studies on Treatment and Recovery from Anorexia Nervosa. *European Eating Disorders Review*, *21*(5), 352–360. https://doi.org/10.1002/erv.2239

Bohrer, B. K., Foye, U., & Jewell, T. (2020). Recovery as a process: Exploring definitions of recovery in the context of eating-disorder-related social media forums. *International Journal of Eating Disorders*, *53*(8), 1219–1223. https://doi.org/10.1002/eat.23218

Bourne, L., Bryant-Waugh, R., Cook, J., & Mandy, W. (2020). Avoidant/restrictive food intake disorder: A systematic scoping review of the current literature. *Psychiatry Research*, *288*, 112961. https://doi.org/10.1016/j.psychres.2020.112961

Bradbury, L. (2020). Young People’s Perspectives. In R. Bryant-Waugh & C. Higgins (Eds.), *Avoidant Restrictive Food Intake Disorder in Childhood and Adolescence: A Clinical Guide* (pp. 3–13). Routledge.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2021a). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, *21*(1), 37–47. https://doi.org/10.1002/capr.12360

Braun, V., & Clarke, V. (2021b). *Thematic Analysis: A Practical Guide* (1st edition). SAGE Publications Ltd.

British Psychological Society. (2014). *Code of human research ethics*. British Psychological Society.

Bryant-Waugh, R. (2013). Avoidant restrictive food intake disorder: An illustrative case example. *The International Journal of Eating Disorders*, *46*(5), 420–423. https://doi.org/10.1002/eat.22093

Bryant-Waugh, R. (2020a). Avoidant restrictive food intake disorder: In need of a dose of kindness? *Clinical Child Psychology and Psychiatry*, *25*(3), 712–715. https://doi.org/10.1177/1359104520929054

Bryant-Waugh, R. (2020b). *The Short ARFID Screen*. Maudsley Centre for Child and Adolescent Eating Disorders. Short ARFID Screen – Rater Instructions - MCCAEDhttps://mccaed.slam.nhs.uk › uploads › 2020/06

Bryant-Waugh, R. (2020c). Overview of diagnosis and presentation. In C. Higgins & R. Bryant-Waugh, *Avoidant Restrictive Food Intake Disorder in Childhood and Adolescence: A Clinical Guide* (pp. 42–54). Routledge.

Bryant-Waugh, R. (2020d). Overview of treatment and management. In R. Bryant-Waugh & C. Higgins, *Avoidant Restrictive Food Intake Disorder in Childhood and Adolescence: A Clinical Guide* (pp. 137–148). Routledge.

Bryant-Waugh, R., Loomes, R., Munuve, A., & Rhind, C. (2021). Towards an evidence-based out-patient care pathway for children and young people with avoidant restrictive food intake disorder. *Journal of Behavioral and Cognitive Therapy*, *31*(1), 15–26. https://doi.org/10.1016/j.jbct.2020.11.001

Cecchin, G. (1987). Hypothesizing, Circularity, and Neutrality Revisited: An Invitation to Curiosity. *Family Process*, *26*(4), 405–413. https://doi.org/10.1111/j.1545-5300.1987.00405.x

Chafe, R. (2017). The Value of Qualitative Description in Health Services and Policy Research. *Healthcare Policy*, *12*(3), 12–18.

Coelho, J. S., Norris, M. L., Tsai, S. C. E., Wu, Y. J., & Lam, P.-Y. (2021). Health professionals' familiarity and experience with providing clinical care for pediatric avoidant/restrictive food intake disorder. *International Journal of Eating Disorders*, *54*(4), 587–594. https://doi.org/10.1002/eat.23438

Coglan, L., & Otasowie, J. (2019a). Avoidant/restrictive food intake disorder: What do we know so far? *BJPsych Advances*, *25*(2), 90–98. https://doi.org/10.1192/bja.2018.48

Coglan, L., & Otasowie, J. (2019b). Avoidant/restrictive food intake disorder: What do we know so far? *BJPsych Advances*, *25*(2), 90–98. https://doi.org/10.1192/bja.2018.48

Colton, A., & Pistrang, N. (2004). Adolescents' experiences of inpatient treatment for anorexia nervosa. *European Eating Disorders Review*, *12*(5), 307–316. https://doi.org/10.1002/erv.587

Cooke, L. (2020). Information from qualitative research. In R. Bryant-Waugh & C. Higgins, *Avoidant Restrictive Food Intake Disorder in Childhood and Adolescence: A Clinical Guide* (pp. 27–37). Routledge.

Cooney, M., Lieberman, M., Guimond, T., & Katzman, D. K. (2018). Clinical and psychological features of children and adolescents diagnosed with avoidant/restrictive food intake disorder in a pediatric tertiary care eating disorder program: A descriptive study. *Journal of Eating Disorders*, *6*, 7. https://doi.org/10.1186/s40337-018-0193-3

Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A Black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. *University of Chicago Legal Forum*, *8*(1), 139–167.

Department of Health and Social Care. (2021). *The NHS Constitution for England*. GOV.UK. https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england

Dolman, L., Thornley, S., Doxtdator, K., Leclerc, A., Findlay, S., Grant, C., Breakey, V. R., & Couturier, J. (2021). Multimodal therapy for rigid, persistent avoidant/restrictive food intake disorder (ARFID) since infancy: A case report. *Clinical Child Psychology and Psychiatry*, *26*(2), 451–463. https://doi.org/10.1177/1359104520981401

Dovey, T. M., Kumari, V., Blissett, J., & Mealtime Hostage Parent Science Gang. (2019). Eating behaviour, behavioural problems and sensory profiles of children with avoidant/restrictive food intake disorder (ARFID), autistic spectrum disorders or picky eating: Same or different? *European Psychiatry*, *61*, 56–62. https://doi.org/10.1016/j.eurpsy.2019.06.008

DuBois, D., Ameis, S. H., Lai, M.-C., Casanova, M. F., & Desarkar, P. (2016). Interoception in Autism Spectrum Disorder: A review. *International Journal of Developmental Neuroscience*, *52*, 104–111. https://doi.org/10.1016/j.ijdevneu.2016.05.001

Dumont, E., Jansen, A., Kroes, D., de Haan, E., & Mulkens, S. (2019). A new cognitive behavior therapy for adolescents with avoidant/restrictive food intake disorder in a day treatment setting: A clinical case series. *The International Journal of Eating Disorders*, *52*(4), 447–458. https://doi.org/10.1002/eat.23053

Eddy, K. T., Harshman, S. G., Becker, K. R., Bern, E., Bryant-Waugh, R., Hilbert, A., Katzman, D. K., Lawson, E. A., Manzo, L. D., Menzel, J., Micali, N., Ornstein, R., Sally, S., Serinsky, S. P., Sharp, W., Stubbs, K., Walsh, B. T., Zickgraf, H., Zucker, N., & Thomas, J. J. (2019). Radcliffe ARFID Workgroup: Toward operationalization of research diagnostic criteria and directions for the field. *International Journal of Eating Disorders*, *52*(4), 361–366. https://doi.org/10.1002/eat.23042

Eddy, K. T., Thomas, J. J., Hastings, E., Edkins, K., Lamont, E., Nevins, C. M., Patterson, R. M., Murray, H. B., Bryant-Waugh, R., & Becker, A. E. (2015). Prevalence of DSM-5 avoidant/restrictive food intake disorder in a pediatric gastroenterology healthcare network. *The International Journal of Eating Disorders*, *48*(5), 464–470. https://doi.org/10.1002/eat.22350

Emmons, K. M., & Rollnick, S. (2001). Motivational interviewing in health care settings: Opportunities and limitations. *American Journal of Preventive Medicine*, *20*(1), 68–74. https://doi.org/10.1016/S0749-3797(00)00254-3

Feillet, F., Bocquet, A., Briend, A., Chouraqui, J.-P., Darmaun, D., Frelut, M.-L., Girardet, J.-P., Guimber, D., Hankard, R., Lapillonne, A., Peretti, N., Rozé, J.-C., Simeoni, U., Turck, D., & Dupont, C. (2019). Nutritional risks of ARFID (avoidant restrictive food intake disorders) and related behavior. *Archives de Pédiatrie*, *26*(7), 437–441. https://doi.org/10.1016/j.arcped.2019.08.005

Fisher, M., Gonzalez, M., & Malizio, J. (2015). Eating disorders in adolescents: How does the DSM-5 change the diagnosis? *International Journal of Adolescent Medicine and Health*, *27*(4), 437–441. https://doi.org/10.1515/ijamh-2014-0059

Fisher, M., Rosen, D. S., Ornstein, R. M., Mammel, K. A., Katzman, D. K., Rome, E. S., Callahan, S. T., Malizio, J., Kearney, S., & Walsh, B. T. (2014). Characteristics of avoidant/restrictive food intake disorder in children and adolescents: A ‘new disorder’ in DSM-5. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, *55*(1), 49–52. https://doi.org/10.1016/j.jadohealth.2013.11.013

Fox, G., Coulthard, H., Williamson, I., & Wallis, D. (2018). “It’s always on the safe list”: Investigating experiential accounts of picky eating adults. *Appetite*, *130*, 1–10. https://doi.org/10.1016/j.appet.2018.07.023

Franko, D. L., Keshaviah, A., Eddy, K. T., Krishna, M., Davis, M. C., Keel, P. K., & Herzog, D. B. (2013). A Longitudinal Investigation of Mortality in Anorexia Nervosa and Bulimia Nervosa. *American Journal of Psychiatry*, *170*(8), 917–925. https://doi.org/10.1176/appi.ajp.2013.12070868

Gaigg, S., Crawford, J., & Cottell, H. (2019). *An Evidence Based Guide to Anxiety in Autism*. Autism Research Group. https://www.city.ac.uk/__data/assets/pdf_file/0020/557201/Anxiety-in-Autism-Guide-021219.pdf

Golding, J., Steer, C., Emmett, P., Bartoshuk, L. M., Horwood, J., & Smith, G. D. (2009). Associations between the ability to detect a bitter taste, dietary behavior, and growth: A preliminary report. *Annals of the New York Academy of Sciences*, *1170*, 553–557. https://doi.org/10.1111/j.1749-6632.2009.04482.x

Gonçalves, S., Vieira, A. I., Machado, B. C., Costa, R., Pinheiro, J., & Conceiçao, E. (2019). Avoidant/restrictive food intake disorder symptoms in children: Associations with child and family variables.

Children's Health Care, *48*(3), 301–313. https://doi.org/10.1080/02739615.2018.1532796

Gottfried, M. A. (2011). The Detrimental Effects of Missing School: Evidence from Urban Siblings. *American Journal of Education*, *117*(2), 147–182. https://doi.org/10.1086/657886

Greder, K. A., Brotherson, M. J., & Garasky, S. (2004). Listening to the Voices of Marginalized Families. In *Family and Community Policy: Strategies for Civic Engagement* (pp. 95–121). Amer Home Economics.

Greenwood, J. D. (1994). *Realism, Identity and Emotion: Reclaiming Social Psychology*. SAGE.

Harper, D. (2011). Choosing a qualitative research method. In D. Harper & A. R. Thompson (Eds.), *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners* (pp. 83–98). Wiley-Blackwell.

Harrison, A. (2021). Falling Through the Cracks: UK Health Professionals' Perspective of Diagnosis and Treatment for Children and Adolescents with Avoidant/Restrictive Food Intake Disorder. *Child Care in Practice*, *0*(0), 1–11. https://doi.org/10.1080/13575279.2021.1958751

Harrison, R., Warburton, V., Lux, A., & Atan, D. (2019). Blindness Caused by a Junk Food Diet. *Annals of Internal Medicine*, *171*(11), 859–861. https://doi.org/10.7326/L19-0361

Harvey, A. G., Watkins, E., & Mansell, W. (2004). *Cognitive Behavioural Processes Across Psychological Disorders: A Transdiagnostic Approach to Research and Treatment*. Oxford University Press.

Heins, T., & Ritchie, K. (1985). *Beating Sneaky Poo: Ideas for faecal soiling.* Child and Adolescent Unit, Mental. Health Branch, ACT Health Authority.

Hendrick, H. (2008). The child as a social actor in historical sources. In P. Christensen & A. James (Eds.), *Research With Children: Perspectives and Practices* (2nd edition, pp. 40–65). Routledge.

Inoue, T., Otani, R., Iguchi, T., Ishii, R., Uchida, S., Okada, A., Kitayama, S., Koyanagi, K., Suzuki, Y., Suzuki, Y., Sumi, Y., Takamiya, S., Tsurumaru, Y., Nagamitsu, S., Fukai, Y., Fujii, C., Matsuoka, M., Iwanami, J., Wakabayashi, A., & Sakuta, R. (2021). Prevalence of autism spectrum disorder and autistic traits in children with anorexia nervosa and avoidant/restrictive food intake disorder. *BioPsychoSocial Medicine*, *15*. https://doi.org/10.1186/s13030-021-00212-3

Jamieson, N., Fitzgerald, D., Singh-Grewal, D., Hanson, C. S., Craig, J. C., & Tong, A. (2014). Children’s experiences of cystic fibrosis: A systematic review of qualitative studies. *Pediatrics*, *133*(6), 1683–1697. https://doi.org/10.1542/peds.2014-0009

Keery, H., LeMay-Russell, S., Barnes, T. L., Eckhardt, S., Peterson, C. B., Lesser, J., Gorrell, S., & Le Grange, D. (2019). Attributes of children and adolescents with avoidant/restrictive food intake disorder. *Journal of Eating Disorders*, *7*(1), 31. https://doi.org/10.1186/s40337-019-0261-3

Khalsa, S. S., Berner, L. A., & Anderson, L. M. (2022). Gastrointestinal Interoception in Eating Disorders: Charting a New Path. *Current*

Psychiatry Reports, *24*(1), 47–60. https://doi.org/10.1007/s11920-022-01318-3

Koruth, N., Nevison, C., & Schwannauer, M. (2012). A Grounded Theory Exploration of the Onset of Anorexia in Adolescence. *European Eating Disorders Review*, *20*(4), 257–264. https://doi.org/10.1002/erv.1135

Kreipe, R. E., & Palomaki, A. (2012). Beyond picky eating: Avoidant/restrictive food intake disorder. *Current Psychiatry Reports*, *14*(4), 421–431. https://doi.org/10.1007/s11920-012-0293-8

Krom, H., van der Sluijs Veer, L., van Zundert, S., Otten, M. A., Benninga, M., Haverman, L., & Kindermann, A. (2019). Health related quality of life of infants and children with avoidant restrictive food intake disorder. *International Journal of Eating Disorders*, *52*(4), 410–418. https://doi.org/10.1002/eat.23037

Kurz, S., van Dyck, Z., Dremmel, D., Munsch, S., & Hilbert, A. (2015). Early-onset restrictive eating disturbances in primary school boys and girls. *European Child & Adolescent Psychiatry*, *24*(7), 779–785. https://doi.org/10.1007/s00787-014-0622-z

Langlois, E. V., Tunçalp, Ö., Norris, S. L., Askew, I., & Ghaffar, A. (2018). Qualitative evidence to improve guidelines and health decision-making. *Bulletin of the World Health Organization*, *96*(2), 79–79. https://doi.org/10.2471/BLT.17.206540

Linville, D., Brown, T., Sturm, K., & McDougal, T. (2012). Eating Disorders and Social Support: Perspectives of Recovered Individuals. *Eating Disorders*, *20*(3), 216–231. https://doi.org/10.1080/10640266.2012.668480

Lock, J., Robinson, A., Sadeh-Sharvit, S., Osipov, L., Kirz, N., Derenne, J., & Utzinger, L. (2018). Applying family-based treatment (FBT) to three clinical presentations of avoidant/restrictive food intake disorder: Similarities and differences from FBT for anorexia nervosa. *The International Journal of Eating Disorders*, *52*(4), 439–446. https://doi.org/10.1002/eat.22994

Magel, C. A., Hewitt, K., Dimitropoulos, G., von Ranson, K. M., & McMorris, C. A. (2021). Who is treating ARFID, and how? The need for training for community clinicians. *Eating and Weight Disorders: EWD*, *26*(4), 1279–1280. https://doi.org/10.1007/s40519-020-01007-1

Mammel, K. A., & Ornstein, R. M. (2017). Avoidant/restrictive food intake disorder: A new eating disorder diagnosis in the diagnostic and statistical manual 5. *Current Opinion in Pediatrics*, *29*(4), 407–413. https://doi.org/10.1097/MOP.0000000000000507

Martin, C. I., Dovey, T. M., Coulthard, H., & Southall, A. M. (2013). Maternal Stress and Problem-Solving Skills in a Sample of Children with Nonorganic Feeding Disorders. *Infant Mental Health Journal*, *34*(3), 202–210. https://doi.org/10.1002/imhj.21378

Martins, Y., Young, R. L., & Robson, D. C. (2008). Feeding and eating behaviors in children with autism and typically developing children. *Journal of Autism and Developmental Disorders*, *38*(10), 1878–1887. https://doi.org/10.1007/s10803-008-0583-5

Mayall, B. (2008). Conversations with Children: Working with Generational Issues. In P. Christiansen & A. James (Eds.), *Research With Children* (2nd ed., pp. 109–124). Routledge.

Mayes, S. D., & Zickgraf, H. (2019). Atypical eating behaviors in children and adolescents with autism, ADHD, other disorders, and typical development. *Research in Autism Spectrum Disorders*, *64*, 76–83. https://doi.org/10.1016/j.rasd.2019.04.002

Micali, N., & Cooper-Vince, C. E. (2020). Aetiology and epidemiology. In R. Bryant-Waugh & C. Higgins (Eds.), *Avoidant Restrictive Food Intake Disorder in Childhood and Adolescence* (pp. 55–68). Routledge.

Mitchell, G. L., Farrow, C., Haycraft, E., & Meyer, C. (2013). Parental influences on children's eating behaviour and characteristics of successful parent-focussed interventions. *Appetite*, *60*, 85–94. https://doi.org/10.1016/j.appet.2012.09.014

Morse, J. (2020). The changing face of qualitative inquiry. *International Journal of Qualitative Methods*, *19*, 1–7. https://doi.org/10.1177/1609406920909938

National Institute for Health and Care Excellence, (NICE). (2017). *Eating disorders: Recognition and treatment*. NICE. https://www.nice.org.uk/guidance/ng69/chapter/Context

NHS. (2021, February 3). *Overview – Eating disorders*. Nhs.Uk. https://www.nhs.uk/mental-health/feelings-symptoms-behaviours/behaviours/eating-disorders/overview/

Nicely, T. A., Lane-Loney, S., Masciulli, E., Hollenbeak, C. S., & Ornstein, R. M. (2014). Prevalence and characteristics of avoidant/restrictive food intake disorder in a cohort of young patients in day treatment for eating disorders. *Journal of Eating Disorders*, *2*(1), 21. https://doi.org/10.1186/s40337-014-0021-3

Nilsen, J.-V., Hage, T. W., Rø, Ø., Halvorsen, I., & Oddli, H. W. (2020). External support and personal agency - young persons' reports on recovery after family-based inpatient treatment for anorexia nervosa: A qualitative descriptive study. *Journal of Eating Disorders*, *8*(1), 18. https://doi.org/10.1186/s40337-020-00293-5

Norris, M. L., Obeid, N., Santos, A., Valois, D. D., Isserlin, L., Feder, S., & Spettigue, W. (2021). Treatment Needs and Rates of Mental Health Comorbidity in Adolescent Patients With ARFID. *Frontiers in Psychiatry*, *12*, 1144. https://doi.org/10.3389/fpsyt.2021.680298

Norris, M. L., Spettigue, W. J., & Katzman, D. K. (2016). Update on eating disorders: Current perspectives on avoidant/restrictive food intake disorder in children and youth. *Neuropsychiatric Disease and Treatment*, *12*, 213–218. https://doi.org/10.2147/NDT.S82538

Oates, J., Carpenter, D., Fisher, M., Goodson, S., Hannah, B., Kwiatowski, R., Prutton, K., Reeves, D., & Wainwright, T. (2021). *BPS Code of Human Research Ethics*. British Psychological Society. https://www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy%20-%20Files/BPS%20Code%20of%20Human%20Research%20Ethics.pdf

Offord, A., Turner, H., & Cooper, M. (2006). Adolescent inpatient treatment for anorexia nervosa: A qualitative study exploring young adults' retrospective views of treatment and discharge. *European Eating Disorders Review*, *14*(6), 377–387. https://doi.org/10.1002/erv.687

Ornstein, R. M., Essayli, J. H., Nicely, T. A., Masciulli, E., & Lane-Loney, S. (2017). Treatment of avoidant/restrictive food intake disorder in a cohort of young patients in a partial hospitalization program for eating disorders. *International Journal of Eating Disorders*, *50*(9), 1067–1074. https://doi.org/10.1002/eat.22737

Ornstein, R. M., Rosen, D. S., Mammel, K. A., Callahan, S. T., Forman, S., Jay, M. S., Fisher, M., Rome, E., & Walsh, B. T. (2013). Distribution of eating disorders in children and adolescents using the proposed DSM-5 criteria for feeding and eating disorders. *Journal of Adolescent Health*, *53*(2), 303–305. https://doi.org/10.1016/j.jadohealth.2013.03.025

Parslow, R. M., Harris, S., Broughton, J., Alattas, A., Crawley, E., Haywood, K., & Shaw, A. (2017). Children's experiences of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): A systematic review and meta-ethnography of qualitative studies. *BMJ Open*, *7*(1), 1–14. https://doi.org/10.1136/bmjopen-2016-012633

Pavlov, I. P. (1957). *Experimental Psychology, and Other Essays*. Philosophical Library.

Peterson, C. B., Becker, C. B., Treasure, J., Shafran, R., & Bryant-Waugh, R. (2016). The three-legged stool of evidence-based practice in eating disorder treatment: Research, clinical, and patient perspectives. *BMC Medicine*, *14*(1), 14–69. https://doi.org/10.1186/s12916-016-0615-5

Piaget, J. (1971). The theory of stages in cognitive development. In *Measurement and Piaget* (pp. 283–283). McGraw-Hill.

Pilato, I. (2021). *Sensory Sensitivity, Disgust, and Temperament in Children with Avoidant/Restrictive Food Intake Disorder* [Fairleigh Dickinson University].

https://www.proquest.com/openview/1bece396f7f14b27095a44c5b87f32f8/1?pq-origsite=gscholar&cbl=18750&diss=y

Pilgrim, D., & Bentall. (1999). The medicalisation of misery: A critical realist analysis of the concept of depression. *Journal of Mental Health*, *8*(3), 261–274. https://doi.org/10.1080/09638239917427

Pinhas, L., Nicholls, D., Crosby, R. D., Morris, A., Lynn, R. M., & Madden, S. (2017). Classification of childhood onset eating disorders: A latent class analysis. *International Journal of Eating Disorders*, *50*(6), 657–664. https://doi.org/10.1002/eat.22666

Ptacek, R., Kuzelova, H., Stefano, G. B., Raboch, J., Sadkova, T., Goetz, M., & Kream, R. M. (2014). Disruptive patterns of eating behaviors and associated lifestyles in males with ADHD. *Medical Science Monitor: International Medical Journal of Experimental and Clinical Research*, *20*, 608–613. https://doi.org/10.12659/MSM.890495

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

Rich, E. (2006). Anorexic dis(connection): Managing anorexia as an illness and an identity. *Sociology of Health & Illness*, *28*(3), 284–305. https://doi.org/10.1111/j.1467-9566.2006.00493.x

Richards, H. J., Benson, V., Donnelly, N., & Hadwin, J. A. (2014). Exploring the function of selective attention and hypervigilance for threat in anxiety. *Clinical Psychology Review*, *34*(1), 1–13. https://doi.org/10.1016/j.cpr.2013.10.006

Richmond, T. K., Woolverton, G. A., Mammel, K., Ornstein, R. M., Spalding, A., Woods, E. R., & Forman, S. F. (2020). How do you define recovery? A qualitative study of patients with eating disorders, their parents, and clinicians. *International Journal of Eating Disorders*, *53*(8), 1209–1218. https://doi.org/10.1002/eat.23294

Rogers, C. R. (1957). The necessary and sufficient conditions of therapeutic personality change. *Journal of Consulting Psychology*, *21*(2), 95–103. https://doi.org/10.1037/h0045357

Rosenthal, R. (2008). Science and ethics in conducting, analyzing, and reporting psychological research. In *Ethical conflicts in psychology, 4th ed* (pp. 390–397). American Psychological Association. https://doi.org/10.1037/10171-000

Santiago, E., Eck, K. M., Delaney, C., Famodu, O. A., Olfert, M. D., Shelnutt, K. P., & Byrd-Bredbenner, C. (2019). “It’s Good, It’s Delicious, It’s Great”: Cognitions, Barriers, and Supports for Fruit and Vegetable Intake of Parents and School-Aged Children. *Topics in Clinical Nutrition*, *34*(2), 100–113. https://doi.org/10.1097/TIN.0000000000000172

Schmidt, R., Vogel, M., Hiemisch, A., Kiess, W., & Hilbert, A. (2018). Pathological and non-pathological variants of restrictive eating behaviors in middle childhood: A latent class analysis. *Appetite*, *127*, 257–265. https://doi.org/10.1016/j.appet.2018.04.030

Schöffel, H., Hiemisch, A., Kiess, W., Hilbert, A., & Schmidt, R. (2021). Characteristics of avoidant/restrictive food intake disorder in a general paediatric inpatient sample. *European Eating Disorders Review*, *29*(1), 60–73. https://doi.org/10.1002/erv.2799

Sharp, W. G., & Stubbs, K. H. (2019). Avoidant/restrictive food intake disorder: A diagnosis at the intersection of feeding and eating disorders necessitating subtype differentiation. *International Journal of Eating Disorders*, *52*(4), 398–401. https://doi.org/10.1002/eat.22987

Shimshoni, Y., & Lebowitz, E. R. (2020). Childhood Avoidant/Restrictive Food Intake Disorder: Review of treatments and a novel parent-based approach. *Journal of Cognitive Psychotherapy*, *34*(3), 200–224. https://doi.org/10.1891/JCPSY-D-20-00009

Singh, A. A., Appling, B., & Trepal, H. (2020). Using the Multicultural and Social Justice Counseling Competencies to Decolonize Counseling Practice: The Important Roles of Theory, Power, and Action. *Journal of Counseling & Development*, *98*(3), 261–271. https://doi.org/10.1002/jcad.12321

Strand, M., Hausswolff-Juhlin, Y. von, & Welch, E. (2019). A systematic scoping review of diagnostic validity in avoidant/restrictive food intake disorder. *International Journal of Eating Disorders*, *52*(4), 331–360. https://doi.org/10.1002/eat.22962

Symon, G., & Cassell, C. (2012). *Qualitative Organizational Research: Core Methods and Current Challenges* (1st edition). SAGE Publications Ltd.

Tan, J. O. A., Hope, T., & Stewart, A. (2003). Anorexia nervosa and personal identity: The accounts of patients and their parents. *International Journal of Law and Psychiatry*, *26*(5), 533–548. https://doi.org/10.1016/S0160-2527(03)00085-2

Tan, J. O. A., Stewart, A., Fitzpatrick, R., & Hope, T. (2010). Attitudes of patients with anorexia nervosa to compulsory treatment and coercion. *International Journal of Law and Psychiatry*, *33*(1), 13–19. https://doi.org/10.1016/j.ijlp.2009.10.003

Thomas, J. J., Becker, K. R., Kuhnle, M. C., Jo, J. H., Harshman, S. G., Wons, O. B., Keshishian, A. C., Hauser, K., Breithaupt, L., Liebman, R. E., Misra, M., Wilhelm, S., Lawson, E. A., & Eddy, K. T. (2020). Cognitive-behavioral therapy for avoidant/restrictive food intake disorder: Feasibility, acceptability, and proof-of-concept for children and adolescents. *International Journal of Eating Disorders*, *53*(10), 1636–1646. https://doi.org/10.1002/eat.23355

Thomas, J. J., Lawson, E. A., Micali, N., Misra, M., Deckersbach, T., & Eddy, K. T. (2017). Avoidant/Restrictive Food Intake Disorder: A three-dimensional model of neurobiology with implications for etiology and treatment. *Current Psychiatry Reports*, *19*(8), 54–70. https://doi.org/10.1007/s11920-017-0795-5

Thompson, C., Cummins, S., Brown, T., & Kyle, R. (2015). What does it mean to be a ‘picky eater’? A qualitative study of food related identities and practices. *Appetite*, *84*, 235–239. https://doi.org/10.1016/j.appet.2014.09.028

Tierney, S. (2008). The Individual Within a Condition: A Qualitative Study of Young People’s Reflections on Being Treated for Anorexia Nervosa. *Journal of the American Psychiatric Nurses Association*, *13*(6), 368–375. https://doi.org/10.1177/1078390307309215

Torpy, J. M., Lynm, C., & Glass, R. M. (2004). Malnutrition in Children. *JAMA*, *292*(5), 648. https://doi.org/10.1001/jama.292.5.648

Tracy, S. J. (2010). Qualitative Quality: Eight “Big-Tent” Criteria for Excellent Qualitative Research. *Qualitative Inquiry*, *16*(10), 837–851. https://doi.org/10.1177/1077800410383121

Trofholz, A. C., Schulte, A. K., & Berge, J. M. (2017). How Parents Describe Picky Eating and Its Impact on Family Meals: A Qualitative Analysis. *Appetite*, *110*, 36–43. https://doi.org/10.1016/j.appet.2016.11.027

van der Kolk, B. A. (1994). The body keeps the score: Memory and the evolving psychobiology of posttraumatic stress. *Harvard Review of Psychiatry*, *1*(5), 253–265. https://doi.org/10.3109/10673229409017088

Victora, C. G., Adair, L., Fall, C., Hallal, P. C., Martorell, R., Richter, L., Sachdev, H. S., & Maternal and Child Undernutrition Study Group. (2008). Maternal and child undernutrition: Consequences for adult health and human capital. *Lancet (London, England)*, *371*(9609), 340–357. https://doi.org/10.1016/S0140-6736(07)61692-4

Walton, E., & Allen, S. (2011). Malnutrition in developing countries. *Paediatrics and Child Health*, *21*(9), 418–424. https://doi.org/10.1016/j.paed.2011.04.004

Williams, D. (2010). Theory of own mind in autism: Evidence of a specific deficit in self-awareness? *Autism*, *14*(5), 474–494. https://doi.org/10.1177/1362361310366314

Williams, D. L., Goldstein, G., & Minshew, N. J. (2006). The profile of memory function in children with autism. *Neuropsychology*, *20*(1), 21–29. https://doi.org/10.1037/0894-4105.20.1.21

Williams, K., Hendy, H., Field, D., Belousov, Y., Riegel, K., & Adams, W. (2015). Implications of Avoidant/Restrictive Food Intake Disorder (ARFID) on Children with Feeding Problems. *Children's Health Care*, *44*, 307–321. https://doi.org/10.1080/02739615.2014.921789

Williams, S., & Reid, M. (2012). 'It's like there are two people in my head': A phenomenological exploration of anorexia nervosa and its relationship to the self. *Psychology & Health*, *27*(7), 798–815. https://doi.org/10.1080/08870446.2011.595488

Williamson, C. (2013). Questionnaires, individual interviews and focus groups. In K. Williamson & G. Johanson (Eds.), *Research Methods* (pp. 349–372). Tilde University Press.

Willig, C. (2012). Perspectives on the epistemological bases for qualitative research. In *APA handbook of research methods in psychology, Vol 1: Foundations, planning, measures, and psychometrics* (pp. 5–21). American Psychological Association. https://doi.org/10.1037/13619-002

Wolstenholme, H. (2020). *A qualitative investigation of family perceptions, experiences and management of childhood fussy eating behaviours*. National University of Ireland.

Wolstenholme, H., Kelly, C., Hennessy, M., & Heary, C. (2020). Childhood fussy/picky eating behaviours: A systematic review and synthesis of qualitative studies. *International Journal of Behavioral Nutrition and Physical Activity*, *17*(1), 2. https://doi.org/10.1186/s12966-019-0899-x

Woodhead, M., & Faulkner, D. (2008). Subjects, objects or participants? Dilemmas of psychological research with children. In P. Christiansen & A. James (Eds.), *Research With Children* (pp. 10–39). Routledge.

Zucker, N. L., LaVia, M. C., Craske, M. G., Foukal, M., Harris, A. A., Datta, N., Savereide, E., & Maslow, G. R. (2019). Feeling and body investigators (FBI): ARFID division-An acceptance-based interoceptive exposure treatment for children with ARFID. *International Journal of Eating Disorders*, *52*(4), 466–472. https://doi.org/10.1002/eat.22996

APPENDICES

Appendix A: Reflective Log Entry

28th of March: Reflections on Coding.

After starting to code my first couple of transcripts am I aware of the pull, as a clinician, a pragmatist, and a 'fixer' to be drawn more to the data which could be used for clinical applications. I also wonder if the comments from parents that I was exposed to in the online support groups which spoke about the sheer desperation for help and change have increased a sense of personal pressure to create some real change from this project. To deal with this I have been going on lots of walks to reflect and reduce the pressure I am feeling. I have also found great comfort in Braun and Clark's book especially the parts which validate anxiety around the data analysis. From the book I have been working hard at my 'researcher hat' to truly capture a rich summary of the data set from the codes. Understanding the difference between inductive and deductive analysis has been very helpful and has reminded me to pay attention to the full texts and not just parts which evoke ideas for intervention change. I can also rationalise that rich information from an array of topics from the CYP will all ultimately help to add knowledge and understanding to the world of ARFID.

Further into coding I have also been reflecting on my relationship to food. As I do not identify as a picky eater, I am wondering if some of the behaviours around food are sticking out to me more as they feel different to my own perspective on what is 'normal'. I am wondering if choosing a code like 'inspecting food' from a child talking about picking burnt cheese off pizza, would be as salient to someone who has ARFID or is a fussy eater. Is that just 'normal' eating behaviour? I am having thoughts like 'is this making the othering that I am hearing about worse?'. It is helpful to reflect on my positioning and why I might have interpreted the data in the way I have.

After finishing the first round of the coding I am feeling overwhelmed about the sheer number of codes (386) and information I have got. I have tried to go back over my codes, and I am finding it frustrating and pedantic. It feels hard to separate out some of the codes (like 'not eating with others', 'not eating with friends' and 'not eating at restaurants') and I am once again questioning the reasons why I am making the decisions I am making. I am finding it helpful to take long breaks outside the house, copy down points into the log and refer to Braun and Clark's book and think about more of the latent ideas behind the reasons for not eating with others to see if the codes need to be merged or remain separate.

Appendix B: Recruitment Posters

ARFID

RESEARCH

YOUNG PEOPLE NEEDED

NO FORMAL DIAGNOSIS REQUIRED

aged 10-17 and living in the UK

ONLINE INTERVIEW WITH QUESTIONS ABOUT WHAT IT IS LIKE TO LIVE WITH EATING DIFFICULTIES AS A YOUNG PERSON

DM ME FOR MORE INFO

OR EMAIL U1945445@UEL.AC.UK

ARFID RESEARCH

Young People Needed

Online Interview

QUESTIONS AROUND LIVING WITH ARFID
30-60 MINUTE VIDEO CALL
£5 VOUCHER TO SAY THANK YOU

Who & Why?

- CHILDREN AND YOUNG PEOPLE AGED 10-17
- WITH A DIAGNOSIS OF ARFID
- BASED IN THE UK

CURRENT RESEARCH DOES NOT INCLUDE THE VOICES OF CHILDREN AND YOUNG PEOPLE LIVING WITH ARFID. WE WANT TO CHANGE THIS TO HELP INFORM SERVICES FOR YOUNG PEOPLE

FOR MORE INFORMATION ABOUT ME AND THE STUDY EMAIL:
REBECCA DOLEMAN - U1945445@UEL.AC.UK

ARFID RESEARCH

Young People Needed

My name is Rebecca and I am a doctoral level student in the School of Psychology at the University of East London. I am conducting research to help understand what it is like to live with ARFID through the eyes of children and young people.

WHO?

- Children and young people aged between 10-17
- With a diagnosis of ARFID (or diagnosis highly likely)
- based in the UK

HOW?

- Online interview
- Questions around the positive and negatives of having ARFID
- 30-60 minute video call
- £5 voucher to say thank you

WHY?

- Current research does not include the voices of children and young people living with ARFID
- We want to change this to help inform services for young people

FOR MORE INFORMATION ABOUT ME AND THE STUDY EMAIL:
REBECCA DOLEMAN - U1945445@UEL.AC.UK

University of East London

Appendix C: Interview Schedule

Child Interview Schedule

1. Read through info sheets and sign consent forms.
2. Ice breaker game.

Interview:

1. **What do you know about ARFID?**
   Prompts: what does ARFID mean?, why do you think some children find it hard to eat?

2. **How does this impact on your day to day life?**
   Prompts: positive and negative aspects, health, peers, anxiety, socialising, school, celebrations.

3. **How does it impact on your family?**
   Prompts: differences in opinions, mealtimes, supportive, strain on relationships.

4. **What makes ARFID easier?**
   Prompts: things that help, people that help, techniques that help.

5. **What makes ARFID worse?**
   Prompts: people not understanding, pressure.

6. Who knows about the difficulties?
Prompts: friends, who do you speak to about it

7. Do you think that it is useful to have a diagnosis of ARFID?

8. Is there anything else you would like to tell me?

9. I am going to speak to other young people going through similar things. Is there any message that you would like to give to them about staying hopeful?
(explain about confidentiality)

Close interview with praise and appreciation then and read through de-brief sheet.

Appendix D: Initial Email

Dear ___

Thank you for your interest in my project. I am very pleased that you have made contact and I hope that you are as excited and motivated as I am to add more knowledge to the world of ARFID.

There are a few formalities that need to be covered which are detailed below before the interview can go ahead. Please read this carefully and then if you want to proceed then please reply to this email as soon as possible.

The project has been granted ethical approval by the school of Psychology at the University of East London. In order to maintain the safety of my participants I have inclusion and exclusion criteria which needs to be met by each child or young person to be deemed eligible to take part. Please read the below criteria carefully and think with your young person whether or not they are suitable to take part.

Inclusion criteria:

- Aged 10-17 at the time of inquiry on the project.
- Have been given a diagnosis of ARFID or diagnosis would be highly likely considering the criteria documented in the DSM-V.
- ARFID is currently their main difficulty (this can be alongside ASD).
- Currently living in the UK.
- Can engage in questions about ARFID/their life for at least 20 minutes over video call.

Exclusion Criteria:

- Young people with eating difficulties which can be better explained by another diagnosis (e.g. low mood or anorexia).
- Young people who have been engaging in self-harm behaviours in the last 6 months.
- Young people who would need lots of support to be able to answer the questions independently.
- Young people who are currently experiencing other significant mental health difficulties which may mean the interview could cause considerable distress.

If you believe your young person is suitable for the study, then please read the information sheets attached. The information included will help you make an informed choice about allowing your young person to take part. I have provided a sheet for parents/guardians and one for young people. The young person's information sheet explains the study in a basic way and depending on your young person's understanding it may be useful to provide them with both versions.

If after reading the information sheets you and your young person would like to take part then please reply to this email with an idea of days and times which work best for you. Before taking part, the consent forms (parent/guardian and young person) will need to be completed and sent back to me.

If your child does not have a diagnosis then we would need to speak further about their current difficulties and how they meet the criteria of avoidance and restriction of food. This can be done over email, over the phone, or video call.

I would finally like to thank you for getting in contact with me, reading all of the information provided and for considering your young person as a participant in my study.

As outlined in the information sheets I am happy to answer any questions that you or your young person may have.

I look forward to hearing from you.

Appendix E: Information Sheets

Information sheet for CYP

My eating and me

Hello my name is Rebecca!

I am doing a research project about children who find it difficult to eat some foods. Research is something we do to try and find more information about things.

Not many adults have spoken to children about what it feels like to have difficulties with eating. I would really like to hear about what it is like for you.

If you to do the research I will video call you over the internet.

I will ask you some general questions about things that you like and things to do with food and eating. I want to try to understand what it is like for you, so that professionals and parents can get a better understanding of what it is like and what may be helpful.

You don't have to answer all the questions if you don't know the answer or if you don't want to speak about something.

I will record what we talk about so I don't forget. What you tell me will be kept safe and will not have your name on. If you would like your parents to sit with you during the interview they can.

I will then speak to some other children who may have similar difficulties with eating and then write about everything that I have been told in a big project, a bit like a true life story. When I do this I won't use names, so no one knows who has taken part.

If you tell me something that makes me worried about you then I might have to tell someone else but I would try and let you know first.

If you have any questions, you can ask me at any point.

CYP INFO SHEET | Version 3

Information Sheet for Parents

UNIVERSITY OF EAST LONDON
Parent/Guardian Information Sheet

Consent for My Child to Participate in a Research Study

This is to give you information that you need to consider in deciding whether you agree to your child taking part in a research study. Your child has also been given a copy of this information and you need to agree for him or her to take part. The study is being conducted as part of my Professional Doctorate in Clinical Psychology at the University of East London. Please take some time to read this information sheet in detail.

“My Eating and Me”.
Children and Young People’s Experience of Avoidant/Restrictive Food Intake Disorder (ARFID)

Who am I?
My name is Rebecca and I am a doctoral level student in the School of Psychology at the University of East London, on the clinical psychology training course. I am conducting this research study in order to fulfil the course requirements.

What am I seeking to study?
I am conducting research to help understand what it is like to live with ARFID through the eyes of children and young people. Currently there has been no published research on this. I hope that the findings can help to inform future interventions and increase understanding. My research has been approved by the ethics committee at UEL and this approval means that the panel has deemed my research to be ethical.

What will the project involve?
Your child will be invited to answer some questions on their experience of having difficulties with eating. The questions are set beforehand and will help guide the interview. The time would also allow your child to speak about what they wanted to on this subject. This research would be separate to any treatment your child may be receiving.

Are there any negative consequences to taking part?
Your child will be asked questions about the positive and negative things which come with having eating difficulties. It could be that your child may find

talking about some of these things anxiety provoking or upsetting. To minimise any distress to participants we advise that young people who have a recent history of self-harm (within the last 6 months) or who are experiencing other significant mental health difficulties to not take part in this study.

What will be done to keep my child safe?
I have a full DBS (disclosure and baring service) check and have worked with children and young people in mental health services. I will be using my clinical skills to judge if your child is able to cope with the questions I will be asking. I will pause, change the topic or end the interview if see high levels of distress in your child. It will be also made clear to your child that they can skip questions, pause or end the interview at any point. You and your child will also be provided with information at the end of the interview of how to seek support if needed.

Why am I being asked about this?
When young people (under 16 years) are asked to take part in research, a parent or legal guardian must also agree to this, before taking part and we will seek your consent. There is a good reason for this, as a parent or legal guardian is responsible for keeping their child safe and helping them to make important decisions. If your young person is aged 16 years and over, parental or guardian's consent is not required, however we encourage people involved to discuss and inform their parents about taking part. Ideally, we would ask you to sign the consent alongside your young person signing their assent form. If you are a young person who is over 16 and would like to take part without your parent's consent, then please email me for further information.

Do both parents have to agree?
Only one parent or legal guardian has to agree to a young person under 16 years of age taking part, though if possible it would be good for everyone to agree together. The important point is that an adult who has parental responsibility agrees to the young person under 16 years of age taking part, whether this is their mum, dad or another adult who has parental responsibility for them.

Where will the project take place?
This interview will take place online over secure video link. The interviews will be recorded. The interview should be around 1 hour. There are options for this to be in two parts if this would be too long for your child.

What happens to the things my child shares? Will they be kept private?
Everything that your child shares with me will be treated as confidential. This confidentiality would be broken if I felt worried about the safety of your child or someone around them, and I would then share the information to appropriate people.

Once I have recorded your child’s interview it will be automatically saved in a secure, password protected online drive. I will then transcribe the interview, removing any potentially identifying information. I will then delete the recordings. Anonymised extracts of what your child has said will be used in the thesis. The thesis will be publicly accessible on UEL’s institutional repository after it is completed. This means that people will be able to access the study via the university’s website, including you.

I will not include your child’s name or any other identifying details in any reports that I write up. Some broad demographic information may appear in the thesis and works based on it, but this will not be such as to permit the identification of your child. No one will be able to identify your child from the data that is included in the write-up. Your child’s anonymised data will be seen by my supervisors and the people who grade my thesis. The data may also be published in a journal after I have completed the doctorate. After the study has been completed, I will delete the recording of your child’s interview and their details. I will keep the transcripts of the interviews for five years following completion, in keeping with data management procedures. The transcripts will be stored securely in a password-protected file, and I will have sole access to them.

Will they get anything for taking part?

Your child will receive a £5 Amazon voucher as a token of appreciation of their time. If you would like to accept this I will need to take the details of your address due to HMRC regulations. Once the research is completed I would also like to offer your child a feedback session, either individually, or in a group with the other participants to share with them the findings of the study. This would be sometime in spring 2022. I also hope that they will find the discussions and participating in this research interesting and a helpful opportunity.

Do they have to take part?

Your child does not have to take part in this study and should not feel under any pressure to do so. You are also under no obligation to agree to them taking part. Both you and your child are free to change your mind at any time and withdraw them from the study. You can do this within three weeks of the interview. After this, your data may be included in the final write up, although with all identifying information removed. If your child withdraws from the study they may do so without disadvantage to either of you and there is no need to give a reason. If your child withdraws after three weeks of their interview date things that they have already shared or written may be used in the write-up of the study and any further analysis that may take place. All identifying information is removed in this write up.

Please feel free to ask me any questions. If you are happy to continue your child will be asked to sign a consent form. You will also be asked to sign a consent form before he or she can take part. Please hold on to this invitation letter in case you want to look at it again in the future. If you have any questions or concerns about how the study has been carried out, please contact:

Rebecca Doleman
U1945445@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact:

Research Supervisor: Dr Claire Higgins, Clinical Psychologist and Associate Clinical Tutor, School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: *c.higgins@uel.ac.uk*

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

Information Sheet for CYP aged 16 and above.

UNIVERSITY OF EAST LONDON
CYP Information Sheet

Consent for to Participate in a Research Study

This is to give you information that you need to consider in deciding whether you agree to take part in a research study. The study is being conducted as part of my Professional Doctorate in Clinical Psychology at the University of East London. Please take some time to read this information sheet in detail.

“My Eating and Me”.
Children and Young People’s Experience of Avoidant/Restrictive Food Intake Disorder (ARFID)

Who am I?
My name is Rebecca and I am a doctoral level student in the School of Psychology at the University of East London, on the clinical psychology training course. I am conducting this research study in order to fulfil the course requirements.

What am I seeking to study?
I am conducting research to help understand what it is like to live with ARFID through the eyes of children and young people. Currently there has been no published research on this. I hope that the findings can help to inform future interventions and increase understanding. My research has been approved by the ethics committee at UEL and this approval means that the panel has deemed my research to be ethical.

What will the project involve?
You will be invited to answer some questions on your experience of having difficulties with eating. The questions are set beforehand and will help guide the interview. The time would also allow you to speak about what you want to on this subject. This research would be separate to any treatment you are receiving.

Are there any negative consequences to taking part?
You will be asked questions about the positive and negative things which come with having eating difficulties. It could be that you might find talking about some of these things anxiety provoking or upsetting. To minimise any distress to participants we advise that young people who have a recent

history of self-harm (within the last 6 months) or who are experiencing other significant mental health difficulties to not take part in this study.

What will be done to keep me safe?
I have a full DBS (disclosure and baring service) check and have worked with children and young people in mental health services. I will be using my clinical skills to judge if you are able to cope with the questions I will be asking. I will pause, change the topic or end the interview if see that you are feeling stressed or upset. You will also be allowed to skip questions, pause or end the interview at any point. You will also be provided with information at the end of the interview of how to seek support if needed.

Do I need permission from my parents?
When young people (under 16 years) are asked to take part in research, a parent or legal guardian must also agree to this, before taking part. For young people aged 16 years and over, parental or guardian's consent is not required, however we encourage people involved to discuss and inform their parents about taking part.

Where will the project take place?
This interview will take place online over secure video link. The interviews will be recorded. The interview should be around 1 hour. There are options for this to be in two parts if this would be too long for you.

What happens to the things I share? Will they be kept private?
Everything that you share with me will be treated as confidential. This confidentiality would be broken if I felt worried about the safety of you or someone around you and I would then share the information to appropriate people.

Once I have recorded your interview it will be automatically saved in a secure, password protected online drive. I will then transcribe the interview, removing any potentially identifying information. I will then delete the recordings. Anonymised extracts of what you have said will be used in the thesis. The thesis will be publicly accessible on UEL's institutional repository after it is completed. This means that people will be able to access the study via the university's website, including you.

I will not include your name or any other identifying details in any reports that I write up. Some broad demographic information may appear in the thesis and works based on it, but this will not be such as to permit your identification. No one will be able to identify you from the data that is included in the write-up. Your anonymised data will be seen by my supervisors and the people who grade my thesis. The data may also be published in a journal after I have completed the doctorate. After the study has been completed, I will delete the recording of your interview and your details. I will keep the transcripts of the interviews for five years following completion, in keeping with data management procedures. The transcripts will be stored securely in a password-protected file, and I will have sole access to them.

Will I get anything for taking part?
You will receive a £5 Amazon voucher as a token of appreciation of your time. If you would like to accept this I will need to take the details of your parent's address due to HMRC regulations. Once the research is completed I would also like to offer you a feedback session, either individually, or in a group with the other participants to share with them the findings of the study. This would be sometime in spring 2022. I also hope that you will find the discussions and participating in this research interesting and a helpful opportunity.

Do I have to take part?
You do not have to take part in this study and should not feel under any pressure to do so. You are free to change your mind at any time and withdraw from the study. You can do this within three weeks of the interview. After this, your data may be included in the final write up, although with all identifying information removed. If you withdraw from the study you may do so without disadvantage to you and there is no need to give a reason. If you withdraw from the study after three weeks of the interview date things that you have already shared or written may be used in the write-up of the study and any further analysis that may take place. All identifying information is removed in this write up.

Please feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form. Please hold on to this invitation letter in case you want to look at it again in the future. If you have any questions or concerns about how the study has been carried
out, please contact:

Rebecca Doleman
U19945445@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact:

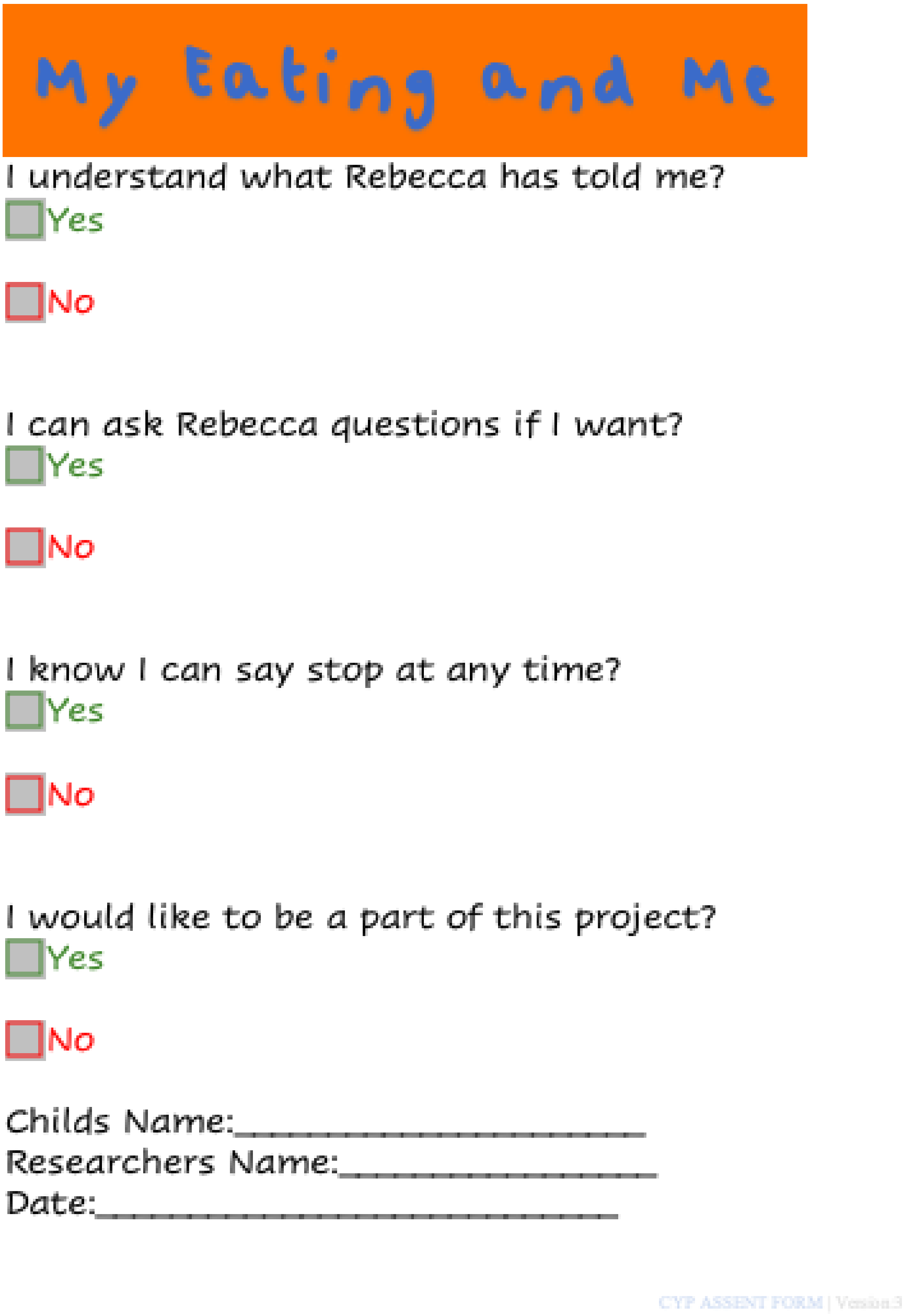
Research Supervisor: Dr Claire Higgins, Clinical Psychologist and Associate Clinical Tutor, School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: *c.higgins@uel.ac.uk*

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

Appendix F: Consent and Assent Forms

CYP Assent Form



My Eating and Me

I understand what Rebecca has told me?

☐ Yes

☐ No

I can ask Rebecca questions if I want?

☐ Yes

☐ No

I know I can say stop at any time?

☐ Yes

☐ No

I would like to be a part of this project?

☐ Yes

☐ No

Childs Name:___________________________
Researchers Name:____________________
Date:__________________________________

CYP ASSENT FORM | Version 3

Parent Consent Form

UNIVERSITY OF EAST LONDON

Consent to for Child to Participate in "My eating and me" or Children and Young People's Experience of Avoidant/Restrictive Food Intake Disorder [ARFID]

Professional Doctorate in Clinical Psychology
Rebecca Doleman

Please tick as appropriate:

	YES	NO
I have read the information leaflet relating to the above programme of research in which my child has been asked to participate and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which my child will be involved have been explained to me.		
My child has been given an age appropriate assent form and is willing to participate.		
I understand that the interview is going to be recorded and I give my consent to this.		
I understand that my child's involvement in this study, and particular data from this research, will remain strictly confidential as far as possible. Only the researchers involved in the study will have access to the data.		
I understand that my child will be asked about things which they might find difficult to discuss and to the best of my knowledge deem my child able to cope.		
I understand that maintaining strict confidentiality is subject to the following limitations: • if the researcher felt worried about the safety of your child or someone around them then confidentiality would be broken by the sharing of information to appropriate people.		

I understand that anonymised quotes and some broad demographic data will be used in publications.		
I understand that the final research paper will appear on the publicly accessible university website, and that the researcher may also seek to publish this finalised piece in an online journal. I am aware that this publication will not include any identifying information.		
I understand that my child's participation in this study is entirely voluntary, and I am free to withdraw them at any time during the research without disadvantage to myself or my child and without being obliged to give any reason. I understand that my data can be withdrawn up to the point of data analysis (3 weeks after interview date) and that after this point it may not be possible to withdraw the anonymised data.		
I understand that once the researcher leaves UEL, all anonymised data will be shared with my supervisor and my supervisor will store this data online on the UEL OneDrive.		
I understand that if I want to accept a voucher for my child then I will need to provide my address due to HMRC regulations.		
I hereby freely and fully consent to for my child to participate in the study which has been fully explained to me and for the information obtained to be used in relevant research publications.		

Child's Name (BLOCK CAPITALS)
……………………………………………………

Parent/Guardian's Name (BLOCK CAPITALS)
……………………………………………………………………..

Participant's Signature
………………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)
……………………………………………………………………..

Researchers's Signature
………………………………………………………………………………………

Date: ……………………………

CYP Over 16 Consent Form

UNIVERSITY OF EAST LONDON

Consent to take part in "My eating and me" or Children and Young People's Experience of Avoidant/Restrictive Food Intake Disorder [ARFID]

Professional Doctorate in Clinical Psychology
Rebecca Doleman

Please tick as appropriate:

	YES	NO
I have read the information leaflet relating to the above programme of research in which I have been asked to participate and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.		
I understand that the interview is going to be recorded and I give my consent to this.		
I understand that my involvement in this study, and particular data from this research, will remain strictly confidential as far as possible. Only the researchers involved in the study will have access to the data.		
I understand that I will be asked about things which I might find difficult to discuss and to the best of my knowledge I feel able to cope with this.		
I understand that maintaining strict confidentiality is subject to the following limitations: • if the researcher felt worried about the safety of you or someone around you then confidentiality would be broken by the sharing of information to appropriate people.		
I understand that anonymised quotes and some broad demographic data will be used in publications.		

I understand that the final research paper will appear on the publicly accessible university website, and that the researcher may also seek to publish this finalised piece in an online journal. I am aware that this publication will not include any identifying information.		
I understand that my participation in this study is entirely voluntary, and I am free to withdraw at any time during the research without disadvantage to myself and without being obliged to give any reason. I understand that my data can be withdrawn up to the point of data analysis (3 weeks after interview date) and that after this point it may not be possible to withdraw the anonymised data.		
I understand that once the researcher leaves UEL, all anonymised data will be shared with my supervisor and my supervisor will store this data online on the UEL OneDrive.		
I understand that if I want to accept a voucher I will need my parents to provide my address due to HMRC regulations.		
I hereby freely and fully consent to participate in the study which has been fully explained to me and for the information obtained to be used in relevant research publications.		

Participant's Name (BLOCK CAPITALS)
………………………………………………………………………..

Participant's Signature
………………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)
………………………………………………………………..

Researcher's Signature
……………………………………………………………………………………

Date: ………………………….

Appendix G: Debriefing Sheets

CYP Debrief

Thank you so much for taking part in the project. You really helped a lot!

You are a star!

I can now use what you said to me in my big project. Remember I won't be using your name.

Next year when I have finished the research I will be able to tell you all the things I found out. I can send this to your parents by their email. I will only say things like "lots of children thought this.." so I will not say anything about you or anyone else.

We might have spoken about things that made you feel sad, angry or worried. That is okay. Lots of people have feelings like that if they speak about big things. You might like to speak to your parents or the adults that look after you about our interview.

If you are feeling sad, worried or angry for a long time after our interview then it might be a good idea to speak to an adult you trust like, a teacher or your GP if you ask your parents to book an appointment.

You could also talk to someone at Childline, an organisation that supports children. By calling 0800 1111

CYP DEBRIEF | Version 3

Parent Debrief

UNIVERSITY OF EAST LONDON

Debriefing Sheet

Thank you for consenting for your child to participate in this research. Their time and contribution is valued and appreciated. We were interested in hearing about how they understand, make sense and cope with their eating difficulties. The questions I asked were centred around these ideas. In talking about food, eating and emotions we may have spoken about things that might be difficult for your child to talk about. Together we spoke about how this can bring up feelings of worry, sadness or anger. I advised them that these feelings are okay and normal and to speak to an adult they trust if these feelings don't go away after the interview.

I also wanted to remind you that their data will be stored safely and securely, and any information that you gave, that will be written up either in the thesis or subsequent published work, will be done anonymously. This means that your name or your child's name or any identifying information will not be included. If, for any reason you would like to withdraw from the study, you can do this within three weeks of the interview. After this, the data may be included in the final write up, although with all identifying information removed.

If you would like to discuss any of the issues that arose further, or if you or your child feel distressed by any of the topics discussed, please contact your GP.

Thank you again for taking part in this research, it is much appreciated.

Researcher
Rebecca Doleman
U1945445@uel.ac.uk

Research supervisor Claire Higgins
School of Psychology,
University of East London,
Water Lane, London E15 4LZ,
c.higgins@uel.ac.uk

CYP Over 16 Debrief

UNIVERSITY OF EAST LONDON

Debriefing Sheet

Thank you for consenting for to participate in this research. You are a star, and your time and contributions are very appreciated.

We might have spoken about things that made you feel sad, angry or worried. That is okay. Lots of people can have intense feelings if they speak about emotional or difficult things. You might like to speak to your parents or the adults that care for you about our interview. If you are feeling sad, worried or angry for a long time after our interview then it might be a good idea to speak to an adult you have a good relationship with like, a teacher or your GP. You could also talk to someone at Childline, an organisation that supports children. By calling 0800 1111.

I also wanted to remind you that your data will be stored safely and securely, and any information that you gave, that will be written up either in the thesis or subsequent published work, will be done anonymously. This means that your name or any identifying information will not be included. If, for any reason you would like to withdraw from the study, you can do this within three weeks of the interview. After this, the data may be included in the final write up, although with all identifying information removed.

Thank you again for taking part in this research, it is much appreciated.

Researcher
Rebecca Doleman
U1945445@uel.ac.uk

Research supervisor Claire Higgins
School of Psychology,
University of East London,
Water Lane, London E15 4LZ,
c.higgins@uel.ac.uk

Appendix H: Messages of Hope

Messages of Hope

FROM OTHER YOUNG PEOPLE

"It does get better. Sometimes when you're in a really bad place, it doesn't feel like it and you feel stuck like this forever or you are never going to get better, but eventually in time and help it does."

"Don't get stressed."

I believe in me

"If you ever have to get a NG tube, don't worry. It doesn't hurt and it really helps."

"ARFID is not something that's weird, it's something that a lot of people go through and they shouldn't be judged for it."

"When I was growing up, I always felt sad because I thought it was it was just me. But now I know it's a recognised thing that other people have. I know it's a thing that people are researching and it is becoming a more recognised and an understood thing."

"I feel like people forget how hard it can be and that sometimes you just need to give yourself time to think and be proud of yourself."

"Keep trying new foods. They might be scary at first, but if you try them and you don't like them, you don't eat them again. "

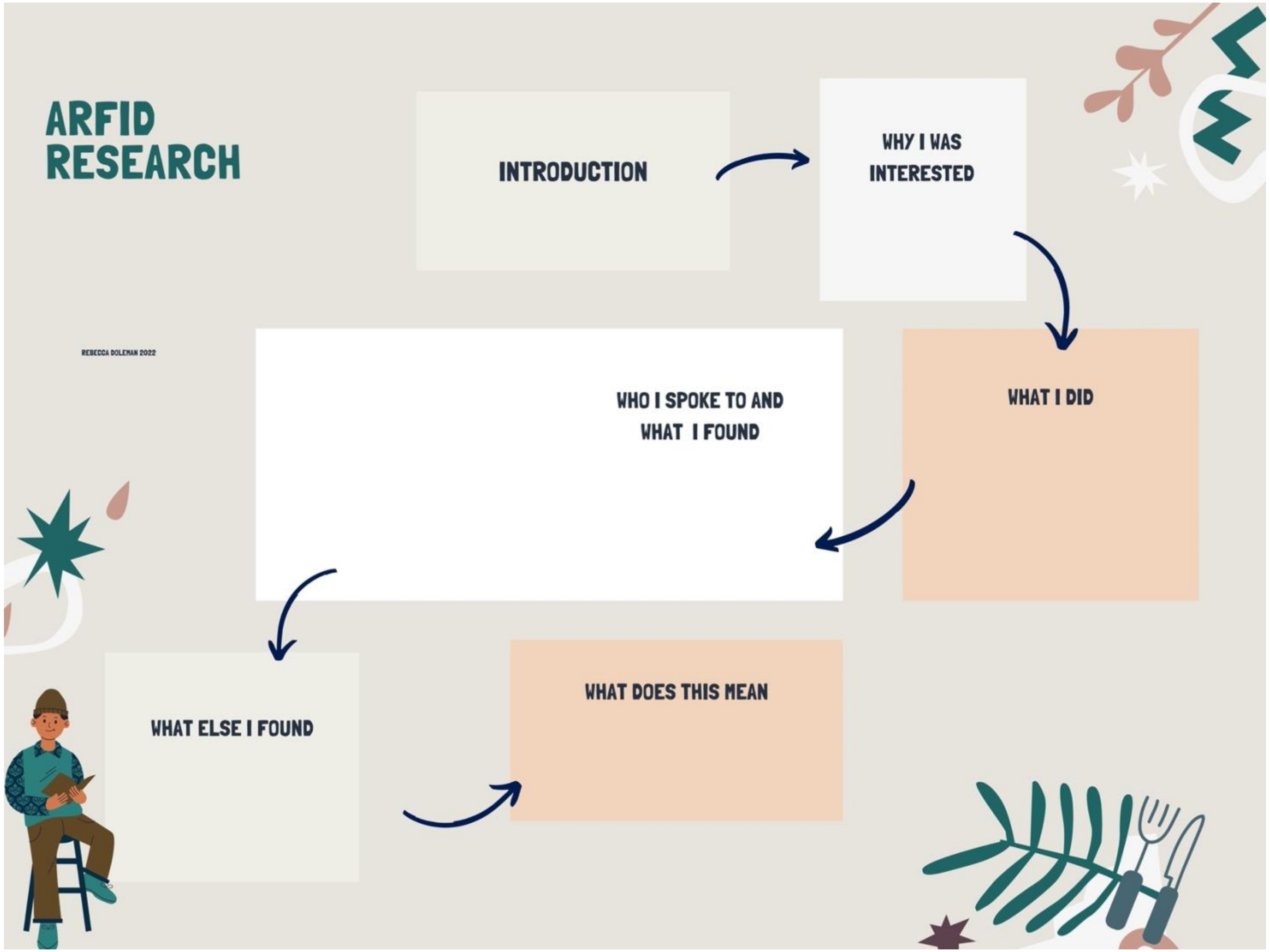
"I want people to know that it's not your fault. And it sucks that there are people who won't understand. But you are brave! It's a really brave thing to live with!"

"You aren't alone and you can get better. I'm feeling like I am getting there. So you can also recover from it just like you can recover from any other disordered eating."

I am brave

Rebecca Doleman (2022)

Appendix I: Draft Outline of Easy Read Summary



ARFID
RESEARCH

REBECCA DOLEMAN 2022

INTRODUCTION

WHY I WAS
INTERESTED

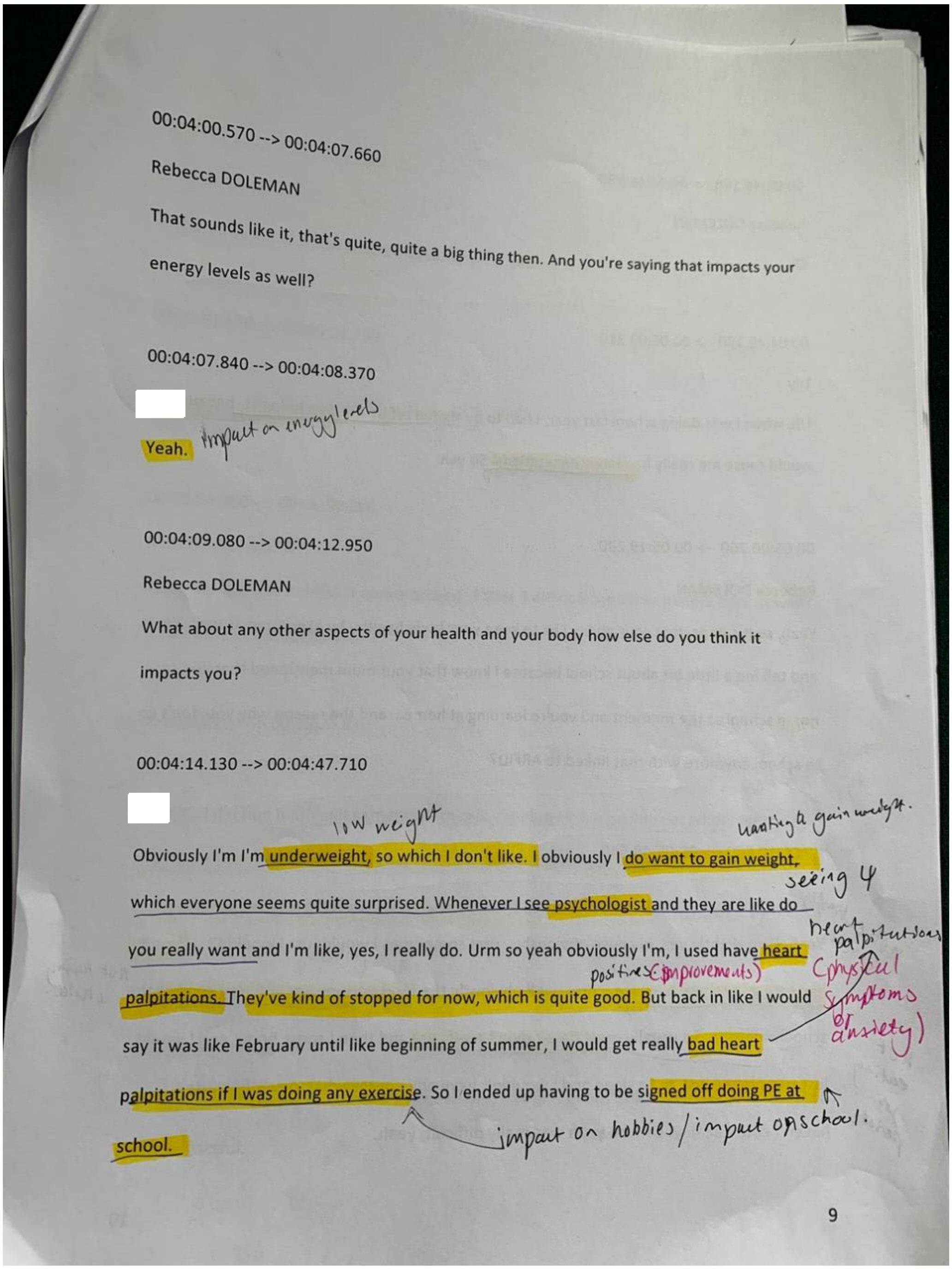
WHAT I DID

WHO I SPOKE TO AND
WHAT I FOUND

WHAT ELSE I FOUND

WHAT DOES THIS MEAN

Appendix J: Sample of The Coding Process



00:04:00.570 --> 00:04:07.660

Rebecca DOLEMAN

That sounds like it, that's quite, quite a big thing then. And you're saying that impacts your energy levels as well?

00:04:07.840 --> 00:04:08.370

[redacted]

Yeah. impact on energy levels

00:04:09.080 --> 00:04:12.950

Rebecca DOLEMAN

What about any other aspects of your health and your body how else do you think it impacts you?

00:04:14.130 --> 00:04:47.710

[redacted]

low weight

wanting to gain weight.

Obviously I'm I'm underweight, so which I don't like. I obviously I do want to gain weight, which everyone seems quite surprised. Whenever I see psychologist and they are like do you really want and I'm like, yes, I really do. Urm so yeah obviously I'm, I used have heart palpitations. They've kind of stopped for now, which is quite good. But back in like I would say it was like February until like beginning of summer, I would get really bad heart palpitations if I was doing any exercise. So I ended up having to be signed off doing PE at school.

seeing ψ

heart palpitations

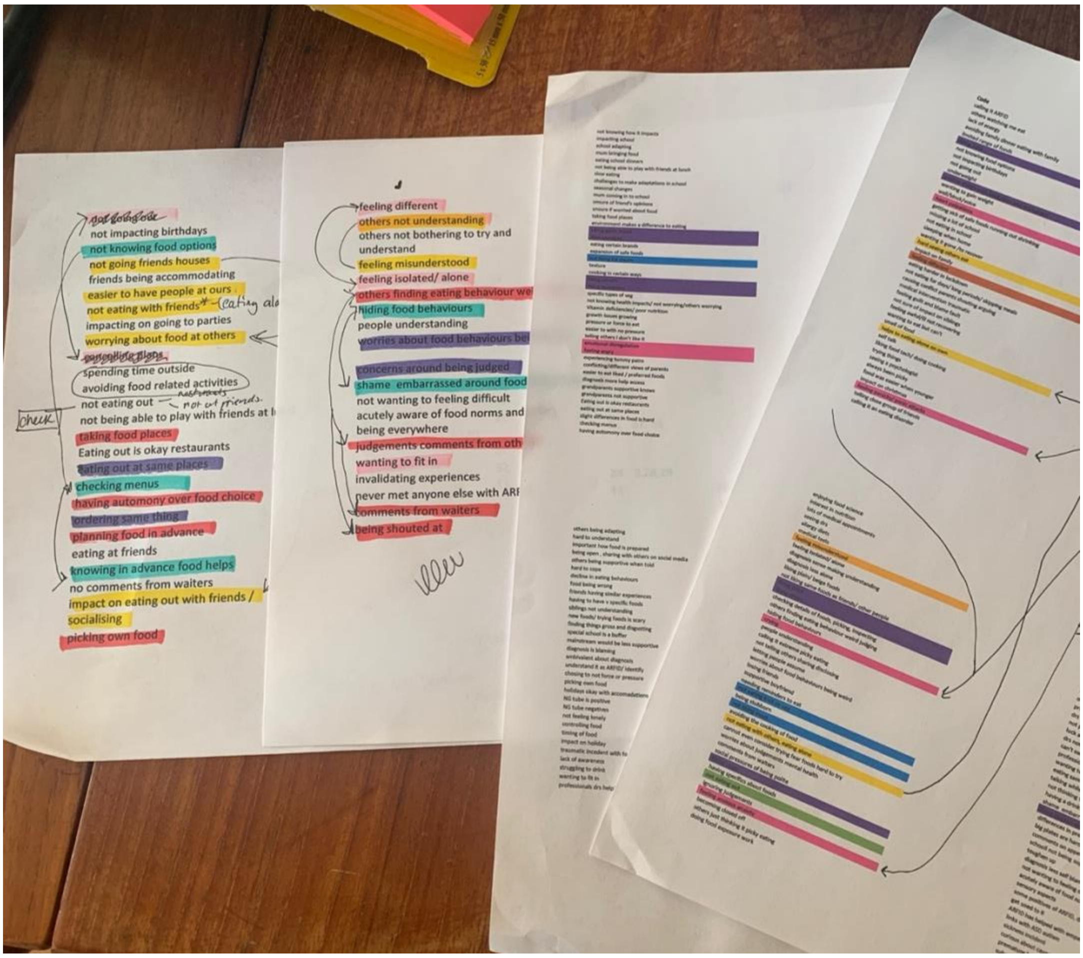
positives (improvements)

(physical symptoms of anxiety)

impact on hobbies / impact on school.

9

Appendix K: Photo of Codes being Re-Examined

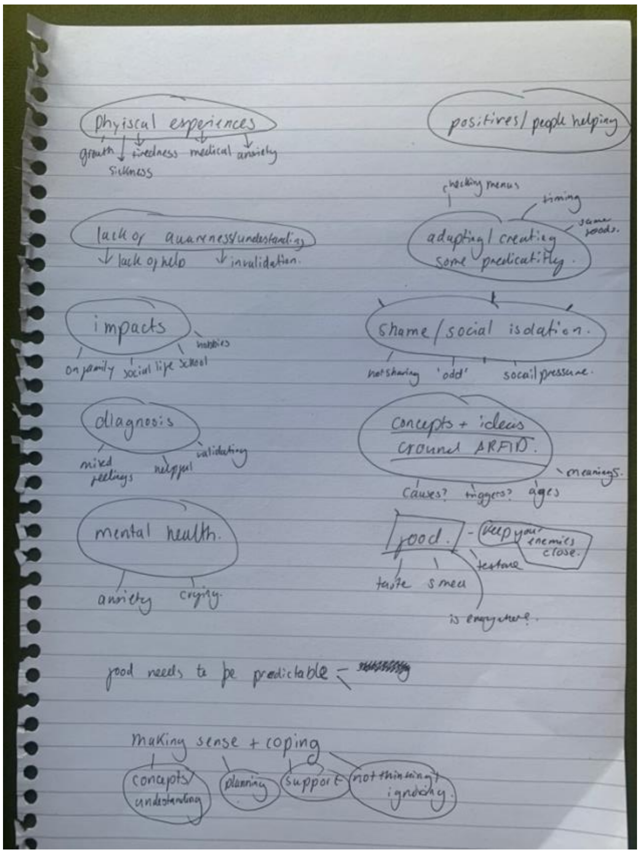


~~not going out~~
not impacting birthdays
not knowing food options
not going friends houses
friends being accommodating
easier to have people at ours
not eating with friends* (eating alo
impacting on going to parties
worrying about food at others
~~cancelling plans~~
spending time outside
avoiding food related activities
not eating out — restaurants not at friends.
not being able to play with friends at l
taking food places
Eating out is okay restaurants
Eating out at same places
checking menus
having automony over food choice
ordering same thing
planning food in advance
eating at friends
knowing in advance food helps
no comments from waiters
impact on eating out with friends /
socialising
picking own food

check

feeling different
others not understanding
others not bothering to try and understand
feeling misunderstood
feeling isolated/ alone
others finding eating behaviour we
hiding food behaviours
people understanding
worries about food behaviours be
concerns around being judged
shame embarrassed around food
not wanting to feeling difficult
acutely aware of food norms and being everywhere
judgements comments from oth
wanting to fit in
invalidating experiences
never met anyone else with ARF
comments from waiters
being shouted at

Appendix L: Photos of Themes Being Developed



Appendix M: Draft Themes

Appendix N: List of Codes, Subthemes, Themes and Corresponding Transcript Page Number

			Participant and Page Number							
Theme	**Subtheme**	**Code name**	**Lily**	**Alice**	**Demi-gamer**	**John**	**Ella**	**Anne**	**Evie**	**Lucy**
The Challenge of being in my body	**Food as a threat**	big portions are hard		32						
		struggling to drink								22
		(worries about) shrinking safe food list	23	28			8	16,17		
		not eating in school	10		10,35			19		
		eating harder in lockdown	25					10		10
		not eating for prolonged periods and/or irregularly	10,12,18	3,10,15			22		3	5,22,25
		wanting to eat but not being able to	16,23				19	15	26	
		needing reminders to eat		15						
		cannot even consider trying fear foods		16				2,12		
		slow eating			9					5
		refusing food, not being able to eat after event	33	22		7	24			21
		not eating a lot or enough		9	35	14	10		3	10
		decline in eating behaviours					32			
		not liking any of food options	10,12	3,17		3,5,22	11,16,17	10		
		lack of enjoyment with food		31		11	4,7			
		disliking foods	37	15,16	15	9,13				15
		limited range of foods	8,34	31	14	4,10	4,8	7,21,21	1	

		liking plain/ beige foods		12			8			
		eating same (safe) foods	16,23, 25,34	28	14	3,11,15	8,8,10	6,7	24,24	
		environment makes a difference to eating	34,35		12, 14		13,21, 22	18	23,26, 27	8,9
		easier to eat liked / preferred foods			8,14, 25	15		13		
		slight differences in food is hard			32			3		
		eating at the same places/having the same things			32	2				
		food being wrong						3		
		food needing to be very specific		17	15,15, 17		4	6,6,7,9,10	6,26	
		how food is prepared		31	16		21	7,13,14	26	
		having specific fear foods		2,3,7,24,16			4,12	11		
		smell of food	16	10, 37			31	11,17	7	
		not touching disliked foods		1,5,6				11		
		inspecting small elements of food		12,31, 35		4,5,18		15,16, 17,19		
		sensory aspects		38			31		6	
		texture			16	9,13	31	12,15		15
		taste				9				15
		hard to be around others eating	11,19	3,5,16, 24	26		4,10,22		7	
	Physical and medical impacts	traumatic medical intervention	13,14	26					12	
		medical appointments	12	25,11	18		5,17,18		11	10,28
		allergy diets		11,42						

		medical tests		11, 24						
		doing food exposure work		18	39				26	
		negatives with a NG tube	16						11,18	
		underweight	9				5			10
		wanting to gain weight	9							16
		feeling awful or ill	16	19,28					10	10
		impact on health		19				7		10
		impact on appearance		8,9						16
		not putting on weight		24	17					
		vitamin deficiencies/ poor nutrition			17		4	2		
		issues with growing			17		5,7,18		10	16
		worried about health					5			
		feeling tired		8, 19,20, 27					10	
		lack of energy	8,9,16	8,9	6				4,10	10
		sitting around/lying around a lot	16	9,19					10	
		sleeping after returning home	10,25	19					10	
	Unpleasant Emotions and Sensations	feeling distress				7		3,18	6	4,17
		feeling sick	16	8, 20	23	8, 15,15		15	20	15
		crying		13						
		worries about choking or vomiting		21,43						6,6
		can't swallow tablets/ not liking supplements		26	23					
		experiencing tummy pains			24					
		(not) feeling hungry	12	10		6,22	13			4,23

		not liking feeling full				14				23
		finding things gross and disgusting						14		
		experiencing physical symptoms of anxiety	8,9,10,15,36	6,7			18,19			
		impact on mental health/mood	26	10,20		8	11	3		8,13,17
		experiencing anxiety/worry	14	18,20,38		7	18		5	3,4,13
		emotional dysregulation			21,34		19	19		
		feeling angry/annoyed			22			18,19,21		
No one gets it so how do I	**Lack of Knowledge and Validation and help**	others not understanding		4			17			
		others not bothering to try and understand	30	5,17,29,33,33,34,38	34,35		24	9		13
		invalidating experiences	28	3,28,29						24
		having others watch my eating	20,21,27,35	30						21
		other assuming anorexia		4, 33						10,16
		others just thinking it picky eating		4, 18,28			17,24		5	
		traumatic event at school		4,33			13,30			
		siblings not understanding						9		
		lack of awareness	28							16,24
		dad not understanding	26	23	31	12	21			18
		worries that even close family don't understand		23						
		others being patronising		23						
		comments on appearance		33					14	16

		school not being supportive		33	10,34		12,13	19		
		challenges to make adaptations in school			9,10					
		pressure or force to eat	27		20,22	12	13,23, 24		5	
		grandparents not supportive			31					
		professionals not really helping/ understanding	28	26		5				
		drs professionals not aware not knowing			37				32	28
		drs not interested if not underweight			38					
		postcode lottery			39					
		searching for/wanting professional help	30		28		19,32, 34		31	27
		drs not listening		24	28					
		luck around getting diagnosis		25	36					
		drs not have answers		26						
		exposure work not helpful		18,27, 28	39				26	
	Feeling Different	guilt/self blame	13,40, 41	28,28			19,20, 22,23			29
		telling close group of friends	36,35	14			25		28	
		disclosing in context	36,38	10,17			27	17		
		being selective with who disclose to	37	5, 29			25	21		
		not telling others	35	6,14, 28,35	11	16,18, 19		17,21	30	24
		letting people assume		14						
		feeling different	11	37		5,6	6		3,14	
		feeling isolated/ alone	45	11,38			17			31
		others judging/finding it odd		12,17 33,35		12,17,27			14	10,19

		hiding food behaviours		12,13, 35					3	25
		concerns around being judged		17			17	21	2,3,13, 14	25
		wanting to fit in					4,28			25
		never met anyone else with ARFID	44	36		22	17			
		wanting to be polite/not cause a fuss	36	17, 21,35, 37		4, 18,16	15			13
		acutely aware of food norms	11	37,37			4,11			19,20, 29
	Tentative Sense Making	Indifference/ambivalence	15,25, 27		6,17,11	7,2,20	21	3,8,7, 20	10,17, 22	18
		becomes more real with diagnosis	40							
		Thoughts on causes	19,41	42,43	10,40, 42	19	13			11,14
		hard to cope with					29			
		calling it ARFID	7	1	5		3			
		experiencing a mental block	19,23, 33	2,28,37		14,7,19	7	12,20	16	29
		wanting ARFID gone/to recover		27	29					19
		calling it an eating disorder	36							4
		no positives of ARFID	46		30					
		not everyone with ARFID is the same	46							
		calling it extreme picky eating		14				1		
		links with ASD		41			31			
		ARFID is a problem	40		36	20	3,4,29			4
		it’s a 'fear of food'					7			6,17
		hard to understand		28			21	3		

		understand it as ARFID/ identify						21,22		
		not feeling lonely							30	
		food being everywhere								12,17,29
ARFID Shrinks my Life	**Hobbies and Activities**	impact on christmas	20			4				12
		Impact on activities	16						4,18,19	32
		impact on hobbies/sports	9	9	6, 29					
		not liking cooking		10			10			
		impact on holidays								10
		not going out	8	6						5
		avoiding food related activities		6,7						5,8
	Relationships	impact on family	8,13,26		19	2	20	8		18,19
		causing conflict with parents	26	26	20	12			21	
		not liking same foods as friends/ other people		12	12		4,22	9		18
		losing friends		14						
		becoming closed off		18						
		conflicting/different views to parents			24		28,29			
		harder new people					15			
		not eating as a family	20,21		25		4		7	18,19
		difficult to eat out with friends	8	6			4,7			8,9
		avoiding/(difficulties with) eating at friend's houses		3	11	16	15	3	4	
		difficulties with parties/birthdays		6,12		22	16		8	
		difficulties/avoiding eating at restaurants	8	17,23	32	2,3	4,7,17		8,30	13,19
		not being able to play with friends at lunch			9					

	School/ work	missing a lot of school	34	8,25	10,35			5		5,7
		impacting work		1						
		impact on cognitions/learning		9			13			7
		not going to university		10						
		missing food technology					10			
		impacting school	9		6,8		10		10	
How I get by	**Gaining Control and Adapting**	controlling food	33							4
		timing of food	26,27							5,21
		preferring to eat alone	11,20, 26,27		25	13	9,11,10,22		2,3,23, 25	8
		self talk	28	21			23		24	20
		trying new foods		27,33	39					
		seeing a psychologist	9,29,31		39				26	1
		ignoring judgements		18, 40						
		talking while eating helps		30						
		not thinking too much about food when eating		30						
		having a drink with food		30		8				
		get used to it		29,38					15	
		easier to with no pressure			21				25	
		substituting/changing food				10				
		knowing how to get the taste away				16				
		cooking lots of different foods meals				10,21	4	9,10		
		choosing to not force or pressure				21		21,24	22	
		easier to have friends round		5	12					

		checking menus			32			8		
		advance planning				4,5,21	11	8	6	
		taking own food to places	12,16		8,12	3,5	9,11,14		1,3,4,6	
		autonomy over food choice	22,34,37		33	21	12,16	21		20
		bringing food into school			8	3,5	9,11,14		1,3	
	Finding the positives	enjoying food science		10	26					
		becoming strongwilled		15						
		bringing closer to mum		22						
		toughening up		33, 29,35						
		some positives of ARFID, difference can be good		39			29	1		30
		ARFID has helped with empathy		40						
		no comments from waiters				18	16		30	
		liking food technology or cooking	18					12	9	
		expansion of safe foods			15,					
		achievement from trying foods			40					
		Improvements or stability	9			19		21,22		
		being open, sharing with others					25,26,27			
		holidays okay with accommodations							7	
		NG tube as a positive			39				10,10,12,13,19,22	
		not impacting birthdays/parties	22		13	3		3		
		being able to eat at restaurants			32,33		15			

	The diagnosis and external support	supportive boyfriend		14						
		siblings helping		22						
		mum being supportive/ parents		24		12	15		21,31	18
		school adapting			8, 9,10			5,18	2,3,30	25
		mum coming into school			10					
		grandparents supportive			31	18,15				
		others being supportive when told					26			
		friends having similar experiences						3,18		
		special school is a buffer						18	15,29	
		friends being accommodating	37	5	12			3,3,4	5	
		people understanding		13			22,26	4	15	
		diagnosis is helpful	39	37	28		32		33	
		Diagnosis, sense making understanding		11,37	37	24	6,20		33	
		Diagnosis, less alone		11, 38	38					
		diagnosis, less self blame		37			31			
		Diagnosis, more help	39		28,29		32			26
		Diagnosis, validation from others					15,21			

Appendix O: Original Ethics Application Form

UNIVERSITY OF EAST LONDON
School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL
FOR RESEARCH INVOLVING HUMAN PARTICIPANTS
(Updated October 2019)

FOR BSc RESEARCH
FOR MSc/MA RESEARCH
FOR PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

Completing the application

Before completing this application please familiarise yourself with the British Psychological Society's Code of Ethics and Conduct (2018) and the UEL Code of Practice for Research Ethics (2015-16). Please tick to confirm that you have read and understood these codes: ☒

Email your supervisor the completed application and all attachments as ONE WORD DOCUMENT. Your supervisor will then look over your application.

When your application demonstrates sound ethical protocol, your supervisor will submit it for review. By submitting the application, the supervisor is confirming that they have reviewed all parts of this application, and consider it of sufficient quality for submission to the SREC committee for review. It is the responsibility of students to check that the supervisor has checked the application and sent it for review.

Your supervisor will let you know the outcome of your application. Recruitment and data collection must NOT commence until your ethics application has been approved, along with other research ethics approvals that may be necessary (see section 8).

Please tick to confirm that the following appendices have been completed. Note: templates for these are included at the end of the form.

The participant invitation letter ☒

The participant consent form ☒

The participant debrief letter ☒

The following attachments should be included if appropriate. In each case, please tick to either confirm that you have included the relevant attachment, or confirm that it is not required for this application.

A participant advert, i.e., any text (e.g., email) or document (e.g., poster) designed to recruit potential participants.
Included or ☐

Not required (because no participation adverts will be used) ☒

A general risk assessment form for research conducted off campus (see section 6).
Included or ☒

Not required (because the research takes place solely on campus or online) ☐

A country-specific risk assessment form for research conducted abroad (see section 6).
Included or ☐

Not required (because the researcher will be based solely in the UK) ☒

A Disclosure and Barring Service (DBS) certificate (see section 7).
Included or ☒

Not required (because the research does not involve children aged 16 or under or vulnerable adults) ☐

Ethical clearance or permission from an external organisation (see section 8).
Included or ☐
(NHS ethics is currently being sought, but this is running alongside this application)

☒
Not required (because no external organisations are involved in the research)

Original and/or pre-existing questionnaire(s) and test(s) you intend to use.
Included or ☐

Not required (because you are not using pre-existing questionnaires or tests) ☒

Interview questions for qualitative studies.
Included or ☒

Not required (because you are not conducting qualitative interviews) ☐

Visual material(s) you intend showing participants.
Included or ☐

Not required (because you are not using any visual materials) ☑

Your details

Your name: Rebecca Doleman

Your supervisor's name: Claire Higgins

Title of your programme: Professional Doctorate in Clinical Psychology

UEL assignment submission date (stating both the initial date and the resit date): May 2022

Your research

Very little qualitative research has been conducted with children and young people who have a diagnosis of Avoidant/Restrictive Food Intake Disorder [ARFID]. ARFID can have a very detrimental effect on children/young people's mental and physical health yet there are currently no national guidelines for intervention. This study aims to centre the voice of the child and explore what it is like to live with a diagnosis of ARIFD. The findings will inform future practice leading to interventions which are positive, empowering and validating experience for the child.

The title of your study:

Children and Young People's Experience of Avoidant/Restrictive Food Intake Disorder [ARFID]

Your research question:

What is the impact of ARFID on a child/young person?
How do children/young people understand, make sense and cope with ARFID?

Design of the research:
The study will use a qualitative approach. Individual semi-structured interviews will be used and transcribed by the researcher.

Participants:

10-20 children/ young people aged 10-16 with a diagnosis of ARFID receiving or have received a clinical intervention.

Recruitment:

Social media platforms and accounts will be used to advertise the study. The poster will include an email address to contact for more information around taking part in the study.

Measures, materials or equipment:

A sample interview schedule has been created. There is an aim for the questions to be reviewed by a
focus group of children with AFRID to check for understanding and relevance. Questions will
focus on understanding, broader impact and enablers and barriers to coping.

Data collection:

Participants will be asked to take part in interviews up to an hour long. Children will be provided with the option of breaks, or splitting the interview in two halves over different days if needed. The interviews will be conducted over video messaging and recorded. Recordings will be transcribed verbatim by the researcher.

Data analysis:

Interviews will be analysed with inductive thematic analysis.

Confidentiality and security

It is vital that data are handled carefully, particularly the details about participants. For information in this area, please see the UEL guidance on data protection, and also the UK government guide to data protection regulations.

Will participants data be gathered anonymously?
No as data is collected via qualitative interviews.

If not (e.g., in qualitative interviews), what steps will you take to ensure their anonymity in the subsequent steps (e.g., data analysis and dissemination)?

All names and identifying information will be removed from the interviews and transcripts. Only the researcher will have access to these names and contact details and the recorded Team interviews. Only the researcher, the supervisor and the examiner will have access to the transcriptions, and then only if necessary. The names and contact details and video/audio recordings of the participants will be destroyed at the end of the study, and raw data will be kept on a secure password protected drive. Any quotes used in write-up will be anonymised.

How will you ensure participants details will be kept confidential?

See above.

How will the data be securely stored?

All data will be stored on UEL OneDrive for business cloud.

Audio/video files of interviews will be uploaded from Teams. Microsoft Teams provides a transcription function which creates transcripts in word files. Transcribed files from Microsoft Teams will be stored on the Microsoft Stream Library by default and subsequently uploaded to UEL OneDrive. In case of technical difficulties with recordings a dicatphone may have to be used. If that is the case then the recording will be downloaded from the researcher's unencrypted dictaphone onto the researcher's laptop immediately and then to the recordings should be uploaded to UEL OneDrive for Business after the interview. Once audio files have been uploaded (which only the researcher has access to) the files will be deleted from the Dictaphone and laptop. Any local copies will be deleted from my downloads/temporary folders and I will ensure that data are not stored on personal cloud storage.

Audio/video files and transcripts will be stored on separate password protected folders only accessible by the researcher on a UEL OneDrive for business.

Transcripts will be stored on both the researchers and supervisors secure accounts (so there is a backup)

Contact details and other identifiable information will be stored in a folder separate from the audio/video files and transcripts. Electronic copies of the consent forms will be gathered via email and be stored on the UEL OneDrive for Business.

Audio/video files and transcripts will be saved in separate folders. Each audio file will be named with the participants' initials and the date of the interview. Each participant will be attributed a participant number, in chronological interview order. Transcription files will be named e.g. "Participant 1". No list will be kept of participant numbers linked to personal identifying information.

Who will have access to the data?

Only the researcher will have access to these names and contact details, and only the researcher, the supervisor and the examiner will have access to the transcriptions, and then only if necessary.

How long will data be retained for?

Transcripts will be kept for three years on UEL's OneDrive for business by the research supervisor, after which point they will be deleted. Copies of the anonymised transcripts will be kept for 5 years on an encrypted external hard drive in a locked cabinet on the researcher’s private property in case of publication.

Informing participants

Please confirm that your information letter includes the following details:

Your research title: ☒

Your research question: ☒

The purpose of the research: ☒

The exact nature of their participation. This includes location, duration, and the tasks etc. involved:

That participation is strictly voluntary: ☒

What are the potential risks to taking part: ☒

What are the potential advantages to taking part: ☒

Their right to withdraw participation (i.e., to withdraw involvement at any point, no questions asked): ☒

Their right to withdraw data (usually within a three-week window from the time of their participation): ☒

How long their data will be retained for: ☒

How their information will be kept confidential: ☒

How their data will be securely stored: ☒

What will happen to the results/analysis: ☒

Your UEL contact details: ☒

The UEL contact details of your supervisor: ☒

Please also confirm whether:

Are you engaging in deception? If so, what will participants be told about the nature of the research, and how will you inform them about its real nature.

NO

Will the data be gathered anonymously? If NO what steps will be taken to ensure confidentiality and protect the identity of participants?

No. All names and identifying information will be removed from the interviews and transcripts. Only the researcher will have access to these names and contact details and the recorded videos. Only the researcher, the supervisor and the examiner will have access to the transcriptions, and then only if necessary. The names and contact details and video recordings of the participants will be destroyed at the end of the study, and raw data will be kept on a secure password protected drive. Any quotes used in write-up will be anonymised.

Will participants be paid or reimbursed? If so, this must be in the form of redeemable vouchers, not cash. If yes, why is it necessary and how much will it be worth?

The children/young people will be given a £5 gift voucher as a token of thanks for their time. Offering only a small amount of money can help to reduce coercion to taking part.

Risk Assessment

Please note: If you have serious concerns about the safety of a participant, or others, during the course of your research please see your supervisor as soon as possible. If there is any unexpected occurrence while you are collecting your data (e.g. a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.

Are there any potential physical or psychological risks to participants related to taking part? If so, what are these, and how can they be minimised?

Risk of harm to child as deemed as vulnerable because they are under 18 and have a mental health diagnosis. There is a risk of children becoming upset during interview. These risks are minimised by the researcher having an extended DBS check and experience of working clinically with children. Parental consent to be sought as well as assent from child. Ethical approval required before conducting any interviews. Parents/guardians will be given the option to sit in on the video call. Check-ins throughout the interview will take place to ensure child is safe and flexible options with either terminating the interview or stopping the interview and recommencing at a later date will be used. Breaks will also be encouraged to reduce video calling fatigue. Interview questions formed to explore both positive and negative aspects of the feeding/eating disorder to minimise risk of upsetting the participants. Participants will be aware of right to withdraw and skip questions.

Participants will be given age appropriate de-brief sheets and information on how to seek help if needed after the interview. Participants will be reminded that confidentially may need to be broken in order to seek help for the participant.

Are there any potential physical or psychological risks to you as a researcher? If so, what are these, and how can they be minimised?

No risk

Have appropriate support services been identified in the debrief letter? If so, what are these, and why are they relevant?
Yes, Childline and advice to speak to GP.

Does the research take place outside the UEL campus? If so, where?

Interviews will take place over video call. Participants and researcher will most likely be in their homes.

If so, a 'general risk assessment form' must be completed. This is included below as appendix D. Note: if the research is on campus, or is online only (e.g., a Qualtrix survey), then a risk assessment form is not needed, and this appendix can be deleted. If a general risk assessment form is required for this research, please tick to confirm that this has been completed: ☒

Does the research take place outside the UK? If so, where?

No

If so, in addition to the 'general risk assessment form', a 'country-specific risk assessment form' must be also completed (available in the Ethics folder in the Psychology Noticeboard), and included as an appendix. [Please note: a country-specific risk assessment form is not needed if the research is online only (e.g., a Qualtrix survey), regardless of the location of the researcher or the participants.] If a 'country-specific risk assessment form' is needed, please tick to confirm that this has been included: ☐

However, please also note:

For assistance in completing the risk assessment, please use the AIG Travel Guard website to ascertain risk levels. Click on 'sign in' and then 'register here' using policy # 0015865161. Please also consult the Foreign Office travel advice website for further guidance.

For on campus students, once the ethics application has been approved by a reviewer, all risk assessments for research abroad must then be signed by the Head of School (who may escalate it up to the Vice Chancellor).
For distance learning students conducting research abroad in the country where they currently reside, a risk assessment must be also carried out. To minimise risk, it is recommended that such students only conduct data collection on-line. If the project is deemed low risk, then it is not necessary for the risk assessments to be signed by the Head of School. However, if not deemed low risk, it must be signed by the Head of School (or potentially the Vice Chancellor).
Undergraduate and M-level students are not explicitly prohibited from conducting research abroad. However, it is discouraged because of the inexperience of the students and the time constraints they have to complete their degree.

Disclosure and Barring Service (DBS) certificates

Does your research involve working with children (aged 16 or under) or vulnerable adults (*see below for definition)?

YES. You may notice my DBS is older than 6 months but I have included this as it covers my current clinical role within the NHS for 3 years until September 2022.

If so, you will need a current DBS certificate (i.e., not older than six months), and to include this as an appendix. Please tick to ☒ confirm that you have included this:

Alternatively, if necessary for reasons of confidentiality, you may email a copy directly to the Chair of the School Research Ethics Committee. Please tick if you have done this instead: ☐

Also alternatively, if you have an Enhanced DBS clearance (one you pay a monthly fee to maintain) then the number of your Enhanced DBS clearance will suffice. Please tick if you have included this instead: ☐

If participants are under 16, you need 2 separate information letters, consent form, and debrief form (one for the participant, and one for their parent/guardian). Please tick to confirm that you have included these: ☒

If participants are under 16, their information letters consent form, and debrief form need to be written in age-appropriate language. Please tick to confirm that you have done this ☒

* You are required to have DBS clearance if your participant group involves (1) children and young people who are 16 years of age or under, and (2) ‘vulnerable’ people aged 16 and over with psychiatric illnesses, people who receive domestic

care, elderly people (particularly those in nursing homes), people in palliative care, and people living in institutions and sheltered accommodation, and people who have been involved in the criminal justice system, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak to your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible. For more information about ethical research involving children click here.

Other permissions

Is HRA approval (through IRAS) for research involving the NHS required? Note: HRA/IRAS approval is required for research that involves patients or Service Users of the NHS, their relatives or carers as well as those in receipt of services provided under contract to the NHS.

NO If yes, please note:

You DO NOT need to apply to the School of Psychology for ethical clearance if ethical approval is sought via HRA/IRAS (please see further details here).
However, the school strongly discourages BSc and MSc/MA students from designing research that requires HRA approval for research involving the NHS, as this can be a very demanding and lengthy process.
If you work for an NHS Trust and plan to recruit colleagues from the Trust, permission from an appropriate manager at the Trust must be sought, and HRA approval will probably be needed (and hence is likewise strongly discouraged). If the manager happens to not require HRA approval, their written letter of approval must be included as an appendix.
IRAS approval is not required for NHS staff even if they are recruited via the NHS (UEL ethical approval is acceptable). However, an application will still need to be submitted to the HRA in order to obtain R&D approval. This is in addition to a separate approval via the R&D department of the NHS Trust involved in the research.
IRAS approval is not required for research involving NHS employees when data collection will take place off NHS premises, and when NHS employees are not recruited directly through NHS lines of communication. This means that NHS staff can participate in research without HRA approval when a student recruits via their own social or professional networks or through a professional body like the BPS, for example.

Will the research involve NHS employees who will not be directly recruited through the NHS, and where data from NHS employees will not be collected on NHS premises?

No

If you work for an NHS Trust and plan to recruit colleagues from the Trust, will permission from an appropriate member of staff at the Trust be sought, and will HRA be sought, and a copy of this permission (e.g., an email from the Trust) attached to this application?

No

Does the research involve other organisations (e.g. a school, charity, workplace, local authority, care home etc.)? If so, please give their details here.

I will be using social media platforms to advertise the project. (facebook, Instagram)

Furthermore, written permission is needed from such organisations if they are helping you with recruitment and/or data collection, if you are collecting data on their premises, or if you are using any material owned by the institution/organisation. If that is the case, please tick here to confirm that you have included this written permission as an appendix: ☐

In addition, before the research commences, once your ethics application has been approved, please ensure that you provide the organisation with a copy of the final, approved ethics application. Please then prepare a version of the consent form for the organisation themselves to sign. You can adapt it by replacing words such as ‘my’ or ‘I’ with ‘our organisation,’ or with the title of the organisation. This organisational consent form must be signed before the research can commence.

Finally, please note that even if the organisation has their own ethics committee and review process, a School of Psychology SREC application and approval is still required. Ethics approval from SREC can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committee/s as may be necessary.

Declarations

Declaration by student: I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor.

Student's name (typed name acts as a signature): Rebecca Doleman

Student's number: u1945445 Date: 22/04/2021

As a supervisor, by submitting this application, I confirm that I have reviewed all parts of this application, and I consider it of sufficient quality for submission to the SREC committee.

Draft of Semi-Structured Interview

Child Interview Schedule

3. Read through info sheets and sign consent forms.
4. Ice breaker game.

Interview:

6. **What do you know about ARFID?**
Prompts: what does ARFID mean?, why do you think some children find it hard to eat?

7. **How does this impact on your day to day life?**
Prompts: positive and negative aspects, health, peers, anxiety, socialising.

8. **How does it impact on your family?**
Prompts: differences in opinions, mealtimes, supportive, strain on relationships.

9. **What makes ARFID easier?**
Prompts: things that help, people that help, techniques that help.

10. **What makes ARFID worse?**
Prompts: people not understanding, pressure.

11. **Do you think that it is useful to have a diagnosis of ARFID?**

12. **Is there anything else you would like to tell me?**

Close interview with praise and appreciation then and read through de-brief sheet.

UEL Risk Assessment Form

Name of Assessor:	Rebecca Doleman	**Date of Assessment**	02/04/2021
Activity title:	Doctoral thesis data collection	**Location of activity:**	Online via video call.
Signed off by Manager (Print Name)	Claire Higgins	**Date and time (if applicable)**	April-Oct 2021

**Please describe the activity/event in as much detail as possible (include nature of activity, estimated number of participants, etc)
If the activity to be assessed is part of a fieldtrip or event please add an overview of this below:**

20-60 minutes individual interviews via Microsoft Teams to gather data for thesis.

Overview of FIELD TRIP or EVENT:

10-20 interviews with children or young people to be conducted online. Interviews to be around the child's experience of having a feeding/eating disorder called ARFID.

Guide to risk ratings:

a) Likelihood of Risk	b) Hazard Severity	c) Risk Rating (a x b = c)
1 = Low (Unlikely)	1 = Slight (Minor / less than 3 days off work)	1-2 = Minor (No further action required)
2 = Moderate (Quite likely)	2= Serious (Over 3 days off work)	3-4 = Medium (May require further control measures)
3 = High (Very likely or certain)	3 = Major (Over 7 days off work, specified injury or death)	6/9 = High (Further control measures essential)

Hazards attached to the activity

Hazards identified	Who is at risk?	Existing Controls	Likelihood	Severity	Residual Risk Rating (Likelihood x Severity)	Additional control measures required (if any)	Final risk rating
Risk of harm to child as deemed as vulnerable because they are under 18 and have a mental health diagnosis.	Participants	Researcher has extended DBS check and experience of working clinically with children. Parental consent to be sought as well as assent from child. ethical approval required before conducting any interviews.	1	1-3	1	Parents will be given the option to sit in on the video call. Check-ins throughout the interview will take place to ensure child is safe.	1

Risk of children becoming upset during interview.	Participants	Interview questions formed to explore both positive and negative aspects of the feeding/eating disorder to minimise risk of upsetting the participants. Participants will be aware of right to withdraw and skip questions. Participants will be given age appropriate de-brief sheets and information on how to seek help if needed after the interview.	2	1-2	2	Parents will be given the option to sit in on the video call. Participants will be reminded that confidentially may need to be broken in order to seek help for the participant. Flexible options with stopping the interview and recommencing at a later date.	2

UNIVERSITY OF EAST LONDON
Parent/Guardian Information Sheet

Consent for My Child to Participate in a Research Study

This is to give you information that you need to consider in deciding whether you agree to your child taking part in a research study. Your child has also been given a copy of this information and you need to agree for him or her to take part. The study is being conducted as part of my Professional Doctorate in Clinical Psychology at the University of East London. Please take some time to read this information sheet in detail.

Project Title

"My Eating and Me".
Children and Young People's Experience of Avoidant/Restrictive Food Intake Disorder (ARFID)

Who am I?

My name is Rebecca and I am a doctoral level student in the School of Psychology at the University of East London, on the clinical psychology training course. I am conducting this research study in order to fulfil the course requirements.

What am I seeking to study?

I am conducting research to help understand what it is like to live with ARFID through the eyes of children and young people. Currently there has been no published research on this. I hope that the findings can help to inform future interventions and increase understanding. My research has been approved by the ethics committee at UEL and this approval means that the panel has deemed my research to be ethical.

What will the project involve?

Your child will be invited to answer some questions on their experience of having difficulties with eating and a diagnosis of AFRID. The questions are set beforehand and will help guide the interview. The time would also allow your child to speak about what they wanted to on this subject. This research would be separate to any treatment your child may be receiving.

Why am I being asked about this?
When young people (under 16 years) are asked to take part in research, a parent or legal guardian must also agree to this, before taking part and we will seek your consent. There is a good reason for this, as a parent or legal guardian is responsible for keeping their child safe and helping them to make important decisions. For young people aged 16 years and over, parental or guardian's consent is not required, however we encourage people involved to discuss and inform their parents about taking part.

Do both parents have to agree?
Only one parent or legal guardian has to agree to a young person under 16 years of age taking part, though if possible it would be good for everyone to agree together. The important point is that an adult who has parental responsibility agrees to the young person under 16 years of age taking part, whether this is their mum, dad or another adult who has parental responsibility for them.

Where will the project take place?
This interview will take place online over secure video link. The interviews will be recorded. The interview should be around 1 hour. There are options for this to be in two parts if this would be too long for your child.

What happens to the things my child shares? Will they be kept private?
Everything that your child shares with me will be treated as confidential. This confidentiality would be broken if I felt worried about the safety of your child or someone around them, and I would then share the information to appropriate people.

Once I have recorded your child's interview it will be automatically saved in a secure, password protected online drive. I will then transcribe the interview, removing any potentially identifying information. I will then delete the recordings. Anonymised extracts of what your child has said will be used in the thesis. The thesis will be publicly accessible on UEL's institutional repository after it is completed. This means that people will be able to access the study via the university's website, including you.

I will not include your child's name or any other identifying details in any reports that I write up. Some broad demographic information may appear in the thesis and works based on it, but this will not be such as to permit the identification of your child. No one will be able to identify your child from the data that is included in the write-up. Your child's anonymised data will be seen by my supervisors and the people who grade my thesis. The data may also be published in a journal after I have completed the doctorate. After the study has been completed, I will delete the recording of your child's interview and their details. I will keep the transcripts of the interviews for five years following completion, in keeping with data management procedures. The transcripts will be stored securely in a password-protected file, and I will have sole access to them.

Will they get anything for taking part?
Your child will receive a £5 Amazon voucher as a token of appreciation of their time. If you would like to accept this I will need to take the details of your address due to HMRC regulations. I also hope that they will find the discussions and participating in this research interesting and a helpful opportunity.

Do they have to take part?
Your child does not have to take part in this study and should not feel under any pressure to do so. You are also under no obligation to agree to them taking part. Both you and your child are free to change your mind at any time and withdraw them from the study. You can do this within three weeks of the interview. After this, your data may be included in the final write up, although with all identifying information removed. If your child withdraws from the study they may do so without disadvantage to either of you and there is no need to give a reason. If your child withdraws after three weeks of their interview date things that they have already shared or written may be used in the write-up of the study and any further analysis that may take place. All identifying information is removed in this write up.

Please feel free to ask me any questions. If you are happy to continue your child will be asked to sign a consent form. You will also be asked to sign a consent form before he or she can take part. Please hold on to this invitation letter in case you want to look at it again in the future. If you have any questions or concerns about how the study has been carried
out, please contact:

Rebecca Doleman
U19454445@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact:

Research Supervisor: Dr Claire Higgins, Clinical Psychologist and Associate Clinical Tutor, School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: *c.higgins@uel.ac.uk*

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

UNIVERSITY OF EAST LONDON

Consent to for Child to Participate in "My eating and me" Children and Young People's Experience of Avoidant/Restrictive Food Intake Disorder [ARFID]

Professional Doctorate in Clinical Psychology
Rebecca Doleman

Please tick as appropriate:

	YES	NO
I have read the information leaflet relating to the above programme of research in which my child has been asked to participate and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which my child will be involved have been explained to me.		
My child has been given an age appropriate assent form and is willing to participate.		
I understand that the interview is going to be recorded and I give my consent to this.		
I understand that my child's involvement in this study, and particular data from this research, will remain strictly confidential as far as possible. Only the researchers involved in the study will have access to the data.		
I understand that maintaining strict confidentiality is subject to the following limitations: • if the researcher felt worried about the safety of your child or someone around them then confidentiality would be broken by the sharing of information to appropriate people.		
I understand that anonymised quotes and some broad demographic data will be used in publications.		
I understand that the final research paper will appear on the publicly accessible university website, and that the researcher may also seek to publish this finalised piece		

in an online journal. I am aware that this publication will not include any identifying information.		
I understand that my child's participation in this study is entirely voluntary, and I am free to withdraw them at any time during the research without disadvantage to myself or my child and without being obliged to give any reason. I understand that my data can be withdrawn up to the point of data analysis (3 weeks after interview date) and that after this point it may not be possible to withdraw the anonymised data.		
I understand that once the researcher leaves UEL, all anonymised data will be shared with my supervisor and my supervisor will store this data online on the UEL OneDrive.		
I understand that if I want to accept a voucher for my child then I will need to provide my address due to HMRC regulations.		
I hereby freely and fully consent to for my child to participate in the study which has been fully explained to me and for the information obtained to be used in relevant research publications.		

Child's Name (BLOCK CAPITALS)
………………………………………………………

Parent/Guardian's Name (BLOCK CAPITALS)
…………………………………………………………………..

Participant's Signature ………………………………………………………………………………..

Investigator's Name (BLOCK CAPITALS) ………………………………………………………………..

Investigator's Signature ………………………………………………………………………………

Date: …………………………

UNIVERSITY OF EAST LONDON

Debriefing Sheet

Thank you for consenting for your child to participate in this research. Their time and contribution is valued and appreciated. We were interested in hearing about how they understand, make sense and cope with having a diagnosis of ARFID. The questions I asked were centred around these ideas. In talking about food, eating and emotions we may have spoken about things that might be difficult for your child to talk about. Together we spoke about how this can bring up feelings of worry, sadness or anger. I advised them that these feelings are okay and normal and to speak to an adult they trust if these feelings don't go away after the interview.

I also wanted to remind you that their data will be stored safely and securely, and any information that you gave, that will be written up either in the thesis or subsequent published work, will be done anonymously. This means that your name or your child's name or any identifying information will not be included. If, for any reason you would like to withdraw from the study, you can do this within three weeks of the interview. After this, the data may be included in the final write up, although with all identifying information removed.

If you would like to discuss any of the issues that arose further, or if you or your child feel distressed by any of the topics discussed, please contact your GP. Your child has also been provided with the number for Childline.

Thank you again for taking part in this research, it is much appreciated.

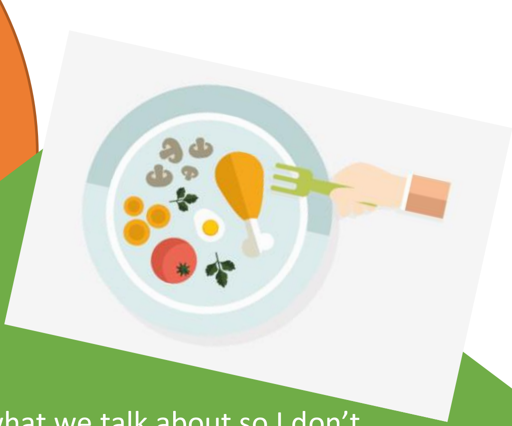
Researcher
Rebecca Doleman
U1945445@uel.ac.uk

Research supervisor Claire Higgins
School of Psychology,
University of East London,
Water Lane, London E15 4LZ,
c.higgins@uel.ac.uk

My eating and me

Hello my name is Rebecca!
I am doing a research project about children who find it difficult to eat some foods.
Research is something we do to try and find more information about things.
Not many adults have spoken to children about what it feels like to have difficulties with eating. I would really like to hear about what it is like for you.

If you to do the research I will video call you over the internet.
I will ask you some general questions about things that you like and things to do with food and eating. I want to try to understand what it is like for you, so that professionals and parents can get a better understanding of what it is like and what may be helpful.
You don't have to answer all the questions if you don't know the answer or if you don't want to speak about something.



I will record what we talk about so I don't forget. What you tell me will be kept safe and will not have your name on. If you would like your parents to sit with you during the interview they can.
I will then speak to some other children who may have similar difficulties with eating and then write about everything that I have been told in a big project, a bit like a true life story. When I do this I won't use names, so no one knows who has taken part.
If you tell me something that makes me worried about you then I might have to tell someone else but I would try and let you know first.

If you have any questions you can ask me at any point.

My Eating and Me

I understand what Rebecca has told me?

☐ Yes

☐ No

I can ask Rebecca questions if I want?

☐ Yes

☐ No

I know I can say stop at anytime?

☐ Yes

☐ No

I understand that the interview will be written up, and that no one will be able to identify that I took part

☐ Yes

☐ No

I would like to be a part of this project?

☐ Yes

☐ No

Childs Name:_________________________
Researchers Name:___________________
Date:______________________________

Thank you so much for taking part in the project. You really helped a lot!

I can now use what you said to me in my big project. Remember I won't be using your name.

Next year when I have finished the research I will be able to tell you all the things I found out. I can send this to your parents by their email. I will only say things like "lots of children thought this.." so I will not say anything about you or anyone else.

We might have spoken about things that made you feel sad, angry or worried. That is okay. Lots of people have feelings like that if they speak about big things.

You might like to speak to yours parents or the adults that look after you about our interview.

If you are feeling sad, worried or angry for a long time after our interview then it might be a good idea to speak to an adult you trust like, a teacher or your *GP if you ask your parents to book an appointment.*

You could also talk to someone at Childline, an organisation that supports children. By calling 0800

ARFID RESEARCH

Young People Needed

My name is Rebecca and I am a Trainee Clinical Psychologist studying at the University of East London. I am conducting research to help understand what it is like to live with ARFID through the eyes of children and young people.

WHO?

- Children and young people aged between 10-16
- With a diagnosis of ARFID

HOW?

- Online interview
- Questions around the positive and negatives of having ARFID
- 30-60 minute video call
- £5 voucher to say thank you

WHY?

- Current research does not include the voices of children and young people living with ARFID
- We want to change this to help inform services for young people

FOR MORE INFORMATION ABOUT ME AND THE STUDY EMAIL:
REBECCA DOLEMAN - U1945445@UEL.AC.UK

University of East London

Recruitment Email

Hello ,

My name is Rebecca and I'm a Trainee Clinical Psychologist in the 2nd year of my doctorate at the University of East London.

I'm contacting you as I am currently exploring ways that I can recruit for my thesis. I am hoping to interview children around their experience of having a diagnosis of ARFID, because their voice is often left out of the research which is published.

This is a doctoral level thesis, ethical approval will be given by UEL and I am supervised by a senior researcher on the programme. I would be hoping to publish my findings in order for the research to be used to inform practice, helping to improve the experience of treatment for children with ARFID.

There is no pressure to commit to supporting recruitment but I hope that you are interested in the project and are able to pass on my details to other interested parties.

Thank you very much for reading.

Best wishes

Rebecca Doleman

Original Ethics Form Included DBS certificate of research which has been removed for confidentiality.

Appendix P: Original Ethics Review Decision Letter

SCHOOL OF PSYCHOLOGY RESEARCH ETHICS COMMITTEE NOTICE OF ETHICS REVIEW DECISION
FOR RESEARCH INVOLVING HUMAN PARTICIPANTS
BSC/MSC/MA/PROFESSIONAL DOCTORATES IN CLINICAL, COUNSELLING AND EDUCATIONAL PSYCHOLOGY

REVIEWER: Jeeda Alhakim

SUPERVISOR: Claire Higgins

STUDENT: Rebecca Doleman

Course: Prof Doc in Clinical Psychology

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

Approved with Minor amendments

Minor amendments required *(for reviewer)*:

- It would be helpful to consider specific inclusion and exclusion criteria for your participants – you may want to consider exclusion if the participant is actively engaging in any self-harming behaviour or may have comorbidity with other mental illnesses.

Major amendments required *(for reviewer)*:

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature):* Rebecca Doleman
Student number: u1945445

Date: 30/06/2021

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

[✓ YES] / NO

Please request resubmission with an adequate risk assessment

If the proposed research could expose the <u>researcher</u> to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐ HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

☐ MEDIUM (Please approve but with appropriate recommendations)

☒ LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*: Dr Jeeda Alhakim

Date: 08/06/2021

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

Appendix Q: Letter Confirming Ethical Approval for Amendments July 2021

UNIVERSITY OF EAST LONDON

School of Psychology

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology.

Note that approval must be given for significant change to research procedure that impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Trishna Patel (Deputy Research Director/Chair of School Research Ethics Committee).

HOW TO COMPLETE & SUBMIT THE REQUEST

Complete the request form electronically and accurately.
Type your name in the 'student's signature' section (page 2).
When submitting this request form, ensure that all necessary documents are attached (see below).
Using your UEL email address, email the completed request form along with associated documents to: Dr Trishna Patel at t.patel@uel.ac.uk
Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
Recruitment and data collection are not to commence until your proposed amendment has been approved.

REQUIRED DOCUMENTS:

A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.
Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.
A copy of the approval of your initial ethics application.
Name of applicant: Rebecca Doleman
Programme of study: Prof Doc in Clinical Psychology

Title of research: Children and Young People's Experience of Avoidant/Restrictive Food Intake Disorder
Name of supervisor: Claire Higgins

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
Changes to more appealing font and pictures on the poster, info sheet and debrief for the young people.	Consultations with experts by experiences suggested the changes to make the forms more age appropriate and easy to engage with.
Small changes to the prompts on the interview schedule to include more relevant points around school, friends and celebrations.	Consultations with experts by experiences suggested the changes to as they spoke about gaps in the interview schedule.
Addition to the interview to ask each participant if they would like to write a 'message of hope' to others within the study which will be anonymously shared with all the participants.	Experts by experience spoke about the value of knowing that they were not alone in their difficulties around food. Having anonymous sharing of positive messages will help to ensure that the young people will get an added benefit from taking part in the study.
As well as a debrief straight after the interviews all participants will be offered either an individual or group feedback session where the results will be disseminated in an age appropriate manner.	Experts by experience spoke about the value of knowing that they were not alone in their difficulties around food. They also shared concerns around the findings being made too complicated by professionals and losing the voice of children. Having a feedback session of the results will ensure that the young people can see the product of their time and understand the similarities and differences in their experiences in an accessible way.

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	x	

Student's signature (please type your name): Rebecca Doleman
Date: 27/07/2021

TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	YES	

Reviewer: Trishna Patel

Date: 27/07/2021

Appendix R: Letter Confirming Ethical Approval for Amendments January 2022

School of Psychology Ethics Committee

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology

Note that approval must be given for significant change to research procedure that impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor or contact Dr Trishna Patel (Chair of the School Research Ethics Committee).

How to complete and submit the request

1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	When submitting this request form, ensure that all necessary documents are attached (see below).
4	Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: t.patel@uel.ac.uk
5	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.
6	Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

Required documents

A copy of your previously approved ethics application with proposed amendment(s) added with track changes.	**YES** ☒
Copies of updated documents that may relate to your proposed amendment(s). For example, an updated recruitment notice, updated participant information sheet, updated consent form, etc.	**YES** ☒
A copy of the approval of your initial ethics application.	**YES** ☒

Details

Name of applicant:	**Rebecca Doleman**
Programme of study:	**DclinPsy**
Title of research:	**Children and Young People's Experience of Avoidant/Restrictive Food Intake Disorder**
Name of supervisor:	**Claire Higgins**

Proposed amendment(s)

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	**Rationale**
Increase age range of participants from 10-16 to 10-17	Create a bigger pool of children to recruit from
Include children/young people who would meet the criteria for a diagnosis of ARFID but do not have an official diagnosis	Create a bigger pool of children to recruit from and to capture the experience for many families who cannot get access to a diagnosis
Proposed amendment	Rationale for proposed amendment
Proposed amendment	Rationale for proposed amendment

Confirmation

Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?	**YES** ☒	**NO** ☐

Student's signature

Student: (Typed name to act as signature)	**Rebecca Doleman**
Date:	**27/01/2022**

Reviewer's decision

Amendment(s) approved:	**YES** ☒	**NO** ☐
Comments:		

Reviewer: (Typed name to act as signature)	**Trishna Patel**
Date:	**28/01/2022**