Towards an evidence base for clinical practice in Avoidant Restrictive Food Intake Disorder (ARFID): A multi-method investigation

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Doctor of Philosophy (PhD)

May 2024

Declaration

I, Laura Bourne, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Laura Bourne

18th May 2024

Acknowledgements

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Abstract

ARFID was introduced to psychiatric nosology in 2013 to capture a disturbance in feeding or eating that results in failure to meet appropriate nutritional and/or energy needs, and/or causes a marked impairment in psychosocial functioning, without the underlying weight or body image disturbances that are characteristic of other eating disorders.

Given its relatively recent introduction, the evidence-base in relation to ARFID is limited, and as a result, so too are recommendations for best clinical practice. This thesis presents a multi-method investigation, using evidence from the current published literature, longitudinal data, and patient perspectives, with the aim of contributing to the ARFID evidence-base to inform practice and improve clinical management.

Chapter 1 provides a general introduction to the central issues and key concepts that will be explored and sets out the aims and scope of the thesis. Chapter 2 provides a comprehensive and critical review of current ARFID research to assess the extent and nature of the literature, identifying gaps in understanding and posing recommendations for further study. Chapter 3 provides a further review of the literature, focusing on studies relating to ARFID and ARFID-like eating difficulties in autistic children and young people. Chapters 4 and 5 use longitudinal cohort data to explore the overlap between developmentally normal childhood picky eating behaviours and clinically significant difficulties with food and eating. Chapter 6 presents a thematic analysis of qualitative interviews with caregivers of young people with ARFID to provide insight into its impact, nature and course, and causal, maintaining, and protective factors. Chapter 7 uses the same interviews to explore caregivers' experiences of service use, and examines the barriers associated with accessing treatment. Finally, Chapter 8 discusses the findings of this thesis and considers the strengths and limitations of the research, as well as implications for future research and clinical practice.

Impact Statement

The research within this thesis contributes to the current ARFID evidence base, highlights essential gaps in our understanding, and proposes key areas for future study that are needed to inform service provision and support evidence-based practice that responds to the varying clinical needs of this heterogeneous population.

This thesis makes a key contribution via two separate evidence syntheses. Chapter 2 delivers a comprehensive and systematic overview of the ARFID literature. At the time of starting this thesis, no such reviews were available. Chapter 3 offers a further evidence synthesis of studies pertaining to ARFID and severe food selectivity amongst autistic children and young people. Given an increasing focus on eating disorders and neurodivergence in both clinical and research fields, this scoping review offers a valuable contribution to the literature, evaluating the nature of feeding and eating difficulties in autistic children and young people and uncovers key gaps in the evidence base. An update of these findings was also presented at the London Eating Disorder Conference in February 2024, to share an overview of the current evidence in relation to ARFID and autism with clinicians, academic researchers, and members of the eating disorder community.

This thesis also presents a detailed exploration of the experiences of those living with and caring for a child or young person with ARFID. Indeed, the two interview studies make a valuable contribution to the limited qualitative work in the ARFID field, offering unique caregiver insights into what it means to live with ARFID, and the challenges associated with accessing appropriate care, thus exposing gaps in current service provision. Based on these analyses, a model of ARFID development and maintenance is also proposed, which could be used to test potential mechanisms that drive and maintain food avoidance or restriction.

Research presented within this thesis has been widely disseminated via publication in peer-reviewed journals. A version of Chapter 2 was published in Psychiatry Research (Bourne et al., 2020) and has been well received amongst the ARFID and broader eating disorder research communities. A version of Chapter 3 was published in Developmental Medicine and Child Neurology (Bourne et al., 2022) and was recognised by the journal as a top cited article between 2022-2023. This review was completed in partnership with the UK's national autism research charity, Autistica, on behalf of NHS England to contribute to an evidence summary that could feed into policy development. Evidence briefing sessions, based on the findings of this review, were delivered to staff at Beat, the UK's eating disorder charity, and to commissioners, providers, and eating disorder clinicians working within NHS England. A version of Chapter 4 was published in Eating Behaviors (Bourne et al., 2023) and has been widely accessed and well cited. Chapters 5, 6 and 7 are intended for submission and publication.

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Avoidant/restrictive food intake disorder: A systematic scoping review of the current literature

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Laura Bourne conducted the literature search and led the data analysis, interpretation of findings and manuscript writing.

Rachel Bryant-Waugh contributed to the study design, analysis of the results and the writing of the manuscript.

Julia Cook acted as a second independent rater to screen articles against the eligibility criteria for inclusion in the review.

Will Mandy contributed to the study design, analysis of the results and the writing of the manuscript.

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Avoidant/restrictive food intake disorder and severe food selectivity in children and young people with autism: A scoping review.

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Will Mandy contributed to the study design, analysis of the results and the writing of the manuscript.

Rachel Bryant-Waugh contributed to the study design, analysis of the results and the writing of the manuscript.

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Investigating the prevalence and risk factors of picky eating in a birth cohort study

b. Please include a link to or doi for the work.

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Laura Bourne conceptualised and designed the study, drafted the initial manuscript, and led the data analysis, interpretation of findings and manuscript writing.

Rachel Bryant-Waugh contributed to the conceptualisation and design of the study, data analysis and reviewed and revised the manuscript.

William Mandy contributed to the conceptualisation and design of the study, data analysis and reviewed and revised the manuscript.

Francesca Solmi contributed to the conceptualisation and design of the study, supervised data analysis and interpretation of results, and reviewed and revised the manuscript.

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Chapter 4

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List of Abbreviations and Acronyms

In alphabetical order

ADHD	Attention Deficit Hyperactivity Disorder
APA	American Psychiatric Association
ARFID	Avoidant Restrictive Food Intake Disorder
ASD	Autism Spectrum Disorder
BED	Binge Eating Disorder
BC1	Birth Cohort 1 (Growing up in Scotland Dataset)
BMI	Body Mass Index
CBT-AR	Cognitive Behavioural Therapy for ARFID
CBT	Cognitive Behavioural Therapy
CI	Confidence Interval
DASS-21	Depression, Anxiety and Stress Scales
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
DSM-5-TR	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision
EDE-ARFID	Eating Disorder Examination - ARFID module
EDNOS	Eating Disorder Not Otherwise Specified
EDY-Q	Eating Disturbances in Youth Questionnaire
FBT	Family Based Therapy
GAD-7	Generalised Anxiety Disorder Assessment
GUS	Growing up in Scotland
ICD-10	International Classification of Diseases, 10th Revision
ICD-11	International Classification of Diseases, 11th Revision

NIAS	Nine Item ARFID Screen
NHS	National Health Service
OSFED	Other Specified Feeding and Eating Disorder
PARDI	Pica, ARFID and Rumination Disorder Interview
PEG	Percutaneous Endoscopic Gastrostomy (tube)
PRISMA-ScR	Preferred Reporting Items for Systematic reviews and Meta-Analyses, Extension for Scoping Reviews
RTA	Reflexive Thematic Analysis
RCT	Randomised Controlled Trial
RRR	Relative Risk Ratio
SDQ	Strengths and Difficulties Questionnaire
UFED	Unspecified Feeding or Eating Disorder
WHO	World Health Organisation

Chapter 1: General Introduction

Chapter Overview

The current chapter provides a general overview of the relevant literature, presents key clinical concepts relating to ARFID, and considers the central issues that this thesis engages with. The chapter then introduces the rationale for this research, specifies its principal aims, and outlines the thesis structure.

What is ARFID? Diagnostic Criteria and Symptomology

The diagnostic category of avoidant restrictive food intake disorder (hereafter 'ARFID') was formally introduced to psychiatric nosology in 2013 in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; American Psychiatric Association [APA], 2013), and more recently, a very similar description and diagnostic guidelines were entered into the International Classification of Diseases, 11th Revision (ICD-11; World Health Organisation [WHO], 2018). In March 2022, a revised version of the DSM-5 diagnostic criteria were released to improve consistency and accuracy, and to bring the DSM-5 criteria in line with the ICD-11 (Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision; DSM-5-TR; APA, 2022).

ARFID manifests as an enduring disturbance in feeding or eating that results in failure to meet appropriate nutritional and/or energy needs, and/or causes significant psychosocial impairment. Notably, while some individuals with ARFID can present with extreme low weight, the condition is distinct from Anorexia Nervosa in that it is not driven by a body weight or shape disturbance or an intense fear of weight gain (APA, 2013).

Current evidence and clinical observations suggest that ARFID has a heterogeneous presentation with diverse contributing factors. The DSM-5 definition currently posits three common drivers of ARFID symptomology:

(1) An apparent lack of interest in food or eating.

(2) An avoidance based on the sensory characteristics of food.

(3) A concern about aversive consequences of eating.

This is not intended to act as an exhaustive list of contributing factors, however, and drivers can occur independently or in combination, in varying severities (APA, 2013; Reilly et al., 2019; Thomas et al., 2017b).

Prior to its introduction to the DSM-5, ARFID symptomology was captured by various terms and diagnostic entities. These include Diagnostic and Statistical Manual of Mental Disorder, Fourth Edition (DSM-IV) classifications such as Feeding Disorder of Infancy or Early Childhood and Eating Disorder Not Otherwise Specified (EDNOS; APA, 1994) and Feeding Disorders of Infancy and Childhood in the International Classification of Diseases, 10th Revision (ICD-10; WHO, 1992). The current DSM-5-TR classification of ARFID encompasses the lifespan and acknowledges various manifestations not related to weight (APA, 2022; WHO, 2018). Specifically, the DSM-5 details four criteria, all of which must be met for a diagnosis to be conferred. Criterion A refers to the impact of the avoidant or restrictive eating behaviours and stipulates that one or more of the following must be observed: (Ai) significant weight loss (or failure to achieve expected weight gain or faltering growth in children), (Aii) significant nutritional deficiency, (Aiii) a dependence on enteral feeding or oral nutritional supplements and/or (Aiv) a marked interference with psychosocial functioning.

Criteria B, C and D are exclusionary, thus detailing factors which cannot be present for the individual to qualify for a diagnosis of ARFID. First, the eating disturbance cannot be better explained by an associated culturally sanctioned practice, or by a scarcity of available food (Criterion B). Second, such behaviours must not be predominantly driven by a fear of weight gain or a preoccupation with body image (Criterion C). Finally, the eating disturbance must not be attributable to a concurrent medical or mental health condition, unless the

severity of the eating disturbance exceeds that routinely associated with the condition or disorder and warrants additional clinical attention (Criterion D; APA, 2022).

A Nosological History

The publication of the fifth edition of the DSM in 2013 brought about significant structural changes to the categorisation of eating disorders, and to existing diagnostic criteria. A new comprehensive chapter, Feeding and Eating Disorders, was introduced combining two existing disorder classes from DSM-IV; Eating Disorders, and Feeding and Eating Disorders of Infancy or Early Childhood, in an effort to capture all eating-related diagnoses in one place to ease comparison and classification (see **Table 1**). By broadening criteria for existing diagnoses, and introducing several new independent diagnoses, the changes also filled an important clinical gap by providing diagnostic specificity to those who may have been previously categorised by default under the poorly defined residual DSM-IV diagnosis of Eating Disorder Not Otherwise Specified (Bryant Waugh & Kreipe, 2012).

Table 1. DSM-IV to DSM-5 comparison of eating disorder diagnoses

DSM-IV (1994)
Disorder Class: Eating Disorders
Anorexia Nervosa
Bulimia Nervosa
Eating Disorder Not Otherwise Specified (EDNOS)
Disorder Class: Feeding and Eating Disorders of Infancy and Early Childhood
Feeding Disorder of Infancy or Early Childhood
Rumination Disorder
Pica
DSM-5 (2013)
Disorder Class: Feeding and Eating Disorders
Anorexia Nervosa
Bulimia Nervosa
Binge Eating Disorder
ARFID
Pica
Rumination Disorder
Other Specified Feeding and Eating Disorders (OSFED)
Unspecified Feeding or Eating Disorder (UFED)

ARFID is situated within the DSM-5 Feeding and Eating Disorders chapter alongside five other independent eating disorder diagnoses:

- Anorexia nervosa, which is characterised by a significant and persistent restriction of food intake driven by an intense fear of weight gain, leading to extremely low body weight (APA, 2013). Anorexia nervosa has a mortality rate among the highest of any other mental health disorder (Walsh, 2013).

- Bulimia nervosa, which is used to describe recurrent episodes of binge eating followed by compensatory behaviours such as self-induced vomiting, excessive exercise, or misuse of laxatives, to prevent weight gain (APA, 2013).
- Binge eating disorder, which is characterised by recurrent episodes of eating significantly more food than most people would consume in a short period of time, with episodes marked by feelings of a lack of control (APA, 2013).
- Pica, a diagnostic term to describe an eating disturbance characterised by the persistent consumption of non-nutritive, non-food substances over a period of at least one month (APA, 2013).
- Rumination disorder, which is characterised by the repeated regurgitation of undigested or partly digested food. The food can be re-chewed, re-swallowed or spat out, and the behaviour is repeated over a period of at least one month (APA, 2013).

This DSM-5 chapter also features two further residual diagnoses: other specified feeding and eating disorder (OSFED) and unspecified feeding or eating disorder (UFED). Both are used to capture those who do not meet full criteria for any of the other eating disorder diagnoses but exhibit marked disturbances in eating behaviours leading to clinically significant impairment. Specifically, OSFED is used to diagnose atypical or subthreshold presentations of independent eating disorder diagnoses (for example, anorexia nervosa not meeting weight criterion) whereas UFED is reserved for presentations where insufficient information is available to make a more specific diagnosis, or when clinicians are unable to, or choose not to specify why criteria are not met (Jenkins et al., 2021; Wilkop et al., 2023).

Current Empirical Understanding of ARFID

The next section will briefly summarise what is known about ARFID according to current research. Chapter 2 of this thesis presents a more detailed and comprehensive

synthesis of the literature, based on a systematic search conducted in 2019, covering diagnosis and assessment, clinical characteristics, treatment interventions, clinical outcomes, and prevalence (Bourne et al., 2020). It is important to note that this chapter represents a survey of the evidence at the beginning of this PhD (as at 2019). Chapter 8 draws on more recent research and considers developments in the literature since this time.

Since its introduction to DSM-5, various measures have been developed for the purposes of screening, evaluating, and diagnosing ARFID. These include the Pica, ARFID and Rumination Disorder Interview (PARDI; Bryant-Waugh et al., 2019), the Eating Disorder Examination-ARFID module (EDE-ARFID; Schmidt et al., 2019) and the Eating Disturbances in Youth Questionnaire (EDY-Q; Hilbert & van Dyck, 2016). Currently, however, there is no national guidance for the assessment of ARFID in the UK (National Institute for Health and Care Excellence [NICE], 2017).

Currently, consensus and national guidance is also lacking for the treatment of ARFID. Treatment modalities vary considerably, from outpatient multidisciplinary management to hospitalisation with medical monitoring (Mammel & Ornstein, 2017) but there are no gold-standard or empirically tested treatment protocols, and guidelines are yet to be established (Datta et al., 2022; NICE, 2017; Watts et al., 2023; Willmott et al., 2023).

Epidemiological data relating to ARFID is limited. Prevalence estimates vary significantly across different settings and populations, and studies are limited by sample size, scope, and generalisability (Sanchez-Cerezo et al., 2022). Several factors contribute to this. These include a lack of awareness amongst healthcare professionals resulting in under recognition or misdiagnosis, inconsistencies in the characterisation of ARFID across different disciplines, and the absence of any universal screening tools for the valid and objective measurement of symptoms (Archibald & Bryant-Waugh, 2023; Bourne et al., 2020). Population studies and prospective surveillance studies are crucial to provide accurate

prevalence data in order to inform resource planning and to aid the development of evidence-based interventions.

The literature also indicates that ARFID is highly comorbid with various psychiatric and medical conditions (i.e., Kambanis et al., 2021; Sanchez-Cerezo et al., 2022; Watts et al., 2023; Willmott et al., 2023). High rates of comorbid anxiety disorders have been observed (Okereke, 2018; Schermbrucker et al., 2017), as well as neurodevelopmental disorders (Lucarelli et al., 2017; Pennell et al., 2016), and gastrointestinal disorders (Bryson et al., 2018). Such comorbidities may precede the onset of ARFID, occur alongside it, or manifest as a result of ARFID behaviours (Van Alsten & Duncan, 2020).

ARFID and Picky Eating

Picky eating, which can also be referred to as fussy eating, selective eating, or faddy eating, is a widely used umbrella term capturing a range of eating behaviours including food neophobia, limited interest in eating, and strong food preferences (Dovey et al., 2008; Taylor et al., 2015; Tharner et al., 2014). Currently, there is no consistent or operational definition for picky eating (Taylor et al., 2015), nor are there validated tools for assessment (Taylor et al., 2019b; Samuel et al., 2018).

Picky eating is a commonly observed behaviour in children and is often reported to peak in early childhood (Cardona Cano et al., 2015a; Cardona Cano et al., 2015b; Keen, 2008). As such, these problems are typically transient and reach a natural resolution with minimal or no need for clinical intervention (Samuel et al., 2018; Taylor et al., 2015). Such behaviours are not trivial however, as they can elicit significant concern in parents, and have been associated with a range of negative outcomes, including family conflict, stress at mealtimes (Cole et al., 2017; Gibson & Cooke, 2017) and child anxiety (Dovey, 2008).

Although it is considered developmentally typical for children to demonstrate these behaviours during early childhood (Keen, 2008; Taylor et al., 2015), such patterns of food

restriction may pose a greater risk if they begin to impact weight or growth outcomes, nutritional health, or cause psychosocial distress or impairment. Thus, it may be the case that clinical attention is warranted, or indeed, that a diagnosis of ARFID is needed. Differentiating between the two, however, can be a challenge clinically. The dismissal of clinically relevant eating concerns can lead to the under-recognition and under diagnosis of ARFID, thereby presenting a risk to longer term health outcomes and psychosocial wellbeing (Silvers & Erlich, 2023). Another consideration is the role that picky eating plays in the aetiology of ARFID. It is plausible that picky eating behaviours contribute to the development of severe eating difficulties, or that they represent a marker or symptom of underlying issues, although research is yet to evidence this.

Chapters 4 and 5 further explore this topic by identifying the potential risk factors and outcomes of picky eating in childhood. In particular, these studies distinguish between different trajectories of picky eating, namely transient picky eating behaviours in early childhood which are considered developmentally 'normal', and picky eating behaviours which persist into later childhood, which may represent ARFID.

ARFID and Autism

Autism spectrum disorder (hereafter 'autism') is a lifelong neurodevelopmental condition characterised by a diverse set of behaviours, including differences in sensory processing or integration, socio-communicative challenges, and restricted and repetitive interests (APA, 2013; WHO, 2018).

Food selectivity and eating problems are common in autism across all ages and cognitive abilities (Baraskewich et al., 2021; Kinnaird et al., 2019; Råstam, 2008; Vissoker, 2015). Atypical eating behaviours in the autistic population include disruptive mealtime behaviours, oral motor delays, chewing and swallowing problems, fluctuations in hunger, and high frequency single food intake (Esposito et al., 2023; Keen, 2008; Marí-Bauset et al.,

2014). Behavioural and cognitive traits characteristic of autism are theorised to contribute to selectivity and restriction, for example, cognitive rigidity, sensitives relating to the sensory properties of food, or issues with detecting and responding to hunger and satiety cues, to name just a few (Adams et al., 2022; Chen et al., 2022; Kinnaird et al., 2019; Zickgraf et al., 2022). While such behaviours may have a negative impact on the individual and those around them, for example, because of mealtime conflict, family tension, or parental concern, there is often little need for formal intervention. Importantly, while eating problems are commonly associated with autism (Leader et al., 2021), they are not fixed or inevitable.

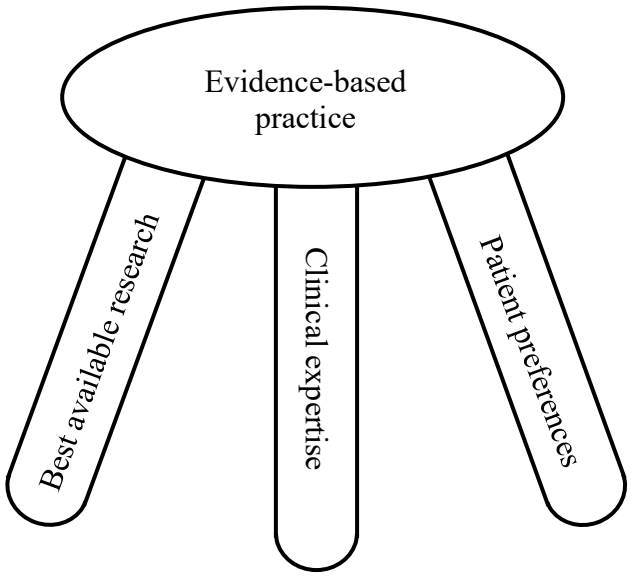
For the majority of autistic people, selective eating behaviours or idiosyncratic food preferences can be managed and will not significantly impact health and/or day-to-day functioning. If the restriction is the cause of clinically significant health concerns or negative psychosocial outcomes, however, then a diagnosis of ARFID will be warranted. In fact, research indicates that ARFID and autism frequently co-occur (Farag et al., 2021; Nicely et al., 2014), likely because of various features of autism which may contribute to the onset and perpetuation of feeding and eating difficulties. Aside from increased sensory reactivity and lower interceptive awareness, autistic individuals also display neurocognitive differences which can foster eating problems. Cognitive rigidity or a preference for sameness may promote an adherence to routine or food neophobia, and weak central coherence or hyper-attention to detail could result in the rejection of different food types or brands (Cermak et al., 2010; Fithall et al., 2023; Kinnaird & Tchanturia, 2021; Pooni et al., 2012). Thus, various inherent and developmental features characteristic of autism could underlie ARFID.

This topic is further explored in Chapter 3 as part of a review of the literature on ARFID in the autistic population.

Evidence-Based Practice and the Three-Legged Stool

Evidence-based practice has long been promoted as an approach within healthcare delivery which links personal experience, practice, and research evidence to inform clinical decision making (American Psychological Association, 2006; Peterson et al., 2016; Spring, 2007). Specifically, three main evidence components are encompassed: (1) the use of best available research evidence, (2) the contribution of clinical expertise, and (3) the consideration of patient preferences. This approach was first conceptualised in the medical field by Sackett et al. (1996) as the three-legged stool of evidence-based practice (**Figure 1**).

Figure 1. Three-legged stool of evidence-based practice



While each metaphorical leg is considered integral to providing optimal care, there is some variation in the extent to which these three features are valued in a practical setting (Peterson et al., 2016). For example, studies have shown that practitioners often discount research evidence and patient preferences in favour of clinical experience (Duff et al., 2020; Gyani et al., 2014; Stewart et al., 2012; Stewart et al., 2018). The source of this resistance is

varied and comprises general misconceptions about the efficacy of evidence-based practice, practical challenges relating to time and financial constraints, and difficulties accessing and interpreting the research evidence (Lilienfeld et al., 2013; Peterson et al., 2016; Stewart et al., 2012). The converse of this may also be true, for example, if academics and policy makers place too heavy an emphasis on research evidence and underestimate the value of clinical experience and patient perspectives. Thus, despite its status as the gold-standard of care, there are questions marks surrounding the universal acceptance and consistent use of evidence-based practice (Pitsillidou et al., 2021; Walker & Bukhari, 2018).

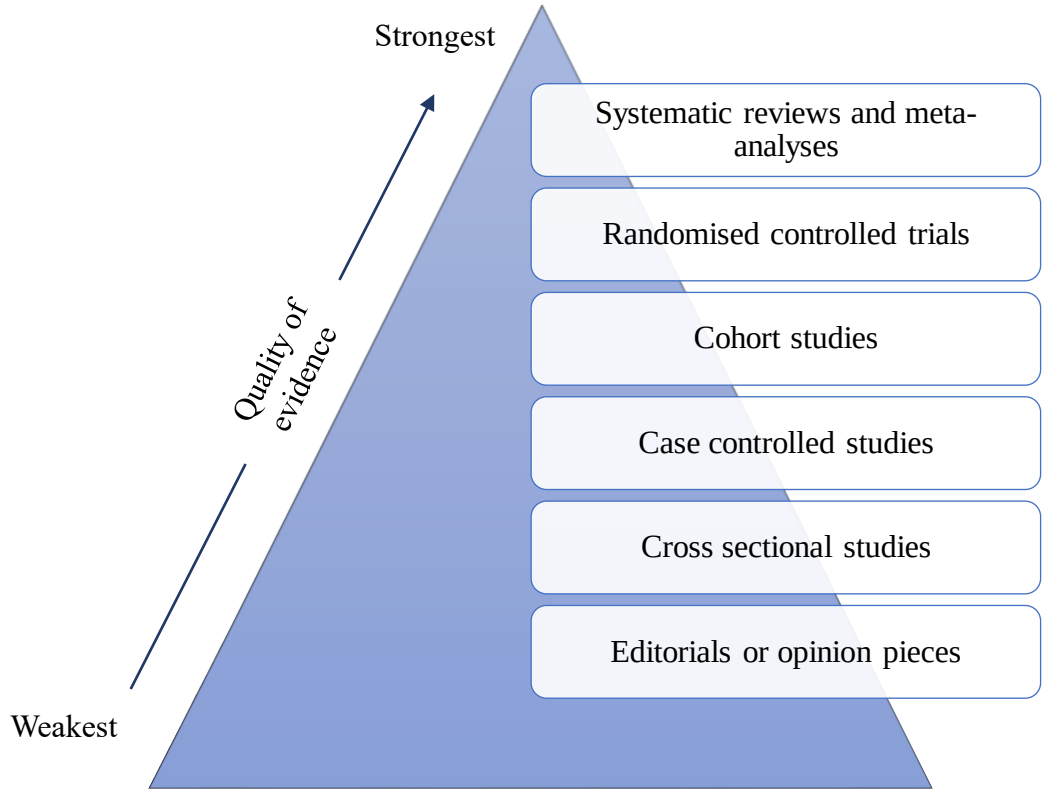
Best Available Research Evidence

In considering what constitutes the best available research evidence, it is useful to refer to the hierarchy pyramid (**Figure 2**). This heuristic, which is used commonly in healthcare and medical domains, provides a clear framework for assessing the quality and credibility of the study design and thus, assists with ranking the relative strength and methodological rigour of the research evidence (Evans, 2002).

Generally speaking, high-quality randomised controlled trials and systematic reviews sit at the apex of the pyramid, descending to observational designs, such as cohort studies and case-controlled studies in the middle, and then opinion pieces and cross-sectional studies at the base.

While this is a useful tool for providing a loose framework to rank evidence, it is important to consider that study design is often dependent on the research aim, for example, questions relating to aetiology, or outcomes may necessitate data from a longitudinal cohort study (Spring, 2007). It is therefore important to critically appraise and contextualise the evidence in relation to the specific research and/or clinical question being addressed.

Figure 2. Pyramid of evidence hierarchy



Clinical Expertise

In conceptualising the three-legged stool of evidence-based practice, Sackett et al. (1996, 2000) also recognised the contribution of the clinician in decision making and the provision of care. Such expertise is crucial, particularly in cases where research is yet to be conducted, or where there are shortcomings in research evidence. Further, studies have shown that, at times, clinicians dispute the translational capacity of research findings in a practical setting, with many arguing that studies in controlled settings cannot be directly applied to the real-world without a degree of nuance or clinical wisdom to integrate into practice (Lilienfield et al., 2013). As such, the clinical expertise leg of the stool incorporates the experience and judgement of the practitioner in interpreting and applying the research

evidence while assessing the needs of the patient and recognising the potential risks and benefits of particular interventions (Lilienfield et al., 2013; Straus et al., 2011).

Patient Preferences

The final leg of Sackett's three-legged stool of evidence-based practice refers to patient preferences. This component recognises the individual needs, characteristics, and expectations of the patient, promoting client engagement and individualised intervention. It also encourages increased commitment to care and supports the patient in engaging more deeply with managing their own outcomes (Spring, 2007).

While current National Health Service (NHS) policy does emphasise the need for patient centred care (Care Quality Commission, 2022) and includes it as part of their 'Long Term Plan' (NHS, 2019), there are currently no established methods for integrating patient values into clinical practice (Zhang et al., 2017). An understanding of patient preferences is reliant on engagement with the individuals themselves, via patient and public involvement work and good-quality, relevant qualitative studies. This will add valuable insights from patients' experiences and establish their views, needs, and expectations. It is worth noting, however, that such studies do not appear on the standard pyramid of evidence hierarchy.

While this component has received comparatively less research attention than the other two, it represents a critical step towards collaborative decision making between health care providers and patients (Gravel et al., 2006).

Evidence-Based Practice and ARFID

While in theory, the three-legged stool provides a clear framework for delivering best clinical practice, achieving the most favourable outcomes, and bridging the gap between research and practice, there are occasions where the three legs will be unbalanced, for example, if valid research evidence is yet to be established. This is particularly true in fast-

moving and emerging fields such as ARFID, where robust empirical evidence from rigorous research studies is not yet available, or not yet sufficient.

Since research evidence takes time to accumulate, clinical knowledge and patient perspectives, the other two components of the three-legged stool, are currently of particular importance for informing the clinical management of ARFID. While clinical knowledge is relatively plentiful, patient perspectives are not. In particular, there is a current lack of qualitative evidence relating to ARFID that systematically and rigorously seeks to capture service user perspectives (Bryant-Waugh., 2020). Since clinical expertise is therefore arguably the most supported leg of the stool and the main driver of decision making, there is a need for further work which captures both research evidence and patient values to complement evidence-based practice in ARFID.

Rationale and Outline of Thesis

ARFID is a serious and impactful disorder associated with considerable physical and psychological distress, including delayed growth, malnutrition, and impaired social and emotional functioning (Archibald & Bryant-Waugh, 2023; Coglan & Otasowie, 2019; Hay et al., 2017; Mahoney et al., 2022). Significant developments in our understanding of ARFID have been observed since its introduction in 2013, but at present, there are no evidence-based treatment recommendations or guidance for best clinical practice (NICE, 2017).

Given the complex nature and heterogeneous presentation of ARFID, onward referrals are unpredictable and can involve any number of specialists, including speech and language therapists, mental health services, gastroenterologists, and paediatricians (Norris et al., 2016). Across such settings, professionals have reported low confidence in identifying ARFID and providing clinical care to patients (Coelho et al., 2021). Such uncertainty paired with the current lack of any validated diagnostic measures means that ARFID is frequently under-

recognised and under-diagnosed in clinical settings (Harrison, 2021), resulting in inaccurate prevalence data needed to inform resource planning and guide service provision.

Furthermore, despite a growing body of research, our understanding of ARFID is still in its relative infancy. The patient voice is largely unrepresented in ARFID research, and robust randomised controlled trials are lacking. Thus, the three-legged stool of evidence-based practice for the management of ARFID is unbalanced. As such, ARFID management is largely supported by the clinical expertise leg of the stool. This gives rise to inconsistencies in the clinical management of symptoms and likely contributes to the aforementioned lack of confidence reported by healthcare professionals (Coelho et al., 2021; Harrison, 2021). Thus, there is still a pressing need to advance the research evidence and develop an understanding of patient values to strengthen the two remaining legs of the stool, in order to support evidence-based practice for this heterogeneous disorder (Bryant-Waugh, 2013a; Coglan & Otasowie, 2019; Ornstein et al., 2017).

This thesis employs a multi-method approach to gather evidence from the current literature, longitudinal data, and patient perspectives, upon which clinical recommendations for the assessment and treatment of ARFID can be based. Specifically, the current thesis aims to:

1. Evaluate the best available research evidence by synthesising and appraising the current literature relating to ARFID and identifying key gaps in the evidence base (PART I, see below).
2. Enhance understanding of ARFID and contribute to best current research evidence by considering the overlap between clinically severe restrictive eating, as is captured by the diagnosis of ARFID, and picky eating, and investigating risk factors and outcomes associated with different trajectories of food pickiness in childhood (PART II).

3. Increase the prominence of patient voices by systematically investigating how those with ARFID and their families understand and experience ARFID, including their experiences of seeking help for the condition (PART III).

Part I - Review and Synthesis of Literature

- Chapter 2 - ARFID systematic review

  To appraise the relative strength and methodological rigour of the available research evidence, this chapter provides a comprehensive and systematic overview of what is known about ARFID since its introduction to psychiatric nomenclature in 2013, from existing research, case studies, and clinical expertise across various domains.

- Chapter 3 - ARFID and autism scoping review

  Given the established literature on feeding difficulties in autism, a second review summarises and evaluates the research evidence in relation to ARFID in the autistic population. Since very few studies have reported on those with concurrent diagnoses of ARFID and autism, study inclusion criteria are extended to those who exhibit severe food selectivity that would likely meet the diagnostic threshold for ARFID.

Part II - Secondary Data Analyses of a Longitudinal Birth Cohort Study

- Chapter 4 - Prevalence and risk factors of picky eating

  To contribute to the research evidence leg of the stool, this study uses non-clinical secondary data from a longitudinal cohort study to better understand the course and prevalence of restrictive eating difficulties in childhood. Specifically, this chapter aims to capture those who exhibit picky eating behaviours in early childhood before they present to clinical settings, in order to identify child and family characteristics which may present as risk factors for developing clinically significant eating problems.

- Chapter 5 - Physical and mental health correlates of picky eating

  To further contribute to the research evidence and explore the relationship between picky eating and ARFID, this study uses the same cohort to investigate the levels of functional impairment associated with normal range, transient picky eating in childhood compared to those who exhibit picky eating which persists into later childhood and may indicate clinically severe restrictive eating behaviours, such as those seen in ARFID.

Part III - Qualitative Exploration of Lived Experience

- Chapter 6 - Experiences of parents/carers

  To capture patient values as per the three-legged stool and to develop a rounded view of the issue, this interview study explores the experiences of parents and carers of children and young people with ARFID. Specifically, this study provides insight into the development and course of ARFID, as well as the nature of its presentation and the impact it has on the individual and their family.

- Chapter 7 - Perspectives on seeking and accessing care

  To gain further insight into the patient experience, inform evidence-based practice and highlight gaps in the provision of ARFID services, this study draws on the same interviews with caregivers to explore the barriers associated with accessing treatment and engaging with practitioners.

Chapter 2: ARFID: A Systematic Scoping Review of the Current Literature

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This chapter is a version of a peer-reviewed published paper:

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

Abstract

Background and aims: Avoidant restrictive food intake disorder (ARFID) was recently introduced to psychiatric nosology to describe a group of patients who have avoidant or restrictive eating behaviours that are not motivated by a body image disturbance or a desire to be thinner. This scoping review aimed to systematically assess the extent and nature of the ARFID literature, to identify gaps in current understanding, and to make recommendations for further study.

Methods: An extensive literature search was conducted across Embase, Medline, PsycInfo, Scopus, Web of Science, and Cochrane Library databases. Two-hundred and ninety-one unique references were identified and matched against pre-determined eligibility criteria.

Results: 77 full-text publications from 14 countries were found to report primary, empirical data relating to ARFID. This literature was synthesised and categorised into five subject areas according to the central area of focus: diagnosis and assessment, clinical characteristics, treatment interventions, clinical outcomes, and prevalence.

Conclusions: The current evidence base supports ARFID as a distinct clinical entity, but there is a limited understanding in all areas. Several possible avenues for further study are indicated, with an emphasis placed on first parsing this disorder's heterogeneous presentation. A better understanding of the varied mechanisms which drive food avoidance and/or restriction will inform the development of targeted treatment interventions, refine screening tools and impact clinical outcomes.

Introduction

Avoidant restrictive food intake disorder (ARFID) was introduced as a formal diagnostic category in 2013 in the Diagnostic and Statistical Manual, Fifth Edition (DSM-5) and more recently in the 11th Revision of the International Classification of Diseases (ICD-11; WHO, 2018). ARFID is defined as a persistent disturbance in feeding or eating that can result in severe malnutrition, significant weight loss or a failure to gain weight, growth compromise, and/or a marked interference with psychosocial functioning. ARFID provides a diagnostic label for a heterogeneous group of individuals across the age range who engage in avoidant or restrictive eating behaviours without weight or body image concerns (APA, 2013; WHO, 2019).

Since clinical observations and scientific reports have demonstrated substantial variability in the presentation of ARFID, three examples of features that may be driving disturbances in eating behaviours are currently included in the DSM-5 diagnostic criteria: (1) an apparent lack of interest in eating; (2) an avoidance based on the sensory characteristics of food; and (3) a concern about the aversive consequences of eating (APA, 2013). It is important to note that this list is not mutually exclusive and not intended to be exhaustive, with the diagnostic manuals acknowledging that other causal processes can underpin restrictive eating in ARFID. Instead, they are intended as a first step towards parsing variability in ARFID and understanding its underlying causes.

Despite a burgeoning body of literature, to our knowledge no studies have systematically synthesised the full ARFID evidence base. A search of existing evidence syntheses identified three systematic reviews; one focusing on evaluating the diagnostic validity of the ARFID DSM-5 criteria (Strand et al., 2018), another assessing the standard of care provided to patients with chronic food refusal, including those with ARFID (Sharp et al., 2017b) and finally, one reviewing the use of cyproheptadine in stimulating appetite and

weight gain (Harrison et al., 2019). Similarly, despite an encouraging number of non-systematic reviews which provide valuable insights into existing research and current understanding (Bryant-Waugh & Kreipe, 2012; Bryant-Waugh, 2013a; Coglan & Otasowie, 2019; Herpertz-Dahlmann, 2017; Kreipe & Palomaki, 2012; Mammel & Ornstein, 2017; Norris et al., 2016; Ushay & Seibell, 2018; Zimmerman & Fisher, 2017), a systematic overview of the literature as a whole is lacking. Thus, the present review sought to investigate the scope and nature of available evidence relating to ARFID in order to (1) synthesise current knowledge on ARFID and (2) identify key gaps in the evidence base.

Methods

Literature Search

In consultation with a subject liaison librarian for biosciences & psychology, a systematic search was conducted in December 2018. An additional update search was conducted in April 2019 just prior to final analyses and newly published studies retrieved for inclusion. Studies were identified by searching the electronic databases Embase, Medline, PsycInfo, Scopus, Web of Science, and Cochrane Library using the search terms “ARFID” OR “Avoidant Restrictive Food Intake Disorder” without filters, restrictions, or limits.

As our principal aim was to identify studies presenting primary data explicitly relating to ARFID as a diagnostic entity, it was felt that this search terminology would adequately capture all studies relevant for the purpose of this review. As such, no further search terms, keyword combinations or search variations were used. Following this, reference lists of relevant papers were hand-searched for further citations of interest which were missed by the initial database search.

Eligibility Criteria

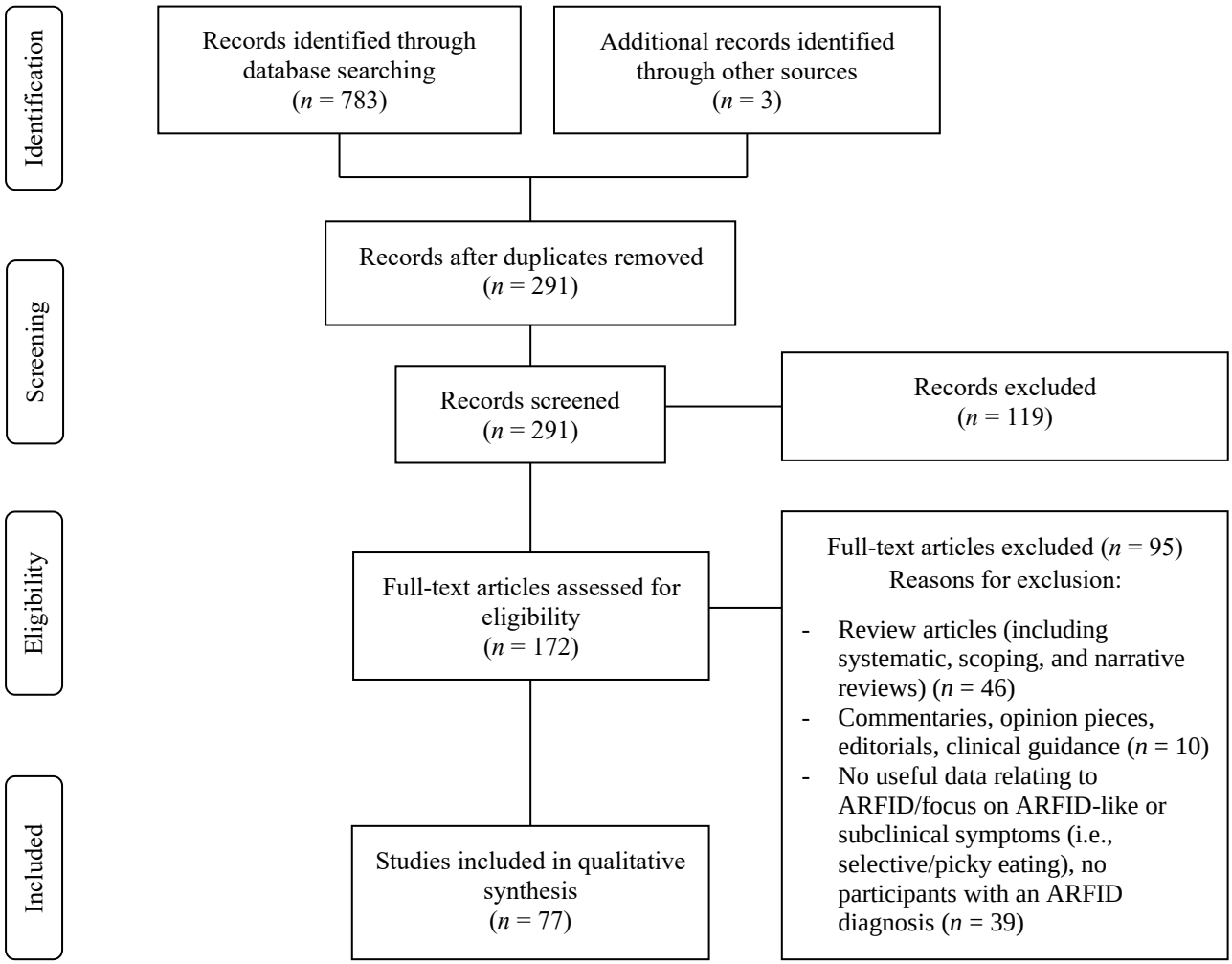
Studies adhering to the following criteria were included in this review:

1. Full-text publications reporting primary, empirical data explicitly relating to the diagnostic entity of ARFID (as described in DSM-5 or ICD-11).
2. Studies including one or more individual of any age with an ARFID diagnosis (or those found to meet ARFID criteria retrospectively), including single case studies and case series presenting quantitative data regarding the presentation, course, treatment, or outcomes of ARFID.
3. Articles available in English.

Screening and Selection Process

The primary database search yielded a total of 783 records and three additional records were identified through hand-searching. Following the removal of 492 duplicate publications, titles and abstracts were screened manually, with book chapters, articles not available in English and studies not relating to ARFID as a feeding or eating disorder excluded (see **Figure 3**). For articles passing the initial screening, full text journal articles were retrieved, read, and screened against eligibility criteria. To check the reliability of this process, a second independent rater (J.C.) was given a random sample of 40 of the 172 full-text articles to review against the inclusion criteria. Interrater reliability between the first and second rater was almost perfect (97.5% agreement).

Figure 3. Flow diagram of reviewed studies

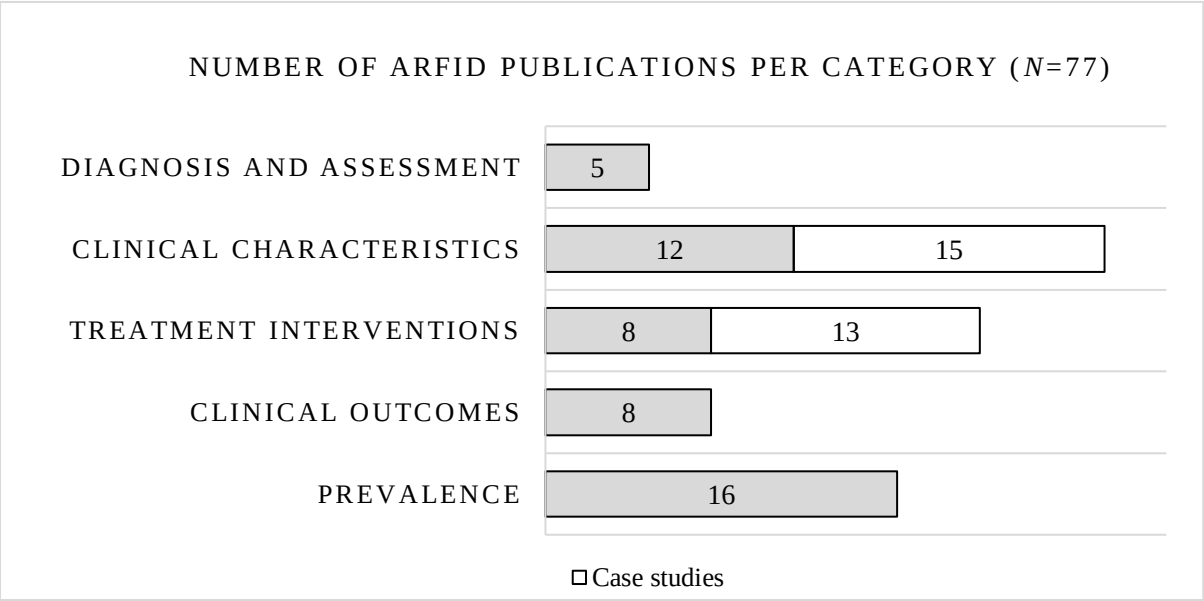


Results

Following a comprehensive search across a range of databases, 77 studies were identified for inclusion in the review. To synthesise this literature, articles were categorised into five subject areas according to their central focus: diagnosis and assessment, clinical characteristics, treatment interventions, clinical outcomes, and prevalence (**Figure 4**). This process was completed independently by both the first (L.B.) and second (J.C.) raters. Any discrepancies highlighted during the categorisation process were discussed and consensus reached. **Table 2**, **Table 3** and **Table 4** provide a comprehensive overview of all included

studies. The three categories, clinical characteristics, treatment interventions, and clinical outcomes overlap to some extent, but each provide unique information relating to the topic of ARFID. As such, we have discussed them separately in the results section but presented them together in **Table 3**.

Figure 4. Number of articles per category



Diagnosis and Assessment

Diagnostic Instruments

Given the varied presentation of ARFID, a standardised and well-validated clinical instrument is key to confer diagnosis. Two articles presented data on tools used to assess the presence of ARFID symptoms and generate a diagnosis, namely the Pica, ARFID and Rumination Disorder Interview (PARDI) and the Eating Disorder Examination - ARFID module (EDE-ARFID).

Bryant-Waugh et al. (2019) tested the feasibility and psychometric properties of the PARDI, a multi-informant, semi-structured interview designed to assess both the global presence of ARFID and provide dimensional ratings across its three main profiles. This initial

pilot study, which recruited participants with ARFID (n = 39), those without an ARFID diagnosis but displaying clinically significant avoidant or restrictive eating (n = 8) and healthy controls (n = 10), revealed good internal consistency across all subscales and moderate inter-rater reliability. Larger scale studies are now underway to test the PARDI's sensitivity, specificity, convergent and discriminant validity.

In a similar study, Schmidt et al. (2019) tested the EDE-ARFID module, which is both a diagnostic instrument and a tool used to gather clinical information relating to ARFID psychopathology. Two independent raters administered the EDE-ARFID module to a non-clinical sample of 39 children with restrictive eating behaviours as well as their parents. High convergence of diagnoses was shown between the two raters and between the child and parent report, which indicates that that the EDE-ARFID may have the potential to accurately capture ARFID symptoms (Schmidt et al., 2019).

Screening Instruments

A further three articles were found to present empirical data on self-report screening instruments designed to identify ARFID-like behaviours, yield initial symptomatic data and aid with clinical decision making.

Based on DSM-5 criteria for ARFID (APA, 2013), the Eating Disturbances in Youth Questionnaire (EDY-Q; Hilbert & van Dyck, 2016) is a self-report measure comprising 12-items designed to detect early-onset eating disturbances in 8- to 13-year-olds. Two preliminary studies, both using the same non-clinical cohort of 1444 school children in Switzerland, demonstrated adequate discriminant and convergent validity, and offered initial support for the existence of distinct variants of avoidant/restrictive eating behaviours (Kurz et al., 2015; 2016). Though further validations are needed, the EDY-Q seems to be a promising tool which warrants further study.

The literature regarding screening for ARFID behaviours in the adult population is scant. Indeed, just one measure, the Nine Item ARFID Screen (NIAS), was found with an exclusive focus on evaluating selective and restrictive eating behaviours in adults. Zickgraf and Ellis (2018) administered the NIAS to a non-clinical sample of 1271 US adults and college undergraduates, reporting preliminary success in detecting ARFID-associated eating behaviours as well as high internal consistency, and convergent and discriminant validity with other measures used to assess eating disturbances. The validity of this measure across different age groups as well as clinical populations is, however, yet to be established.

Clinical Characteristics

Twenty-seven of the publications reviewed reported primary data relating to the clinical characteristics of ARFID, over half of which (n = 15) were single case studies or case series. The literature states that ARFID commonly presents alongside various medical and psychiatric comorbidities, including attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (hereafter 'autism') and internet gaming disorder (Bryant-Waugh, 2013b; Cooney et al., 2018; Eddy et al., 2015; Fisher et al., 2014; Hadwiger et al., 2019; Lucarelli et al., 2017; Nicely et al., 2014; Pennell et al., 2016). Further, though associated with a high degree of co-morbid anxiety disorders (Norris et al., 2018; Okereke, 2018; Zickgraf et al., 2019b) ARFID patients are found to be less prone to mood disorders than those with other eating disorders (Fisher et al., 2014; Nicely et al., 2014).

The current literature supports the existence of different ARFID presentations which vary according to the main driver of food avoidance. This has prompted efforts to investigate the validity of the three examples of features included in the DSM diagnostic criteria (Norris et al., 2018; Reilly et al., 2019; Zickgraf et al., 2019a). Though presentations characterised by one of each of these three features have been observed and reported (Lopes et al., 2014; Lucarelli et al., 2017; Thomas et al., 2017a), individuals often present with multiple

characteristics which overlap and co-occur (Aloi et al., 2018; Görmez et al., 2018; Murphy & Zlomke, 2016).

Additional work investigating different ARFID 'types' has also emerged from a surveillance study performed across Australia, Canada, and the UK, in which paediatricians and child psychiatrists were asked to report symptoms of any child younger than 12 years (n = 436) with a newly diagnosed restrictive eating disorder. Latent class analysis across all three countries revealed two distinct clusters, one of which was characterised by considerable weight preoccupation and/or body image distortion and the other was related to a greater incidence of somatic complaints (Pinhas et al., 2017).

The search yielded nine studies which compared the medical and psychological profile of patients with ARFID and other restrictive eating disorders. Whilst similar levels of dietary restriction were observed in the cohorts studied, patients with ARFID were found to display clinically distinct presentations compared to those with other eating disorders, including a history of abdominal pain, a longer length of illness and a distinct absence of any cognitions relating to weight or body image (Becker et al., 2018; Izquierdo et al., 2018; Lieberman et al., 2019; Nakai et al., 2017). Several case studies (n = 6) also reported that ARFID can develop in the context of various secondary medical or psychiatric illnesses, including food avoidance associated with drug use (Lazare, 2017), dietary restriction due to gastrointestinal discomfort following surgery (Tsai et al., 2017) and two cases of ARFID occurring alongside psychosis (Wassenaar et al., 2018; Westfall et al., 2018).

Treatment Interventions

Pharmacological Treatment

Six studies reported on the pharmacological treatment of ARFID and in particular, the use of medication as an adjunct to therapeutic intervention, which is recognised as an increasingly common treatment approach. Owing to its success in treating anorexia nervosa

(Brewerton, 2012), olanzapine was presented as a potential treatment strategy for relieving related symptoms of anxiety and promoting appetite (Brewerton & D'Agostino, 2017).

Several other medications, including mirtazapine and buspirone, have surfaced as pharmacological candidates in the treatment of ARFID, both of which were found to relieve anxiety associated with choking and/or vomiting (Okereke, 2018; Tanidir and Hergüner, 2015). Gray et al. (2018) also reported on the use of mirtazapine to increase appetite and facilitate weight gain, but in contrast to Tanidir and Hergüner (2015), the authors noted heightened anxiety associated with an increased dosage. Thus, varying results have been observed.

The only double-blind, placebo-controlled study found to report on the efficacy of using medication to treat chronic food refusal took 15 children with ARFID and randomly assigned them to one of two conditions (Sharp et al., 2017a). While both groups participated in daily intensive behavioural intervention, eight were administered D-cycloserine as an adjunct to therapy, and remaining participants given a placebo. Though a substantial improvement in mealtime behaviours was observed in both groups, D-cycloserine was found to enhance response to behavioural intervention. These preliminary findings are a promising indicator that D-cycloserine is an effective adjunct to behavioural intervention, although larger clinical trials are warranted to fully verify this.

Psychological Treatment

Five case studies were found to report on the use of cognitive behavioural therapy (CBT) to treat ARFID. In four studies, the interventions used CBT approaches to formulate and address eating-associated anxiety and fears about food consumption, without the focus on weight and shape concerns used in CBT methods for other eating disorders, such as anorexia nervosa (Aloi et al., 2018; Fischer et al., 2015; Görmez et al., 2018; King et al., 2015). A fifth study employed a novel 4-week, exposure-based CBT intervention, developed to target other

drivers of food avoidance and/or restriction (i.e., disgust sensitivity, dysfunctional cognitions about feared foods, the aversive consequences of eating; Dumont et al., 2019). This method, which has been designed specifically for adolescents with ARFID and integrates inhibitory learning principles, has demonstrated preliminary success in treating a number of ARFID presentations.

Two case series and one feasibility study were found to report on the use of family-based therapy to treat ARFID (Lock et al., 2018; Lock et al., 2019; Spettigue et al., 2018). Family based therapy, which is designed to empower caregivers, reduce familial guilt, and support recovery at home, is often used in the treatment of eating disorders. Although family-based therapy for ARFID employs many of the same principles, it has been adapted to address the needs of patients with different ARFID presentations, targeting those with sensory sensitivities, fear-based concerns and little interest in eating (Lock et al., 2018). Though limited by small sample sizes and lack of a long-term follow up, the evidence suggests that family-based therapy may prove to be a feasible treatment approach. In a similar manner, a small number of parent training curricula have been trialled which aim to coach caregivers in implementing at-home behavioural feeding interventions. Initial findings indicate that both parent teleconsultation and attendance at group education sessions can adequately prepare caregivers to support children who engage in severe selective eating but do not require treatment in a hospital setting (Bloomfield et al., 2019; Dahlsgaard and Bodie, 2019).

Multi-Modal Approach

Intervention-focused papers commonly endorse a multi-modal approach, characterised by input from a multidisciplinary team and incorporating a wide range of interventions (Lenz et al., 2018; Murphy & Zlomke., 2016; Spettigue et al., 2018). The efficacy of such an approach was supported by a randomised controlled trial investigating the treatment of

chronic food refusal in a day treatment programme (Sharp et al., 2016). The researchers randomly assigned twenty children aged 13-72 months to either a waiting list or a five-day intensive behavioural intervention with treatment input from a multidisciplinary team. Despite a small sample, the intervention group displayed significantly greater improvements ($p < .05$) on all primary outcomes, suggesting that a collaborative approach to treatment can safely and effectively address the challenging nature of food refusal.

Clinical Outcomes

Given the relatively recent introduction of ARFID to psychiatric nosology, little research has monitored treatment outcomes. Six studies were identified with a focus on shorter-term clinical outcomes for ARFID patients amongst a larger, heterogeneous sample of those with DSM-5 restrictive eating disorders. In one such study, The Children's Hospital of Philadelphia's inpatient nutritional rehabilitation protocol was tested with 215 eating disorder patients (4% ARFID), reporting excellent outcomes in percent median body mass index (%MBMI), both at discharge and four weeks post-intervention. Though limited by a small sample, the researchers recognised that ARFID patients were more likely to rely on nasogastric feeds than patients with other eating disorders and that this subgroup of patients only demonstrated a significant weight gain later on in their hospital stay (Peebles et al., 2017). Bryson et al. (2018) found similar improvements in %MBMI for ARFID and anorexia nervosa patients treated in the same partial hospitalisation programme, with weight gain sustained at follow up (average 31 months after discharge) and Strandjord et al. (2015) found that ARFID patients required longer periods of inpatient admission than patients with anorexia nervosa. Despite these differences during treatment, ARFID and anorexia nervosa patients had similar outcomes 1 year after admission, with less than one quarter requiring readmission.

A further two papers were found to contribute longer-term outcome data relating to ARFID. Lange et al. (2019) followed 56 children originally treated for low-weight eating disorders (anorexia nervosa - 37, retrospective ARFID diagnosis - 19) after a mean of 15.9 years. At follow-up, a relatively high rate of eating disorder was maintained in both the anorexia nervosa and ARFID group (21.6% and 26.3% respectively), although the anorexia nervosa group later presented with differing eating disorder diagnoses, including eating disorder not otherwise specified and binge eating disorder. This was in contrast to the ARFID group, where all current eating disorder cases continued to meet criteria for ARFID, providing support for the symptomatic stability of the disorder.

The second long-term study followed a cohort of children originally diagnosed with infantile anorexia, evaluating level of malnutrition, eating attitudes and emotional/behavioural functioning at four assessment points (two, five, seven and 11 years; Lucarelli et al., 2018). Although a steady improvement in the severity of malnutrition was observed over time, 61% continued to exhibit moderate to severe malnutrition at 11 years of age, and participants' emotional and behavioural problems and their mothers' psychopathological symptoms had worsened. It is important to note that participants were diagnosed with infantile anorexia, regarded for the purpose of the study as the ARFID subtype "lack of interest in food or eating". Thus, the findings do not consider other features which may be driving the avoidance or restriction.

Prevalence

The search yielded 16 articles which sought to determine the prevalence of ARFID. Significant variation in prevalence estimates is observable, with preliminary estimates among clinical eating disorder populations ranging from 1.5% to 64% (Cooney et al., 2018; Fisher et al., 2014; Forman et al., 2014; Krom et al., 2019; Nicely et al., 2014; Norris et al., 2014;

Ornstein et al., 2013; Williams et al., 2015) and <1% - 15.5% in non-clinical cohorts (Chen et al., 2019; Gonçalves et al., 2018; Hay et al., 2017).

Further, although ARFID comprises multiple aetiologies, clinical populations are found to display some demographic similarities. The literature consistently reports that ARFID patients are younger than non-ARFID eating disorder patients, more likely to be male and report a longer duration of illness, on average, compared to anorexia nervosa or bulimia nervosa (Fisher et al., 2014; Fisher et al., 2015; Forman et al., 2014; Nicely et al., 2014; Norris et al., 2014). Importantly, however, much of our current understanding is based on the study of relatively small, clinical samples, particularly those who have presented to an eating disorder programme or sought help from a physician specialising in eating disorders (Cooney et al., 2018; Fisher et al., 2014; Fisher et al., 2015; Forman et al., 2014; Nicely et al., 2014; Norris et al., 2014; Ornstein et al., 2013; Williams et al., 2015).

While the vast majority of studies surveyed the prevalence of ARFID in children and adolescents, one study focused on older adolescents and adults (Hay et al., 2017). The authors conducted two population-based surveys in 2014 (n = 2732) and 2015 (n = 3005) which sought to determine the three-month community prevalence of various eating disorders as well as health-related quality of life. Participants over the age of 15 were systematically recruited from "collector" districts in South Australia and interviews designed to elicit information about various eating disorder features. The authors reported a very similar three-month prevalence of ARFID in 2014 and 2015 (0.3% CI 0.1-0.5 and 0.3% CI 0.2-0.6 respectively) and found that those with ARFID experienced more non-functional days compared to those without eating disorders. The authors also observed poor mental health-related quality of life across all eating disorder groups but noted that this was particularly poor for those with ARFID. Further, although numbers were too low to confidently comment on the sex distribution of ARFID in adults, the authors did observe that it is more likely to

occur in males, as is the case with children (Fisher et al., 2014; Nicely et al., 2014). Despite the need to validate presumptive diagnoses born from the subjective, self-evaluative interviews used, the study highlights the potential negative impact and functional impairment associated with ARFID symptoms.

Discussion

This systematic scoping review explored the extent and nature of the ARFID literature, with two main aims: (1) to synthesise current knowledge of ARFID and (2) to identify key gaps in the evidence base.

The literature evidences ARFID as a distinct clinical entity with a specific symptomatic profile, but its heterogeneity has not yet been well captured by scientific studies. An understanding of the different drivers of food avoidance and/or restriction will help to develop effective treatments which impact clinical outcomes, and to refine screening tools which inform prevalence figures. Thus, developing our understanding of ARFID will be an iterative process whereby progress in one domain can contribute to advances in another.

What do we know about the presentation of ARFID?

The literature consistently shows that ARFID captures a broad range of presentations, but little is understood about the nature of this heterogeneity. A common misconception perpetuated throughout current research is that ARFID patients can be classified according to one of three groups. While the DSM-5 criteria do include three ARFID presentations commonly seen in clinical settings, these are merely intended to serve as examples of features which may be driving the food avoidance or restriction. Though some headway has been made in exploring different drivers of food avoidance (Eddy et al., 2015; Norris et al., 2018), there is currently no conceptual or empirical evidence that shows discrete groups exist.

Are there sound measures for assessing ARFID?

Research efforts are currently underway to design and validate instruments which reliably identify ARFID behaviours and capture meaningful clinical change, with promising psychometric validity observed thus far. Of these, the PARDI (Bryant-Waugh et al., 2019) shows particular promise, largely due to its sensitivity to three relevant ARFID profiles. Initial reliability and validity data show good feasibility and acceptability and adequate to good internal consistency for the three ARFID profiles (sensory sensitivity - 0.77, lack of interest in food or eating - 0.89 and fear of aversive consequences - 0.89) and larger scale, rigorous psychometric testing is underway.

How common is ARFID?

Since few epidemiological studies have reported on rates of ARFID, its true prevalence is currently unknown. While significant variation has been observed, estimates in the general population are consistently lower than those in clinical eating disorder samples, where figures as high as 64% are reported (Krom et al., 2019). There are a number of challenges associated with the effective gathering of prevalence data, arguably the most crucial of which is the need for a structured assessment tool sensitive to the full range of ARFID presentations administered by a trained individual.

How can we treat ARFID?

Broadly speaking, ARFID treatment is focused on increasing the amount or variety of food consumed by tackling the underlying driver of food avoidance and/or restriction. The literature evidences several promising treatment avenues which warrant further study, particularly family-based therapy (Lock et al., 2018, 2019), CBT (Dumont et al.,2019) and adjunctive pharmacological intervention (Gray et al., 2018; Sharp et al., 2017a; Spettigue et al., 2018), which appear to be the methods with the best evidence, resulting in the decrease or resolution of ARFID behaviours. A multi-modal approach is also endorsed, particularly for

those with severe feeding difficulties (Sharp et al., 2017b) and the overall consensus is that this must be individualised, depending on the main concern and degree of severity. Despite the phenotypically heterogeneous nature of ARFID, there is currently no direct evidence that different presentations warrant diverse interventions. Indeed, Dumont et al. (2019), have demonstrated that a flexible CBT approach can be used to treat ARFID with several presentations. Of course, we will only be able to recognise whether different methods are necessary when we know more about the nature of this heterogeneity and begin to test patient responses.

What are the outcomes for ARFID patients?

The literature regarding ARFID outcomes is scarce and relies largely on the medical monitoring of low-weight patients who have presented to eating disorder inpatient programmes (Forman et al., 2014; Peebles et al., 2017). Given that outcomes relating to weight restoration do not provide a complete picture of recovery, further work should look to measure the full range of physical and/or psychosocial consequences of ARFID.

What's next for ARFID?

Despite notable efforts to address pressing knowledge gaps, there is still a paucity of research and a continued need to develop a more sophisticated understanding of all aspects of this disorder. Looking ahead, we propose the following four areas of focus for the next five years:

(1) Parse the heterogeneity of ARFID by testing the different drivers of food avoidance/restriction

The findings of this review indicate that little can be learned from studying ARFID patients as a homogenous group. Thus, it is important that we better characterise the presentation of ARFID and proceed with an individualised appraisal. Although the current DSM-5 criteria offer three examples of features which may be driving food avoidance/restriction (APA, 2013), there are likely to be alternative causal processes

which play a role in the onset and perpetuation of ARFID. As an example, cognitive inflexibility, a need for control and a preference for routine, which are commonly seen in autism and anxiety disorders, could all encourage restrictive eating behaviours, a limited food repertoire and/or rigidity relating to when, what or how food is consumed. Thus, these may offer promising avenues for further study.

(2) Rigorous psychometric testing of assessment instruments

Valid and reliable assessment instruments sensitive to a range of presenting features are fundamental for the accurate diagnosis of ARFID, the gathering of consistent prevalence data, and for measuring outcomes in treatment trials. While early evidence appears to support the sensitivity and validation of existing screening and diagnostic tools, it is clear that larger scale studies aimed at testing the performance and psychometric properties in both clinical and non-clinical populations across the lifespan are necessary. It is also important to recognise that advancements in our understanding of ARFID and in particular, a better conceptual understanding of the various presentations, will impact what, when and how we assess symptoms.

(3) Gather epidemiological data

Accurate and in-depth epidemiological data is central to advancing our understanding of ARFID. Asking questions such as ‘When is ARFID most likely to emerge?’, ‘Are there sex/gender effects?’ and ‘Does this vary according to the type of ARFID presentation?’ will provide invaluable information about possible risk factors as well as informing prevention strategies and appropriate health care provisions. Looking ahead, there is also a need to clearly separate prevalence data derived from clinical samples, where figures are likely to be much higher, and non-clinical samples.

(4) Look beyond the scope of existing research

Most of the current ARFID literature is set within the context of feeding or eating disorders, but there may be value in looking beyond this. The psychobiology of appetite, for example, and its role in food avoidance may yield insights into the underlying biological bases of certain ARFID presentations. Research has shown that individuals who engage in binge eating behaviours exhibit a greater hedonic response to food (Dalton & Finlayson, 2014). It is therefore possible that individuals with ARFID, particularly those who exhibit an apparent lack of interest in eating, experience different responses to food, whether relating to sensory properties, taste, sensations of hunger and satiety or implicit wanting. Work in this area may contribute to a deeper understanding of the internal processes which determine the overall expression of appetite and reasons for avoidance/restriction. There are several other worthwhile directions for further research including an exploration of the occurrence and consequences of a late or false diagnosis, as well as an investigation into ARFID's psychiatric comorbidity, since it has been found to co-occur with various other diagnoses such as generalised anxiety disorder, obsessive compulsive disorder and autism (Cooney et al., 2018; Fisher et al., 2014; Kambanis et al., 2019). This will highlight shared underlying features which could be targeted for treatment and help to build an understanding of the symptoms that are unique to ARFID.

Limitations

Our search terms were confined to “ARFID” OR “Avoidant Restrictive Food Intake Disorder” without filters, restrictions, or limits, to ensure that we captured only those papers relating specifically to the diagnostic entity of ARFID. Though beyond the scope of this review, there is a wealth of literature relating to sub-clinical restrictive eating behaviours which are symptomatically similar to ARFID as well as studies pre-dating the introduction of

ARFID, both of which provide valuable data for the field. An evidence synthesis capturing the broader literature may offer novel insights into alternative treatment options, early symptoms, risk factors, or clinical outcomes.

Table 2. Summary of articles relating to ARFID measurement instruments

Author (Year) and country			Methodology and sample	Outcomes and psychometric findings (reliability and validity)
Kurz et al. (2015)[i] Switzerland	Eating Disturbances in Youth-Questionnaire (EDY-Q)	Self-report scale which screens for ARFID symptoms based on the DSM-5 criteria	Screening for ARFID symptoms Children recruited from regular schools in Switzerland (*n* = 1,444), 8-13 years, 53.9% female	3.2% met ARFID criteria Three subgroups identified Good psychometric properties including adequate discriminant and convergent validity and acceptable internal consistency (Cronbach's a = 0.62)
Kurz et al. (2016)[ii] Switzerland	Eating Disturbances in Youth-Questionnaire (EDY-Q)	Self-report scale which screens for ARFID symptoms based on the DSM-5 criteria	Factor analysis of EDY-Q Children recruited from regular schools in Switzerland (*n* = 1,444), 8-13 years, 53.9% female	Three factors covering functional dysphagia, selective eating and food avoidance emotional disorder identified
Zickgraf & Ellis (2018) USA	Nine Item Avoidant/Restrictive Food Intake Disorder screen (NIAS)	Brief multidimensional instrument to measure ARFID-associated eating behaviours	Exploratory and confirmatory factor analysis (1) Semi-representative sample (*n* = 505, 69.5% female) - parents/guardians of children aged 5-17 who had been separately recruited for a study regarding their children's eating behaviour (2) Clinical sample (*n* = 455, 48.6% female) - US adults recruited from Amazon's Mechanical Turk with self-reported eating difficulties (3) College undergraduate sample (*n* = 311, 68.6% female) recruited through an advertisement with no mention of eating behaviour	Three-factor structure evidenced, supporting ARFID subtypes in the DSM-5 High internal consistency and test-retest reliability

[i] article also presented in Table 4 (relating to ARFID prevalence)

[ii] article also presented in Table 4 (relating to ARFID prevalence)

Bryant-Waugh et al. (2019) UK, Switzerland & USA	Pica, ARFID and Rumination Disorder Interview (PARDI)	Multi-informant, semi-structured interview designed to assess the presence and severity of ARFID (as well as pica and rumination disorder)	Initial pilot study. Participants 10-22 years who completed either the child (*n* = 26) or young person/adult (*n* = 31) version of the PARDI Sample included healthy controls (*n* = 10) and those with clinically significant avoidant/restrictive eating/ARFID (*n* = 47)	All subscales achieved internal consistency ≥ 0.77 and inter-rater reliability for the ARFID diagnosis was moderate (k = 0.75)
Schmidt et al. (2019) Germany	Eating Disorder Examination: ARFID Module	ARFID module for the child and parent version of the Eating Disorder Examination (ChEDE) (diagnostic instrument)	Nonclinical sample of children (*n* = 39) with underweight and/or restrictive eating behaviours (8-13 years)	*n* = 7 children received an ARFID diagnosis High inter-rater reliability for ARFID diagnosis (92% for children and 97% for parents), high convergence between child and parent report (κ = 0.80)

Table 3. Summary of articles relating to ARFID clinical characteristics, treatment interventions, and clinical outcomes

Author (year) and country	Study aim	Methodology and sample	Symptoms/presentation	Treatment	Outcome
Bryant-Waugh (2013b) UK (Clinical characteristics)	To present a case example of a patient with ARFID	Case study 13-year-old male BMI 16.5 (17th centile)	• Diet missing major food groups (low in calcium, iron, and vitamins) • Episodes of dizziness and lethargy • Fussy eater since childhood	• Broad CBT approach with parental involvement • Strategies included joint setting of goals, cognitive restructuring, anxiety management	• Growth velocity improved (height increased from 10th to 35th centile) • Better management of anxiety and improved nutritional intake although diet far from extensive
Chandran et al. (2015) Australia (Clinical characteristics)	To discuss an ARFID patient with multiple complex medical comorbidities	Case study 17-year-old male BMI 20.7kg/m^2	• Selective diet of 5 foods since age 5 • Patient in malnourished state - lethargy, dehydration, poor appetite, vomiting • Concurrent diagnosis of subacute combined degeneration of the spinal cord	• Inpatient management, multidisciplinary approach • Nasogastric tube fitted, routine psychotherapy, anxiety medication (quetiapine), family therapy	• BMI increased to 22.7kg/m^2, nasogastric tube removed, greater variety of food consumed • Progress appointment – weight increased to 100kg, and patient no longer met criteria for ARFID
Fischer et al. (2015) USA (Treatment interventions)	To evaluate the effects of an intervention for chronic food selectivity in an adolescent with ARFID	Case study 16-year-old-male	History of extreme food selectivity, associated feeding anxiety and some acute sensory aversion to certain foods	• Intervention incorporating both a clinic (behavioural treatment and CBT) and concurrent in-home component (enforced by the patient's mother) • Follow-up 1- and 3-month post treatment	• Greater consumption of foods (both quantity and variety) • Reduced anxiety and ability to eat out in a social environment • Daily bowel movements and increased energy (findings maintained post-treatment)
King et al. (2015) USA	To present a case of ARFID successfully treated with CBT	Case study 41-year-old female, BMI 15.5 kg/m^2	Patient had Crohn's disease as a child and developed severe illness anxiety	• Inpatient treatment - 8 sessions of CBT including	• At discharge, patient was consuming 1650 calories daily and BMI 16.5 kg/m^2,

(Treatment interventions)			following acute gastroenteritis which caused her to limit food intake	psychoeducation, systemic desensitisation (in vivo exposure) and cognitive restructuring • Follow-up 8-months post treatment	and reported reduced anxiety and increased energy • At 8 months post-discharge, patient BMI was 19.4 kg/m^2
Strandjord et al. (2015) USA (Clinical outcomes)	To compare patients with ARFID and AN (looking at differences in presentation, treatment response and 1-year outcomes)	Retrospective chart review of patients hospitalised between 2008 and 2014 ARFID patients (n = 41), 85% female, 14-18 years AN patient (*n* = 203), 89% female, 15-20 years	Patients treated for nutritional insufficiency and meeting DSM-5 criteria for an eating disorder	• Hospitalisation for acute medical stabilisation • Follow-up 1 year after discharge	• ARFID and AN patients had similar outcomes 1 year after initial admission • Around half met criteria for remission and less than one-quarter for readmission • ARFID patients relied on more enteral nutrition and required longer hospitalisations
Tanidir and Hergüner (2015) Turkey (Treatment interventions)	To present a case of ARFID successfully treated with mirtazapine	Case study 10-year-old female Weight 26kg on admission (below 10^{th} percentile)	Refusal to eat solid food after choking incident at 4 years old	• Initial behavioural approach • 10mg/day fluoxetine increased over time to 30mg/day for 2 months with no success • 15mg/day mirtazapine for 6 months	• Weight increased to 34kg (25-50^{th} percentile) • Mirtazapine well tolerated - marked and rapid improvement in symptoms relating to choking phobia • Within 2 weeks, the patient reported less anxiety during mealtimes and experienced an increase in appetite • No re-emergence of complaints at 6-month follow up

Murphy and Zlomke (2016) USA (Treatment interventions)	To describe a behavioural feeding intervention used to treat a patient with ARFID	Case study 6-year-old female BMI 81st percentile (normal range)	• Gastroesophageal reflux disease • Began food refusal at 9 months old • Selective about food based on type, colour, texture, flavour, and brand	• Behavioural feeding intervention with parent-training strategies • Follow-up 6-weeks post treatment	Increased dietary repertoire and clinically significant decrease in problematic child and parent feeing behaviours
Pennell et al. (2016) Canada (Clinical characteristics)	To report two cases of patients with coexisting ARFID and ADHD	Case series (1) 10-year-old male BMI 17.2 (2) 9-year-old female BMI 11.4	(1) 1-year history of increasing food avoidance, oppositional mealtime behaviour and weight loss (11.8kg lost over 15 months) following initiation of ADHD medication (2) 3-6-month history of weight and height stunting following initiation of ADHD medication. Eating difficulties since infancy	(1) Inpatient case with 0.5mg risperidone to help restore appetite and target anxiety followed by biweekly outpatient care (2) Inpatient care, 30mg risperidone to restore appetite and improve concentration and anxiety followed by biweekly outpatient therapy	(1) Patient fully weight restored, and his mother reported a marked improvement in appetite and increased variety of foods eaten (2) Following 10 weeks of outpatient therapy, the patient was fully weight restored, experienced a substantial improvement in appetite and decreased oppositional behaviour
Sharp et al. (2016) USA (Treatment interventions)	To investigate the feasibility and preliminary efficacy of an intensive, manual-based behavioural feeding intervention for patients with chronic food refusal and/or dependence on enteral feeding	Randomised controlled trial at a multidisciplinary day treatment programme in the US (n = 20), 40% female, 13-72 months	Children exhibiting active and persistent food refusal with dependence on enteral or oral supplementation	• Manual based and technology supported behavioural feeing intervention - integrated eating aversion treatment (iEAT) • iEAT vs. waiting list control (10 children randomised to each condition) • 14 40-minute meal blocks across 5	• Children assigned to iEAT showed significantly greater improvements on all primary outcome measures compared with controls • At post-treatment follow up, all caregivers reported high levels of overall satisfaction with treatment

				consecutive days (meals 1-11 with trained therapists and 12, 13 and 14 parent-led) • Follow-up 1-month post treatment	
Brewerton and D'Agostino (2017) USA (Treatment interventions)	To document the clinical progress of ARFID patients treated with low doses of adjunctive olanzapine	• Retrospective chart review of 9 patients (8 females and 1 male) (9-19 years) • Mean admission BMI 15.6 ± 1.8 kg/m^2	Participants diagnosed with ARFID using DSM-5 criteria	• Adjunctive low-dose olanzapine (alongside meal behaviour therapy and other treatment modalities offered to eating disorder patients) • Mean number of days on olanzapine 53.4 ± 22.4	• Mean change in BMI 3.1 ± 1.34kg/m^2 • Mean change in BMI index-for-age percentile 11.0 ± 14.7 to 35.9 ± 27.5 • Olanzapine promoted weight gain in all patients and relieved symptoms of anxiety, depression, and cognitive impairment
Kapphahn et al. (2017) USA (Clinical outcomes)	To assess outcomes at 1-year follow up for patients who were hospitalised compared to those who were not	• Retrospective chart review • Patients with restrictive eating disorders treated at 14 medicine-based eating disorder treatment programmes in 2010 (n = 140) • 10% ARFID, 86% female, 9-21 years	N/A	• Various treatment modalities including medical hospitalisation, psychiatric hospitalisation, residential eating disorder treatment, intermediate level care and outpatient treatment	Patients who were hospitalised had 4 x the odds of being at least 90% MBMI at 1-year follow-up compared with those who were not hospitalised
Lazare (2017) Canada (Clinical characteristics)	To describe a patient with an initial diagnosis of ARFID complicated by	Case study 30-year-old female BMI 17	Reported use of cannabis to control nausea and increase appetite, low mood, anxiety and panic attacks, induced	• Admittance to inpatient medicine service and presumptive diagnosis	• Patient's eating completely normalised within a few days

	cannabis use and a later diagnosis of Addison's disease		vomiting after eating without marijuana use, preference for high fat foods	of Addison's disease made • Hydrocortisone 10mg daily • Eventual discharge to residential facility	• Patient reported no nausea or vomiting, and anxiety resolved
Lucarelli et al. (2017) USA (Clinical characteristics)	To present a case of a young girl with a concurrent diagnosis of ARFID and ASD	Case study 4-year-old female	• Comorbid diagnoses of Gastroesophageal Reflux Disease and ASD • Limited diet and rigidity around other aspects of feeding	• Feeding therapy using a systematic desensitisation approach with rewards	• Parents discontinued therapy with concerns that it was too harsh • Patient's weight stable but more difficult to manage behaviourally
Maertens et al. (2017) Canada (Clinical characteristics)	To discuss the diagnosis, course, presentation, and management of two patients with significant weight loss, food restriction and fear of vomiting	Case study (1) 15-year-old female (2) 10-year-old male	(1) Severe malnutrition (approx. 70% ideal body weight), recent episode of stomach flu, longstanding fear of vomiting, diagnosed with ARFID and OCD (2) 81% ideal body weight, intense fear of vomiting following bout of gastroenteritis	(1) 20mg Escitalopram once daily and 5mg Olanzapine for anxiety. CBT attempted for exposure to germs and contamination and for body image acceptance (2) Admitted to eating disorder unit at 13-years-old. 5mg Olanzapine, later switched to 25mg Clomipramine. CBT with graded exposure to address illness fears and rituals	(1) Discharged from eating disorder unit following weight restoration but struggled to maintain weight. Patient continued to meet criteria for OCD and later met criteria for AN (2) Patient discharged from eating disorder unit following weight restoration with a diagnosis of AN, generalized anxiety disorder, and OCD
Maginot et al. (2017) USA	To evaluate the safety of a higher calorie nutritional rehabilitation protocol	Retrospective chart review of eating disorder inpatients admitted to the Rady	Patients diagnosed with AN, OSFED or ARFID based on the DSM-5 criteria met medical criteria	• Inpatient nutritional rehabilitation protocol • Average length of stay 15.3 days	• Higher calorie nutritional rehabilitation protocol tolerated for inpatients with restrictive eating disorders

(Treatment interventions)	for treating inpatients with restrictive eating disorders	Children's Hospital in San Diego between Jan 2015 and Mar 2016 (*n* = 87) (11.5% ARFID), 8-20 years	for hospitalisation. 29% were severely malnourished (<75% expected body weight)		• Lower expected body weight on admission was a more important predictor of hypophosphatemia than initial calorie level
Nakai et al. (2017) Japan (Clinical characteristics)	To compare the clinical presentation of patients with ARFID compared to those with AN	Retrospective chart review of patients who sought treatment for an eating disorder at Kyoto University Hospital between 1990-1997 (*n* = 134), 15-40 years, (20% ARFID)	• Patients meeting criteria for ARFID or AN • All ARFID patients were female • No patients reported food avoidance relating to sensory characteristics or functional dysphagia and all had amenorrhea	• Inpatient treatment programme combining individual psychotherapy and somatic therapy (nutritional management and enteral feeding) • All inpatient stays were <3 months • Follow-up 85.2 months (mean duration after entry)	• No significant group differences in the physical state scores (BMI and menstrual pattern) • ARFID group showed a significantly greater improvement in eating behaviours, psychological state, and psychosocial state than the AN group • ARFID group also had a significantly shorter duration of illness and lower rates of admission history
Ornstein et al. (2017) USA (Clinical outcomes)	To compare outcomes of patients with ARFID treated in a family-centred PHP compared to those with other eating disorders	Retrospective chart review of eating disorder patients admitted to a family-centred PHP between Aug 2008 and May 2012 (*n* = 130) (25% ARFID), 92.3% female, 7-17 years	Patients exhibiting an acute onset of severe food restriction resulting in significant weight loss or failure to gain weight, patients who restrict their intake in an effort to avoid certain outcomes (choking, vomiting) or due to disgust	PHP with a focus on acute onset of severe food restriction resulting in significant weight loss or failure to gain weight (5 days per week for eight and a half hours a day)	• ARFID patients spent significantly fewer weeks in the programme than those with AN • Similar increase in %MBMI observed in AN, ARFID and OSFED patients • All patients demonstrated significant improvements in psychopathology (measured the ChEAT and RCMAS)

Peebles et al. (2017) USA (Clinical outcomes)	To report outcomes at admission, discharge and 4-week follow-up for patients with eating disorders	Retrospective chart review of eating disorder patients admitted to the CHOP for a first time stay between 2012 - 2014 (*n* = 215) (4% ARFID), 88% female, mean age 15.3 years	20% malnourished below 75% MBMI, 335% bradycardic, 15% hypotensive and nearly 53% orthostatic on admission	• Medical stabilisation for inpatient nutritional rehabilitation (average length of stay 11 days) • Follow-up 4 weeks after discharge	At follow up, patients averaged 100.9% MBMI at follow-up. Just 3.8% were re-hospitalised in the 30 days after discharge
Schermbrucker et al. (2017) Canada (Clinical characteristics)	To report a case of ARFID and explore the role of culture in diagnosis	Case study 11-year-old male, height 148.9cm (75th percentile, weight 33.1kg (10th percentile)	• Acute food refusal, medical instability, epigastric pain, constipation, dysphagia, fear of choking, bradycardic (56 BPM) • Concurrent diagnoses - generalised anxiety disorder, separation anxiety disorder	• Admittance to eating disorder unit for weight restoration and nasogastric feeding • Fluoxetine to target anxiety symptoms • Patient refused to engage with food exposure tasks and complained of a physical aberrancy in his throat • Follow-up 2-months post-discharge	• Family self-discharged patient. At discharge, the patient weighed 39.8kg (97% of ideal body weight) • At two months follow-up, patient returned to clinic with a diagnosis of globus (physical, mobile lump in throat impeding the passage of food)
Sharp et al. (2017a) USA (Treatment interventions)	To examine the feasibility and preliminary efficacy of combining D-cycloserine with a behavioural intervention in treating young children with chronic food refusal	Double-blind, placebo-controlled study 16 children (37.5% female) 18 months – 6 years	Active and persistent food refusal which severely restricted the volume of food consumed	• Randomisation to intensive behavioural intervention + D-cycloserine OR intensive behavioural intervention + placebo over 5 days (15 meals in total) • Follow-up 1-month post-treatment	Mealtime behaviours improved significantly in both groups, but D-cycloserine further enhanced response to intervention, rapidly increased food acceptance and reduced disruptive behaviours

Thomas et al. (2017a) USA (Clinical characteristics)	To describe a case of ARFID relating to an acute choking incident	Case study 11-year-old female, BMI 12.5	• Sudden onset of food refusal and weight loss following acute choking incident Patient had been highly selective eater since infancy and disliked many foods	• Period of hospitalisation followed by cognitive behavioural intervention to target choking phobia and to increase dietary variety • Follow-up 1-year after initial assessment	• Patient gained 6.4 kg and grew 8cm in height one year after initial assessment • Diet still limited but all previously consumed solid foods were reincorporated Patient no longer reported a fear of choking
Tsai et al. (2017) USA (Clinical characteristics)	To present a case of ARFID resulting from testicular cancer surgery	Case study 56-year-old male	• Significant weight loss over the past 5 years, severe malnourishment due to restricted diet (liquid and pureed foods to reduce bowel movements) • Severe scarring in pelvic floor region following testicular cancer surgery causing pudendal nerve entrapment syndrome	• 22-day inpatient stay, IV fluid administration, liquid nutritional supplements • 7.5mg mirtazapine	• Upon discharge, patient was still fixated on constipation, failed to follow up with medical professionals and did not adhere to medication • Patient continued to eat pureed foods, drink nutritional drinks, and use enemas to relive constipation • Continued weight loss, severe malnourishment, and eventual anasarca
Aldridge et al. (2018) UK (Clinical characteristics)	To compare the feeding behaviours of children with ARFID to those of typically developing children	Observational study 18 children with ARFID and 21 typically developing children	N/A	N/A	• Group differences appear to relate to frequency rather than type of behaviour (food intake, visual and physical engagement with feeding, and movement during mealtimes)
Aloi et al. (2018) Italy (Treatment interventions)	To present a case of ARFID successfully treated with CBT and family involvement	Case study 24-year-old male, slightly overweight with BMI 25.5 kg/m2	• Dysfunctional eating behaviours dating back to the age of 2	• Psychotherapeutic intervention once a week for one hour over six months	• Many new foods introduced to the patient's diet • Improved social relationships and

			• Avoidance based on an unpleasant sensory experience • Complaints of anxiety relating to shared meals, resulting in social withdrawal	• Phase 1 (session 1-4) psychoeducation • Phase 2 (session 5-7) family therapy • Phase 3 (session 8-18) CBT • Phase 4 (session 19-20) relapse prevention • Follow up 6 months post-treatment	willingness to engage in shared meals
Becker et al. (2018) USA (Clinical characteristics)	To compare the clinical presentations of ARFID and AN	138 individuals with an eating disorder (*n* = 67 with ARFID, *n* = 71 with AN), 10-78 years, 73.8% female	N/A	N/A	• ARFID group - significantly higher proportion of males and presented for treatment at a younger age than the AN sample • Individuals with ARFID scored lower on measures of eating pathology, depression, anxiety, and clinical impairment but did not differ from those with AN on restrictive eating
Bryson et al. (2018) USA (Clinical outcomes)	To assess long-term outcomes of patients with ARFID treated in a PHP for eating disorders	Retrospective chart review ARFID and AN patients treated in a PHP from Aug 2008 to May 2013: • ARFID (*n* = 20), 70% female, mean age 11.43 years	• *n* = 5 patients with reported gastrointestinal complaints • *n* = 8 with a reported fear of choking or vomiting • *n* = 7 with restrictive eating due to: low appetite related to comorbid psychological conditions, severe picky	• PHP (including cognitive-behavioural interventions, meal planning and family therapy) • Follow up at least 12 months after discharge	• At follow up, all participants exhibited a significant increase in %MBMI from intake to discharge and maintained this at follow-up • Significant reduction in eating disorder symptoms from intake to discharge and from discharge to

		• AN (*n* = 42), 97.6% female, mean age 14.12 years	eating, hypersensitivity to sensory qualities of food, idiosyncratic food rules, and/or family conflict		follow-up (measured by the ChEAT) • Significantly smaller percentage of patients with ARFID were receiving outpatient services (compared to AN)
Chiarello et al. (2018) Italy (Clinical characteristics)	To discuss the presentation and clinical characteristics of an individual with ARFID	Case study 18-year-old male	• Very selective eating habits and nausea in the presence of non-preferred foods • Malnutrition causing progressive decrease in vision	• Inpatient care with multidisciplinary approach to treatment followed by outpatient CBT and parental psychoeducation • Sertraline up to 150mg/day • Follow-up 1-year post-treatment	• Improved nutritional intake, decreased anxiety during meals, improvement in right eye vision • One year follow up: no further recurrence of visual loss and no further improvements
Görmez et al. (2018) Turkey (Treatment interventions)	To present a case of ARFID successfully treated with CBT	Case study 27-year-old female BMI 16kg/m^2 (lost 6kg in the past 2 months	Nausea, retching, vomiting and unable to tolerate the sight and smell of food	• 12 40-minute weekly CBT sessions as an inpatient and 8 sessions as an outpatient as well as psychoeducation and dietary supervision • Also 30-45mg of mirtazapine	• 4kg gained (BMI 17.5kg/m^2. A further 2kg gained (BMI 18.3kg/m^2) 6-months post discharge • Improvement on cognitive domains, energy levels and anxiety
Gray et al. (2018) USA (Treatment interventions)	To evaluate the use of mirtazapine in treating patients with ARFID	6 females, 8 males (7-23 years) who received treatment at the University of California, San Diego Eating Disorders Clinic from 2015 to 2016.	Difficulty eating related to low appetite cues, taste, or texture sensitivity, anxiety of an adverse event (e.g., choking), or significant functional gastrointestinal distress	• Six patients treated with mirtazapine as monotherapy and 8 on additional medications • Average dose of mirtazapine 25.5mg • Follow-up 6-months post-treatment and	• Average change in BMI without mirtazapine - 0.10 BMI point per week • Average change in BMI with mirtazapine - 0.23 BMI point per week (t_{13} = -3.11, $p < .05$) • Overall, mirtazapine was safe, well tolerated and

		Mean BMI at intake 16.8 ± kg/m^2		monthly follow-ups thereafter	encouraged greater weight gain than treatment-as-usual programme
Guss et al. (2018) USA (Treatment interventions)	To assess the inpatient medical management of adolescents with ARFID	Survey United States-based physician members of the Society for Adolescent Health and Medicine's Eating Disorder Special Interest Group's listserv or the National Eating Disorders Quality Improvement Collaborative (*n* = 37)	N/A	N/A	• Half of respondents did not use protocol for refeeding • 55% of those with a protocol used an AN treatment protocol • Solid food and nasogastric feeds were most commonly used for nutritional rehabilitation • Few typically prescribed medications in the hospital during medical stabilisation • There is considerable variability of practice in the treatment of ARFID
Izquierdo et al. (2018) USA (Clinical characteristics)	To assess implicit attitudes towards dieting and thinness in adolescents with fat-phobic AN, non-fat-phobic AN, low-weight ARFID and those with no eating disorder	Comparative study *N* = 94 adolescent females, 10-22 years (*n* = 39 fat-phobic AN, *n* = 13 non-fat-phobic AN, *n* = 10 low-weight ARFID, *n* = 32 healthy controls)	• Participants meeting DSM-5 criteria for a low-weight eating disorder or age-matched healthy controls	N/A	• Individuals with fat-phobic and non-fat-phonic AN had implicit associations with dieting and true statements but those with ARFID and HCs did not • Implicit association between non-dieting and true statements in those with ARFID is consistent with explicit endorsements of the absence of weight and shape

Lenz et al. (2018) USA (Treatment interventions)	To describe the successful use of an intensive inpatient behavioural intervention in treating ARFID	Case study 8-year-old female diagnosed with ARFID	• Initially presenting with abdominal pain, nausea and vomiting which caused acute food refusal • Patient also stopped drinking fluids following a choking incident, which resulted in the placement of a nasogastric tube	• Initial outpatient treatment which employed family and individual therapy within a CBT framework • Subsequent inpatient admission to adolescent medicine service • 16 outpatient sessions over a 12-week period and a 6-day inpatient stay • Follow-up 4-months post discharge	• Patient weight increased from lowest 21.8kg to 26.5kg (52nd percentile) at 4-month follow up • Full remission of ARFID symptoms
Lock et al. (2018) USA (Treatment interventions)	To illustrate the use of FBT in treating pre-adolescents with ARFID	Case study (1) 8-year-old female (2) 9-year-old female (3) 11-year-old female	3 different ARFID presentations: (1) Low appetite and lack of interest in eating (2) Sensory aversion to food (3) Fear of eating and extreme fear of vomiting	Family Based Therapy	(1) No major changes in interest in food but capable of eating sufficient quantities and eating-related family conflicts decreased (2) Greatly increased range of food, increased flexibility in social situations (3) Coping strategies used to manage fears, steady weight gain and increased participation in school and social activities
Lucarelli et al. (2018) Italy	To assess the type and degree of malnutrition over time in children with IA	Longitudinal study evaluating children (and their mothers) originally diagnosed	Patients originally diagnosed with IA but now meeting the criteria for the ARFID subtype “apparent	• Patients and their mothers had received some psychoeducation at the time of diagnosis	• Steady improvement in malnutrition but 73% continued to exhibit mild,

(Clinical outcomes)		with IA (*n* = 113), 49% female, 2.3 years (mean age at first assessment)	lack of interest in eating or food."	but did not pursue any psychotherapeutic treatment for various reasons • Patients assessed at a mean age of 2 and thereafter at 5, 7 and 11 years	moderate, or severe malnutrition at 11 years • Girls' emotional/behavioural problems and mothers' psychopathology were more severe than that of the boys and their mothers
Norris et al. (2018) Canada (Clinical characteristics)	To assess characteristics of ARFID and describe subtypes	Retrospective chart review Patients (*n* = 77) assessed in an eating disorder clinic at a tertiary care paediatric hospital between 2000 - 2017, 73% female, mean age 13.7 years	N/A	• N/A	• Three specific sub-types identified: 1. Apparent lack of interest in eating 2. Restriction as a result of sensory sensitivity 3. Restriction based on fear of aversive consequences • Clinical characteristics of patients varied depending on assigned subtype • Some mixed presentations observed
Okereke (2018) USA (Treatment interventions)	To describe the successful treatment of anxiety using buspirone in an individual with ARFID	Case study 14-year-old female BMI 20.3kg/m^2 (58th percentile)	Complaints of anxiety, abdominal pain and vomiting resulting in food restriction (later diagnosed with ARFID as well as irritable bowel syndrome)	• Individual and family therapy • Sertraline at 50mg/day (discontinued when patient experienced agitation and thoughts of suicide) • Buspirone 5mg twice daily increased to 7.5mg twice daily at 1 month follow up and 10mg twice daily at 6-month follow-up	• BMI at 8-month follow up was 22.0kg/m^2 (73rd percentile) • SSRIs can be used to treat eating-related anxiety but may cause adverse side effects, particularly in children and adolescents • Buspirone successfully treated anxiety symptoms associated with eating (patient denied any significant side effects)

				• Follow-up 1, 2, 4, 6, and 8-months post-treatment	
Pitt and Middleman (2018) USA (Clinical characteristics)	To describe the presentation and treatment of two cases of ARFID	Case series (1) 17-year-old female, height 172.5cm, weight 46.9kg (2) 13-year-old female, height 141.3cm, weight 24.80kg	(1) 12 episodes of vomiting with 36-hour period, dizziness, abdominal pain, denied difficulties with body image, picky eating habits since childhood (2) Long-standing malnutrition, persistent complaints of constipation and nausea, denied difficulties with body image, picky eating with poor weight gain since 6 months	• Both patients hospitalised for malnutrition • Nasogastric tube placement was used followed by nasojejunal • Individualised behaviour plans provided to reinforce oral nutritional consumption • Family therapy provided	• No information regarding patients' outcomes • Authors conclude that treatment for ARFID may need to address behavioural components that contribute to food restriction (compared to treatments which focus on body image disturbances)
Sharp et al. (2018) USA (Clinical characteristics)	To examine the clinical presentation of severe food selectivity in children with ASD	70 children (2-17 years) with ASD and severe food selectivity referred to an outpatient programme	Complete omission of one or more food groups or consumption of a narrow range of items (five or fewer)	N/A	• 67% omitted vegetables & 27% omitted fruits • 78% percent consumed a diet at risk for five or more nutritional inadequacies • Severe food selectivity was not associated with compromised growth or obesity
Spettigue et al. (2018) Canada (Treatment interventions)	To examine the efficacy of treating ARFID patients with modified FBT or psychopharmacological treatment	5 females and 1 male (10-14 years)	Various presentations including fear following choking incident, abdominal pain and nausea, problems concentrating and severe anxiety	• Family Based Therapy • Medication - olanzapine, fluoxetine and cyproheptadine • CBT	All six patients achieved their goal weight

Wassenaar et al. (2018) USA (Clinical characteristics)	To present the case of an individual with co-occurring ARFID, psychosis and Gitelman syndrome	Case study 27-year-old woman BMI 15.8 kg/m^2	• Patient experienced 20lbs weight loss in the last year by restricting portion sizes • History of anxiety as well as confusion and persecutory auditory and visual hallucinations	• Admittance to inpatient care for specialised eating disorder treatment and nutritional rehabilitation • Medication included aripiprazole, gabapentin for anxiety and methocarbamol and tramadol for pain	• Patient discharged at a restored weight with a plan to see outpatient nephrology and continue aripiprazole • On clinical examination, patient was emotionally flat, had psychomotor restriction, poor eye contact, monotoned speech and did not engage with peers • Patient continued to meet calorie goals but remained resistant to food flexibility • Later diagnosed with Gitelman syndrome
Westfall et al. (2018) USA (Clinical characteristics)	To present the case of an individual with acute psychosis and ARFID driven by religious delusions	Case study 16-year-old male	Patient hospitalised for the third time for acute psychosis, refusal to eat or drink driven by religious delusions, failure to take care of personal hygiene, covert food purging and intermittent marijuana use	• Olanzapine 5mg daily for psychosis and weight gain • Patient discharged after several days but did not continue medication or attend follow-up appointments • Patient readmitted 15 months later and eventually transferred to paediatric medical unit for dehydration and nasogastric feeding • Trials of olanzapine, haloperidol,	The patient did well after discharge but was readmitted to paediatric medicine 2½ weeks later but when his clozapine ran out

				cyproheptadine, risperidone and megestrol acetate failed • Clozapine appeared to resolve acute psychosis and refusal to eat	
Zucker et al. (2018) USA (Treatment interventions)	To present an acceptance-based interoceptive exposure treatment for young people with ARFID and demonstrate its success in treating a young girl with lifelong poor appetite	Case study 4-year-old female	• Patient had percutaneous endoscopic gastrostomy (PEG tube) since 14 months of age • Indifference to food, lack of awareness of hunger, difficulty adjusting to a change in routine	8 weekly sessions followed by 4 bi-monthly sessions of acceptance-based interoceptive exposure treatment - Feeling and Body Investigators (FBI)-ARFID Division (also mirtazapine for a month prior to exposure treatment)	• Patient no longer met criteria for ARFID • Notable improvement in capacity to cope with change, unknown internal sensations no longer viewed as a threat • Increase in quantity of food consumed and need for supplemental feeds reduced • PEG tube eventually removed
Bloomfield et al. (2019) USA (Treatment interventions)	To examine the use of teleconsultation in treating a patient with ARFID	Case study 8-year-old-male	Frequent refusal of non-preferred foods resulting in tantrum behaviour (whining, crying, gagging) upon sight or smell	• Parent teleconsultation (behavioural feeding intervention to increase food variety) • Follow-up 1- and 4-months post-treatment	• Increase in the frequency of bites of non-preferred foods
Dahlsgaard and Bodie (2019) USA (Treatment interventions)	To report the acceptability, feasibility, and initial outcomes of the Picky Eaters Clinic	Pilot trial 21 children (4-11 years) and their parents	Picky eaters (eating less than 20 foods, difficulty socialising, refusal to eat non-preferred foods)	• 7 sessions (90 minutes each) of parent-led behavioural intervention • Follow-up 3-months post-treatment	• Reduction in picky eating and negative mealtime behaviours
Dumont et al. (2019)	To test a new 4-week exposure-based CBT day treatment for	Case series Patients referred to SeysCentra, a	Various presentations including: anxiety-driven (phobia), lack of interest in	• Exposure based CBT treatment designed to address a variety of	• At follow up, 10 of the 11 patients were at a healthy

The Netherlands (Treatment interventions)	adolescents with ARFID	specialised treatment facility for children with feeding disorders (*n* = 11), 36% female, 10-18 years	food, driven by disgust or aversion	ARFID presentations (i.e., disgust sensitivity, distorted cognitions about the consequences of eating feared foods) • A non-concurrent multiple baseline design followed by 4-week CBT • Various measures taken at baseline and throughout including measurement of DSM-5 ARFID diagnosis, food neophobia, body weight and anxiety • Follow-up 3-months post-treatment	weight and had an age-adequate nutritional intake • For most, food neophobia scores decreased to a non-clinical range • Dysfunctional cognitions about food intake/eating and anxiety decreased • Tube feeding eliminated in 6 patients • All 11 patients demonstrated a more varied food repertoire • Demonstrates a CBT approach which has the potential to treat various issues which drive restrictive/avoidant eating behaviours in ARFID
Hadwiger et al. (2019) USA (Clinical characteristics)	To highlight the relationship between ARFID and internet gaming disorder and to illustrate two clinical cases with both disorders	Case series (1) 17-year-old male, height 167cm, weight 43.4kg (2) 15-year-old male, height 180.4cm, weight 48.2kg	(1) Poor weight gain, frequent vomiting, emetophobia, disinterest in eating, excessive video gaming (4+ hours a day) (2) Weight loss, post-meal vomiting, restricted food interests, emetophobia, 1 hour or more daily exercise, excessive video gaming (4+ hours a day), orthostasis, bradycardia,	• Hospitalisation in the Disorder Eating Programme for refeeding, placed on malnutrition protocol (including psychoeducation and individual and family therapy) • Interventions aimed at changing eating and faming behaviours	• Both patients achieved the minimum medical and psychological goals and were discharged to follow-up in outpatient clinic • Both patients maintained medical progress but returned to gaming behaviours once discharged

			feelings of anxiety and depression		
Lai et al. (2019) Singapore (Clinical characteristics)	To describe the clinical profile of patients diagnosed with ARFID	Case series Five males and three females (15-39 years) presenting to an eating disorder treatment facility at Singapore General Hospital, diagnosed with ARFID between 2013 - 2016 Mean BMI 16.1kg/m^2	• Heterogeneous presentation including severe food restriction, lack of interest in eating, anxiety with certain foods, emetophobia, nausea and vomiting • 7 participants displayed symptoms of ARFID in childhood/adolescence and one in adulthood • Comorbid major depressive disorder, ASD, deliberate self-harm, low mood, lethargy, and cold intolerance	• Inpatient or outpatient treatment with multidisciplinary team • All patients completed nutritional rehabilitation with a dietitian and two were referred to a psychologist	• Two patients reached a BMI within the healthy weight range after returning regularly for treatment • The remaining six patients defaulted follow-up appointments
Lange et al. (2019) Sweden (Clinical outcomes)	To compare the long-term outcomes of those with AN and low-weight ARFID	Retrospective chart review of consecutive patients diagnosed at a regional eating disorder service in southern Sweden from 1983 - 2007 (*n* = 56) (*n* = 19 diagnosed retrospectively with ARFID), 95% female	N/A	• Follow up after a mean of 15.9 years	• Mean BMI for ARFID group 21.9 kg/m^2 (range 16.5–29.9; SD 3.33) • In the ARFID-group, 26.3% had a current eating disorder, 26.3% had other psychiatric diagnoses (including anxiety and depression), and 47.4% had no psychiatric diagnosis • For the ARFID group, eating disorder diagnoses

					at follow-up were all ARFID (possible symptomatic stability) whereas the AN group showed heterogeneity
Lieberman et al. (2019) Canada (Clinical characteristics)	To compare the medical and psychological characteristics of children with ARFID and AN	Comparative study Inpatient and outpatient participants in a specialised programme at the Hospital for Sick Children (*n* = 106), 8-13 years	• Patients meeting DSM-5 criteria for AN or ARFID • Criteria for inpatient admission - heart rate <50 BPM and/or treatment goal weight <80% • Criteria for outpatient acceptance - primary diagnosis of an eating disorder and medical stability	• Inpatient or outpatient care at the Hospital for Sick Children	• Children with ARFID had a longer length of illness, history of abdominal pain and infections preceding diagnosis and more likely to be diagnosed with an anxiety disorder • Those with AN had a higher drive for thinness, lower self-esteem, scored higher on depression and were more likely to be admitted for inpatient care
Lock et al. (2019) USA (Treatment interventions)	To assess the feasibility of conducting an RCT comparing FBT-ARFID to usual care	Feasibility study 28 children (5-12 years) and their families	Patients meeting DSM-5 criteria for diagnosis of ARFID	• Participants randomised to receive immediate treatment with FBT for ARFID or usual care for a period of 3 months (and then offered FBT-ARFID) • Dose and duration of treatment were allowed to fluctuate according to clinical need	• Effect size differences on measures of weight and clinical severity of symptoms were moderate to large, favouring FBT-ARFID over usual care • Improvements also observed in parental self-efficacy • An RCT comparing FBT-ARFID, and usual care would be feasible
Makhzoumi et al. (2019) USA (Clinical outcomes)	To assess weight restoration and discharge outcomes of patients with ARFID	Retrospective chart review Consecutive underweight first admissions to an	• Various symptoms including fear of vomiting or choking, food restriction for avoidance of GI	The John Hopkins IP-PHP which employs a meal-based behavioural rapid refeeding protocol (including, dialectical–	• ARFID group had a slower weekly weight gain compared to those with AN

	compared to those with AN	integrated hospital-based IP-PHP eating disorder treatment programme between 2003 - 2017 (*n* = 275) (10% ARFID), 86% female, 11-26 years patients	symptoms, reliance on parenteral/enteral tubes • Psychiatric comorbidities included major depression and anxiety disorders	behavioural, cognitive-behavioural, and family-based therapies)	• Both groups had similar programme discharge BMIs • No group differences found on IP length of stay or PHP rate of weight gain
Reilly et al. (2019) USA (Clinical characteristics)	To explore the potential co-occurrence of behavioural phenotypes in ARFID	Retrospective chart review ARFID patients presenting for treatment at a PHP between June 2014 and May 2018 (*n* = 59)	• 49% classified as underweight (<85% expected body weight) • Variety of psychiatric and medical comorbidities including ADHD, OCD and Crohn's Disease	N/A	• Over 50% endorsed symptoms characteristic of more than one proposed behavioural phenotype • Sensory sensitivity phenotype was most common and frequently co-occurred with both other phenotypes
Schorr et al. (2019) USA (Clinical characteristics)	To investigate bone mineral density and hip strength in men with AN, ATYP and ARFID	103 patients: AN (*n* = 26), ARFID (*n* = 11), ATYP (*n* = 18), healthy controls (*n* = 48), 100% male, 18-63 years	N/A	N/A	• Mean BMI was lowest in AN and ARFID, higher in ATYP and highest in healthy controls (AN 14.7 ± 1.8, ARFID 15.3 ± 1.5, ATYP 20.6 ± 2.0, HC 23.7 ± 3.3 kg/m^2) • Mean bone mineral density Z-scores at spine and hip were lower in AN and ARFID than healthy controls • Men with ARFID (as well as AN and ATYP) are at risk of low bone mineral density and those who are low weight, have low

					muscle mass or long illness duration may be at particularly high risk
Trompeter et al. (2019) Australia (Clinical characteristics)	To investigate whether fear of negative evaluation is associated with a greater chance of meeting criteria for an eating disorder	Australian adolescents (*n* = 4,030) from the EveryBODY study (53% female)	• ARFID (*n* = 107), AN (*n* = 19), BN (*n* = 167) • Various other eating disorders including ATYP, BED and UFED • *n* = 2,985 classified as having no disorder	N/A	• Fear of negative evaluation was found to be associated with higher odds of meeting criteria for any eating disorder but significantly more for those characterised by weight/shape concerns
Zickgraf et al. (2019a) USA (Clinical characteristics)	To identify potential ARFID presentations based on the nature of eating restriction	Retrospective chart review 83 patients (8-17 years) with ARFID admitted to a PHP (76% female)	• Selective eating behaviours based on sensory properties, lack of interest in eating/low appetite and fear of aversive consequences • Also, a subset of patients with both selectivity and limited interest/appetite	N/A	• Four primary presentations differed on core ARFID criteria, symptom trajectory, illness duration, mood, medical comorbidities, age, gender, and parent-reported symptoms of psychopathology • Suggests that there are diagnostically meaningful ARFID subtypes
Zickgraf et al. (2019b) USA (Clinical characteristics)	To describe the clinical characteristics of individuals diagnosed with the selective/neophobic presentation of ARFID	Retrospective chart review 22 consecutive outpatients (4-25 years) diagnosed at a university clinic between 2014 - 2017 (18.2% female)	• Patients with selective/neophobic ARFID presentation • Unwilling to try new/non-preferred foods • Rigid about preparation and presentation of food	N/A	• Results evidence a selective/neophobic ARFID presentation • All patients met criteria for psychosocial impairment

*Note. ARFID = avoidant restrictive food intake disorder; AN = anorexia nervosa; BN: bulimia nervosa; ASD = autism spectrum disorder; BMI = body mass index; ATYP = atypical anorexia; BED: binge eating disorder; UFED: unspecified feeding or eating disorder; CBT = cognitive-behavioural therapy; ChEAT = children's eating attitude test; RCMAS = revised children's manifest anxiety scale; CHOP = The Children's Hospital of Philadelphia; %MBMI = percent median body mass index

Table 4. Summary of articles relating to ARFID prevalence

Author (Year)	Country	Sample size (*n* =)	Gender, age range (Mean, SD)	Sample	Type of assessment	ARFID prevalence estimate
Ornstein et al. (2013)	USA	215	88.6% female 8-21 years (15.4 ± 3.3)	Patients presenting for initial eating disorder evaluation to adolescent medicine physicians in 2010 or 2011	Clinical interview (retrospective or concurrent presumptive diagnosis assigned)	14%
Fisher et al. (2014)	USA & Canada	712	8-18 years	Patients presenting to 7 adolescent medicine eating disorder programmes in 2010	Retrospective chart review	13.8%
Forman et al. (2014)	USA	700	86.3% female 9-21 years (15.3 ± 2.4)	Patients presenting to 14 adolescent medicine eating disorder programmes in 2010	Retrospective chart review	12.4%
Nicely et al. (2014)	USA	173	92% female 7-17 years (13.5 ± 2.03)	Patients admitted to an eating disorder day programme between 2008 and 2012	Retrospective chart review	22.5%
Norris et al. (2014)	Canada	205	13.7 ± 2.5	Patients who received an initial eating disorder intake assessment between 2000 and 2011	Retrospective chart review	5%
Eddy et al. (2015)	USA	2,231	53.4% female 8-18 years (13.0 ± 3.0)	Consecutive new referrals to 19 paediatric gastroenterology clinics in 2008	Retrospective chart review	1.5% (a further 2.4% with one or more ARFID symptoms)
Fisher et al. (2015)	USA	309	83.2% female Mean age 15.4	Referrals to outpatient office of division of adolescent medicine for an eating disorder evaluation	Evaluation by physician, nutritionist, and social worker	19.4%
Kurz et al (2015)[iii]	Switzerland	1444	53.9% female 8-13 years (10.55 ± 1.89)	Children from regular schools in Switzerland (3rd to 6th Grade)	Self-report (EDY-Q, ChEDE-Q)	3.2%

[iii] article also presented in Table 2 (relating to ARFID measurement instruments)

Williams et al. (2015)	USA	422	32% female 4-219 months (54.5 months ± 41.0)	Children referred to a multi-disciplinary paediatric feeding programme	Clinical assessment (BMI measurement, assessment of dietary intake and physical examination)	32%
Kurz et al (2016)[iv]	Switzerland	1444	53.9% female 8-13 years (10.55 ± 1.89)	Children from regular schools in Switzerland (3rd to 6th Grade)	Self-report (EDY-Q, ChEDE-Q)	26.1% selective eating, 19.3% food avoidance emotional disorder and 5.0% functional dysphagia
Seike et al. (2016a)	Japan	655 teachers	100% female	Yogo teachers working at elementary/junior high/senior high/special schools in Chiba Prefecture	Questionnaire survey	ARFID encounter rate 10.7% (14.8% - senior high schools, 11.1% - junior high schools, 10.0% - elementary schools, 6.3% - special needs schools)
Seike et al. (2016b)	Japan	1,886 teachers		Yogo teachers working at elementary/junior high/senior high/special schools working in four prefectures	Questionnaire survey	ARFID encounter rate 13.0%
Hay et al. (2017)	Australia	2732 (2014) 3005 (2015)	>15 years	Population-based study. Metropolitan and rural districts in South Australia systematically selected and 10 dwellings chosen within each district. Participants selected from each household	Interview featuring questions about eating behaviours)	2014: 0.3% (0.1-0.5) 2015: 0.3% (0.2-0.6)
Nakai et al. (2017)	Japan	1029	100% female	Patients who sought treatment for an eating disorder at Kyoto University Hospital between 1990 and 2005	Retrospective chart review	9.2%

[iv] article also presented in Table 2 (relating to ARFID measurement instruments)

Cooney et al. (2018)	Canada	369	<18 years	Patients who were assessed for an eating disorder in a tertiary care paediatric hospital between 2013 and 2016	Retrospective chart review	8.4%
Gonçalves et al. (2018)	Portugal	330	50.9% female 5-10 years (7.6 ± 1.2)	Children attending primary schools and fluent in Portuguese and their parents	Child and parent-self report questionnaires (including the ARFID questionnaire, based on DSM-5 criteria)	15.5%
Chen et al. (2019)	Taiwan	4,816	47.7% female 7-14 years	Children from 69 schools in Taiwan	Face-to-face interviews using the K-SADS-E modified for the DSM-5 (plus parent completed questionnaires)	<1%
Krom et al. (2019)	The Netherlands	100	64.1% female Mean age 1.85	Patients referred by paediatricians or GPs because of feeding difficulties to the Diagnostic Centre for Feeding Problems in the Emma Children's Hospital/Amsterdam UMC	Participants assessed against DSM-5 criteria for ARFID	64%

Chapter 3: ARFID and Severe Food Selectivity in Children and Young People with Autism: A Scoping Review

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This chapter is a version of a peer-reviewed published paper:

Bourne, L., Mandy, W. & Bryant-Waugh, R. (2022). Avoidant/Restrictive Food Intake Disorder and Severe Food Selectivity in Children and Young People with autism: A Scoping Review. *Developmental Medicine and Child Neurology*, *64*(6), 691-700.

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Abstract

Aims: This review aimed to assess the extent of the scientific literature on ARFID in autistic children and young people in order to evaluate and synthesise the evidence on: (1) the nature of feeding and eating difficulties in autistic children and young people, (2) the consequences of a severely restricted diet, and (3) what is known about effective treatment approaches.

Methods: PubMed and PsycInfo databases were searched, identifying fifty-six studies, and a narrative synthesis was effected.

Results: The literature suggests that ARFID-like presentations are common in autistic children and young people, with severe consequences for physical and mental health. The three drivers mentioned in the DSM-5 criteria, namely a sensory-based avoidance, fear- or phobia-based restriction, and a lack of interest in eating, are present in this population, although sensory sensitivities are currently the most commonly described. Research suggests that ARFID symptoms in autistic children and young people can be amenable to treatment, with evidence that behavioural interventions are feasible and potentially effective in this population.

Conclusions: ARFID is a common and impactful problem amongst autistic young people but is currently under researched. Work is required to: (1) identify the prevalence of ARFID in autistic children and young people; (2) uncover the key drivers of ARFID in this population; (3) adapt currently available interventions for use with autistic children and young people; (4) rigorously test these interventions in clinical trials.

Introduction

Feeding and eating difficulties are commonly reported in early childhood. These may include, but are not limited to, food sensory issues, food selectivity or fussiness, reduced appetite, challenging or problematic mealtime behaviours and repetitive or rigid food preferences as well as a fear of or reluctance to try new foods (food neophobia), which is considered to be a typical stage of children's development (Castro et al., 2016; Gray & Chiang, 2017; Leung et al., 2012). Although widely accepted as a passing phase of development which peaks in early childhood (Cardona Cano et al., 2015a; Cardona Cano et al., 2015b, Keen, 2008; Marchi & Cohen, 1990) continued or severe disturbances in eating can represent a clinically significant concern.

Avoidant restrictive food intake disorder, or ARFID, first emerged as a diagnostic category in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; APA, 2013) and more recently in the 11th Revision of the World Health Organisation's International Classification for Diseases (ICD-11; Claudino et al., 2019; WHO, 2018). ARFID was introduced to describe clinically significant restrictive eating behaviours which are not driven by body image disturbances or fears of weight gain and covers a heterogeneous group of patients across the lifespan who limit food intake, whether by type, amount, or both. Such behaviours can be driven and maintained by a number of factors, and work is still underway to fully understand the varied aetiology of ARFID (Bourne et al., 2020). Nevertheless, the original DSM-5 diagnostic criteria acknowledge three features which have been frequently observed in clinical practice and serve to represent examples that may drive the avoidance/restriction, namely: (1) an apparent lack of interest in eating; (2) an avoidance based on the sensory characteristics of food; and/or (3) a concern about the aversive consequences of eating (APA, 2013).

The persistent disturbances in eating that are the core feature of ARFID can result in a number of clinical manifestations, the most common of which are considerable weight loss (or faltering growth in children), marked nutritional deficiencies, dependence on oral nutritional supplements and/or reliance on enteral feeding. Physical consequences aside, ARFID can also have a significant impact on psychosocial functioning, for example, if an individual is isolated as a result of their inability to engage in social mealtimes or if eating difficulties interfere with their ability to foster or sustain close relationships (APA, 2013).

Autism spectrum disorder (hereafter 'autism') is a neurodevelopmental condition associated with restricted, repetitive, or stereotyped behaviours or interests, as well as impairments in social communication and social reciprocity (APA, 2013). The characteristic pattern of behaviours, needs and sensitivities associated with autism can give rise to a limited food repertoire, specific sensory preferences, and rigid rules regarding mealtimes. This can result in substantial limitations relating to the type and/or amount of food consumed (Bandini et al., 2010; Cermak et al., 2010; Esteban-Figuerola et al., 2019), which may mean that autistic individuals are at an increased risk of significant feeding difficulties compared to those who are not autistic and may even meet the diagnostic threshold for ARFID (Farag et al., 2021; Field et al., 2003; Mayes & Zickgraf, 2019; Sharp et al., 2013b). It is important to note, however, that this continues to be investigated, with some research suggesting that autistic traits contribute to the exacerbation of severe feeding difficulties rather than their onset (Inoue et al., 2021).

Evidence suggests that autistic individuals are at a heightened risk of long-term physical health conditions and premature mortality (Gillberg et al., 2010; Hirvikoski et al., 2016; Mouridsen et al., 2008), but the reasons for this remain unclear. Weir et al. (2021) found that autistic adults are less likely than non-autistic adults to meet minimal recommendations for diet, exercise, and sleep. Indeed, feeding problems and dietary

restriction affect nutrition and as such, may be an important contributing factor in health status.

Several studies have reviewed eating disorders, food selectivity, and disordered eating behaviours in the autistic population (Baraskewich et al., 2021; Marí-Bauset et al., 2014; Stensbjerg et al., 2018; Westwood & Tchanturia, 2017) although currently, very little is known about the course, development, management, and outcomes for those with co-occurring ARFID and autism. ARFID research, and in particular, the literature regarding ARFID in the autistic population, is still limited. One study was found to review the presence and management of scurvy in autistic children as a result of severe food selectivity consistent with ARFID (Sharp et al., 2020) and another qualitative systematic review reported on nutritional deficiency diseases in the autistic population as a result of ARFID (Yule et al., 2021). To our knowledge, however, this is the first review to assess the current status of available evidence in relation to ARFID in autistic children and young people. In particular, we aim to address the following questions:

- What is the reported nature of feeding and eating difficulties in autistic children and young people with ARFID/significant food restriction?
- What is known about the consequences of a severely restricted diet (e.g., a significant restriction of the type or amount of food) in this population?
- What is known about effective treatment approaches for ARFID/significant food restriction in autistic children and young people?

Methods

The reporting of this scoping review was guided by the standards of the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR; Tricco et al., 2018). Scoping reviews are an approach to knowledge synthesis that are useful for addressing broad questions as they map the extent and nature of available

research (Arksey & O'Malley, 2005). Such reviews are particularly useful when the need for information on a particular topic is time sensitive as they streamline the systematic review process but nevertheless possess the key features of a systematic review, ensuring rigour, transparency, and replicability. These include: (1) a prespecified question; (2) the use of an electronic search; (3) defined inclusion and exclusion criteria; (4) the selection of studies based on the inclusion criteria; (5) the extraction of data; and (6) the interpretation and presentation of the results. As such, the findings can be used to aid planning of future research and inform policy decisions.

We completed this review in partnership with Autistica, the UK's national autism research charity, in response to a request from NHS England and leading charities in the field for an evidence summary which would feed into policy development. Specifically, we were asked to review and synthesise the published literature addressing the overarching review question: What is currently known about ARFID and autism?

Literature Search

Searches were conducted in PubMed and PsycInfo on 27th January 2020 and updated just prior to analysis on 3rd March 2021. We employed keywords relating to ARFID and autism in order to capture studies with a clear focus on feeding or eating difficulties in autistic children and young people (see **Table 5** and **Table 6** for search terms).

Table 5. Search terms and results from PsycInfo search

1. Autism	**2. Eating disorder**
autism.ti. OR autism.ab. OR pervasive developmental disorder*.ti. OR pervasive developmental disorder*.ab. OR Asperger*.ti. OR Asperger*.ab.	ARFID.ti. OR ARFID.ab. OR avoidant restrictive food intake disorder.ti. OR avoidant restrictive food intake disorder.ab. OR feeding.ti. OR feeding.ab. OR eating.ti. OR eating.ab.
1: 3531	2: 3821
1 AND 2: 52	

Note. * = Boolean operator used to search for words with a common prefix or suffix., i.e., the search engine will return and highlight any word that begins with the root/stem of the word truncated by the asterisk

Table 6. Search terms and results from PubMed search

1. Autism	**2. Eating disorder**
Autism[tiab] OR autistic[tiab] OR pervasive developmental disorder*[tiab] OR Asperger*[tiab]	ARFID[tiab] OR avoidant restrictive food intake disorder[tiab] OR feeding[tiab] OR eating[tiab]
1: 36106	2: 98800
1 AND 2: 518	

Note. [tiab] = searches for words and numbers included in a citation's title, collection title, abstract, other abstract and keywords

Since few studies have reported on those with concurrent diagnoses of ARFID and autism, we chose to also include all studies which describe autistic children and young people with severe feeding and eating difficulties that may have been considered for a clinical diagnosis of ARFID if they were assessed against the diagnostic criteria (see below). Specifically, we selected only those studies that expressly described at least one participant with (1) a diagnosis of autism, as well as (2) severe disturbances in eating (i.e., limited intake

of the variety or quantity of food) which manifests as one or more of the following (in accordance with ARFID DSM-5 diagnostic criteria):

- Individuals experiencing significant weight loss, faltering growth, or persistent failure to achieve expected weight (in the absence of any body weight or shape disturbances).
- Individuals with a significant nutritional deficiency.
- Individuals experiencing marked difficulties in psychosocial functioning as a result of a restricted diet.

Eligibility Criteria

The following studies were eligible for inclusion in this review:

- Full text journal articles with human participants published after 1994 (to ensure autism diagnoses did not predate the DSM-IV diagnostic criteria)
- Studies involving children and young people under the age of 18 with a concurrent diagnosis of autism/Asperger's/pervasive developmental disorder and ARFID (or participant(s) displaying food avoidance, restriction or selectivity which would meet criteria for ARFID)

Study Selection and Data Extraction

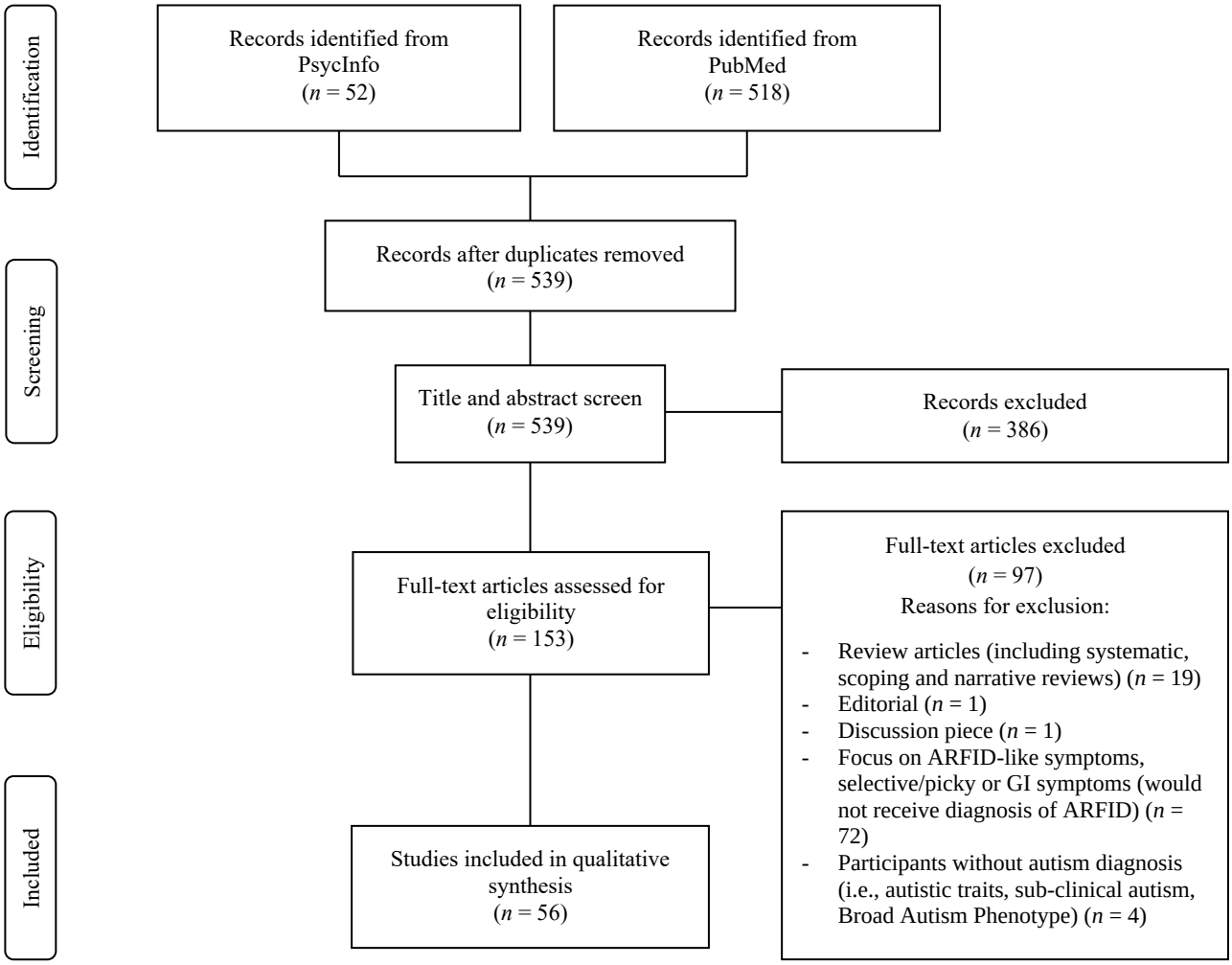
One reviewer (L.B) conducted the search, screening, and selection process. Following the removal of duplicates, a primary inspection of study titles and abstracts was conducted, and book chapters, conference proceedings, editorials, dissertation abstracts, theses, and review articles (including meta-analyses) were removed. Following this initial screen, full text articles of the remaining studies were retrieved and assessed against eligibility criteria (see **Figure 5** for flow diagram). Records were then independently reviewed by two experts in the field (R.B.W. and W.M.) and all reviewers met to resolve any conflicts and to ensure that selected papers were in line with the aims of the review. Once agreement was reached on the literature to be included in the review, studies were synthesised and categorised according

to their main area of focus and the findings presented narratively to provide a summary related to the research questions.

Results

The search yielded fifty-six studies, the majority of which were case studies or case series (n = 38, 68%), although various other studies were also identified including retrospective chart reviews, qualitative interviews, and randomised controlled trials (32%). Participants ranged in age from 3 years to 20 years, and studies were conducted worldwide, from the UK to Australia, although the majority were from the USA (n = 43, 77%). Just two of the papers reported specifically on those with a concurrent diagnosis of ARFID and autism (Lucarelli et al., 2017; Sharp et al., 2018). Thus, the majority of the literature discussed in this review describes participants with significant disturbances in feeding and/or eating, which closely mirror the symptoms of ARFID as defined by the DSM-5 criteria (APA, 2013). **Table 7** provides a comprehensive overview of all included articles.

Figure 5. Flow diagram of reviewed studies according to PRISMA-ScR guidelines



What is the reported nature of feeding and eating difficulties in autistic children and young people with ARFID/significant food restriction?

Although the literature on autistic children and young people reliably evidences the three main reasons of food avoidance and restriction in ARFID, as per the original diagnostic guidelines (APA, 2013), sensory sensitivities are currently the most cited. This is perhaps unsurprising given the atypical sensory processing associated with autism (Crane et al., 2009; De la Marche et al., 2012; Tomchek & Dunn, 2007). Aversion to texture is the most commonly reported concern (González & Stern, 2016; Johnson et al., 2015; Laud et al., 2009;

Marshall et al., 2013; Rafee et al., 2019; Roth et al., 2010; Seiverling et al., 2019; Sharp & Jaquess, 2009; Tanner & Andreone, 2015; Williams et al., 2008) although sensitivity to taste, temperature, type, colour, and appearance have also been described (González & Stern, 2016; Johnson et al., 2015; Keown et al., 2014; Marshall et al., 2013; Rafee et al., 2019; Rogers et al., 2012; Roth et al., 2010; Seiverling et al., 2011a; Tanner & Andreone, 2015). This has been shown to result in gagging, spitting, vomiting, self-injury, and aggression (Binnendyk & Lucyshyn, 2009; Freeman & Piazza, 1998; Rogers et al., 2012; Smith et al., 2019). Such preferences tend to give rise to a very limited diet, consisting of bland, starchy and 'beige' foods, such as crackers, potatoes, rice, and bread products (Pineles et al., 2010; Rafee et al., 2019).

The second example ARFID presentation, a fear- or phobia-based avoidance or restriction of intake, has also been evidenced amongst autistic young people, with anxieties relating to swallowing (Knapp et al., 2012), contamination (Keen, 2008), fears of trying new foods (Binnendyk & Lucyshyn, 2009) and choking preceded by a traumatic event (Gravestock et al., 2007).

Just one definitive case of a lack of interest in eating is reported (Keen, 2008) but other studies do describe participants who engage in slow eating (Williams & Hendy, 2014) and have difficulty sitting at the table for a full meal (Muldoon & Cosbey, 2018), both of which may be driven by low interest in food or eating.

Finally, certain thinking styles appear to co-occur with disturbed eating patterns in autistic young people. For example, a preference for routine, cognitive rigidity and/or intolerance of uncertainty can manifest as a reluctance to participate in social mealtimes (Cosbey & Muldoon, 2017), a preference for the use of the same vessel, container or cutlery (Kadey et al., 2013; Lucarelli et al., 2017; Rogers et al., 2012; Tang et al., 2011) or insistence on the consumption of a particular brand of food or drink (Cosbey & Muldoon, 2017;

Johnson et al., 2015; Keown et al., 2014; Knox et al., 2012; Muldoon & Cosbey, 2018; Roth et al., 2010; Tang et al., 2011; Tanner & Andreone, 2015).

What is known about the consequences of a severely restricted diet in this population?

There is reliable evidence to suggest that ARFID and severe food restriction in autistic children and young people is associated with a greater risk of poor health outcomes (Amos et al., 2016; Baird & Ravindranath, 2015; Ma et al., 2016; Stewart & Latif, 2008; Tang et al., 2011; Zavaleta & Burt, 2020).

Arguably the most observable consequence of a severely restricted diet is low weight or significant weight loss, which in children tends to manifest as a persistent inability to meet expected growth or developmental expectations (Gravestock et al., 2007; Kinlin et al., 2018; Knapp et al., 2012; Noble et al., 2007; Roth et al., 2010). Despite this, ARFID does not always correspond to low weight. The literature also evidences children and young people who are overweight as a result of the consumption of a narrow range of energy-dense foods or those high in fat, sugar, or salt (Cosbey & Muldoon, 2017; Williams & Hendy, 2014).

Body weight considerations aside, poor dietary variety can also lead to nutritional deficiencies. The literature on autistic children and young people with severe food restriction reports a number of health issues stemming from the lack or absence of certain micronutrients, including jaundice, anaemia, scurvy, rickets, gingivitis, and hypogonadism (Amos et al., 2016; Berube et al., 2013; Planerova et al., 2017; Rafee et al., 2019; Saavedra et al., 2018; Stewart & Latif, 2008; Tang et al., 2011; Zavaleta & Burt, 2020).

Aside from the obvious consequences of malnutrition, a number of additional serious health concerns have also been cited in this population. These include chronic constipation, ulcers, visual impairment as a result of Vitamin A and B_{12} deficiencies, arthritis, laboured breathing, movement difficulties and liver dysfunction (Baird & Ravindranath, 2015; Duvall et al., 2013; Gongidi et al., 2013; Muldoon & Cosbey, 2018; Pineles et al., 2010; Rafee et al.,

2019; Uyanik et al., 2006). For those not getting enough food to meet caloric or nutritional needs, oral nutritional supplements can be a useful way to ensure the adequate intake of macro- and micronutrients (Luiselli et al., 2005; Marshall et al., 2013; Sharp & Jaquess, 2009). It is important to note, however, that these are not always readily accepted by autistic children and young people due to sensory preferences and sensitivities. Extreme cases may require enteral feeding via the alimentary canal (e.g., nasogastric, percutaneous endoscopic gastrostomy) or, more rarely, parenteral feeding, which is typically intravenous, may be required to deliver nutritional support (Baird & Ravindranath, 2015; González & Stern, 2016; Seiverling et al., 2011b; Taylor et al., 2017).

ARFID can also markedly impair psychosocial functioning if the individual can only tolerate eating alone and avoids social situations where food is served. This can lead to difficulty integrating at school or in the workplace and often results in social isolation (Cosbey & Muldoon, 2017). This is of particular significance for autistic children and young people who are already at a higher risk of social exclusion due to differences in communication and cognitive processing as well as difficulties understanding interactions and social expectations. The added challenge of eating non-preferred or feared foods is likely to cause significant distress during social mealtimes.

What is known about effective treatment approaches for ARFID/significant food restriction in autistic children and young people?

A multidisciplinary approach is commonly evidenced as an effective way to assess and manage those with autism and severe food restriction (Gravestock et al., 2007; Keen, 2008; Keown et al., 2014; Laud et al., 2009). This involves intensive and often continued input from a number or combination of services and clinicians, including speech and language therapists, occupational therapists, medical doctors, autism services, dietitians, local social networks, and mental health day services.

The primary objective is to recognise and target what is driving the eating difficulty in the autistic child or young person. Various behavioural interventions, including backward chaining, stimulus fading procedures, repeated taste exposure, escape extinction and positive reinforcement interventions have been reported to improve intake and diminish the impact of limited intake for autistic children and young people displaying severe food selectivity, sensory dysfunction, and food and liquid refusal (Dellatan, 2003; Freeman & Piazza, 1998; Hagopian et al., 1996; Luiselli et al., 2005; Paul et al., 2007; Peterson et al., 2019; Roth et al., 2010; Seiverling et al., 2018; Sharp et al., 2011; Smith et al., 2019). It is worth noting, however, that the majority of the studies presenting success with behavioural interventions are case studies with few participants, often just one or two. Whilst such studies provide a rich and in-depth source of information, the basis for generalisation is limited.

For those with serious physical concerns, medical input may be necessary. Various studies report on the medical management of autistic children and young people with severe food restriction, including assessment and management of gastroesophageal reflux disease, gut disturbances (vomiting, constipation), underlying nutritional deficiencies that drive certain behaviours (e.g., iron deficiency, anaemia, and pica), enteral or parenteral nutrition to increase weight (Noble et al., 2007; Tang et al., 2011) as well as intravenous or oral nutritional supplementation to treat severe malnutrition (Baird & Ravindranath, 2015; Duvall et al., 2013; Gongidi et al., 2013; Planerova et al., 2017; Rafee et al., 2019; Saavedra et al., 2018; Stewart & Latif, 2008; Tang et al., 2011; Uyanik et al., 2006).

Finally, the literature on autistic children and young people with severe food restriction evidences eight case studies, one pilot trial, one randomised controlled trial and one retrospective chart review reporting on family-centred or caregiver/teacher-led interventions used to treat food avoidance, increase consumption and tackle challenging mealtime behaviours (Binnendyk & Lucyshyn, 2009; Cosbey & Muldoon, 2017; Johnson et al., 2015;

Johnson et al., 2019; Knox et al., 2012; Muldoon & Cosbey, 2018; Seiverling et al., 2018; Sharp & Jacquess, 2009; Smith et al., 2019; Tanner & Andreone, 2015; Taylor, 2020). The findings appear to support family/parent-led approaches, with reported increases in dietary diversity, food acceptance and participation in meal and snack times observed, as well as reduced parental anxiety and increased family quality of life.

Discussion

This scoping review aimed to assess the current state of available evidence relating to ARFID in autistic children and young people. Despite a growing body of literature relating to ARFID in clinical and general populations, the findings of this review suggest that there is a paucity of research relating to co-occurring ARFID and autism. Just two studies reported on formally diagnosed ARFID in the autistic population (Lucarelli et al., 2017; Sharp et al., 2018). Consequently, we chose to extend the inclusion parameters to accept literature on autistic children and young people with severe food selectivity or restriction consistent with ARFID. In total, fifty-six studies were eligible for inclusion.

Despite the lack of literature relating directly to autism and ARFID, our review shows that this is likely to be a highly prevalent and impactful problem amongst autistic children. The literature evidences the presence of all three of the main drivers of food avoidance and restriction mentioned in the original diagnostic guidelines (APA, 2013), although sensory sensitivities are currently the most commonly described in autistic children and young people. These features are not mutually exclusive, however, and studies with non-autistic children and young people have evidenced ARFID presentations with multiple drivers of food avoidance and/or restriction (Bryant-Waugh, 2013b; Murphy & Zlomke, 2016). Further work is needed to explore other presentations of ARFID, including a lack of interest in eating and anxiety related avoidance, and basic epidemiological studies are needed to provide data on the prevalence of ARFID and main drivers of food avoidance in the autistic population.

In terms of treatment, most studies trial behavioural techniques used to tackle standard food selectivity or avoidance (e.g., picky/fussy eating). While there are no ARFID/autism specific treatment interventions, several case studies have demonstrated the success of core ARFID treatments, particularly behavioural interventions, in a non-autistic population (Dumont et al., 2019; Lock et al., 2018; Sharp et al., 2016), which may be implementable and effective with autistic children and young people. In particular, preliminary evidence has supported cognitive behavioural therapy for ARFID (CBT-AR) as an effective treatment for heterogeneous presentations of ARFID in children, adolescents, and adults (Thomas et al., 2018; Thomas et al., 2020; Thomas et al., 2021). Importantly, however, this is yet to be fully trialled with an autistic population. Since difficulties with feeding and eating in autistic children and young people can be further compounded by sensory sensitivities, idiosyncratic behaviours, social anxieties, and difficulties with communication (Cermak et al., 2010; Seiverling et al., 2011a; Schreck & Williams, 2006), individual requirements should be taken into consideration and adaptations made to facilitate access to interventions for autistic children and young people.

Current national and international guidelines advocate the use of psycho-behavioural therapy, typically on an outpatient basis, for all eating disorders, including ARFID, as well as treatment which addresses important nutritional, physical and mental health comorbidities (Hay, 2020). Further to this, the National Institute for Health and Care Excellence (NICE, 2017) make several recommendations when treating an individual with an eating disorder as well as a comorbid mental health condition. Clinicians are advised to consider the severity and complexity of the eating difficulty and the comorbidity, the person's level of functioning, and the preferences of the person with the eating disorder, as well as their family or carers if appropriate.

There is a particular dearth of research relating to the measurement of ARFID behaviours. No studies were found to report on tools used to diagnose ARFID or to assess symptomatology in the autistic population, although work is currently underway to design and validate reliable screening and diagnostic instruments in non-autistic cohorts (Bryant-Waugh et al., 2019; Hilbert & van Dyck, 2016; Schmidt et al., 2019). As above, it is likely the case that existing ARFID measurement tools are appropriate but that reasonable adjustments are needed to accommodate particular sensitivities or preferences and to ensure best fit.

This study has several limitations. First, we restricted our inclusion criteria to full text journal articles, therefore excluding dissertations, conference proceedings and book chapters which may have provided valuable insight into the topic. Similarly, just two databases were searched. Although PsycInfo and PubMed were considered an effective combination that would generate sufficient relevant literature for the purpose of this scoping review, it is possible that the search did not adequately identify all literature relating to the topic. Secondly, we chose to extend the parameters of our search to include autistic children and young people with severe feeding or eating difficulties that may have met the diagnostic criteria for ARFID. This process was subjective and based on an examination of the description of symptoms provided by the study authors. As such, it is not possible to be sure that every participant included in each study for this review would receive a diagnosis of ARFID. Finally, the majority of the studies yielded from the search were single case studies or case series (68%). Such studies are unlikely to be fully representative of the larger population, and therefore, provide little basis for generalisability of results.

In summary, this review highlights a clear need for further research on ARFID in autistic children and young people. Despite substantial literature on food selectivity and feeding problems in autism (food refusal, limited food repertoire, high frequency single food

intake, disruptive mealtime behaviours, oral motor delays), few studies to date have focused exclusively on the presence of ARFID in the autistic population. Much of our current understanding of ARFID is based on case reports or cross-sectional studies which are limited by small sample sizes and tend to represent the most notable or extreme examples. While these are useful, we will need randomised controlled trials over the coming years if we are to build a solid evidence base. Epidemiological studies are needed to establish the extent and nature of severe food selectivity and there may be value in exploring differences across the age range, for example, comparing eating disturbances in autistic toddlers vs. autistic adolescents. Finally, experimental work is needed to understand the mechanisms which underlie such issues. There are numerous drivers of food avoidance and restriction, for example, the role of oral health status and dental issues in autistic children and young people (Yashoda & Puranik, 2014), which warrant further research. This can lead to the selection and adaptation of pre-existing interventions that have proved successful, which in turn can give way to randomised controlled trials to establish effective ARFID treatments for autistic children and young people. In the longer term, such work may provide an insight into the contributing role of nutrition in poorer health outcomes for autistic individuals.

Table 7. Summary of articles relating to ARFID and severe food selectivity in autistic children and young people

Author(s) and year	Study aims	Study design and sample	Feeding/eating concerns and consequences	Main findings/outcomes
Hagopian et al. (1996)	To describe the feeding concerns and subsequent treatment of a patient with total food and liquid refusal	Case study 12-year-old autistic male	• Total food and liquid refusal and NG tube dependency • Medical history of life-threatening GI conditions • Admitted to inpatient unit • Frequent emesis resulting in total parenteral nutrition	• Backward chaining, fading and reinforcement used to increase liquid consumption
Freeman and Piazza (1998)	To report a patient with food refusal and destructive behaviour	Case study 6-year-old autistic female	• 4-year history of food refusal • Severe weight loss and dehydration • Occasionally consumed food that had been left out if others were not present • Aggression and self-injurious behaviour when required to eat	• Treated using stimulus fading, reinforcement and escape extinction • Intake increased and patient consuming 50% of age-appropriate meal
Dellatan (2003)	To describe the use of a music intervention of a 5-year-old male with chronic food refusal	Case study 5-year-old male with a diagnosis of PDD and autism	• Diagnosed with failure to thrive at 13.5 months • Oral food aversion • Dependence on NG tube (1-8 months) followed by a gastrostomy tube	• Significant decrease in food refusal behaviours • Increase in the quantity of food consumed
Luiselli et al. (2005)	To describe a liquid fading procedure used to increase consumption of milk	Case study 4-year-old autistic female	• Food selectivity and limited food repertoire (3 foods and fruit juice) • Reliance on oral nutritional supplement (Pediasure/50% whole milk)	• Taught to drink milk through a liquid fading procedure • Concentration of milk mixed with Pediasure gradually increased until at 100%
Uyanik et al. (2006)	To present the case of a child with autism and significant malnutrition resulting in xerophthalmia	Case study 8-year-old autistic male with epilepsy	• Very limited diet – fried potatoes and water • Vitamin A deficiency • Progressive visual impairment (unable to open eyes for the last 4 months)	• Treated with antibiotic drop therapy and intramuscular and oral multivitamin supplementation (including vitamin A palmitate) • Ophthalmic examination 1-month post-treatment showed prominent corneal

				improvement, patient was able to open his eyes and had regained some of his vision
Gravestock et al. (2007)	To describe the management of a man with Asperger's disorder, a chromosomal condition, and food refusal	Case study 20-year-old male with Asperger's disorder and XYY syndrome BMI 17.1 kg/m^2	• Choking episode at 19 years, triggering marked anxiety with eating and swallowing • Liquid food supplements given • Solid food refusal and 6kg weight loss in 3 months	• Intervention from speech and language therapist to re-introduce wider range of fluids and semi-solid foods, as well as individual CBT • Patient also given access to dietetic and mental health day services, advice from local social and employment support network and autism services • Patient more willing to eat preferred semi-solid foods and liquids and gradually gained weight over the next year (BMI 19.6) • Anxiety about swallowing and choking still significant and patient still reliant on Fortisip food supplements several times a day
Noble et al. (2007)	To describe the presentation and treatment of a child with severe nutritional deficiency and medical concerns as a result of severe food selectivity	Case study 5-year-old male with PDD, BMI 13.6 kg/m^2 (height 25th percentile, weight < 5th percentile) (Case 2 featured but no diagnosis of autism or PDD)	• Progressively restricted diet. By 3½ years, diet consisted largely of crackers, ice cream and water • Vitamin C level undetectable and diagnosis of scurvy given	• Patient hospitalised and gastrostomy tube placed for adequate caloric and vitamin intake • Vitamin C supplementation resulted in improved range of motion in legs, behaviour, and pain control • 2 months later – patient gained 12lbs and returned to school • 6 months later – 20lb weight gain
Paul et al. (2007)	To describe an intervention combining repeated taste exposure and escape prevention to treat two cases of food selectivity and refusal	Case study (1) 3½-year-old autistic male (2) 5-year-old autistic female	(1) Very limited diet (milk, grilled cheese sandwiches, hot dogs). Aggressive and disruptive mealtime behaviours and food refusal (2) Complete food refusal since acute illness 6 months ago (although diet was limited beforehand). Now completely dependent on gastrostomy tube	(1) Acceptance of 65 foods after 15 days of intensive treatment (2) Gastrostomy tube no longer required, and 49 foods accepted after 13 days of intensive treatment

Casey et al. (2008)	To describe chronic food refusal in a child with autism	Case study 8-year-old autistic male Below 5th percentile for weight and height	• History of food aversion and total food refusal • Lack of sufficient caloric intake to meet normal growth standards (diagnosed with failure to thrive) • Gastrostomy tube in place for four years	• Following behavioural intervention, total bite acceptance varied but was consistently above baseline levels • Weight increased (between 5th and 10th percentile) • G-tube removed
Keen (2008)	To describe the association between significant feeding difficulties and early onset failure to thrive	Case study 7 autistic patients (6 male, 1 female) Sample from a clinic population	• Severe feeding problems including refusal of solids, contamination fears, disinterest/absence of enjoyment, vomiting • Significant failure to thrive (fall across two major weight centile lines and BMI below the 0.4th centile in all cases) • Three children required enteral feeding (nasogastric/gastrostomy)	• Intensive, multimodal intervention to tackle dysfunctional sensory processing, attachment, cognitive inflexibility and learnt behaviours, and anxiety/phobia • The presence of severe and persistent feeding problems/failure to thrive in young children may indicate clinicians to the possibility of autism
Stewart and Latif (2008)	To describe the clinical characteristics and consequences of a severely restricted diet in a patient with autism	Case study 15-year-old autistic male (below the 0.3rd centile for height and weight)	• Poor diet since infancy (mainly chips and gravy, complete refusal of dairy) • Complaints of tiredness and muscular weakness • Reluctant to leave the house (minimal exposure to sunlight) • Diagnosis of vitamin D deficient rickets and hypogonadism	• Referrals made to a local dietitian and regional endocrine team • Calcium supplements and multivitamins given • 6 months later – asymptomatic with no muscle pain and good mobility, most abnormal blood parameters had normalised, beginning to catch up on growth • Meat and dairy products accepted into diet
Williams et al. (2008)	To examine parent feeding practices and their relationship to the weight status, diet variety and mealtime behaviours for a group of children with	*n* = 240 (*n* = 75 with autism, *n* = 85 with other special needs, *n* = 80 typically developing)	• Feeding problems experienced by children in the sample included: Food refusal; selectivity by texture; selectivity of type (narrow range, nutritionally inadequate) • The consequences of such problems were: Children not getting enough food to meet caloric or nutritional	• Multiple regression analyses found that age and diagnosis of autism were found to be significant predictors of weight status • Autistic children tended to exhibit less diet variety, with significantly fewer foods consumed compared to other children (consisting mainly of dairy products and starches)

	problematic eating/feeding		needs; weight to height ratio below 5th percentile; unable to maintain appropriate growth	
Binnendyk and Lucyshyn (2009)	To evaluate the effectiveness of a family-centred positive behaviour support approach to manage food refusal behaviour	Case study 6-year-old autistic male	• Limited diet consisting of soda crackers, rice, water, donuts, and cookies • Refusal to try new foods, with attempts ending in throwing, spitting, vomiting, self-injury, and aggression • Reliance on four cans of Pediasure each day	• Parent-led intervention used (following training and support) • High levels of food acceptance, mealtime behaviour improvements observed (sitting at the table alone, using utensils with minimal assistance) and family quality of life • Mealtime behaviours improved • Progress maintained up to 26 months post-intervention
Laud et al. (2009)	To evaluate treatment outcomes for an interdisciplinary feeding programme for child with challenging feeding behaviours	Retrospective chart analysis 46 autistic children (6 female, 40 male), mean age 69 months	• Various concerns including food refusal, limited variety of foods consumed, food selectivity by texture, failure to thrive	• Intensive interdisciplinary treatment programme involving a gastroenterologist, paediatrician, nurse practitioner and nutritionist • Significant improvement in feeding behaviours observed and maintained at follow-up
Sharp and Jaquess (2009)	To describe a treatment intervention used to increase volume and texture of food consumed by a child with severe food selectivity	Case study 3-year-old autistic male	• Severe food selectivity and food refusal • Diet consisting primarily of Pediasure delivered with a bulb syringe • Occasional acceptance of pureed bananas (stage 1 baby food) presented on a spoon	• Admittance to a day-treatment programme • Four 30-45 min therapeutic meals conducted each day by a trained therapist • Rapid acceptance of all bite sizes (although some gagging occurred with larger bites in the early stages of presentation) • Rapid acceptance of all textures, but some expulsions and gags with higher textures • By 12th day of treatment, caloric intake was sufficient to discontinue syringe feeds

Hendy et al. (2010)	To evaluate parent mealtime actions and their association with children's fussy eating	236 children (50 autistic, 84 with other special needs and 102 without special needs) 153 males, 83 females, mean age = 58.3 months	• Food fussiness, little variety • Parent providing 'special meals' separate to that given to family (consisting of child's favourite foods) • Underweight with BMI% less than 10 (10% of autistic children in current sample) • Reliance on nutritional supplement drinks	• One parent mealtime actions (special meals) was found to explain variance in children's BMI% and diet variety • Although preparation of special meals may improve BMI% and increase weight, it may also exacerbate rigid eating behaviours/food selectivity practices
Pineles et al. (2010)	To describe three cases of vision loss and optic atrophy as a result of vitamin B12 deficiency relating to poor diet in autistic children	Case series (1) 6-year-old autistic male (2) 13-year-old autistic male (3) 7-year-old autistic male	(1) Diet consisting primarily of bagels, cereal, and French fries; 1-month history of decreased visual acuity (2) Diet consisting primarily of potatoes, fruit, and bagels; gradual vision loss over 6-months (3) Diet consisting primarily of French fries and chicken nuggets; changing visual behaviour; recent difficulty navigating familiar areas;	• Visual behaviour improved in all three cases after beginning B12 supplementation
Roth et al. (2010)	To describe a multicomponent behavioural intervention used to manage severe food selectivity in an adolescent	Case study 16-year-old male with Asperger's disorder Height and weight – 3rd percentile	• Very selective eater at 4 years of age and began to refuse most food at 5 years of age • Lack of weight gain, poor growth • Dependence on gastrostomy tube for 9 years • Selectivity by type and texture – only water and 3 brand specific foods consumed (bowtie pasta, ham steak, and cereal)	• Intervention consisted of several components, including stimulus fading for solids and liquids, a token economy for solids, and an escape prevention component for liquids • Need for gastrostomy tube feeds eliminated • 78 foods and 13 drinks accepted • Treatment gains maintained 3 months post-intervention
Seiverling et al. (2011a)	To evaluate the 23-item Screening Tool for Feeding Problems with a sample of	*n* = 142 children (47 female, 95 male), mean age = 61.4 months	• Various feeding problems including food selectivity (type, texture, temperature), food refusal and vomiting	• Factor analysis revealed a more psychometrically sound 15-item version of the original 23-item STEP (Matson & Kuhn, 2001)

	children referred to a hospital-based feeding clinic	*n* = 43 with autism, *n* = 51 with other special needs, *n* = 48 with no special needs	• 33 children (27%) underweight with BMI less than 10th percentile	• Mediation analysis found that "overly permissive" actions by parents explained over 34% of the links between children's feeding problems and poor weight and diet outcomes
Seiverling et al. (2011b)	To develop a simple measure of Texture Problems relating to feeding difficulties and to identify child and parent variables associated with increased risk for Texture Problems	*n* = 248 children from a hospital feeding clinic (85 female, 163 male) mean age = 48.9 months *n* = 50 with autism, *n* = 96 with other special needs, *n* = 102 with no special needs	• Various feeding problems including food refusal, limited food repertoire, texture problems, reliance on enteral feeding, underweight	• Parents completed questionnaires to report their children's demographic and medical information, feeding issues and parent's mealtime actions • Difficulties with food texture was associated with younger age, males, and prematurity
Sharp et al. (2011)	To examine the nutritional status and mealtime behaviours of a group of children following an intensive feeding day-treatment programme	Retrospective chart review *n* = 13 children (2 female, 11 male) with a diagnosis of autism (i.e., autistic disorder, PDD-NOS) Age range: 2 years, 11 months to 7 years, 8 months (mean: 4 years, 5 months)	• Severely restricted diets, low rates of acceptance and swallowing, high rates of disruptive mealtime behaviours • Two children fell below the 3rd weight for height percentile	• Treatment involved escape extinction, reinforcement and stimulus fading procedure • Significant improvements observed in food variety, consumption, and appropriate mealtime behaviours • Caregiver training administered which maintained treatment gains
Tang et al. (2011)	To describe two cases of severe food selectivity and feeding problems	Case series (1) 10-year-old autistic female (2) 3-year-old autistic male	(1) Stopped drinking and food choices had become increasingly restrictive. Severe constipation, severe malnutrition, 20lbs weight loss over 4 months (2) Lethargy and general edema for 6 weeks. 2-year history of restrictive diet (pureed fruit and coconut juice) and refusal to eat anything but a specific brand in a certain container	(1) Admittance to hospital. Nasogastric tube placed which helped to increase weight from 68% to 75% (ideal body weight) but refusal to eat persisted. Behaviour modification plan implemented, and small portions of food were accepted (2) Admittance to hospital. Nutritional formula feedings administered via nasogastric tube. Weight gain was adequate and nutritional deficiencies became normal. Behavioural

			while holding his favourite blanket. Thin, scaly rash throughout body, hair thinning, anaemia, hypoalbuminemia, and hypoproteinaemia	modification programme implemented to overcome severe food aversion
Knapp et al. (2012)	To describe the implementation of a behavioural intervention to tackle severe food refusal and mealtime problem behaviours	Case study 16-year-old female with PDD-NOS	• Food refusal and mealtime problem behaviours including expulsion, head turning and batting at presented food • Patient would not swallow food, instead holding it in her mouth for an extended period of time • Interference with social activities (i.e., eating a meal out with her family) • Severely underweight	• Positive reinforcement intervention conducted in the lunchroom at school during scheduled mealtimes • Clinically significant reduction in problem behaviours observed and increase in acceptance and swallowing of food • Results were maintained at follow-up and the patient successfully ate lunch in various social settings
Knox et al. (2012)	To describe a teacher-led intervention used to treat an adolescent girl with chronic food selectivity	Case study 16-year-old autistic female	• Diet consisting primarily of "crunchy" foods (brand crackers, dry cereal, and apple juice) • Underweight for her age	• Paced-prompting, differential positive reinforcement and demand facing used in a natural setting (participant's school) to increase the quantity of novel foods consumed • Participant consumed 100% of her meals and exhibited no problem behaviours • At 7-month follow-up, improved consumption was maintained
Rogers et al. (2012)	To explore mothers' perspectives of managing the challenges of a child with autism and severe feeding/eating difficulties	Qualitative interviews 11 mothers (aged 28-47 years) 12 children with autism or Asperger's syndrome aged	• Severe food selectivity "more than just picky eating" • Food refusal, restricted and narrowing food repertoire in at least one food group (many in two or three)	• Four feeding processes emerged from the analysis: (1) recognising the feeding challenges, (2) defining the underlying nature of the feeding challenges, (3) seeking support for and validation
		from 4-10 years (11 male, 1 female)	• Sensory aversion, gagging, need for sameness (brands, taste, presentation, vessel) • Reliance on Pediasure for nutrition	• of the feeding challenges, and (4) staging their approach

			• Underweight, not following growth curve	• When feeding problems extend beyond mere picky eating, parents need support from professionals who validate their concerns
Berube et al. (2013)	To describe a patient with experiencing severe physical symptoms as a result of chronic vitamin C deficiency	Case study 11-year-old autistic female	• Diet very restricted for first several years of life (banana, yoghurt, milk, apple juice) • Several foods added as patient grew up, but diet still very restricted by sensory sensitivities • At 11 years, patient experienced difficulty walking, developed extensive bruising over her legs and gingivitis	• Clinicians assessed the patient and suspected that symptoms may be due to severe vitamin C deficiency as a result of her very limited diet • Liquid multivitamin supplement given and consultation with feeding team to implement strategies to broaden food choices and increase vitamin C in diet • Twenty days after hospital discharge, the patient's symptoms had completely resolved
Duvall et al. (2013)	To report a case of severe vitamin malnutrition as a result of a limited diet	Case study 9-year-old autistic male	• Limited diet consisting mainly of white foods. Refusal of milk, juice, vegetables, fruit and not taking any vitamin supplements • Development of a limp which continued to worsen until he was unable to move around, as well as laboured breathing • Tests revealed deficiencies in vitamins C, B1, B6, D (scurvy)	• Hospital admittance • Repletion of vitamin deficiencies via intravenous muscular injections • Respiratory rate returned to normal range and patient able to walk without pain • Patient discharged from hospital after 3 weeks to continue oral supplementation
Gongidi et al. (2013)	To report a case of a child with scurvy as a result of severe nutritional deficiencies	Case study 5-year-old autistic male	• Food-avoidant behaviours resulting in nutritional deficiencies • Development of abnormal gait with inward turning feet as well as leg and back pain • Other symptoms included gingival swelling, tenderness and swelling of wrists and multiple scabs and abrasions	• Hospital admittance • Repletion of Vitamin C which resulted in amelioration of symptoms and subsequent discharge

			• MRI scans revealed abnormalities, leading to a diagnosis of scurvy	
Kadey et al. (2013)	To describe the use of a Nuk brush to increase acceptance of foods and liquids in two children with selective eating behaviours	Case series (1) 3-year-old autistic male (2) 9-year-old autistic female	(1) Consumption of 13 foods, primarily white or beige in colour (no fruits or vegetables). Refused to consume milk from anything other than a baby bottle (2) Severe food and drink selectivity and challenging behaviour. All meals consumed while lying in her parent's bed. Refusal to drink from age-appropriate cup. Lack of (3) nutritional content and consumption of calories well above what was recommended for her age	• Physical guidance using a Nuk brush used to increase acceptance of solids and liquids (1) Improvement in acceptance of foods and liquids. Over time, session durations decreased and feeding sessions more efficient (2) Independent acceptance (picking up the spoon/cup without assistance and placing food/liquid in mouth) occurred very quickly (Analysis 2). With Nuk procedure, independent (3) acceptance increased for all food and liquids except macaroni and cheese
Marshall et al. (2013)	To provide information about the current management of feeding difficulties in children with autism	*n* = 96 respondents (clinicians in Australia working with autistic children with feeding difficulties)	• Patients presented with a number of feeding difficulties including restricted diet, inability to tolerate changes in appearance, type or texture and limited food repertoire (eating the same foods at every meal) • 41% of patients presented with low weight (just 8% were overweight) • Dependency on enteral feeding (35%) • Oral nutritional supplementation	• Electronic survey administered to clinicians • Speech-language pathologists most commonly provide feeding services to this population • Although some trends towards specific service delivery and interventions were observed, overall results indicated variability in practice • Low levels of clinician confidence and perceived success of therapy observed
Keown et al. (2014)	To describe the case of a young child with a restricted diet and nutritional deficiencies	Case study 4-year-old autistic male	• Restricted dietary intake, limited to chocolate bars, wafers, battered chicken breast and dry bread • Food selectivity specific to type and brand	• Consumption of carrot juice weaned gradually • Easting behaviours addressed with structured mealtimes and strategies implemented for diet diversification • Vitamin D and calcium supplement

			• Consumption of excessive amounts of carrots juice (in excess of 2.5L per day) • Orange discolouration of the skin, raised serum carotene in the blood and vitamin D deficiency	• Specialist, multimodal input from autism service, speech and language therapists, dietetics, occupational therapy, and educational psychology • Although carrot juice consumption was significantly reduced, patient refused to take vitamin D supplement, and 6-month follow-up blood tests show persistent deficiency
Levin et al. (2014)	To discuss non-removal procedures used to address two cases of severe food selectivity	Case series (1) 4-year-old autistic male (2) 4-year-old autistic female	(1) Failure to thrive, receiving more than 90% of calories via gastrostomy tube. Consumption of 4-5 ounces of water or juice, small amounts of chicken stars soup and corn puffs, popcorn, and crackers (held in the mouth until dissolved). Also, milk-soy protein intolerance, food allergies, gastroesophageal reflux, and vomiting (2) Limited diet (vanilla rice milk, pear juice, Stages 2 and 3 baby foods) Diagnosis of dysphagia and followed gluten-free, casein-free diet	(1) Outpatient treatment feeding disorders programme. Non-removal procedures increased acceptance of 12 pureed foods, but participant began frequently packing starches and peas. This was successfully reduced with a combination of re-distribution, swallow facilitation and chaser treatment. On discharge, the patient consumed age-appropriate portions of several table foods with just 2 ounces of Neocate Jr. via gastrostomy tube (2) Day-treatment feeding disorders programme. Multi-component treatment needed to reduce packing – re-distribution, swallow facilitation and chaser, as well as differential positive and negative reinforcement.
Williams and Hendy (2014)	To compare child and parent variables associated with complete oral calorie	Chart review 281 children referred to hospital-based feeding clinic	• Underweight (below 5th percentile for height) • Restricted diet • Reliance on nutritional supplements	• Chi-square analyses compared children who received supplements with those who didn't • Children receiving supplements for feeding difficulties were younger, more underweight,

	supplement use among children with feeding problems	*n* = 114 who received supplements (70.2% male, mean age 60.1 months, 23.7% with autism) *n* = 167 not receiving supplements (79.6% male, mean age 67.5 months, 35.9% with autism)	• Mealtime behaviour problems such as lack of enjoyment, slow eating, food fussiness	showed more food satiety, were slower eaters and showed less food responsiveness and less food enjoyment • 78.2% of children receiving supplements were normal weight or overweight, suggesting that parents use them to tackle severe food selectivity (and not just low weight/weight loss)
Baird and Ravindranath (2015)	To review the clinical course of a child with a severely limited diet and vitamin deficiencies	Case study 11-year-old autistic male	• For several years, refusal to eat anything except chicken nuggets from a particular fast-food restaurant and occasional French fries • Had not eaten fruit, vegetables, or any milk products for a number of years • Deficient in multiple micronutrients, including thiamine, pyridoxine, vitamin A, copper, iron, and vitamin K • Several serious health issues recorded, including liver dysfunction and lactic acidosis	• Patient hospitalised and parenteral nutrition initiated • Gradually increased nasogastric tube formula feeds (Pediasure) • Test of liver dysfunction gradually improved and patient discharged 1-month after admission to chronic care facility • Patient lost to follow-up
Johnson et al. (2015)	To pilot a behavioural parent training programme for autistic children and feeding problems	Pilot trial *n* = 14 autistic children (aged 2-7 years)	• Feeding problems defined by specific criteria including: a definite concern about the child's nutrition, child engages in disruptive mealtime behaviours, is selective about texture, colour, brand, appearance • One participant underweight (BMI < 5%)	• Parents participated in a 9-session programme delivered individually over 16 weeks • Feeding concerns and disruptive mealtime behaviours significantly reduced over the trial • Significant reduction in parental stress
Tanner and Andreone (2015)	To describe the use of a graduated exposure intervention to treat a	Case study 3-year-old autistic male	• Consumption of four foods only, 3-5 cups of apple juice per day and reliance on nutritional supplement drink	• 12-step graduated exposure food hierarchy used as well as parent-training

	child with severe food selectivity		• Food selectivity by brand, texture, temperature, and utensil used	• 9-months post-treatment, participant's food repertoire had increased to more than 50 items • Food refusal behaviour had decreased
Amos et al. (2016)	To describe the case of a young adult with a diet severely deficient in ascorbic acid, resulting in scurvy	Case study 17-year-old autistic male	• Diet very limited, consisting primarily of grilled cheese sandwiches, cottage cheese, chocolate milk and soda (no fruits or vegetables) • Food selectivity due to textural aversion • Patient presented to medical care with fever, jaundice, anaemia, constipation, and left knee arthritis • Vitamin C level very low	• Diagnosis of scurvy • Started on intravenous ascorbic acid 250mg daily, which transitioned to 250mg orally twice daily • Decreased swelling in left knee and patient was discharged home • 8-months post-discharge, patient reported no joint pain or selling, jaundice had resolved, and vitamin levels were normal • He remained on vitamin C and multivitamin supplementation
Castro et al. (2016)	To evaluate dietary intake and identify feeding problems in participants with autism compared to neurotypical matched controls	Case control study 49 males with autism (aged 4-16 years) and matched controls	• Limited food repertoire, nutritional deficiency, low height-for-age, low BMI-for-age	• 3-day food record taken, and nutrient intake compared to the Dietary Reference Intake according to age • Behaviour Pediatrics Feeding Assessment Scale (BPFA) used to evaluate parent/caregiver feelings • Autistic patients consumed on average more calories than controls, had a limited food repertoire, and consumed inadequate levels of various nutrients (including calcium, sodium, iron, and vitamin C) • BPFA scores higher in the autistic group, indicating higher levels of problematic feeding behaviour

González and Stern (2016)	To explore the co-occurring behavioural difficulties that present alongside severe food refusal/selectivity	Descriptive study 54 children, aged 2-12 years (28% female) *n* = 15 with autism	• Tube dependence (gastrostomy or nasogastric) (59% of sample) • Liquid dependence (receiving at least 75% of caloric intake from liquids orally) (6%) • Selectivity based on type or texture/limited food repertoire (consumption of type or amount not sufficient to be developmentally and/or nutritionally appropriate) (35% of sample)	• Medical charts of patients reviewed – age, presence of developmental delay/autism, and type of feeding problem examined as predictors of behavioural support • Approximately half of the sample received coaching or individualised intervention • Younger age was a predictor of individualised caregiver coaching • Individualised behavioural interventions were more likely to be provided to autistic children or those with developmental delays • Despite that, behavioural concerns outside of the feeding difficulty (aggression, disruption, self-injury) appear to be common for children with and without developmental delays and autism
Ma et al. (2016)	To review the number of cases of scurvy seen at Boston Children's Hospital over a period of 18 years	Retrospective chart review/case studies *n* = 7 males (3-11 years) 57% with autism	• All children had extremely picky eating habits, choosing from a selective list of foods with minimal sources of vitamin C • 3 cases presented. Symptoms included limping, gingival swelling, knee and hip pain, fatigue, weight loss	• Treatment with vitamin C and a multivitamin led to immediate improvement in symptoms
Cosbey and Muldoon (2017)	To evaluate the effectiveness of a family-centred feeding intervention Easing Anxiety Together with Understanding and Perseverance (EAT-UP) to promote food acceptance	(1) 6-year-old autistic male (2) 8-year-old autistic male (3) 7-year-old autistic male	(1) Refusal to remain at the table to eat family meals. Preference to consume granola bars and other snack foods at non-mealtime (2) Typically ate meals alone at a desk in the living room or in the car. Tendency to spit masticated food into his palm and put it back in his mouth multiple time before swallowing. Participants was significantly overweight, primarily	• Intervention-coaching phase taught caregivers how to implement strategies to increase food acceptance • Once the caregiver demonstrated the ability to implement at least 90% of the strategies, they moved onto an intervention-independent phase • Data collected via direct observation and pre- and post-intervention questionnaires

			consuming highly processed fast food and very particular about brand (no fruits and vegetables) (3) Diet consisted mainly of crunchy and sweet food and milk (reliance on nutritional supplement drink). No fruit or vegetables and dislike of wet foods. No social component to meals and participant often ate alone in front of the television	• All children demonstrated increases in food acceptance and dietary diversity, as well as a decrease in challenging mealtime behaviours
Lucarelli et al. (2017)	To describe the management of a young autistic child with ARFID	Case study 4-year-old autistic female with ARFID	• Persistent bottle refusal and acceptance of few pureed foods • Diet consisted of French fries, Ritz crackers, pretzels and 32 ounces of soy formula daily • Other aspects of feeding controlled including insistence on parking a specific space at a fast-food restaurant and drinking from a particular cup	• Therapy using a systematic desensitisation approach with rewards • Mother also advised to support child at home • Some early progress observed but parents decided to discontinue treatment with concerns that it was too harsh • Weight is stable but diet still very limited
Planerova et al. (2017)	To describe the presentation and treatment of a child with significant nutritional deficiencies as a result of behavioural food aversions	Case study 10-year-old male with Asperger's syndrome BMI 15.29 kg/m^2	• Limited food repertoire. Diet for the last several years of McDonald's pancakes, potato bread and plain cheese pizza • 6 months before presenting for medical care, patient was only consuming water and bread • Complaints of left ankle pain, refusal to walk and gingival bleeding • Other symptoms included cachexia, swollen gums, poor oral hygiene, and significant anxiety	• Admittance to hospital for 17 days • Patient did not tolerate a nasogastric tube, so a percutaneous gastrostomy tube was placed for enteral feeds (Pediasure) • Repletion of vitamin deficiencies and medication to treat anxiety, gingivitis, and leg pain
Taylor et al. (2017)	To compare the effectiveness of using applied behaviour analytic interventions	Children with a diagnosis of autism (*n* = 25) or cerebral palsy *(n* = 33)	• Food refusal resulting in chronic gastrostomy tube dependence • Long history of previous failed attempts to eliminate tube dependence	• Individualised behavioural treatment consisting of escape extinction

	to address feeding difficulties and tube dependence in children enrolled in a hospital-based feeding programme	Age range 20-148 months (mean = 69.53)		• Treatment success similar across groups – increase in gram consumption and decrease in food refusal
Kinlin et al. (2018)	To describe the clinical presentation of a patient with significant nutritional deficiencies resulting in scurvy	Case study 10-year-old autistic male Weight below 3rd percentile	• Long-standing significantly restricted diet • Mild anaemia and deficient in vitamins C, A, D, and zinc (diagnosis of scurvy strongly suspected) • Presented to emergency department with right ankle swelling and bruising	• With treatment, the patient experienced rapid improvement in symptoms • Physiotherapy arranged for ongoing rehabilitation • Referral made to nutrition clinic and vitamin supplementation continued post-discharge
Muldoon and Cosbey (2018)	To outline the usefulness of the family-centred feeding intervention Easing Anxiety Together with Understanding and Perseverance (EAT-UP)	Three families of children with autism receiving services from an outpatient department (1) 3-year-old autistic male (2) 5-year-old autistic male (3) 4-year-old autistic male	(1) Repetitive diet, eating the same food every day. Comorbid diagnoses of insomnia, expressive language disorder and constipation. Not able to remain at the table during mealtime (2) Limited diet of crackers, cookies, chips, and yoghurt. Additional diagnoses of mixed receptive-expressive language disorder and global developmental delay (3) Feeding difficulties and slow weight gain. Difficulty following directions and additional diagnoses of expressive language disorder and global developmental delay	(1) Increased food acceptance and dietary diversity, decrease in problem mealtime behaviours (2) Increase in variety of foods consumed, acceptance of different brand and flavour of yoghurt (3) Weight gain of 8 lbs and increase in food repertoire
Saavedra et al. (2018)	To report the case of a child with suspected scurvy as a result of severe food selectivity	Case study 4-year-old autistic male	• Complaints of hip pain, refusal to walk, petechiae and bruising of lower limbs • Mild anaemia	• Treatment with ascorbic acid and nutritional support offered to increase dietary variety • Patient discharged with reduced pain and gait recovery

			• Suspected scurvy • Severe food selectivity since 18 months of age – mainly wheat and dairy snacks with no fruits or vegetables	
Seiverling et al. (2018)	To compare a behavioural feeding intervention with and without pre-meal sensory integration therapy to treat severe food selectivity	(1) 5-year-old autistic male (2) 6-year-old autistic female	(1) Completely dependent on paediatric formula and whole milk via baby bottle to meet his nutritional needs. Feeding therapy at school had resulted in small licks of soup, apples, and strawberries. Refusal to try anything else (2) Diet included yoghurt, hot breakfast cereal and one type of cookie. Weight had dropped from 73rd to 56th percentile in the last year and a half	• Behavioural feeding intervention + sensory integration therapy – child bite and drink consumption and total intake increased, with decreases in inappropriate mealtime behaviours • Behavioural feeding intervention alone – Sensory integration therapy was discontinued but treatment progress remained stable • Caregiver training was given to continue intervention at home • Follow-up data showed maintenance of treatment gains over time
Sharp et al. (2018)	To examine the demographic characteristics, anthropometric parameters, risk of nutritional inadequacy, dietary variety, and problematic mealtime behaviours of a sample of children presenting to a feeding clinic in the US between Jan 2014 – Jan 2016	Medical record review 70 children (age 2-17 years) with autism and probable ARFID	• 67% of the sample omitted vegetables (n = 47) and 27% omitted fruits (n = 19) • 78% consumed a diet at risk of five or more inadequacies (vitamin D, fibre, vitamin E, calcium) • Severe food selectivity was not found to be associated with compromised growth or obesity	• The study underscores the importance of evaluating nutritional status in children with autism

Johnson et al. (2019)	To evaluate the efficacy of a new 11-session parent training programme to address feeding problems	Pilot RCT 42 children with autism (age 2-11 years)	• Substantial feeding/mealtime problems (score greater than 54 on the Brief Autism Mealtime Behaviour Inventory-Revised (BAMBI-R) • Food selectivity, food refusal, disruptive mealtime behaviours • Nutritional deficiencies	• Participants randomly assigned to 11 sessions of the intervention over 20 weeks or a waitlist control • The intervention group showed significantly greater improvement than the control group on measures of feeding problems including food selectivity and disruptive mealtime behaviours
Peterson et al. (2019)	To evaluate the effects of an intervention used to encourage independent acceptance and mouth clean of healthy, novel, and non-preferred foods	RCT *n* = 6 children with autism (*n* = 4 5-years old, *n* = 1 3-years-old)	• Food selectivity (more than 3 but less than 20 foods consumed by mouth) • Diet nutritionally deficient (i.e., nutrition from one source, daily consumption of less than 80% vitamins and minerals)	• Patients randomly assigned to an applied behaviour analytic intervention or a wait-list control (wait-list control patients later exposed to intervention) • Independent acceptance and mouth clean of 16 novel foods was recorded • % of independent acceptance and mouth clean increased for the intervention group but not for the control group (until intervention was implemented)
Rafee et al. (2019)	To present the case of an adolescent with food selectivity resulting in severe vitamin C deficiency	Case study 14-year-old autistic male	• Limited food repertoire (narrow range of foods consumed, but consumed large amounts of preferred foods) • Food selectivity based on texture, taste, and preparation method. Fruit and vegetables denied (apart from bananas) and severe aversion to citrus fruits • Medical symptoms included pain and swelling of left leg, anaemia, anxious, dehydrated, bruising, painful joints, recurrent nosebleeds, and gingival bleeding (suspected scurvy)	• Admission to hospital for 7 days • Patient was rehydrated and given antibiotics and a blood transfusion after drop in haemoglobin • Vitamin C and iron replacement therapy • Education on nutrition and diet provided • 22 weeks post-discharge – complete resolution of leg swelling, corrected vitamin C and iron levels, improved haemoglobin levels • Three-year follow-up – patient seen by occupational therapy, psychology, gastroenterology to address food selectivity. Marginal improvements noted and use of vitamin supplementation in diet (still experiencing ulcers and chronic constipation)

Seiverling et al. (2019)	To develop and test the 22-item Sensory Eating Problems Scale (SEPS)	449 caregivers and their children (67.9% male, mean age = 69.59 months) Children divided into three groups: autistic (*n* = 156), other special needs (*n* = 144), no special needs (*n* = 149)	• Children referred to feeding clinics for various problems including failure to gain weight, dependence on enteral feeding or oral supplements, difficulties with texture and limited diet variety	• The 22-item SEPS allows clinicians and researchers to examine specific sensory eating problems, including Food Touch Aversion, Single Food Focus, Gagging, Temperature Sensitivity, Expulsion and Overstuffing • Three SEPS subscales (Food Touch Aversion, Expulsion and Overstuffing) were greater in autistic children and those with other special needs • Food Touch Aversion, Gagging, Temperature Sensitivity and Expulsion were associated with younger age
Smith et al. (2019)	To compare the use of escape extinction procedures combined with noncontingent access to escape extinction alone to increase liquid consumption	Case study 4-year-old autistic male	• Inappropriate mealtime behaviours and refusal to eat (gagging, coughing, hitting) • Dependence on gastrostomy tube for caloric and nutritional intake • Failure to thrive	• The results indicated that a combination of escape extinction procedures along with noncontingent access to a reinforcer (music) was more effective at increasing oral consumption and decreasing inappropriate mealtime behaviours • At follow-up, the patient was consistently accepting an average of 60 drinks per 50-min session • Parent training was given so that treatment could continue to be implemented at home
Taylor (2020)	To assess the effectiveness of the side deposit procedure (placing food into the side of the mouth) in an intensive home-based programme setting in Australia	2 male autistic children	• Child 1 (age 5) – no fruits or vegetables, very limited diet, did not dine out or consume school meals. No self-feeding • Child 2 (age 4) – baby bottle/formula dependence, iron deficiency requiring supplementation, no foods eaten from any food groups. Would only consume crackers and cookies, and a homemade fruit smoothie. Would not	• Child 1 (1 month follow-up) – mother reported that child was eating everything at home and in the community. At 3-month follow-up, consumption was 100% and independence high. 3-year follow-up – willing to try new foods but some rigidity (i.e., preferring vegetables boiled his mother's way) • Child 2 (2 week follow up) – consumption at 100%. 6-month follow-up, child reported to eat an adequate volume at home and

			accept multivitamins and some liquid medications	mealtime behaviour better but would not eat a wide variety at school or missed foods (casseroles, spaghetti Bolognese)
Zavaleta and Burt (2020)	To present the case of an autistic adolescent and a limited diet resulting in severe vitamin C deficiency	Case study 13-year-old autistic male	• Significantly restricted diet largely consisting of cheese crackers and soda • Recent history of abdominal pain, progressively decreasing haemoglobin, possible gingivitis, fatigue, mild anaemia • Significant vitamin C deficiency	• Hospital admittance • 7-day course of 100mg vitamin C intravenous every 8 hours normalised the child's vitamin C level

*Note. NG = nasogastric; GI = gastrointestinal; CBT = cognitive behavioural therapy; PDD = pervasive developmental disorder; PDD-NOS = pervasive developmental disorder not otherwise specified; RCT = randomised controlled trial

Chapter 4: Investigating the Prevalence and Risk Factors of Picky Eating in a Birth Cohort Study

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Abstract

Aims: This study aimed to investigate the prevalence of childhood picky eating and to identify risk factors associated with different picky eating trajectories using data from the Growing up in Scotland research survey.

Methods: Picky eating was operationalised using three items across three study sweeps, at ages 2, 5 and 10 years respectively. From this, three picky eating categories were defined: transient picky eating in early childhood (23.3%), persistent picky eating into late childhood (3.7%) and picky eating absent (73.0%). Using multinomial logistic regression, we investigated associations between child and family characteristics and transient and persistent picky eating, adjusting for potential confounders.

Results: We found 13.5% of children with picky eating at age 2, 22.2% at age 5, and 6.4% at age 10. Various factors were associated with increased risk of persistent pickiness, including mothers who smoked during pregnancy and children whose mothers reported feeding challenges at 9-12 months.

Conclusions: These findings support the view that picky eating behaviours are common and tend to remit by adolescence although a small number of children are at risk of experiencing longer term problems. Families of children who are exposed to such risks may benefit from preventative interventions.

Introduction

The term picky eating refers to a range of restrictive eating behaviours. While there is currently no universally agreed definition for picky eating, it is often characterised by limited interest in food or enjoyment of eating, rejection of specific foods and/or new foods, slowness in eating, or strong preferences for certain foods or preparation methods (Dovey et al., 2008; Jacobi et al., 2008; Shim et al., 2011; Tharner et al., 2014).

Picky eating is often regarded as a common phase of development, which peaks in early childhood (Cardona Cano et al., 2015a; Cardona Cano et al., 2015b; Keen, 2008; Marchi & Cohen, 1990; Nicholls et al., 2001; Taylor et al., 2015). Although it can be a concerning time for parents, such behaviours are often transient and there is no evidence to date which suggests that this affects development or physical health. Therefore, it is rarely necessary to conceptualise them as problematic. However, picky eating can pose risks to longer term health and development if characterised by intake of an inadequate variety or amount of food and if persisting into late childhood and adolescence (Taylor et al., 2019a; Taylor et al., 2019b). In such cases, picky eating can be classified as disordered, potentially warranting a diagnosis of avoidant restrictive food intake disorder (ARFID), a clinical eating disorder that describes severe or prolonged restriction of the volume and/or variety of food leading to disruptions in weight/growth trajectories, nutritional deficiencies and/or psychosocial impairment (APA, 2013).

Findings of existing studies suggest that children with picky eating behaviours have stronger likes and dislikes and less acceptance of new foods (Mascola et al., 2010), and tend to consume fewer calories (Jacobi et al., 2003). Some evidence also indicates that children with picky eating behaviours have a lower weight compared to those without (Dubois et al., 2007; Herle et al., 2020), although findings have been mixed (Taylor et al., 2019a). Evidence also shows that the incidence (Mascola et al., 2010) and prevalence (Cardona Cano et al.,

2015b) of picky eating declines across childhood and that it is a persistent phenomenon only in a small proportion of children. For instance, a cohort study of 4018 children found that 27.6% experienced picky eating at age 3 years, but only 13.2% had these behaviours three years later (Cardona Cano et al., 2015b).

Previous studies have evidenced several associated risk factors for persisting picky eating. These include maternal negative affect, early feeding challenges, lower socioeconomic status, and developmental delay (Cardona Cano et al., 2015b; Dubois et al., 2007; Emmett et al., 2018; Hafstad et al., 2013; Putnick et al., 2022). Further, persisting picky eating has been found to be more common in males, in children with a lower birth weight and in those with mothers from ethnic minority groups (Cardona Cano et al., 2015b). Feeding challenges in the first year of life can also be indicative of different issues. For example, early feeding difficulties may present as a risk factor for later concerns, particularly if worried parents feel the need to use force or coercion with food, leading to the development of negative associations with food and mealtimes (Haycraft & Blissett, 2012). Alternatively, they could be an early marker of longer term or inherent issues, such as sensory sensitivities or a low appetite (Zucker et al., 2015).

Understanding risk factors associated with persistent picky eating could lead to a better understanding of their aetiology and the development of preventative interventions. Nevertheless, research is limited, has rarely followed children until late childhood, and has not investigated important correlates such as autism diagnoses, and factors relating to pregnancy and birth. To address these limitations, this study has the following aims:

1. To classify participants according to picky eating status: those who experience picky eating for a short period (transient picky eating in early childhood); those who experience picky eating for a prolonged period (persistent picky eating into late childhood); and those who never experience picky eating (picky eating absent).

2. To investigate the prevalence of transient picky eating in early childhood and persistent picky eating into late childhood.
3. To identify the child and family characteristics associated with different picky eating profiles.

Methods

Sample

Growing up in Scotland (GUS) is a national longitudinal birth cohort study carried out by ScotCen Social Research on behalf of the Scottish Government.

We used data from the first GUS birth cohort, or BC1, a nationally representative cohort of families with children born between June 2004 and May 2005 randomly sampled from those living in Scotland and in receipt of a universal child benefit (97% of the Scottish population). Data were collected annually when the children were around 10 months old up until 6 years of age, and then biennially thereafter. When there was more than one eligible child per household, GUS selected one child at random. We also excluded data from respondents who were non birth mothers[v], as several variables related to pregnancy and birth, and therefore, were most reliably taken from those who had given birth to the study child.

In this study, we described sample characteristics and estimated prevalence of picky eating behaviours among participants with complete outcome data. We conducted our main analyses on all GUS participants meeting our inclusion criteria, imputing any missing exposure or outcome data.

The Scotland 'A' MREC committee (application reference: 04/M RE 1 0/59) gave ethical approval. Further details on the GUS cohort are available at https://growingupinscotland.org.uk/.

[v] Non birth mother refers to caregivers who did not give birth to the study child (i.e., adoptive/foster mothers, fathers, grandparents, etc)

Outcomes

Picky Eating

Given the lack of a universally accepted definition or measure of assessment (Taylor et al., 2015), there is great variability in the measurement of picky eating. We operationalised the outcome variable using three items across three study sweeps.

At ages 2 and 5, parents were asked, "How would you describe the variety of foods that [child] generally eats? Does she/he: (1) Eat most things, (2) Eat a reasonable variety of things, or (3) is she/he a fussy eater?". We classified children with picky eating if parents answered (3). A similar question was used in a previous study by Mascola et al. (2010).

Since the above question was not given to participants in sweep 8, we chose the following item to identify children with picky eating at age 10, "At the main meal, is [child] served different food from adults? (1) Never, (2) Occasionally, (3) Quite often, or (4) Mostly." We classified children with picky eating if parents answered (4). This draws on the definition of picky eating posited by Dubois et al. (2007) as children who always eat a different meal to other members of the family.

We considered children with picky eating at either 2 or 5 years (or both), but not at 10 years as those with transient picky eating in early childhood (hereafter 'transient picky eating') and those with picky eating at either 2 or 5 years (or both) and also at 10 years, as those with persistent picky eating into late childhood (hereafter 'persistent picky eating'). We captured picky eating at age 2 and/or age 5, when food fussiness is considered relatively common. We felt that picky eating at either or both of these time points that no longer posed a problem at age 10, could indicate this common phase (i.e., transient picky eating). Conversely, since children have emerged from 'early childhood' by age 10, any persisting picky eating behaviours may be indicative of a pervasive issue or underlying eating disorder (i.e., ARFID).

Exposures

We considered a number of maternal, child and demographic factors previously suggested as risk factors for picky eating as exposures (Cardona Cano et al., 2015a; Cardona Cano et al., 2015b; Fisher et al., 2014; Hafstad et al., 2013; Moroshko & Brennan, 2013; Shim et al., 2011; Striegel- Moore et al., 2000; Striegel-Moore et al., 2003). These included socioeconomic position (as indexed by maternal education and household income), pregnancy- and birth-related factors (smoking and alcohol consumption during pregnancy, birth weight [in grams], pre-term birth), maternal stress and depression (each measured with three items from the Depression, Anxiety and Stress Scales [DASS-21], Lovibond & Lovibond, 1995; full item list in **Appendix 1**), the presence of an autism diagnosis, and measures of problematic feeding at 0-3 and 9-12 months. Data on all variables were collected via self-report from the child's birth mother, and the majority at sweep 1, thereby ensuring that the exposure preceded the measurement of the outcome and limiting the potential for reverse causation (see supplementary **Appendix 2** for a full list of variables used and the sweep they were measured at).

A measure of autism spectrum disorder (hereafter 'autism') was aggregated at ages 5, 6, 7, 10 and 12. Mothers were asked 'Has child additional support needs?' and if so, required to select from a list, with 'Autistic Disorder' as one option. Children whose mothers replied yes to this question at least once across the five sweeps were noted as autistic, providing that there were no contradictory responses thereafter. If mothers responded yes and then no at a later sweep, autism was not recorded. As a sensitivity analysis to increase statistical power, we also defined children as autistic if the mother said yes at any of the sweeps, regardless of any subsequent contradictory report.

Data Analysis

All statistical analyses were conducted using Stata release 17 (Stata Statistical Software: Release 17, 2021). We describe prevalence of picky eating and describe sample characteristics using frequencies and proportions.

In our main analyses, we imputed missing exposure and outcome data using multiple imputation by chained equations, imputing 50 data sets. Imputation models included all variables in the analyses (outcomes and exposures) and a number of auxiliary variables hypothesised to be associated with missingness to improve precision of imputation (i.e., mother's self-reported general health - see **Appendix 2** for further detail).

In this imputed sample, to investigate the association between exposures and transient or persistent picky eating, we used univariable and multivariable multinomial logistic regressions. For all models, we report relative risk ratios, 95% confidence intervals (CI), and *p*-values. Relying on binary interpretations of *p*-values (i.e., using 0.05 as a threshold for statistical significance) could increase risks of type I and II errors, the latter being a key concern in the presence of uncommon exposure/outcome combinations resulting in low statistical power. To minimise this risk, we jointly used 95% CI and *p*-values - viewed as a continuum of probability - to reflect on the strength of the evidence against the null hypothesis in the context of each model, as recommended by the literature (Sterne & Smith, 2001). Generally, *p*-values exceeding 0.1 are taken to indicate increasingly weaker evidence in support of the null-hypothesis; *p*-values between 0.1 and 0.001 indicate increasingly strong evidence against the null-hypothesis; and *p*-values below 0.001 indicate very strong evidence against the null-hypothesis.

We first ran univariable models for each of the exposures under investigation. Subsequently, we ran multivariable models adjusting each variable for potential confounders of its association with the outcome (picky eating status). We defined confounders as factors

which could have caused both the exposure and the outcome and could not have been on the causal pathway between the two. For instance, we adjusted child's birth weight for gestational age, as prematurely born babies will likely have a lower birth weight than those born at term.

To further assess the robustness of our findings, a number of sensitivity analyses were conducted. We calculated the prevalence of picky eating at each study sweep with the sample including non birth mothers and conducted univariable and multivariable logistic regression models using complete case analyses (participants with complete data on all outcome and exposure variables). We also coded any child as autistic with at least one record of autism and assessed the association between picky eating status and an autism diagnosis.

We only present unadjusted relative risk ratios for both child sex and child ethnicity as neither can be affected by external influences. **Table 8** provides a full list of exposures and confounding variables used for each of these.

Table 8. Confounding structure of risk factors used in regression models

	Risk factors	**Confounders**
1. Child socio-demographic characteristics	Child sex	-
	Child ethnicity	-
2. Family socio-economic/demographic characteristics	Mother's highest education level	Maternal age (at birth of cohort child)
	Maternal age (at birth of cohort child)	Highest education level
	Household income	Maternal age (at birth of cohort child) Highest education level
3. Pre-natal risk factors	Smoking during pregnancy	"Family socio-economic/demographic characteristics" Alcohol pregnancy
	Alcohol consumption during pregnancy	"Family socio-economic/demographic characteristics" Smoking pregnancy
4. Perinatal risk factors	Type of delivery	"Family socio-economic/demographic characteristics" "Pre-natal risk factors" Gestational age
	Child's gestational age	"Family socio-economic/demographic characteristics" "Pre-natal risk factors" Type of delivery
	Child birth weight in grams (standardised)	"Family socio-economic/demographic characteristics" "Pre-natal risk factors" Gestational age Type of delivery
	Did child spend any time in a special baby unit?	"Family socio-economic/demographic characteristics" "Pre-natal risk factors" Type of delivery Gestational age Birth weight in grams (standardised)
5. Maternal mental health	DASS Stress[vi]	"Family socio-economic/demographic characteristics" "Pre-natal risk factors" "Perinatal risk factors" DASS Depression

[vi] DASS-21 Stress measure taken from Sweep 2

	DASS Depression[vii]	"Family socio-economic/demographic characteristics" "Pre-natal risk factors" "Perinatal risk factors" DASS Stress
6. Child factors	Feeding problems 0-3 months	"Family socio-economic/demographic characteristics" "Pre-natal risk factors" "Perinatal risk factors" "Maternal mental health" Child ethnicity Concerns regarding development
	Feeding problems 9-12 months	"Family socio-economic/demographic characteristics" "Pre-natal risk factors" "Perinatal risk factors" "Maternal mental health" Child ethnicity Feeding problems 0-3 months Concerns regarding development
	Age at introduction of solid food (months)	"Family socio-economic/demographic characteristics" "Pre-natal risk factors" "Perinatal risk factors" "Maternal mental health" Child ethnicity Feeding problems 0-3 months Feeding problems 9-12 months Concerns regarding development
	Concerns regarding development	"Family socio-economic/demographic characteristics" "Pre-natal risk factors" "Perinatal risk factors" "Maternal mental health"
	Autism[viii]	"Family socio-economic/demographic characteristics" "Pre-natal risk factors" "Perinatal risk factors" "Maternal mental health" Child sex Concerns regarding development

[vii] DASS-21 Depression measure taken from Sweep 2

[viii] Variable derived from questions at Sweeps 5, 6, 7, 8 and 9

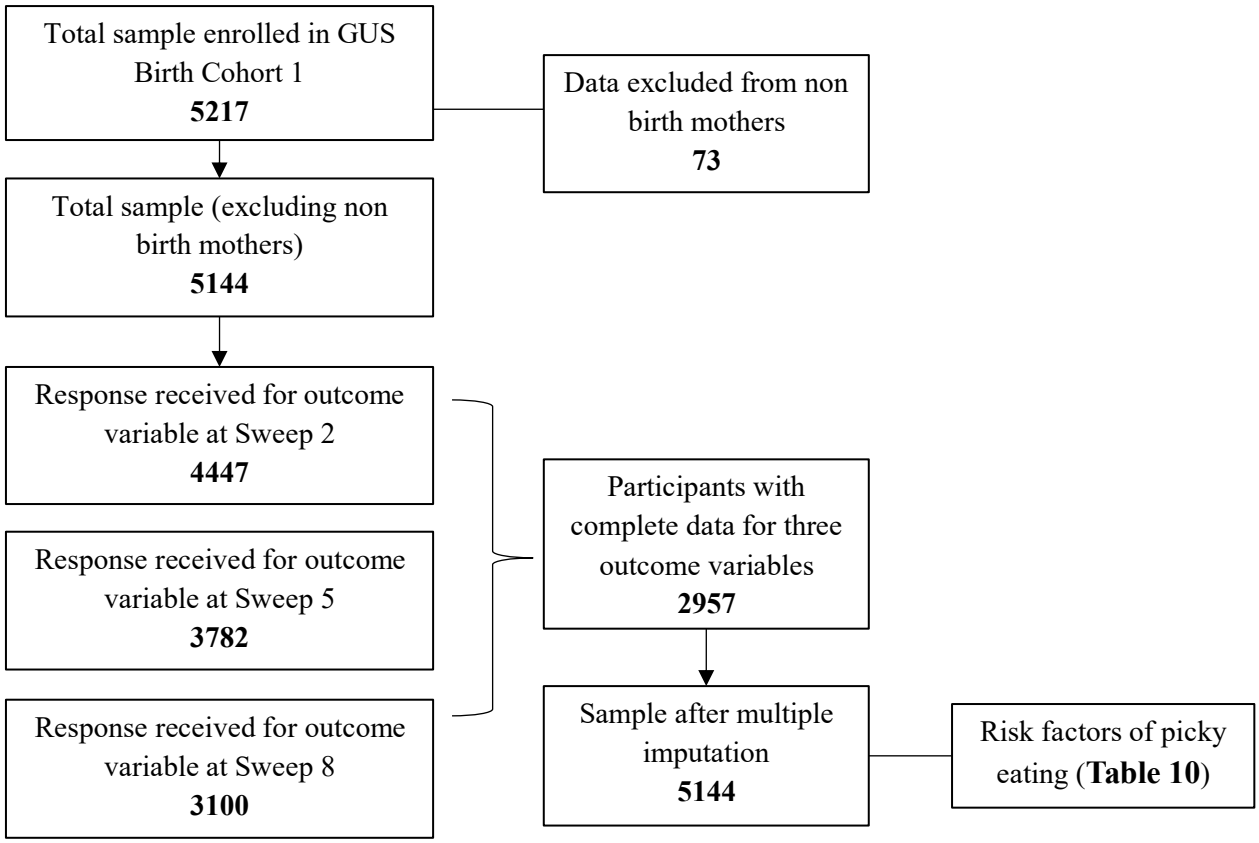
Results

Sample Characteristics

A total of 5217 children were enrolled in GUS BC1, 5144 (98.6%) of whom had their birth mother as main respondent. Among this sample, 2498 (48.6%) were female and 4916 (95.6%) white. Most mothers were aged between 30-39 years at the birth of the cohort child (49.4%) and 72.3% had achieved educational qualifications beyond those which are compulsory in Scotland (**Table 9**). Among these children, 2957 (57.5%) had data on picky eating behaviours available at ages 2, 5, and 10 years (and thus available data on the picky eating outcome) and of these, 2604 (50.6%) also had data available on all exposure variables (see **Figure 6**).

We compared the distribution of sociodemographic characteristics between participants with complete data on all variables of interest (n = 2604, 50.6%) and those who had some missing data on exposures or outcomes (n = 2540, 49.4%). A greater proportion of males (49.8%) and children from ethnic minority backgrounds (68.0%) had some missing data compared to females (49.0%) and children of white ethnicity (48.5%). Missing data was also more common among children born to mothers with compulsory educational qualifications only (66.2%) and younger mothers (under 20 years at birth of cohort child; 75.6%) compared to those whose mothers had continued with further education (42.8%) and those who were 30-39 years when they gave birth (40.0%) (full detail in **Appendix 3**).

Figure 6. Flow chart of study participation



Picky Eating Behaviours

Using all available cohort data, 13.5%, 22.2%, and 6.4% of children at ages 2, 5, and 10 years respectively, displayed picky eating behaviours. A total of 798 (27.0%) children had picky eating behaviours at either 2 or 5 years, or both. Of these, 689 (86.3%) no longer had picky eating behaviours at age 10 years and 109 (13.7%) also displayed picky eating behaviours at age 10 years. We considered the former as having transient picky eating (23.3% of the total sample) and the latter as having persistent picky eating (3.7% of the total sample).

Risk Factors for Picky Eating

Results for the univariable and multivariable regression models (N = 5144) are presented in **Table 10**. Below we report results of multivariable models only.

Child Socio-Demographic Characteristics

Compared to males, there was weak and no evidence that females were at lower risk of persistent (relative risk ratio [RRR]: 0.73, 95% confidence interval [CI]: 0.48-1.10) and transient picky eating (RRR: 0.90, 95%CI: 0.75-1.08), respectively. There was evidence that children from minority ethnic backgrounds had greater risk of experiencing transient picky eating compared to white children (RRR:1.55, 95%CI: 0.98-2.44), and only weak evidence of differences in persistent picky eating (RRR: 1.79, 95%CI: 0.78-4.10).

Family Socio-Economic/Demographic Characteristics

Children whose mothers had only completed compulsory education had higher risk of both transient and persistent picky eating behaviours compared to those whose mothers had remained in education beyond the age of 16 years with evidence of a dose-response association ([transient]RRR:0.77, 95%CI: 0.62-0.96, [persistent]RRR:0.46, 95%CI: 0.30-0.70). Children with younger mothers had higher risk of experiencing transient picky eating (RRR:0.97, 95%CI: 0.96-0.98), however, we only found weak evidence of an association with greater risk of persistent picky eating (RRR:0.98, 95%CI: 0.94-1.01). Greater income was associated with lower risk of transient (RRR:0.86, 95%CI: 0.76-0.98) and persistent picky eating (RRR:0.73, 95%CI: 0.56-0.95).

Pre-Natal Risk Factors

There was evidence that children of mothers who smoked during their pregnancy were at greater risk of persistent picky eating compared to those whose mothers did not smoke at all (RRR:2.18, 95%CI: 1.34-3.57), but we only observed a weak association with transient picky eating (RRR:1.21, 95%CI: 0.93-1.57). There was no evidence of an association between maternal alcohol consumption in pregnancy and child picky eating ([transient]RRR:0.97, 95%CI: 0.79-1.19; [persistent] RRR:0.73, 95%CI: 0.42-1.29).

Perinatal Risk Factors

Babies who were delivered with medical intervention were at greater risk than those born via vaginal delivery to experience persistent picky eating (RRR:1.52, 95%CI: 1.02-2.26), but not transient picky eating (RRR:1.09, 95%CI: 0.90-1.31). Premature birth was not associated with transient (RRR:0.86, 95%CI: 0.63-1.18) or persistent picky eating (RRR:0.88, 95%CI: 0.50-1.55). Similarly, we found weak evidence that children born later than their due date were at lower risk of experiencing transient (RRR:0.81, 95%CI: 0.60-1.08) and persistent picky eating (RRR:0.58, 95%CI: 0.31-1.09). Admission to a special care baby unit was not associated with transient picky eating (RRR:1.08, 95%CI: 0.81-1.44) but there was weak evidence of an association with lower risk of persistent picky eating (RRR:0.49, 95%CI: 0.21-1.13).

There was no evidence of an association between lower birth weight and transient (RRR:0.95, 95%CI: 0.86-1.04) or persistent picky eating (RRR:0.94, 95%CI: 0.76-1.17).

Maternal Mental Health

There was weak evidence of an association between greater symptoms of maternal stress and increased risk of transient picky eating (RRR:1.05, 95%CI: 0.99-1.12) but no evidence of an association with persistent picky eating (RRR:1.07, 95%CI: 0.91-1.25).

Greater depressive symptoms in the mother were not associated with increased risk of child transient picky eating (RRR:1.03, 95%CI: 0.96-1.11) and only a weak association was found with persistent picky eating (RRR:1.11, 95%CI: 0.95-1.29).

Child Factors

Feeding challenges in the first year were associated with greater risk of later picky eating. Children whose mothers reported concerns at 0-3 months were at increased risk of displaying transient (RRR:1.32, 95%CI: 1.06-1.65) but not persistent picky eating (RRR:1.14, 95%CI: 0.69-1.89). Children whose mothers had feeding concerns at 9-12

months were at greater risk of experiencing both transient (RRR:2.40, 95%CI: 1.88-3.06) and persistent picky eating (RRR:2.04, 95%CI: 1.20-3.46). Older age at introduction of solid foods was not associated with transient (RRR:0.98, 95%CI: 0.91-1.06) or persistent picky eating (RRR:1.02, 95%CI: 0.83-1.24).

There was weak evidence that children of mothers who reported concerns regarding their development, learning and behaviour were at increased risk of persistent picky eating (RRR:1.60, 95%CI: 0.82-3.12) but no evidence was found for transient picky eating (RRR:1.11, 95%CI: 0.78-1.59). We found weak evidence of an association between autism and greater risk of persistent picky eating (RRR:1.97, 95%CI: 0.72-5.41), but no evidence of an association with transient picky eating (RRR:1.09, 95%CI: 0.60-1.96).

Sensitivity Analyses

Results of all sensitivity analyses did not differ qualitatively from that of the main analyses. See **Appendix 4**, **Appendix 5** and **Appendix 6.**

Table 9. Sample characteristics ($N = 5144$)

	Participants with complete data (outcomes and exposures) *N* (%)	Picky eating absent *n* (%)	Transient picky eating *n* (%)	Persistent picky eating *n* (%)[ix]
Total[x]	5144 (100%)	2159 (73.0%)	689 (23.3%)	109 (3.7%)
Child sex				
Male	2646 (51.4%)	1081 (71.8%)	360 (23.9%)	64 (4.3%)
Female	2498 (48.6%)	1078 (74.2%)	329 (22.7%)	45 (3.1%)
Child ethnicity				
White	4916 (95.6%)	2099 (73.4%)	656 (23.0%)	103 (3.6%)
Other ethnic background	225 (4.4%)	60 (61.2%)	32 (32.7%)	6 (6.1%)
Mother's highest education level				
Compulsory[xi]	1421 (27.7%)	369 (65.5%)	159 (28.3%)	35 (6.2%)
Non-compulsory	3711 (72.3%)	1788 (74.8%)	530 (22.2%)	73 (3.0%)
Maternal age (at birth of cohort child)[xii]				
Under 20	349 (6.8%)	63 (63.6%)	30 (30.3%)	6 (6.1%)
20-29	2072 (40.3%)	753 (73.8%)	234 (22.9%)	33 (3.2%)
30-39	2540 (49.4%)	1260 (73.3%)	396 (23.0%)	64 (3.7%)
40 or older	182 (3.5%)	83 (70.3%)	29 (24.6%)	6 (5.1%)
Household income[xiii]				
Up to £11,999	1033 (22.4%)	266 (66.7%)	111 (27.8%)	22 (5.5%)
£12,000-£22,999	1137 (24.6%)	443 (68.5%)	173 (26.7%)	31 (4.8%)
£23,000-£31,999	865 (18.7%)	401 (72.3%)	134 (24.1%)	20 (3.6%)
£32,000-£42,999	991 (21.5%)	532 (77.8%)	133 (19.4%)	19 (2.8%)
£50,000 or more	591 (12.8%)	319 (77.8%)	81 (19.8%)	10 (2.4%)

[ix] Picky eating data is available on $n = 2957$. Totals of individual variables may not add up to 2957 due to missing data

[x] Some columns do not total 5144 due to missing data

[xi] In Scotland, education is not compulsory after Standard Grade exams at age 16 (considered to be equivalent to GCSEs)

[xii] Categorical variable used for the purpose of presenting clear sample characteristics. A continuous measure is used in the regression analyses

[xiii] Categorical variable used for the purpose of presenting clear sample characteristics. A continuous measure is used in the regression analyses

Smoking pregnancy				
No	3876 (75.9%)	1795 (74.8%)	534 (22.3%)	70 (2.9%)
Yes (occasionally/always)	1232 (24.1%)	353 (64.9%)	153 (28.1%)	38 (7.0%)
Alcohol pregnancy				
No	3716 (73.3%)	1496 (72.1%)	495 (23.9%)	83 (4.0%)
Yes (occasionally/always)	1352 (26.7%)	639 (75.4%)	185 (21.8%)	24 (2.8%)
Type of delivery				
Vaginal delivery	3159 (61.8%)	1284 (73.3%)	413 (23.6%)	55 (3.1%)
With medical intervention[xiv]	1953 (38.2%)	858 (72.3%)	274 (23.1%)	54 (4.6%)
Child's gestational age				
On time	707 (13.8%)	280 (69.8%)	104 (25.9%)	17 (4.3%)
Early	2125 (41.4%)	876 (72.2%)	284 (23.4%)	53 (4.4%)
Late	2303 (44.9%)	1000 (74.7%)	300 (22.4%)	39 (2.9%)
Low birth weight[xv]				
No	4802 (93.5%)	2029 (73.0%)	647 (23.3%)	103 (3.7%)
Yes	336 (6.5%)	129 (72.9%)	42 (23.7%)	6 (3.4%)
Special care baby unit				
No	4548 (88.4%)	1939 (73.2%)	610 (23.0%)	101 (3.8%)
Yes	595 (11.6%)	220 (71.7%)	79 (25.7%)	8 (2.6%)
Feeding problems 0-3 months				
Not a problem	4261 (82.9%)	1790 (73.9%)	543 (22.4%)	89 (3.7%)
A problem (a bit or big)	882 (17.1%)	368 (68.9%)	146 (27.3%)	20 (3.8%)

[xiv] 'With medical intervention' comprises forceps, Ventouse suction, forceps and Ventouse, caesarean section before labour began, caesarean section after labour began, or other

[xv] Categorical variable used for the purpose of presenting clear sample characteristics. A continuous measure is used in the regression analyses

Feeding problems 9-12 months				
Not a problem	4443 (86.4%)	1929 (75.5%)	537 (21.0%)	88 (3.5%)
A problem (a bit or big)	701 (13.6%)	230 (57.1%)	152 (37.7%)	21 (5.2%)
Age at introduction of solid food (months)				
0-3	329 (12.6%)	259 (71.5%)	88 (24.3%)	15 (4.2%)
4-7	2244 (86.2%)	1855 (73.5%)	581 (23.0%)	89 (3.5%)
8-10	31 (1.2%)	22 (61.1%)	11 (30.6%)	3 (8.3%)
Concerns about child's development, learning and behaviour?				
No concerns	4768 (92.7%)	2024 (73.3%)	640 (23.2%)	97 (3.5%)
Yes (some or a lot)	373 (7.3%)	134 (68.7%)	49 (25.1%)	12 (6.2%)
Does child have additional needs? (Autism)				
No	3452 (97.8%)	2122 (73.2%)	673 (23.2%)	103 (3.6%)
Yes	79 (2.2%)	37 (62.7%)	16 (27.1%)	6 (10.2%)

Table 10. Univariable and multivariable logistic regression model results for the association between picky eating status and child and maternal variables using imputed data ($N = 5144$)

	Picky eating status			
	Transient	**Persistent**	**Transient**	**Persistent**
Variable	**Univariable model, Relative Risk Ratio (95% Confidence Interval); *p*-value**		**Multivariable model, Relative Risk Ratio (95% Confidence Interval); *p*-value**	
Child sex				
Male	Reference	Reference	-	-
Female	0.90 (0.75-1.08); 0.245	0.73 (0.48-1.10); 0.129	-	-
Child ethnicity				
White	Reference	Reference	-	-
Other ethnic background	1.55 (0.98-2.44); 0.061	1.79 (0.78-4.10); 0.160	-	-
Highest education level				
Compulsory	Reference	Reference	Reference	Reference
Non-compulsory	0.68 (0.55-0.83); 0.001	0.41 (0.28-0.61); 0.000	0.77 (0.62-0.96); 0.023	0.46 (0.30-0.70); 0.001
Maternal age (at birth of cohort child)	0.96 (0.95-0.98); 0.000	0.95 (0.92-0.99); 0.007	0.97 (0.96-0.98); 0.000	0.98 (0.94-1.01); 0.154
Household income (std)				
	0.78 (0.71-0.86); 0.000	0.63 (0.51-0.79); 0.000	0.86 (0.76-0.98); 0.020	0.73 (0.56-0.95); 0.021
Smoking pregnancy				
No	Reference	Reference	Reference	Reference
Yes (occasionally/always)	1.49 (1.16-1.90); 0.003	2.84 (1.86-4.33); 0.000	1.21 (0.93-1.57); 0.147	2.18 (1.34-3.57); 0.003
Alcohol pregnancy				
No	Reference	Reference	Reference	Reference
Yes (occasionally/always)	0.88 (0.72-1.07); 0.189	0.67 (0.39-1.15); 0.189	0.97 (0.79-1.19); 0.762	0.73 (0.42-1.29);0.272

Type of delivery				
Vaginal delivery	Reference	Reference	Reference	Reference
With medical intervention	0.96 (0.81-1.14); 0.652	1.31 (0.91-1.87); 0.138	1.09 (0.90-1.31); 0.366	1.52 (1.02-2.26); 0.038
Gestational age				
Early	0.88 (0.65-1.20); 0.396	0.98 (0.56-1.73); 0.950	0.86 (0.63-1.18); 0.336	0.88 (0.50-1.55); 0.649
On time	Reference	Reference	Reference	Reference
Late	0.82 (0.61-1.10); 0.168	0.61 (0.33-1.14); 0.118	0.81 (0.60-1.08); 0.147	0.58 (0.31-1.09); 0.086
Birth weight (std)				
	0.92 (0.84-1.01); 0.065	0.80 (0.65-0.97); 0.027	0.95 (0.86-1.04); 0.264	0.94 (0.76-1.17); 0.557
Special care baby unit				
No	Reference	Reference	Reference	Reference
Yes	1.19 (0.91-1.56); 0.201	0.78 (0.35-1.71); 0.518	1.08 (0.81-1.44); 0.581	0.49 (0.21-1.13); 0.092
DASS Stress				
	1.08 (1.03-1.14); 0.002	1.18 (1.04-1.33); 0.010	1.05 (0.99-1.12); 0.110	1.07 (0.91-1.25); 0.398
DASS Depression				
	1.11 (1.05-1.17); 0.001	1.24 (1.11-1.37); 0.000	1.03 (0.96-1.11); 0.400	1.11 (0.95-1.29); 0.191
Feeding 0-3 months				
Not a problem	Reference	Reference	Reference	Reference
A problem (a bit or big)	1.31 (1.06-1.62); 0.014	1.12 (0.69-1.83); 0.626	1.32 (1.06-1.65); 0.014	1.14 (0.69-1.89); 0.603
Feeding 9-12 months				
Not a problem	Reference	Reference	Reference	Reference
A problem (a bit or big)	2.34 (1.84-2.97); 0.000	1.90 (1.13-3.21); 0.018	2.40 (1.88-3.06); 0.000	2.04 (1.20-3.46); 0.010
Months old – solid food				
	0.96 (0.89-1.04); 0.339	0.97 (0.78-1.20); 0.753	0.98 (0.91-1.06); 0.692	1.02 (0.83-1.24); 0.877
Development concerns				
No concerns	Reference	Reference	Reference	Reference
Concerns (some or a lot)	1.21 (0.85-1.71); 0.284	1.84 (0.96-3.55); 0.066	1.11 (0.78-1.59); 0.547	1.60 (0.82-3.12); 0.160
Autism				
No	Reference	Reference	Reference	Reference
Yes	1.40 (0.79-2.49); 0.243	3.16 (1.19-8.36); 0.023	1.09 (0.60-1.96); 0.775	1.97 (0.72-5.41); 0.176

Discussion

This study is one of very few to examine the prevalence and risk factors of picky eating behaviours in a cohort of young children. We found that picky eating was most common at age 5, but this remitted for the majority of children by age 10 years. Though prevalence estimates vary, our findings support those of previous studies which show that picky eating is often a typical phase of childhood development (Cardona Cano et al., 2015b; Carruth et al., 2004; Marchi & Cohen, 1990) and that picky eating behaviours tend only to persist beyond this stage for a small number of children.

We identified a number of factors which were associated with picky eating presentations. For example, our data suggest that both transient picky eating and persistent picky eating are associated with lower socioeconomic status. While this does not warrant confirmation of a specific risk factor, it calls for increased attention to be paid to those who may have greater difficulties and could benefit from support, for example, school talks given to parents in deprived areas to deliver education around feeding practices and information about access to clinical services and support.

We found some evidence that males appear to be at greater risk of picky eating than females, which is consistent with earlier work (Cardona Cano et al., 2015b). Autism was also found to be associated with picky eating, albeit with some statistical uncertainty. Since the literature suggests that autism is more prevalent, or at least more commonly diagnosed in males than in females (Loomes et al., 2017), it may point to shared aetiological mechanisms between autism and picky eating. Indeed, feeding and eating difficulties including food selectivity, sensory preferences, and rituals regarding preparation and/or presentation are a commonly cited concern for parents of autistic children (Castro et al., 2016; Gray & Chiang, 2017; Sharp et al., 2013a). Clinically, it is important to know that co-morbidities between

picky eating and autism may exist and therefore, children presenting with either should be screened for both in order to ensure appropriate access to care.

We also found a greater risk of picky eating in children whose mothers smoked in pregnancy, which again could point to aetiological mechanisms. Whilst general population studies have previously linked smoking in pregnancy to autism in offspring (Larsson et al., 2009; Ronald et al., 2010), studies using genetically informed designs have found this association to be largely confounded by underlying genetic risk (Caramaschi et al., 2018; Kalkbrenner et al., 2020). More research is therefore needed to disentangle whether the association that we observed between smoking in pregnancy and picky eating is causal.

While this study has several strengths including the use of a large longitudinal dataset with frequent assessment of the same cohort of participants over an extended period, there are some limitations to consider. First, the GUS study exclusively sampled children born in Scotland between 2004 and 2005, 97% of which were white families. Hence, the findings may have limited generalisability to other populations. This may also explain why the analyses did not identify a strong association for ethnicity as we may not have had adequate statistical power to accurately test for this.

We were also limited by the data provided in the GUS study. Assessment of symptoms was based on parent report and therefore rooted in the observations and perceptions of parents and carers, as opposed to the child's own experience. Further, there is no agreed definition for picky eating, or gold standard for the assessment of symptoms, so the main outcome for this study was operationalised using a single item posed to respondents at three study sweeps. While this is a limitation, it is consistent with prior research (Boquin et al., 2014; Carruth et al., 2004) and questions were selected from the GUS dataset that closely mirrored previous studies which assessed picky eating behaviours (Dubois et al., 2007; Mascola et al., 2010). Relatedly, GUS included a different question at age 10 compared to

those asked at ages 2 and 5. Although previous research supports the use of this question at age 10 as a useful indicator of picky eating (Dubois et al., 2007) our measure could have resulted in the misclassification of some participants and potentially, in the over- or underestimation of prevalence of picky eating. We were nevertheless reassured as our estimates are in line with those of previous studies (Cardona Cano et al., 2015b; Mascola et al., 2010).

While there were some sociodemographic differences between the sample of participants with all outcome and exposure data compared to those with some missing, we were reassured to observe that the results of sensitivity analyses using complete cases were compatible with those of the main models using imputed data, although the latter provided more precise estimates (indexed by narrower 95% confidence intervals) likely due to increased statistical power given the larger sample size.

Despite larger than those of most previous studies, our sample might have still been underpowered to detect differences for a number of less common putative risk factors for which we only found weak associations. To account for this, we have interpreted our results in terms of strength of associations rather than relying on strict *p*-value cut offs. Studies with larger samples are warranted in order to replicate these findings.

Finally, our definition of autism relied on receipt of a diagnosis by age 12. As such, it may have missed children diagnosed after school entry or in secondary school, and those who will not receive a diagnosis. As there is evidence that certain groups (i.e., girls, children from more deprived backgrounds) are more likely to be underdiagnosed in childhood (Carruth et al., 2004), this could have biased our estimates if these groups also differed in terms of picky eating. Our estimates of autism prevalence are nevertheless in line with current evidence (Hosozawa et al., 2020). It is also important to note the possible implications of using this particular exposure, namely reverse causation, where the outcome can make the exposure

more likely. Children with picky eating behaviours may visit doctors or other healthcare professionals more often than those with adequate food intake, to monitor their weight and/or nutritional status. Children who are autistic and have picky eating behaviours might have a greater chance of receiving a diagnosis of autism, as an indirect result of regular contact with healthcare professionals and services. This might result in overestimating the association under study. We did observe an increased risk of picky eating for autistic children, although 95% CIs were wide and included the null. Nevertheless, other general population studies and genetically informed designs have shown that autistic children are at a greater risk of selective eating (Remnélius et al., 2022), so our findings, although underpowered, are in line with previous literature.

Conclusions

Picky eating is common throughout childhood but there is little understanding of the trajectories of early food fussiness. We have identified a number of risk factors for persistent picky eating and some that are shared with more transient presentations.

Though not sufficiently definitive to inform actual changes in clinical care for young people presenting with eating disorders, the findings do generate a number of population level implications relating to aetiology and prevention. Further work is now needed to distinguish between picky eating and that associated with clinically significant impairment to health and day-to-day functioning, which is a key feature of ARFID. There is also a need to better understand whether persistent picky eating is associated with adverse physical or mental health outcomes as, to date, this is an under-researched area. A clearer understanding of the causes and outcomes of persistent picky eating would help elucidate aetiological pathways and achieve a better understanding of the clinical needs of this population.

Chapter 5: Investigating Physical and Mental Health Correlates of Picky Eating in a Longitudinal Birth Cohort Study

Abstract

Aims: This study investigated associations between differential trajectories of childhood picky eating and physical and mental health outcomes in adolescence using data from the Growing up in Scotland longitudinal birth cohort study (2005-2020).

Methods: Parent report questionnaire items were used to assigned children to one of three picky eating categories at age 10 years: transient picky eating in early childhood, persistent picky eating into late childhood and picky eating absent. Associations between physical and mental health outcomes at age 14 were then assessed using univariable and multivariable linear regression analyses (n = 2957).

Results: Transient picky eating in early childhood was found to be associated with lower body mass index (BMI) in males, and a weak association was observed between persistent picky eating and increased peer relationship problems in adolescence. Picky eating status did not have a predictive relationship on any other outcome variables.

Conclusions: Despite some weak associations, overall, the findings of this study suggest that childhood picky eating as here defined and investigated did not appear to be associated with BMI or mental health outcomes in adolescence.

Introduction

Picky eating is a commonly used descriptive term encompassing a broad range of selective and/or restrictive patterns of food intake (i.e., Dovey et al., 2008; Jacobi et al., 2008). Picky eating is frequently recognised as a phase of typical childhood development (Cardona Cano et al., 2015a; Cardona Cano et al., 2015b; Keen, 2008) and such behaviours very often remit with little or no need for intervention (Bourne et al., 2023; Cardona et al., 2015b). This is supported by epidemiological studies reporting a peak prevalence of such behaviours in early childhood (i.e., Carruth et al., 2004; Dovey et al., 2008; Mascola et al., 2010), and tailing off thereafter (Bourne et al., 2023; Mascola et al., 2010; Micali et al., 2011). For some, however, picky eating can persist into adolescence and adulthood and therefore may be an indicator of a more pervasive issue, or an eating disorder, such as avoidant restrictive food intake disorder (ARFID; APA, 2013).

A large body of cross-sectional research has investigated whether picky eating in childhood is related to differential growth patterns, health status, and behavioural outcomes (i.e., Berger et al., 2016; Dial et al., 2021; Galloway et al., 2005; Nicholls et al., 2001; Taylor et al., 2019a). In a cohort study, Jacobi et al. (2008) found an association between picky eating and internalising and externalising behaviours in a sample of 8- to 12-year-olds. Similarly, Micali et al. (2011) evidenced psychopathology across various domains including emotional and functional somatic symptoms in a sample of children aged 5- to 7- years with picky eating behaviours.

The longer-term outcomes of picky eating, however, have garnered little attention, particularly in relation to mental health or behavioural outcomes. A longitudinal study by Cardona Cano et al. (2016) gives weight to the importance of differing trajectories of picky eating throughout childhood. The researchers assessed children for picky eating at ages 1.5, 3 and 6 years and assigned participants to one of four picky eating trajectory groups including

those with picky eating before 6 years only (remitting picky eating) and those with picky eating at all ages (persisting picky eating). While persisting picky eating was found to predict pervasive developmental disorders at age 7, the other trajectories were not, indicating that picky eating which persists beyond early childhood may be a symptom of developmental problems. Similarly, Carter Leno et al. (2022) found a potential link between childhood autistic traits and later disordered eating in a longitudinal cohort study. Specifically, the authors noted that higher autistic traits at age 7 years were associated with less of a decline in fussy eating behaviours between 7-13 years, and also that a lower decline in fussy eating was associated with increased disordered eating at age 14. Thus, the findings indicate that it may be possible to reduce the risk of serious disordered eating in adolescence by addressing fussiness in childhood. More longitudinal work assessing older children and adolescents is needed to understand the role of picky eating in certain outcomes, as either a causal factor or marker of underlying psychopathology.

It is unclear whether childhood picky eating has an influence on weight trajectories. Cross-sectional research has evidenced differential outcomes regarding weight status, with some studies suggesting that picky eaters have a lower weight than their non-picky peers (Chao, 2018; Viana et al., 2008; Wright et al., 2007) and others evidencing a link with being overweight (Finistrella et al., 2012). Longitudinal research is also mixed, although there is some suggestion that picky eating in childhood may be a protective factor for being overweight or obese in later childhood and adolescence (Antoniou et al., 2015; Herle et al., 2020; Taylor et al., 2019a). As discussed by Brown et al. (2016), heterogeneous definitions and conceptualisations of picky eating as well as the absence of validated measures of assessment have contributed to inconsistent findings in the picky eating literature.

In summary, much of the current literature relies on cross-sectional design and few studies make a distinction between transient and persistent picky eating behaviours. Further,

of the longitudinal data available, very few track participant trajectories into adolescence. Picky eating behaviours which persist for a prolonged period of time may pose a risk to nutritional health, weight outcomes, or psychosocial functioning, and thus, may meet diagnostic threshold for ARFID. Therefore, it is important to study the course and outcomes of picky eating, and in particular, to differentiate between different trajectories, to establish whether those which represent a more pervasive problem have distinct outcomes.

We used the Growing up in Scotland (GUS) longitudinal birth cohort dataset in a previous study to identify child and family characteristics associated with increased risk of different picky eating profiles (Bourne et al., 2023). Work is now needed to better understand the levels of functional impairment associated with these picky eating profiles, in order to work towards an understanding of the aetiological pathways underpinning picky eating. The present study used the same dataset and picky eating profiles to investigate the physical and mental health outcomes of children at age 14 who were identified as transient or persistent picky eaters in earlier childhood, compared to those who never experienced picky eating.

Methods

Study Design and Population

We used secondary data from the GUS birth cohort study. This national longitudinal study was established in 2005 with the aim of tracking the lives of children living in Scotland throughout childhood and adolescence.

Data from the GUS Birth Cohort 1 (BC1) was used for the present study. BC1 is the first of two cohorts which tracks a nationally representative sample of 5217 infants born in Scotland between June 2004 and May 2005, selected at random from Child Benefit records provided by HM Revenue and Customs. Data were collected annually via face-to-face interviews with children and parents in their homes when the children were around 10 months old up until 6 years of age, and then biennially thereafter. At the most recent study sweep 10,

children were aged between 13 and 14 years of age and most in their third year of secondary school.

GUS received ethics approval by the Scotland 'A' MREC committee. Further details on the GUS cohort are available at https://growingupinscotland.org.uk/.

Outcomes

Data were collected in 2019/2020, via a combination of self-completion questionnaires, web and telephone surveys, and face-to-face interviews when cohort members were 14 years old. A wide range of questions were asked, including those relating to emotional and behavioural symptoms, anxiety symptoms, and perceptions of body image, as well as physical measurements, such as body mass index (BMI). In this study, an outcome is defined as an effect which occurs later than, and is plausibly influenced by, the initial exposure under study even if it has not been proven as a direct consequence.

Measures of Physical Health

BMI

BMI is defined as weight (kg)/square of height (m^2). Trained researchers at the sweep 10 interviews collected measurements of weight and height. Since a child's BMI is confounded by variations in patterns of growth, scores were standardised using the Stata package zanthro according to the sex of the child, and their age in months when the measurements were taken (Cole et al., 2000; Vidmar et al., 2013).

Measures of Mental Health

Emotional and Behavioural Symptoms

Emotional and behavioural development of cohort members was measured using an age-appropriate self-report version of the Strengths and Difficulties Questionnaire (SDQ; Goodman et al., 1998) as part of a postal/online/face to face assessment. The SDQ is a brief behavioural screening questionnaire for 2–17-year-olds which exists in several versions,

including a parent report and youth self-report format. The scale includes 25 multiple-choice items designed to measure five aspects of development: emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and pro-social behaviour. The scales (each scored 0-10) can be combined (excluding the pro-social scale) to calculate a 'total difficulties' score (0-40). Further details on the SDQ can be found at: https://www.sdqinfo.org/a0.html).

Anxiety

Anxiety symptoms were measured via self-report using the Generalised Anxiety Disorder Assessment (GAD-7), a well-validated seven item screening tool for general anxiety disorder. Answers are rated on a 4-point Likert scale including "not at all" (0), "several days" (1), "more than half the days" (2), and "nearly every day" (3) (Spitzer et al., 2006). We combined these scores to derive a continuous scale ranging from 0 to 21, with higher scores indicating greater anxiety symptoms.

Body Image

Body dissatisfaction was captured by a single item: "How do you feel about the way you look? (1) Very happy, (2) Quite happy, (3) Not very happy, or (4) Not at all happy".

Exposure

Picky eating status was operationalised using three questions posed to parents at study sweeps 2, 5 and 8, when the children were aged 2, 5 and 10 years respectively (Bourne et al., 2023).

At sweeps 2 and 5, parents were asked, "How would you describe the variety of foods that [child] generally eats? Does she/he: (1) Eat most things, (2) Eat a reasonable variety of things, or (3) is she/he a fussy eater?". Children whose parents answered (3) were considered picky eaters. As this question was not repeated at sweep 8, we used a related question posed to parents to capture picky eaters in later childhood, "At the main meal, is [child] served

different food from adults? (1) Never, (2) Occasionally, (3) Quite often, or (4) Mostly." We classified children with picky eating if parents answered (4). This is supported by Dubois et al. (2007), who characterised children as picky if they always eat a different meal to their family.

Based on the responses to these questions, participants were assigned to one of three discrete categories: (1) transient picky eating in early childhood (hereafter 'transient picky eating'): children considered by their parents to experience picky eating at age 2 or age 5 (or both) but not at age 10, (2) persistent picky eating into late childhood (hereafter 'persistent picky eating'): children considered by their parents to experience picky eating at age 2 or age 5 (or both) as well as age 10, and (3) picky eating absent.

The same variable and picky eating categories were used in an earlier study using the GUS BC1 dataset (Bourne et al., 2023). Differences typically observed in picky eating research were noted, for example, a greater proportion of males (Cardona Cano et al., 2015b) and cooccurrence of autism (Baraskewich et al., 2021; Cardona Cano et al., 2016), therefore demonstrating the validity of this measure in meaningfully capturing this construct.

Data Analysis

The analytical plan of the study was pre-registered on the Open Science Framework on March 31, 2023 (https://doi.org/10.17605/OSF.IO/NYFCV). Minor modifications were made to this method on January 27, 2024.

Data were analysed using Stata release 17. We imputed missing outcome data using multiple imputation with chained equations imputing 50 datasets. Imputation models included all variables involved in the analyses as well as confounding and auxiliary variables, including participants' parent reported SDQ scores, and questions posed to both the young people and their parents/carers relating to mental health diagnoses or difficulties (see **Appendix 7**).

To investigate the association between childhood picky eating patterns and physical and mental health outcomes at age 14, we used univariable and multivariable linear regression analyses.

First, univariable analyses were used to model the differences in physical and mental health outcomes for children classified as having transient picky eating and persistent picky eating, compared to those in the picky eating absent group. Next, multivariable regression models were performed, adjusting for a number of potentially confounding variables collected at various sweeps throughout the GUS study. A confounder is defined as an extraneous variable which may compete with the exposure in explaining the outcome but is not thought to be a mediator between the two.

Three models were created: The first did not adjust for any confounding variables, the second adjusted for basic demographic variables to describe the association between childhood picky eating and later physical and mental health outcomes, and the third model adjusted for additional factors to inform our understanding of whether picky eating in childhood could be a risk factor for certain outcomes (see **Table 11**).

To investigate any differential associations by sex, we then included an interaction term between the picky variable and child sex for our descriptive model (model 2). If interactions were observed, these were followed by analyses stratified by sex, in order to better understand the nature of the interaction.

Table 11. Factors adjusted for in each analytic model

Model 1	Model 2	Model 3
NA	Child sex	Confounders from Model 1
NA	Child ethnicity	Maternal DASS depression score
NA	Household income	Maternal DASS stress score
NA	Maternal education	Child autism diagnosis
NA	Maternal age at birth	Child feeding problems at 9-12 months
NA		Child measure of SDQ total at 4 years old

Results

Sample Characteristics

In total, 5217 children enrolled in the core GUS sample but 73 were excluded as their birth mothers were not the main respondents in earlier carer interviews[xvi]. Of the 5144 participants remaining, 2957 (57.5%) had complete data on picky eating behaviours at ages 2, 5, and 10 years used to derive the independent variable. Among this sample, 1452 (49.1%) were female and 2858 (96.7%) white. The majority of children were classified as having a healthy BMI (66.5%), did not experience feeding problems as an infant (86.4%) and had a mother who was 30-39 years of age at their birth (58.2%; **Table 12**). In the sample, 23.3% (*n* = 689) of children experienced transient picky eating, 3.7% (*n* = 109) experienced persistent picky eating and 73.0% never experienced picky eating.

Among this sample of participants with complete data on the independent variable (*n* = 2957), 1724 (58.3%) also had full data available on all outcome measures and confounders. The distribution of sociodemographic characteristics between participants with complete data on all variables of interest (*n* = 1724, 33.5%) were compared to those with missing data on

[xvi] In line with Bourne et al. (2023), data from respondents who were non birth mothers was excluded because some variables relied on data relating to pregnancy, birth, and early childhood. Non birth mothers are caregivers who did not give birth to the study child (i.e., adoptive/foster carers, fathers, grandparents, etc)

the exposure variable or any outcome measures or confounders (n = 3420, 66.5%). A greater proportion of males (67.7%) and children from ethnic minority backgrounds (72.9%) had some missing data compared to females (65.2%) and children of white ethnicity (66.2%). Missing data was also more common among children born to mothers with compulsory educational qualifications only (80.0%) and younger mothers (under 20 years at birth of cohort child; 87.4%) compared to those whose mothers had continued with further education (61.2%) and those who were 30-39 years when they gave birth (58.9%). Further, a greater proportion of children reported to have a diagnosis of autism had missing data (60.8%) compared to those without a diagnosis of autism (51.0%) (see **Appendix 8** for full table of results).

Correlates of Picky Eating

Results for all regression models using an imputed sample are presented in **Table 13** below. Results using complete cases can be found in the supplementary material (**Appendix 9**).

Overall, there was a general tendency for picky eating status to have no predictive relationship on our outcome variables. We did, however, find transient picky eating to be associated with lower BMI for boys in model 2, but not for girls, and a weak association was observed between persistent picky eating and increased peer relationship problems in model 2 only.

Table 12. Sample characteristics (participants with complete data on the exposure variable, *n* = 2957)

	Participants with complete data (outcomes and exposures) *N* (%)	**Picky eating absent *n* (%)**	**Transient picky eating *n* (%)**	**Persistent picky eating *n* (%)**
Total	2957 (100%)[xvii]	2159 (73.0%)	689 (23.3%)	109 (3.7%)
Child sex				
Male	1505 (50.9%)	1081 (71.8%)	360 (23.9%)	64 (4.3%)
Female	1452 (49.1%)	1078 (74.2%)	329 (22.7%)	45 (3.1%)
Child ethnicity				
White	2858 (96.7%)	2099 (73.4%)	656 (23.0%)	103 (3.6%)
Other ethnic background	98 (3.3%)	60 (61.2%)	32 (32.7%)	6 (6.1%)
Mother's highest education level				
Compulsory[xviii]	563 (19.1%)	369 (65.5%)	159 (28.3%)	35 (6.2%)
Non-compulsory	2391 (80.9%)	1788 (74.8%)	530 (22.2%)	73 (3.0%)
Maternal age (at birth of cohort child)[xix]				
Under 20	99 (3.4%)	63 (63.6%)	30 (30.3%)	6 (6.1%)
20-29	1020 (34.5%)	753 (73.8%)	234 (22.9%)	33 (3.3%)
30-39	1720 (58.2%)	1260 (73.3%)	396 (23.0%)	64 (3.7%)
40 or older	118 (3.9%)	83 (70.3%)	29 (24.6%)	6 (5.1%)
Household income[xx]				
Up to £11,999	399 (14.8%)	266 (66.7%)	111 (27.8%)	22 (5.5%)
£12,000-£22,999	647 (24.0%)	443 (68.5%)	173 (26.7%)	31 (4.8%)
£23,000-£31,999	555 (20.6%)	401 (72.3%)	134 (24.1%)	20 (3.6%)
£32,000-£42,999	684 (25.4%)	532 (77.8%)	133 (19.4%)	19 (2.8%)
£50,000 or more	410 (15.2%)	319 (77.8%)	81 (19.8%)	10 (2.4%)

[xvii] Picky eating data is available on *n* = 2957. Totals of individual variables may not add up to 2957 due to missing data

[xviii] In Scotland, education is not compulsory after Standard Grade exams at age 16 (considered to be equivalent to GCSEs)

[xix] Categorical variable used for the purpose of presenting clear sample characteristics. A continuous measure is used in the regression analyses

[xx] Categorical variable used for the purpose of presenting clear sample characteristics. A continuous measure is used in the regression analyses

Feeding problems 9-12 months				
Not a problem	2554 (86.4%)	1929 (75.5%)	537 (21.0%)	88 (3.5%)
A problem (a bit or big)	403 (13.6%)	230 (57.1%)	152 (37.7%)	21 (5.2%)
Does child have additional needs? (Autism)				
No	2898 (98.0%)	2122 (73.2%)	673 (23.2%)	103 (3.6%)
Yes	59 (2.0%)	37 (62.7%)	16 (27.1%)	6 (10.2%)

Table 13. Univariable and multivariable linear regression model results for the association between picky eating status and physical and mental health correlates using imputed data (*n* = 2957)

	Picky eating status					
	Transient	**Persistent**	**Transient**	**Persistent**	**Transient**	**Persistent**
Variable	**Model 1 - Univariable Coefficient (95% Confidence Interval); *p*-value**		**Model 2 - Multivariable Coefficient (95% Confidence Interval); *p*-value**		**Model 3 - Multivariable Coefficient (95% Confidence Interval); *p*-value**	
BMI	-0.05 (-0.17,0.07); 0.431	-0.05 (-0.33,0.22); 0.713	-0.07 (-0.19,0.05); 0.249	-0.06 (-0.33,0.21); 0.647	-0.07 (-0.19,-0.05); 0.255	-0.08 (-0.35,0.19); 0.568
BMI (males)	-	-	-0.16 (-0.33,0.01); 0.067	-0.03 (-0.39,0.34); 0.889	-	-
BMI (females)	-	-	0.03 (-0.13,0.19); 0.710	-0.15 (-0.53,0.23); 0.450	-	-
Anxiety (GAD-7)	-0.18 (-0.72,0.37); 0.526	-0.30 (-1.51,0.91); 0.629	-0.12 (-0.65,0.41); 0.659	-0.04 (-1.23,1.15); 0.948	-0.15 (-0.69,0.39); 0.580	-0.11 (-1.31,1.08); 0.851
Body image	-0.02 (-0.09,0.06); 0.657	0.008 (-0.15,0.17); 0.926	-0.01 (-0.09,0.06); 0.687	-0.01 (-0.17,0.15); 0.900	0.001 (-0.07,0.07); 0.979	0.01 (-0.14, 0.17); 0.859
SDQ emotion	0.15 (-0.11,0.42); 0.263	-0.05 (-0.64,0.54); 0.875	0.17 (-0.09,0.42); 0.194	0.08 (-0.49, 0.64); 0.793	0.13 (-0.12,0.39); 0.306	-0.002(-0.12,0.39); 0.993
SDQ conduct	0.05 (-0.12,0.21); 0.581	0.25 (-0.13,0.63); 0.190	-0.02 (-0.18,0.14); 0.845	0.13 (-0.25,0.51); 0.490	-0.05 (-0.21,0.12); 0.566	0.05 (-0.33,0.43); 0.794
SDQ hyper	-0.02 (-0.26, 0.22); 0.861	0.45 (-0.10,0.99); 0.111	-0.08 (-0.32,0.16); 0.216	0.34 (-0.20,0.89); 0.216	-0.12 (-0.36,0.13); 0.345	0.25 (-0.30,0.80); 0.373
SDQ peer	0.10 (-0.07,0.26); 0.261	0.37 (-0.03,0.77); 0.068	0.05 (-0.12,0.22); 0.544	0.30 (-0.09,0.70); 0.135	-0.01 (-0.18,0.15); 0.867	0.14 (-0.26,0.54); 0.491

Discussion

The present study aimed to investigate whether different trajectories of picky eating in childhood were associated with negative physical and mental health outcomes at age 14. We reported an association between transient picky eating and lower BMI in males only in model 2, and a weak association between persistent picky eating and increased peer relationship problems in model 2. Overall, the findings suggest that picky eating behaviours in childhood, including those that are persistent, do not appear to present a lasting or significant risk to BMI outcomes or mental health.

Since 66.5% of our participants did not provide complete data on all variables of interest, we imputed missing outcome data. We observed weaker associations in our imputed sample, compared to analyses performed with complete cases (see **Appendix 9**). This is in direct contrast to what we had expected, since greater sample sizes tend to provide more power to detect an effect (Serdar et al., 2021).

There are a number of reasons why we may have observed attenuations in the sizes of our associations using a larger sample. First, it may be that our exposure variable is not valid and thus, is not accurately measuring picky eating, which threatens the reliability of our results. Indeed, it may even be that the construct of picky eating itself needs refining. There is no agreed definition for picky eating, or gold standard for the assessment of symptoms, so the main exposure for this study was operationalised using a single item posed to respondents at three study sweeps. The GUS questionnaires did not pose the same question about picky eating behaviours to participants at all three study sweeps. Therefore, we used a different question at age 10, compared to that at ages 2 and 5. Although supported by previous research which used a similar question to capture picky eating (Dubois et al., 2007), this item relating to children being served different food from adults could have simply identified families with different food preferences rather than children displaying fussy behaviours. Thus, we may

have misclassified some participants. Nevertheless, we used the same measure of picky eating in our previous study (Bourne et al., 2023) and observed similar findings to those of previous studies relating to picky eating behaviours (Cardona Cano et al., 2015b; Mascola et al., 2010).

Secondly, the data may be missing not at random and thus, imputing the sample could have exposed systematic differences between those who provided complete data on all variables of interest and those who did not. As a result, the imputed sample could have uncovered bias in the sample (Sterne et al., 2009).

Finally, it may be that this is simply not an exposure that predicts the outcomes investigated. The current study was well powered, used longitudinal data, and the main exposure appears to be an appropriate measure for picky eating as it behaved as expected in our previous study (Bourne et al., 2023). Therefore, the absence of associations between picky eating behaviours and physical and mental health outcomes may be a true reflection of this sample. Alternatively, it may be that a subgroup of those with persistent picky eating behaviours are at risk of later negative outcomes, and therefore, further exploration may be warranted.

Is picky eating a marker of an underlying issue or a causal factor for later issues?

We incorporated two multivariable models into our analyses. The first included basic demographic variables as confounders, such as sex, ethnicity, and factors relating to socio-economic status, in order to describe associations between childhood picky eating and later physical and mental health outcomes. The second multivariable model included the same confounding variables as the first multivariable model but also adjusted for the potential influence of an additional set of confounding variables in order to get closer to causal inference.

Previous research has evidenced picky eating in childhood as a risk factor for negative outcomes (Dubois et al., 2007; Jacobi et al., 2008; Micali et al., 2011) and as a marker of pervasive developmental disorders (Cardona Cano et al., 2016) but we did not observe this in the current sample.

Strength and limitations

This study has several strengths, including its population based longitudinal design, and the inclusion of confounders to explore the nature of the association between picky eating and later outcomes. It is also one of very few studies to both explore physical and mental health outcomes of childhood picky eating in the general population and to track participants into adolescence. A number of limitations should also be discussed.

First, the generalisability of our findings may be limited as the data itself was exclusively drawn from a sample of children born in Scotland between 2004 and 2005. A second limitation relates to missing data. Non-response analysis revealed that a greater proportion of children from minority ethnic backgrounds and those born to young mothers and mothers who did not go on to complete further education had missing data and therefore, may not have been adequately represented in the analyses.

Implications for future research

This study examined linear effects only. It may, however, be useful to explore the possibility of non-linear relationships, for example, whether there is a u-shaped curve between weight and fussiness. Further work could also be warranted to explore whether certain factors such as neurodiversity or family conflict act as moderating variables of this relationship.

Work is also needed to unpick the different variants of eating behaviours that comprise picky eating. By refining this construct, we can further explore whether certain picky eating behaviours may present as a risk factor or a symptom of an underlying condition. This will

also rely on resolving the disparity within the literature regarding the conceptualisation and measurement of picky eating. It is likely that picky eating is highly heterogeneous, varying from person to person in terms of its degree of severity and outcomes. The development of a valid measure of picky eating behaviours as well as a universal definition or more specific delineation of the variations in eating behaviours it covers will enhance all areas of understanding, from building a reliable epidemiological picture, to informing successful intervention.

Conclusions

Overall, the findings of this study suggest that childhood picky eating, as here defined and investigated, did not appear to be associated with BMI or mental health outcomes in adolescence.

Chapter 6: "It's Taken Away Such a Big Part of her Life": A Reflexive Thematic Analysis Exploring the Experiences of Those Who Care for Children and Young People with ARFID

Abstract

Background and aims: ARFID is a relatively newly classified eating disorder which can significantly impact physical health and psychosocial function. This qualitative study aimed to gain a rich insight into the experience of living with and caring for a child or young person with ARFID, from the perspective of their caregivers.

Methods: Semi-structured interviews were conducted with the parents and carers of sixteen children and young people with ARFID, who were recruited from an outpatient eating disorder service in the UK. Interview transcripts were analysed using Reflexive Thematic Analysis.

Results: Qualitative analyses revealed four key themes: (1) The development of ARFID, (2) Maintaining factors (3), What helps? and (4) "It really affects us all" - the impact of ARFID. A conceptual model of ARFID development and maintenance is proposed, illustrating the relationships and interactions between the themes captured in the analysis.

Conclusions: This study provides insight into the nature and course of ARFID, highlights the widespread impact on the individual and their family, and illustrates the critical role that parents and carers play in managing this eating disorder.

Introduction

Avoidant restrictive food intake disorder, or ARFID, is a diagnostic category that was first introduced to psychiatric nosology in the Diagnostic and Statistical Manual of Mental Disorders in 2013 (DSM-5; APA, 2013) and then more recently added to the International Classification of Diseases, 11th Revision (ICD-11; WHO, 2018).

ARFID captures a cohort of patients who eat a severely restricted diet for reasons not relating to weight, shape, or body image, which leads to a persistent failure to meet nutritional and/or caloric needs, and/or significant impairment in psychosocial functioning. We know that ARFID captures a range of different presentations which vary according to what is leading to the restriction. These include, but are not limited to, a lack of appetite or little interest in food or eating, an avoidance relating to the sensory characteristics of food, and a fear or phobia-based response. This list is not exhaustive however, and the drivers contributing to the onset and perpetuation of restrictive eating behaviours frequently overlap and co-occur.

The literature indicates that caring for an individual with an eating disorder can be a significantly challenging, highly distressing and burdensome experience (Haigh & Treasure, 2003; Perkins et al., 2004; Robinson et al., 2020) and family involvement during the course of illness has been shown to have a significant impact on recovery outcomes and quality of life (Coelho et al., 2021; Couturier et al., 2020; Erriu et al., 2020). While this has been relatively well explored in other eating disorders (Batchelor et al., 2022; Carpinelli et al., 2022; Whitney et al., 2023), to our knowledge, there are no peer-reviewed qualitative papers detailing the lived experience of ARFID caregivers.

Several studies have qualitatively investigated the perceptions and feeding practices of those experiencing non-clinical fussy eating behaviours. Wolstenholme and colleagues (2020) conducted a synthesis of ten recently published qualitative studies examining non-clinical

fussy eating behaviours in children and young people with a particular focus on the perceptions and feeding practices of families experiencing such challenges. Focusing largely on pre-school children, the authors provide a comprehensive summary of various descriptions and definitions of fussy eating and propose a conceptual model which illustrates the complex nature of the family experience of fussy eating. Specifically, this model draws on the recent qualitative literature to illustrate relationships between five constructs which feed into the manifestation of fussy eating behaviours: parent feeding beliefs, child characteristics, parent feeding practices, parent awareness, and emotional climate at mealtimes.

Two qualitative adult studies have also provided accounts of the challenges and consequences associated with picky eating (Fox et al., 2018; Thompson et al., 2015). While both papers provide rich insight into the first-hand lived experiences of adult picky eaters, there is, to our knowledge, a dearth of service user led research in the field which qualitatively investigates what it means to live with and care for someone with ARFID.

The current literature evidences ARFID as a distinct clinical entity which provides diagnostic specificity to individuals with highly selective and/or restrictive eating behaviours. There is, however, a pressing need to study the experiences of parents/carers or young people with ARFID, thus providing a crucial contribution of the largely absent patient voice to evidence-based practice in ARFID. To this end, the current study aims to gain insights into parent/carer perspectives on:

1. The nature of ARFID, including its course.
2. The causal and maintaining factors of severe food restriction seen in ARFID.
3. The protective factors associated with ARFID.
4. The impact of ARFID on the young person, their parents, and the wider system.

Methods

Interview Participants and Recruitment

We recruited a diverse sample of participants who were undergoing treatment at an ARFID clinic located within an outpatient eating disorder service for children and young people in England. Participants were deemed eligible if they were the caregiver of a child or young person (aged 2-17 years) with a diagnosis of ARFID.

Parents and carers who met the broad criteria and had already expressed a general willingness to be contacted about research studies were approached by clinicians and invited to participate. Interested participants were then provided with the necessary information to contact the research team directly.

The parents and carers of twenty-three children and young people with ARFID were referred to the research team. All potential participants made initial contact, but seven withdrew from the study before completing the interview because of a failure to respond to follow up or return the necessary forms. In total, the parents and carers of sixteen children took part in the interviews: fourteen mothers and two fathers (see **Table 14** for demographic information). All caregivers were biological parents aged 37-58, 69% of whom were white British, and the remainder were from a range of ethnic backgrounds, including Greek British, Irish, and Russian. All children had a current diagnosis of ARFID, and some reported additional diagnoses, namely, ADHD (n = 1), autism (n = 6), Sensory Processing Disorder (n = 1), Depression (n = 1), Anxiety Disorders (n = 2) and Specific Phobias (n = 1). Assigned sex at birth and current gender identity were the same for all children in the sample.

Preliminary data analyses were conducted alongside data collection so the research team could consider data saturation. This was defined as the point at which additional data collection was unlikely to yield no further themes or alter the findings (Guest et al., 2020). Recruitment ceased in March 2023.

Table 14. Participant demographics ($N = 16$)

Child sex	Female	7
	Male	9
Child age at diagnosis	2-4 years	1
	5-8 years	7
	9-12 years	4
	13-17 years	4
Parent/carer age	35-39 years	4
	40-44 years	7
	45-49 years	1
	50-54 years	3
	55-59 years	1
Relationship to child	Mother	14
	Father	2

Materials and Procedure

Semi-structured interviews designed specifically for the study were used to collect qualitative data, lasting between 30-60 minutes each. Interview schedules consisted of open questions covering a list of key topics including the impact of ARFID on the child, main concerns for the caregiver, and treatment expectations, for example: 'Can you tell me about your child's eating?', 'Could you tell me about how these difficulties developed?', 'What do you think maintains the problem, what causes it to keep happening?', 'What impact does this have on your life?' and 'What do you think makes the problem worse?' (see **Appendix 10** for a full interview schedule).

The question schedule was loosely observed, and prompts were used to elicit a rich account of participants' experiences and to encourage discussion of any other topics they felt were relevant. A short demographic questionnaire was also given to participants.

Interviews were conducted by the first author (L.B.) and took place online via video call (Microsoft Teams) at a time suitable for the participants.

Ethical Considerations

This study received ethical approval by the North West - Greater Manchester South Research NHS Ethics Committee (ref. 21/NW/0072). Ethical principles were adhered to, and all caregivers were guaranteed anonymity, made aware of their right to withdraw, and fully briefed before and after participating in the study. Written informed consent was also obtained.

Data Analysis

All interviews were digitally audio recorded and transcribed. To ensure the confidentiality of participants, any personal or identifiable information was redacted in transcripts, and the interview recordings were deleted once transcribed. The transcripts were entered into Qualitative research software, NVivo (version 14; NVivo, 2023) to aid data management and facilitate analysis.

This exploratory study employed an inductive, data-driven approach. Reflexive Thematic Analysis was used according to Braun and Clarke (2006, 2013, 2019, 2021), which is a six-phase method used for identifying and reporting patterns of meaning within qualitative data. The reflexive aspect of the analysis recognises the active role of the researcher and acknowledges the influence of their prior assumptions or biases on the interpretation of data.

First, the lead author (L.B.) became familiar with the data by transcribing the interviews, and then reading and re-reading the transcripts. Recursive line by line coding was conducted to assign descriptive labels to the data, and codes were then organised into broader themes to establish a preliminary thematic framework which reflected key patterns of

meaning within the data. The themes and subthemes were reviewed and refined by the research team until a consensus was reached.

Reflexive practice was observed throughout the data collection and analysis process. Three members of the team are practicing clinical psychologists, one works closely with children and young people with ARFID, and all are engaged with research. Therefore, the research team as a whole are closely positioned to the topic and were aware of their influence on the interpretation of the data. The first author (L.B.) kept a reflexive diary throughout the interview and data analysis (see **Appendix 11** for journal excerpts).

The team considered the philosophical stance of the research prior to commencement of the study as this can influence the research design and interpretation of the data. Data analysis adopted a broadly critical realist framework which asserts that data informs reality, but is not wholly reflective of it (Willig, 2013). Instead, our understanding of the world is a construction of our measurable and observable experiences (Bhaskar, 2009; Bhaskar & Hartwig, 2016; Collier, 1994; Houston, 2001). Participants' accounts were considered a subjective version of the truth, shaped by their understanding of the social world, and further constructed through the researcher's interpretive lens.

Results

Codes were structured around four key themes with further subthemes, which pertained to the experience of living with and caring for a young person with ARFID (see **Table 15**): (1) The development of ARFID, (2) Maintaining factors (3), What helps? and (4) "It really affects us all" - the impact of ARFID.

Table 15. Overview of themes and subthemes

Themes	Subthemes
1. The development of ARFID	Internal vulnerabilities
	External stressors
	Trigger incidents
2. Maintaining factors	
3. What helps?	Practical management strategies
	"Creating a safe haven"
	Finding the intrinsic motivation to recover
4. "It really affects us all" - the impact of ARFID	The impact on the child
	The impact on the family

Theme 1: The development of ARFID

All parents reflected on the development of their child's eating difficulties. In the most part, participants fell into two subgroups: (1) food selectivity and aversions apparent from an early age which were exacerbated by stressors, leading to severe and clinically significant eating restriction (described by Subtheme 1a and Subtheme 1b) and (2) sudden onset of symptoms occurring as a result of a traumatic or distressing trigger incident (described by Subtheme 1c).

Subtheme 1a: Internal vulnerabilities

Most parents reported that prior to the onset of ARFID, their child had a number of characteristics that they believed contributed to the subsequent development of ARFID. Several parents discussed sensory sensitivities that were apparent from an early age. These included sensitivities to texture, temperature, appearance, noise, and a strong disgust reaction:

> *"He only likes wearing jersey tracksuit bottoms, he's sensitive to some fabrics, and he does seem to be quite sensitive to taste and difference. I remember my sister bought*

some macarons from France and he tried one and didn't want any more and said he didn't like it as it's got too much taste".

"We had further sensory issues around packaging, food packaging. She hated the look of it. She didn't like me cooking. She didn't like the sound of the kettle being boiled. Me and my husband couldn't eat in front of her, so it was just this sort of real onset of everything."

Another parent reported that her son had experienced difficulties with attention and maintaining focus from a young age. This was thought to contribute to the onset of ARFID because of the child's inability to sit still, or to pay attention to feelings of hunger:

"He's always had attention issues and struggles to sit still…we've never expected him to sit at the table to eat because he just can't."

Interoceptive awareness, and in particular, hunger, was also mentioned by several other parents, who described recognising and responding to hunger and satiety cues as a challenge for their child:

"Interoception is definitely a big thing because he just doesn't feel hunger until he's absolutely ravenous. So, he's not motivated to eat because he doesn't feel hungry until he's starving, by which time he feels so awful that he doesn't feel like eating anyway."

Subtheme 1b: External stressors

On top of the internal vulnerabilities previously mentioned, parents also noted various stressors which they felt contributed to the development of ARFID. Specifically, there was a sense that the characteristics discussed in Subtheme 1a fostered food selectivity and particular preferences, but that the following additional stressors played a significant role in pushing these challenging eating behaviours into clinically significant territory.

Several parents reported that age-related or developmental changes, such as starting school, exacerbated existing eating difficulties because of emotional over-arousal or sensory over-stimulation:

> "*In school he can't stand being around all the smells and sights of other people's foods…he was suddenly surrounded by all the smells and sights of the hot food, and he hated it, really dreaded lunchtime."*

> *"She was trying to manage a school day and the anxiety that comes with that, and her eating just got worse."*

> *"When she hit four, we had a really explosive year with her and her regulation and sensory issues, which before then, we just hadn't really experienced. So again, it's all the sensory issues, which have settled down now and she's doing well."*

Relatedly, parents discussed their attempts to manage the issue, for example, by involving the school or seeking out professional help. It was felt, however, that the unhelpful input or advice they received may have in fact worsened the situation:

"He was just about to start school, and we were going to send him in with a packed lunch, and she [the dietitian] said don't do that, don't tell the teachers he has any kind of issues around eating and he'll soon get hungry enough that he'll eat school dinners."

"We went to a dietitian once, and again I don't think the advice was very good… all she kept saying was he's going to put on weight if you feed him like that. I said we know about portion control, and we don't normally feed him like that, but she was very focused on the fact that he was going to be overweight, and we shouldn't feed him as much as we were feeding him."

"I put her down for school dinners, I said whatever is being served just give it to her, and I thought she might eat because her peers were eating, but she never did. I kept forcing the school to do it and, in the end, they said they weren't comfortable with it as they'd never met anyone like her, who they couldn't break down. They used their best staff to try to coax her, but she was adamant, she would just shut down and get very emotional."

Subtheme 1c: Trigger incidents

In contrast to the group mentioned above, where ARFID developed gradually and was preceded by a set of internal vulnerabilities, other parents reported that their child's ARFID came on more suddenly following a trigger incident. For those that exhibited this presentation, parent tended to note that prior to the incident, their child had a healthy relationship with food and exhibited very little food selectivity.

For several children, such triggers were related to food specific events, such as a choking or vomiting incident, or a bout of gastroenteritis:

> *"She had a couple of incidents where she vomited in fairly dramatic circumstances - she vomited in her sleep once, and after an evening meal at a family party. And now we think maybe that was something that set it off, but you don't really know at the time, it doesn't come with a flag warning."*

> *"She was one of those babies who was really interested in food. She weaned really easily at 6 months, she ate anything and everything, whatever we had, I just mashed it for her, and she ate it. She was a dream. And she stayed like that until she was around 6 months old. And what seemed to be the trigger was that she got really ill with a chest infection at about 18 months."*

The onset of anxiety difficulties which impacted on food and eating was also discussed. For one participant, vomiting fears and concerns of contamination emerged as a result of the Covid-19 pandemic:

> *"There was a lot of heightened sensitivity, mask wearing, germs, hand washing, all of that although not evident at the time, is something she has since reflected on and realised it affected her fear of germs and emetophobia. She's had a fear of vomiting since she was 6, but that hasn't manifested for her in a way that was problematic on a day-to-day basis with her eating until she reached around 15. She reflected how the pandemic and the cleaning; it was just too much for her."*

For others, the trigger for ARFID was less clear. Parents speculated as to the cause, with theories widespread and varied:

> *"Was it red food? I don't know. Because he used to eat a lot of tomatoes and baked beans. Did something upset his tummy? And maybe now he associated red food with pain."*

> *"While I was pregnant, I had gestational diabetes and I couldn't eat lots of foods because I had to check my blood sugar, so I wonder If that has something to do with how the child developed in utero. I'm not sure if there is a connection between that and her limited diet. I also had a very stressful pregnancy, lots of worries, so maybe that has somehow affected it."*

> *"I ask myself, I'll be honest, was it the MMR, the second vaccine?... something did change with him after than second MMR, he became really poorly, and I had to take him to hospital and the lady said to me it could be that but there is a virus going round. But he was never the same again."*

> *"Actually, take a step back, and this is really a hypothesis, she was born with a tongue tie, and they didn't snip it at birth. I did breastfeed her, but she was a bit of a snacker, little and often, so we do wonder if that set her up for life as she never really got full."*

Theme 2: Maintaining factors

Parents highlighted various factors which they found to act as maintaining factors for their child's ARFID. Attempts to manage the issue were varied, but there was universal agreement

that the application of pressure was counterproductive. This included coercive tactics to encourage the child to try new things, pressure to eat more, and more generally, increased attention or focus on the child at mealtimes:

> *"We went through a phase of having super stressful mealtimes, you know the pressure of getting her to have another bite, and she said she used to feel the dread before a meal."*

> *"If I try and force it, it goes completely the other way, and then he won't have anything."*

Conflict or tension at mealtimes was also found to maintain and, in some cases, to exacerbate ARFID. In particular, disagreements with another parent or carer about how best to tackle the issue was a source of tension, resulting in reduced mealtime engagement or a complete refusal to eat:

> *"We argue about him using his iPad at the dinner table. I see it as a necessity, but his dad will kick off if he's there. And then we get complete shutdown. It's traumatic."*

Finally, several participants noted that periods of illness would maintain ARFID and often, result in increased dietary restriction. For some, this was related to a loss of appetite accompanying the illness and for others, this was related to associating the cause of illness with food eaten around its onset and subsequently cutting it out. For those with a very limited food repertoire, this resulted in the loss of one or more of very few "safe foods", causing significant concern for parents.

"Illness is the big thing - if he becomes ill while he's eating a certain food, that's it, it's gone forever. He will associate that with being ill. That food made me sick so now I can't trust it."

The maintaining factors previously discussed were reported by most parents and could likely be applied to most children and young people with ARFID. There was, however, some mention of more nuanced maintaining factors, which were specific to the individual. For example, for one participant with a fear of vomiting, use of the wrong language could trigger a setback:

"Anyone who mentioned feeling sick or ill, people use it quite interchangeably of course, they might mean they've got a cold, but that was incredibly alarming for her, she would go into panic, she wouldn't eat."

Theme 3: What helps?

Theme 3 captures parents' views on the things they have found to help or improve their child's eating difficulties, as well as techniques and strategies they have adopted over time. All participants in the current study were recruited from an ARFID clinic and therefore, were currently engaging with services and receiving support. Therefore, the following examples are a combination of strategies they have learned themselves, and also from professional advice.

Subtheme 3a: Practical management strategies

Almost all parents discussed practical adaptations they found useful in helping to accommodate their child's eating difficulties. The use of screens and similar distractions was frequently mentioned, as a tool to reduce over-stimulation or over-arousal at mealtimes:

> *"Say we want to go to a restaurant, we just give him his tablet or a phone to play with to distract him, and he can quite happily sit in a restaurant...if we want to go out as a family, you can distract him from the panic, because he will get overwhelmed and upset and then he starts being silly and hiding under the table. But you can give him his tablet and go to places he's familiar with and take his food with him."*

For many, structure, routine and preparation were crucial, both for the parent in ensuring they could take control and for the child in feeling safe and stable. In particular, packed lunches were seen as essential, and allowed many to participate in social events they would otherwise avoid because of concerns around food:

> *"He's very much comforted by a packed lunch. He doesn't feel different or weird or ostracised."*

Relatedly, there was a sense that offering mostly accepted and familiar foods was key to ensuring steady progress and maintaining trust

> *"As long as we're able to give him the things he likes, he will eat to sustain growth and have enough energy, there's just not a lot of variation. The dietitian said it's good*

enough in terms of maintaining growth, and then he needs a multivitamin alongside. So, I feel more confident."

"School is packed lunches; he has a very specific set of accepted foods for that. At home, everything revolves around accepted foods. The shopping is done very specifically to make sure we buy specific brands of things - rice and rice cakes tend to be the main staples."

Subtheme 3b: "Creating a safe haven"

Many parents emphasised the importance of the home environment and in particular, ensuring a calm and unpressurised "safe zone". This included the removal of pressure, gentle encouragement to eat more or try new things, and making sure the child felt in control of the situation:

"At home, she's safe and there are foods that she likes, and she has much longer to eat them. So, it's a lot easier than at school where you've got less control over the environment and eat very quickly before you go out to play."

"Just taking the pressure off anything at home, so keeping home as the real safe zone, you know, giving her safe foods, not trying to overwhelm her with things."

For one parent whose child had developed a fear of food contamination, nurturing trust through honesty and transparency was key to encouraging progress:

"We spoke about how she had to trust us, and watch us cook her food, to reduce the fear of germs. She'd wanted it cooked in a certain way, make sure it was clean. So, trust is a big thing, she needs to trust us that we're giving her good food that won't make her unwell."

Subtheme 3c: Finding the intrinsic motivation to recover

Several parents observed a shift in their child's intrinsic motivation which contributed to positive steps towards recovery. For those who were entering into later childhood and adolescence, this was mostly related to social influences, for example, a desire to fit in with friends, to socialise around mealtimes, or to integrate at school. While there was a general sense that parental pressure had a negative impact on progress, social pressure from peers was seen to act as a positive influence:

"She has got a lot better with her friends…in the last couple of months, they've started doing a Friday night sleepover and interestingly enough, sometimes they cook. She didn't used to cook that much…but she's started doing a bit of cooking and actually she seems to take the lead on that which is really interesting. I think it's about being in control, even if it's trying something new, and with them she tries more things. They made pumpkin pie, they made pastry, it was a miracle."

One participant reflected on her son's new relationship, which brought about positive pressure to try new foods and eat out at restaurants:

"She's a 17-year-old girl who likes to do what she likes to do, and she puts him under pressure to go out and eat. Which she has done. The motivation is there because he's

obsessed with this girl, and she sits there and eats what she likes, and he sits and has chips. And it doesn't seem to bother either of them. In a way it's been quite a positive thing."

For the majority of participants who spoke of intrinsic motivation, there was a sense that this occurred organically alongside treatment, rather than as a direct result of clinical input. Nevertheless, these parents touched on the fact that treatment may not have been as effective if their child had not experienced this shift. For one young person, however, motivation did emerge as a direct result of accessing the right support:

"He's been surrounded by support in the last year, and you can see him blossom. What's so sad is when people don't get that because the difference is phenomenal. You just need that help from professionals who know what they're doing, and as soon as that person sees the improvement, they feel more motivated and then it kind of cascades."

Theme 4: "It really affects us all" - the impact of ARFID

The final theme refers to the impact of ARFID which was a central topic of discussion for all parents. Conversations centred around both the current impact of ARFID and concerns for the future. Such discussions related to the impact of ARFID on the individual themselves, and also the wider impact on the family.

Subtheme 4a: The impact on the child

Participants spoke in depth about the impact of ARFID on the child. A particular source of concern was the physical impact, and in particular, the health consequences of a severely

restricted diet. While the majority of weight or growth concerns related to weight loss or a failure to gain weight, two parents spoke of their concerns around weight gain as a result of a limited diet of calorie dense foods:

> *"One of the main reasons that we came to the clinic in the first place was that he suddenly started putting on weight very quickly. And that was a concern because he couldn't get full up eating hot cross buns and they're full of sugar, and they didn't fill him up."*

Nutritional health outcomes were also widely discussed amongst participants. Parents noted the impact of high sugar diets and a lack of nutritional variety. As such, concerns centred around low energy levels, difficulties with concentrating, the development of diabetes and other medical complications, and dental health:

> *"I was thinking I don't know else what I can do, she's 11 and just about to go through puberty, she needs to eat. And there's nothing more I can do. So that was a real fear that she was going to start hurting her body. She was already very thin and grey, and didn't look very healthy, so what happens as she starts to grow, I can't force feed her, I can't literally make her eat it, the next step is tube feeding. So that was the main fear that this will affect her growth and development".*

> *"My other concern is that she has a lot of sugar too, and I don't like that. I'm worried about the long-term situation if she could develop diabetes. And her teeth; if they will be good if she has so much sugar."*

"The thing that scares me the most is the extreme horror stories you hear, like the man who went blind later on in life."

There were also discussions surrounding the social and emotional impact of ARFID, and concerns for the future about integrating with peers:

"She became very insular and, housebound is a little extreme, but her world became smaller. At the time it had taken hold, she didn't want to go into the outside world, she didn't feel safe. And for a long time, she wouldn't eat outside the home, so we were very restricted to where we could go."

"As it gets progressively further on, and he gets older, and he starts doing play dates and I'm not there to manage his food intake…I'm worried that he's gonna stop being invited. As, you know, he's the child that doesn't eat anything, the child who only eats bread and butter and Marmite and I just worry long term that it's gonna start affecting his social life as well."

A few parents, however, noted that their child had little desire to socialise and form friendships, and thus, they were less concerned about the impact of restrictive eating on social outcomes. For one parent, whose son had a diagnosis of autism, socialising with peers was not a priority:

"Socially, he's not interested at all. He's got one best friend who he's not really interested in seeing at all. He feels that his needs are fulfilled by just being at home with us and his brother."

Subtheme 4b: The impact on the family

Almost all parents acknowledged the wider impact of ARFID on the family. Practically speaking, parents described the burden of pressure they felt in needing to ensure that accepted foods were available, and that food was prepared in advance for days out or holidays:

> *"I have to cook for her to go to birthday parties, which takes many hours. I have to bring my own food, and make sure she eats it. And it has to look perfect, to be the perfect shape."*

> *"When we book a holiday, I have to make sure I book a catering apartment so we can cook for her. Every day, every outing, every holiday you've got to think about how I can make sure she's got the things she needs. You know, the terror when the thing she's eating is not stocked in the supermarket."*

There was also some mention of missed opportunities to spend time together as a family, as a result of ARFID:

> *"I think social elements, for me and my husband. For example, on a Saturday we'd love to go out for breakfast or lunch, it's just a nice social family thing to do. But that's been taken away."*

The emotional weight of dealing with the issue was another point of impact discussed by parents. Various emotions were expressed, including frustration, worry and isolation:

> *"It's just really stressful to watch your child not willing to eat anything."*

"It's been a very, very long and emotional journey, and the impact on a mum is huge."

Finally, the impact on siblings was touched upon by several parents. One parent described the juggle of managing the needs of their son with ARFID, whilst respecting and acknowledging his sister's preferences:

"He gets his accommodations, so it gets tricky when his sister says she doesn't like things. I need to make sure I'm respecting her preferences because to her, it looks like he gets to have what he wants. So, it's just navigating that and not narrowing her range of foods, because she sees that he can refuse things easily, so why can't she."

Another parent commented on the fact that her son was experiencing significant concerns about his sister's eating difficulties:

"He worries himself sick over it. He wrote a letter to Santa that I found saying that he was really worried about his sister, and could Santa fix it?"

Model of ARFID Development

Drawing on the insights gleaned from the data and using the themes that emerged from the analysis, we present a conceptual model of ARFID development and maintenance (**Figure 7**). We consider this to be a set of hypotheses, derived from our qualitative analysis, for future testing.

In terms of development, it would seem that ARFID can arise via two broad pathways. The first proposes that a set of internal vulnerabilities exist within an individual

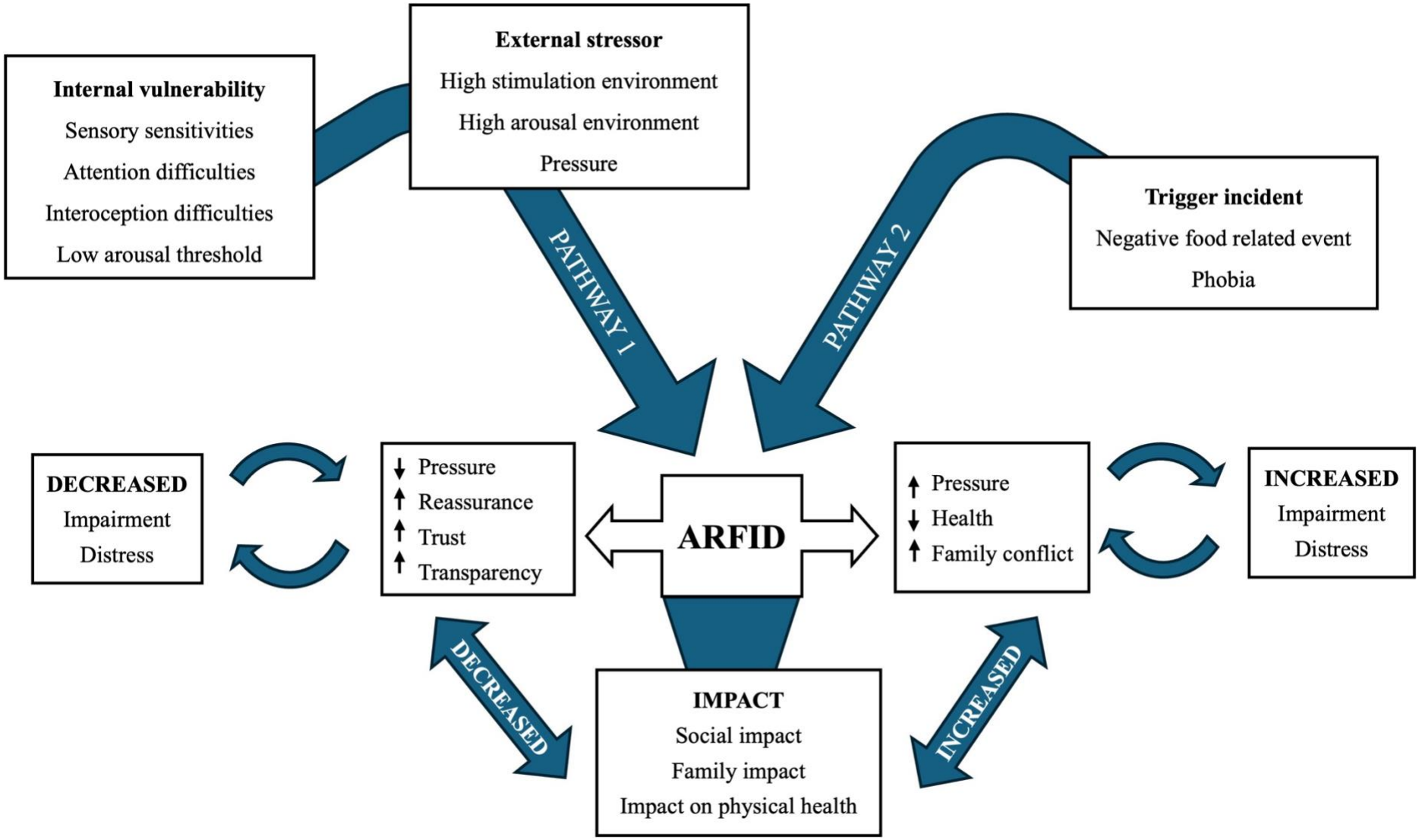
which may increase risk of restrictive eating behaviours. For example, inherent sensory sensitivities may give rise to preferences based on the sensory qualities of foods, interoceptive difficulties could impact an individual's ability to sense feelings of hunger, a low threshold for emotional arousal may impact appetite in stressful or high-arousal situations, and attention difficulties may affect focus during mealtimes. While such characteristics alone are likely manageable and may simply result in food fussiness or idiosyncratic preferences, we suggest that an external stressor or set of stressors, such as a high stimulation (sensory) or high arousal (emotional or attention) environment, could intensify or exacerbate such behaviours and further reduce dietary intake, resulting in clinically significant restrictive eating concerns.

The second pathway identified from the data is via a trigger incident which prompts a sudden or acute onset of symptoms. This could be a food specific related event, such as a choking incident, or a more general phobia, for example, related to vomiting. While we recognise that the above-mentioned predisposing characteristics thought to foster food restriction may be present in anyone presenting with ARFID whatever the pathway of development, we propose that the primary drivers underlying the two pathways, along with treatment approaches and outcomes, are inherently different.

According to the model, once ARFID develops, feedback loops contribute to either the perpetuation or improvement of symptoms. For example, parents reported that by reducing mealtime pressure and promoting trust, transparency, and reassurance, they noticed a decrease in their child's distress and impairment. Consequently, caregivers felt yet more trust in the process, which further reduced pressure around mealtimes, and boosted the level of reassurance and transparency they could offer to their child. As impairment and distress reduced, so too did the impact of ARFID. In contrast, families discussed positive feedback loops, for example, where an increase in pressure on the child, family conflict, particularly

during mealtimes, and instances of illness increased impairment and distress. As a result of this increase, parents responded with increased pressure, and conflict worsened, thus increasing the impact of ARFID.

Figure 7. Proposed model of ARFID development and maintenance



Discussion

This qualitative study aimed to gain insight into what it means to live with and care for someone with ARFID from the perspective of the caregiver. Four key themes and further subthemes were identified pertaining to the onset of ARFID, the worsening, and improvement of symptoms, as well as the impact on the child and their family. Notably, while general themes were found to run through the data, the lived experiences of those with ARFID were seen as distinct and heterogeneous, in line with the phenotype of the condition itself (Norris et al., 2018; Watts et al., 2023).

We propose a conceptual model which draws on the findings and illustrates the relationships and interactions between the themes captured in this study (**Figure 7**). The model demonstrates the complex and heterogeneous nature of ARFID development and maintenance, and highlights the value of appropriate family involvement, parental self-efficacy, and consideration of the emotional and sensory environment. As part of this model, we identified two broad pathways of ARFID development. It is important to note, however, that there was unique variation within these pathways, with perceived contributing factors presenting in different severities and combinations.

The current model aligns somewhat with the conceptual model of picky eating proposed by Wolstenholme et al. (2020). This suggests that characteristics inherent to the child, such as personality, age, and weight status, as well as aspects of the family environment, such as control exerted by parents, the emotional climate at mealtimes, and parent feeding beliefs, work together in fostering and maintaining picky eating behaviours. While the two models represent clinically different disordered eating presentations, both emphasise an interaction between pre-existing characteristics and external influences, most notably, parental influence. This further emphasises the need to unpick the relationship

between picky eating and ARFID, and in particular, to better understand how and why such behaviours develop into a clinically significant concern.

Parents reflected on factors they felt contributed to the improvement and deterioration of their child's eating difficulties. Many parents discussed the methods, behaviours, and practical strategies they had learned to support their child, whether independently or with input from the team at the ARFID clinic. For example, an emphasis was placed on reducing pressure around food and mealtimes, embracing structure, routine, and familiarity, and offering safe and accepted foods. It is interesting to note that many of these are in direct contrast to methods seen to promote recovery in anorexia nervosa treatment, where there is a focus on expanding dietary range (i.e., Schebendach et al., 2011), patients are encouraged to steadily increase food intake in order to ensure adequate caloric intake and interventions support cognitive flexibility and adaptability to change (Schmidt et al., 2014; Schmidt et al., 2015). Thus, while ARFID and anorexia nervosa may appear symptomatically similar, particularly in those who exhibit significant weight loss (Stern et al., 2024), the findings from this study support the view that the underlying drivers are fundamentally different and therefore, the two require different treatment approaches. This also supports the literature which discusses the impact of a misdiagnosis of anorexia nervosa for neurodivergent eating disorder patients who may more appropriately receive a diagnosis of ARFID (Brede et al., 2020; Babb et al., 2022).

Participant perspectives indicated that ARFID is highly impactful, both to the individual in terms of their health and social functioning, but also to the wider family. Parents described their own emotional distress, the bearing on familial relationships, and the practical implications of supporting someone with ARFID. This is in line with research which evidences the significant challenge and burden of caring for an individual with an eating disorder (Haigh & Treasure, 2003; Perkins et al., 2004; Robinson et al., 2020). Importantly,

the findings from this study suggest that the family can have a significant impact on ARFID symptomology, for example, increased pressure at mealtimes can further increase distress. This has important implications for treatment and suggests that a systemic rather than individualised approach to intervention may be more beneficial.

Strengths and Limitations

To our knowledge, this is the first qualitative study of the perceptions, understandings, and personal experiences of those living with and caring for a child or young person with ARFID. Therefore, it addresses a critical gap in the field (Bryant-Waugh, 2020).

There are, however, several limitations to the present study. While the tentative conceptual model does align with a previous model of picky eating (Wolstenholme et al., 2020) and generally speaking, with what is understood about ARFID based on current literature (Fisher et al., 2023), further work is needed to test whether this model can be generalised, and whether it represents a real world understanding of ARFID. Participants were recruited from a single ARFID clinic located within an outpatient eating disorder service for children and young people in England. As such, there is a question as to whether this sample is fully representative of children and young people with ARFID and their families. It is also important to consider whether engagement with ARFID treatment contextualised the experiences of those who took part. For example, psychological formulations given to participants during the course of their treatment could have structured their experiences. Thus, the model will need to be tested with larger samples, across different populations, settings, ages, and socioeconomic backgrounds, as well as levels of impairment and/or severity.

There is also a need to reflexively engage with the process and to consider the position of the research team, all of whom are familiar with ARFID literature, and fully engaged with practice, research, or both. While significant efforts were made to acknowledge pre-existing

interpretations and assumptions via regular reflexive discussion and journaling, consideration should be given to how much of the analyses were influenced by prior perceptions of ARFID.

Implications and Recommendations

This research supports the current view of ARFID as a complex and heterogeneous disorder, with numerous predisposing and perpetuating factors. There is, however, a pressing need for further qualitative research in the ARFID field to further elucidate these mechanisms, and to ensure that the patient voice is appropriately represented in evidence-based practice. It would be beneficial to capture the experiences of the children and young people themselves, and to speak to those who are yet to receive a diagnosis or access to treatment. Qualitative research involving adults would also make an important contribution by providing valuable insight into social and occupational outcomes of ARFID in adulthood, as well as the longer-term health implications.

Finally, this study highlights the critical role of parents and carers in managing ARFID, and the widespread impact it can have on family relationships and the home environment. As such, the findings suggest that parent training is key in targeting the beliefs and emotions around caring for someone with ARFID and equipping families with the necessary skills to implement interventions at home. Relatedly, this adds weight to the use of gentle encouragement, reduced pressure, and the promotion of flexible treatment suited to the needs of the individual and their family.

Chapter 7: "A Stroke of Luck": Caregiver Perspectives on Seeking and Accessing Appropriate Care for ARFID

Abstract

Aims: To qualitatively explore parents' experiences of seeking and accessing support for their child's eating difficulties.

Methods: The parents and carers of sixteen children and young people with ARFID were recruited from an outpatient eating disorder service in the UK. Semi-structured interviews were conducted, and data analysed using Reflexive Thematic Analysis.

Results: One overarching theme was identified through thematic analysis: Gaps in ARFID knowledge and practice. Set within this landscape were four secondary themes: (1) Barriers to accessing support, (2) The impact on the parent/carer, (3) "A stroke of luck" - Finally achieving appropriate ARFID support, and (4) Looking ahead. Together, the themes and their subthemes depict a journey from initially seeking help, to ultimately sourcing and benefiting from appropriate ARFID care.

Conclusions: Overall, the findings indicated that children and young people with ARFID are struggling to access appropriate care, the reasons for which relate to gaps in both knowledge and practice. The resulting implications of these findings include the need to improve understanding of ARFID with further research in all domains, improve public awareness, upskill practitioners, increase ARFID service provision, and refine referral pathways.

Introduction

The diagnostic category of avoidant restrictive food intake disorder, or ARFID, was introduced to psychiatric nosology in the 5th Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; APA, 2013) and replaced and extended the category of feeding disorder of infancy or early childhood in the 11th Revision of the World Health Organisation's International Classification for Diseases (ICD-11; WHO, 2018). ARFID was designed to capture a persistent disturbance in feeding or eating which, in contrast to anorexia nervosa, is not motivated by an obsessive fear of weight gain, a body image disturbance, or a desire to be thinner. Instead, ARFID covers a heterogeneous group of patients who restrict the type and/or amount of food that they eat, resulting in severe malnutrition, significant weight loss or a failure to gain weight, growth compromise, and/or a marked interference with psychosocial functioning (APA., 2013; DSM-5-TR; APA, 2022).

ARFID is an umbrella term encompassing eating problems with diverse contributing factors (Archibald & Bryant-Waugh, 2023; Reilly et al., 2019; Zickgraf et al., 2019a). The DSM-5 definition currently provides three examples of factors which may drive and/or maintain the food avoidance and/or restriction: (1) an apparent lack of interest in eating; (2) an avoidance based on the sensory characteristics of food; and (3) a concern about the aversive consequences of eating (APA., 2013). This list is not exhaustive, and its items are not mutually exclusive. It instead serves to provide examples of features which have been well described in the literature and/or commonly seen in clinical practice.

ARFID is a clinically significant and prevalent eating problem (Archibald & Bryant-Waugh, 2023; Bourne et al., 2020; Nicely et al., 2014; Sanchez-Cerezo et al., 2022). Further, the healthcare needs of young people with ARFID have been found to be in line with other eating disorders, and substantially higher than the general population, according to a retrospective study of young people diagnosed with various eating disorders between 2000

and 2017 (Couturier et al., 2023). Despite this, ARFID is commonly unrecognised and underdiagnosed (Bryant-Waugh, 2020). This is in part due to a lack of familiarity reported by health care professionals with managing and diagnosing ARFID (Coelho et al., 2021), and also because of the complex and heterogeneous nature of its presentation, distinct aetiological underpinnings and need for multi-disciplinary assessment (Bryant-Waugh, 2020; Norris et al., 2016). As a result, it is often poorly managed, with patients repeatedly dismissed and/or referred to any number of inappropriate specialists (Nicely et al., 2014). Furthermore, many eating disorder services in the UK and elsewhere continue to focus predominantly on anorexia nervosa and bulimia nervosa and/or are inadequately equipped to manage the condition, which has created a considerable gap in accessing appropriate clinical expertise (Coglan & Otasowie, 2019).

Despite increasing recognition of the merit of qualitative research in informing healthcare services and improving quality of care (Flemming et al., 2019; Wolstenholme et al., 2020), there is a lack of qualitative evidence relating to ARFID (Bryant-Waugh., 2020). A handful of studies have explored the experiences of children and young people with ARFID and their caregivers in clinical and non-clinical settings (Bradbury, 2020; Doleman, 2022; Milne, 2020) and just one study was found to explore pathways to care through the healthcare system in Aotearoa New Zealand (LaMarre et al., 2023). Since services vary by country, and often between regions within countries, research of this type across a range of settings is warranted to understand problems that need fixing within specific healthcare systems.

There is a real need to understand the specific challenges faced by those who have sought professional help for ARFID, and the barriers associated with accessing treatment for an eating disorder which is largely misunderstood, unrecognised and often trivialised by healthcare professionals (Harrison, 2021). The current study therefore sought to capture the voices of ARFID caregivers, with a particular focus on exploring the journey to accessing

services and engaging with practitioners. As such, we hope to highlight current gaps in ARFID knowledge and in the provision of ARFID services.

Methods

Design

A qualitative research design was employed, with participants interviewed in a semi-structured format.

Recruitment

We recruited participants who were undergoing treatment at an ARFID clinic located in an outpatient eating disorder service for children and young people in England. Participants were deemed eligible if they were the parent or carer of a child or young person (aged 2-17 years) with a current diagnosis of ARFID. Members of the clinical care team identified those eligible for the study and sent out an invitation to participate. If interested, potential participants were then advised to contact the research team to proceed with the consent and interview process.

Sample

Parents and carers who met the broad criteria and had already expressed a general willingness to be approached regarding participation in research studies were approached by clinicians. The parents and carers of twenty-three children and young people with ARFID agreed to participate, but 7 withdrew before completing the interview. Thus, the parents and carers of sixteen young people were interviewed. Basic demographic information was collected from participants and is detailed in **Table 14**.

Ethical Considerations

This research was approved by the North West - Greater Manchester South Research NHS Ethics Committee (ref. 21/NW/0072). All participants were provided with an information sheet and gave written, informed consent prior to participating. Participants were

made aware of their right to withdraw at any point before, during or after participation in the study, and were guaranteed anonymity and confidentiality.

Procedure

Interviews were conducted via remote video chat (Microsoft Teams) by the first author (L.B.) and lasted between 30 and 60 minutes. A semi-structured interview schedule was developed with a focus on the following areas: factors relating to the aetiology and maintenance of ARFID, broad experiences of seeking support, impact on the child and those around them, parent/carer concerns, and goals and expectations for the future. Participants were also invited to highlight any other matters that were missed during the interview (see **Appendix 10** for a full interview schedule). This semi-structured schedule was loosely adhered to in order to ensure all pertinent topics were covered, but free and open discussion was encouraged, with an emphasis placed on reflective thought and personal experience.

Recruitment ceased in March 2023 after preliminary analyses indicated that we had reached saturation. Data saturation is a term used to describe the point at which it is unlikely that additional information will add valuable insights or change the findings (Guest et al., 2020).

Data Analysis

Interviews were audio recorded and transcribed verbatim, with names, personal data and any other identifiable information redacted. Recordings were deleted after transcription. Qualitative research software, NVivo (version 14; NVivo, 2023) was used to organise and explore the data.

Reflexive Thematic Analysis (RTA) was conducted, following the six phases outlined by Braun and Clarke (2006, 2013, 2019, 2021). RTA is a flexible approach to qualitative data analysis which aims to identify and make sense of themes or patterns across a dataset, whilst valuing the researcher's interpretive lens. Rather than seeking objectivity, RTA recognises

the active role of the researcher and embraces their reflexive influence on the interpretation of the data.

First, the lead author (L.B.) read and reread the interview transcripts to ensure full immersion and familiarisation with the data. Next, manual coding was conducted, which involves line by line analysis to describe the content, generate textual units of significance, and identify patterns of meaning at both a latent and semantic level (Braun & Clarke., 2006; 2013; 2021). Codes were then discussed and revised repeatedly with the second author (J.C.) before refocusing at a broader level to consider potential themes. Preliminary themes and subthemes were then identified and via an iterative process of ongoing discussion, review and refinement with the wider research team, a final conceptual framework was agreed with relevant excerpts extracted from the transcripts.

From a philosophical perspective, it is important to recognise and explicitly state the angle from which this research is based. This is a crucial starting point for qualitative research as it shapes research design, outcomes, and interpretation, and reveals to the reader the assumptions that the researcher is making about the data. In the present study, data analysis was approached within a critical realist framework. This accepts the existence of an objective truth but argues that it cannot be directly observed as it exists independently from human perspectives, descriptions, and ideas. Thus, the observable world as we know it is always a subjective construction, shaped by personal experiences and perspectives. Participants' accounts are therefore considered true to them, but since they are a subjective version of their own reality examined in the social world, we acknowledge that a single empirical truth will never be realised and instead, multiple valid accounts of the truth exist simultaneously (Collier, 1994; Houston, 2001; Willig, 2013).

It is important to reflexively engage with the research, particularly within a critical realist approach. Throughout the analytic process, the research team acknowledged that the

resulting codes and themes reflected their own interpretive analyses, rooted in their skills, experiences, and theoretical assumptions. Three of the authors are practicing clinical psychologists, one of whom works directly with children and young people with ARFID. Two authors are autism researchers. None of the research team have any personal experience of living with ARFID. To encourage reflexivity and mitigate bias, the lead author kept a journal throughout the research process (see **Appendix 11** for journal excerpts).

Results

Analysis of participant interviews revealed one principal theme spanning the data: 'Gaps in ARFID knowledge and practice'. Four themes were found to lie within this, some of which included further subthemes (see **Table 16**).

Figure 8 provides a visual depiction of the conceptual map, highlighting the themes generated from thematic analysis and the resulting implications for knowledge and practice.

Table 16. Overview of themes and subthemes

Principal theme: Gaps in ARFID knowledge and practice		
Theme 1	Barriers to accessing support	
	Subtheme 1a	Lack of understanding/awareness of ARFID
	Subtheme 1b	"Dismissed and brushed off"
	Subtheme 1c	Issues with referrals to ARFID services
Theme 2	The impact on the parent/carer	
	Subtheme 2a	The practical impact of ARFID
	Subtheme 2b	"It's just this constant process of explaining it…" - managing the opinions and judgements of others
Theme 3	"A stroke of luck" - finally achieving appropriate ARFID support	
	Subtheme 3a	A lack of clarity - varied routes to accessing care
	Subtheme 3b	Validation and professional input
Theme 4	Looking ahead	
	Subtheme 4a	Views of recovery
	Subtheme 4b	"Opening the doors for others"

Theme 1: Barriers to accessing support

Theme 1 describes the challenges faced by parents when seeking help for their child's eating difficulties, specifically relating to a lack of personal understanding, practitioner awareness and service provision.

Subtheme 1a: Lack of understanding/awareness of ARFID

Parents' lack of understanding of the problem was discussed, particularly in the early years when their child first began exhibiting severe food avoidance:

> *"He always used to cry during mealtimes, and I don't know if that was a sensory thing. His older brother and I used to wear earplugs so we could stay calm and still*

do the family meal thing and thought maybe it would just pass. But thinking it about it now, it must have been some sensory response."

"At first, we thought perhaps it was just a psychological issue, a control issue, and we contacted a child psychologist."

This often resulted in parents accepting advice which was unhelpful and counterproductive:

"She [dietitian] suggested sending him into school. Don't tell the teachers he has any kind of issues around eating and he'll soon get hungry enough that he'll eat school dinners".

"And one of the pieces of advice we got from a midwife was to strap him in his highchair three times a day and leave him there for 20 minutes, which didn't last very long because he would just become absolutely hysterical. Not even because of the food, but from being strapped in. It was horrific. We tried it for a few days thinking he'd get over it, but we didn't persevere for very long. But I do wonder if maybe that caused some problems."

Parents described the process of realising, often over the course of many months and years, that the issue was significant and persistent, and required clinical attention. For several parents, this was accompanied by feelings of guilt that they hadn't acted sooner or taken the issue more seriously:

"In hindsight, I think maybe we should have done something sooner. But until she started refusing her meals and not laying down at night, we didn't realise this was a real thing that she was terrified of."

Subtheme 1b: "Dismissed and brushed off"

Some parents described being dismissed by healthcare professionals, such as GPs, healthcare visitors, and school nurses. This quote illustrates the struggle for one parent whose child was exhibiting severe food restriction but gaining weight as expected, which resulted in the issue being diminished as "not serious enough":

"We spoke to the GP. Anytime we spoke to any medical professional, we'd say he still doesn't really eat anything. And they'd say well he's gaining weight, and he's got lots of energy so I'm sure he's fine."

Healthcare professionals were also reported to misunderstand or misclassify the problem. Some participants explained that their child's eating difficulties were deemed a transient phase of "harmless picky eating":

"I was told that he hadn't been limiting his food for long enough, so a referral wasn't possible. It was just this constantly; he will start eating and all children do this."

Similarly, for some parents, the issue was mistaken for anorexia nervosa, despite insisting that there were no motivations relating to weight loss or body image concerns:

"We spent years just sitting in that room talking about things that weren't ARFID related, and they'd insist that it was anorexia, or at least there were anorexic elements, and I don't think it helped at all because there was no specialist knowledge of ARFID."

In line with this, one parent discussed the potential harm of misclassifying the issue as anorexia nervosa, and the impact it could have had on the trajectory of the eating difficulty:

"We could even have gone down the wrong path, you know with anorexia or something. Because even the GP would say, are you worried about being fat? And she'd never even thought of that, it hadn't occurred to her, it was nothing to do with that at all… I worried that would have frightened her even more, thinking that there was something wrong, or something entirely different, and then you've got the danger of potentially causing other issues."

Subtheme 1c: Issues with referrals to ARFID services

The final issue parents faced with accessing care was the lack of available services or resources. Some participants spoke of healthcare professionals acknowledging the issue and recognising its severity, but having nowhere to refer them on because local NHS eating disorder services were unable to accommodate those with ARFID:

"I just kept pushing and fighting for help, there was an eating disorder service within our CAMHS [Child and Adolescent Mental Health Services] team, but they obviously weren't commissioned to deal with ARFID."

"There is no support. Clinical commissioning groups decide ARFID isn't a thing, and they don't fund it. Nobody at CAMHS ever said to me, we don't but if you apply to the CCG [Clinical Commissioning Group], there might be somewhere else that does."

Relatedly, several participants reported that healthcare professionals were simply unfamiliar with ARFID and therefore unaware of available services in the local area:

"We've got a really good GP, they're really nice and really supportive, but they genuinely didn't know where to go with it."

"I went to the GP and it's not their fault, it's not their specialist area, plus you had covid and the backlash, they were very busy people."

On the whole, participants spoke negatively of their experiences with primary healthcare services. The above quote, however, highlights that this was not always the case and rather, there is the sense that parents and healthcare professionals were simply limited by the constraints of what they were aware of and what was available to them at the time.

Theme 2: The impact on the parent/carer

Theme 2 captures the impact on the parent/carer of coping day-to-day with a child with ARFID, and in particular, of struggling to be taken seriously in order to access support to appropriate services. Practical and emotional implications are discussed, as well as public scrutiny and judgement suffered because of a limited understanding of ARFID amongst the general population.

Subtheme 2a: The practical impact of ARFID

A central theme discussed by participants was the practical impact of caring for a child with severely restrictive eating behaviours and the constrictions it placed on their lives. Family holidays, days out, and restaurant meals required significant accommodations:

> *"The social element is really hard. We can't go to a BBQ or anything like that. I've got to ask friends if I can cook her food, when they've already prepared a lovely spread. It's always in the back of your mind."*

> *"We've learnt, say we want to go to a restaurant, we just give him his tablet or a phone to play with to distract him, and he can quite happily sit in a restaurant. He doesn't eat the food, but if we want to go out as a family, you can distract him from the panic, because he will get overwhelmed and upset and then he starts being silly and hiding under the table."*

For a few participants, however, such events were not an option. Parents opted for the complete avoidance of meals out, parties, and holidays, simply because of the stress and anxiety it can cause:

> *"Going on holiday is my biggest fear. I haven't been on holiday since this all began, because the fear to go away is too much…we used to holiday every year but it's no longer possible."*

> *"…am I going to upset her or dysregulate her by taking her somewhere and putting her in that position? So, in the end you just tend to shy away from things. Which,*

when you're already restricted by the type of activities that you can do because your child's autistic, it just puts more restrictions on what you can do, like what normal society, or every day families do."

Subtheme 2b: "It's just this constant process of explaining it" - managing the opinions and judgments of others.

A final area of impact was the pressure of dealing with and responding to others' opinions on the matter. In the midst of seeking support, participants spoke about the need to manage misguided and unsolicited advice about their child's eating difficulties from other parents, family members, and friends:

"If I had a pound for every person that said don't give her anything and she'll soon eat."

"…the expectations of other people, you know they tell me I shouldn't bend over backwards to accommodate him."

Many parents described feeling forced to justify the issue to others in order to avoid feelings of judgement:

"I felt so ashamed, like I was being blamed. As though he was starving, and we hadn't allowed him something."

"If we go out, we have to explain why he's not eating, or why he's not joining us at the table."

"We talk to everyone in advance and tell them what the issue is and why we're doing things in a certain way, because we've had lots of judgement over the years."

Participants also experienced judgements from others who assumed that such behaviours had been a direct result of certain parenting practices that had in some way fostered restrictive eating behaviours:

"We've had raised eyebrows about his jam sandwiches every day, assumptions that we're possibly negligent parents not caring about his nutrition".

Theme 3: "A stroke of luck" - finally achieving appropriate ARFID support

This theme relates to parents' experiences of encountering useful support not as an inevitable consequence of engaging with the healthcare system, but rather as a stroke of luck, reflecting lack of knowledge about ARFID and substantial gaps in service provision.

Subtheme 3a: A lack of clarity - varied routes to accessing care

Parents described various ways in which they managed to access appropriate support for their child. For almost all parents, an element of luck was highlighted:

"It seems like quite a lucky thing really, it's quite scary that it came down to that piece of luck, as I don't know what would have happened. She was going downhill quite rapidly and getting that intervention at that point has made all the difference."

For most parents, it was a case of taking control of the situation in order to seek out their own answers and gain access to the support that was needed. This involved online research, attendance at relevant lectures, and engagement with social media platforms or forums:

> *"That's when I started researching and I found an article about ARFID and thought it fitted his profile and that's when I contacted the clinic and you know, got his diagnosis and everything."*

> *"This talk was the most amazing thing ever about ARFID and I sat there the whole time with my mouth open literally going, oh my goodness this is my son."*

Some parents described how their own efforts led to them discovering the service. This was often associated with feelings of luck, either relating to the realisation that they were able to access a service that could offer them the help they needed, or because they lived close enough to the ARFID service in order to be eligible for referral:

> *"We were so lucky, it was a mix of my research, sort of stumbling across it, and right place right time."*

> *"I'd just been reading on my own, went away and randomly found out, because we live up the road [from the service] which seems to be a really happy coincidence, and I found the ARFID clinic and saw you could self-refer, and we did that. And that's how we ended up in the clinic. And it seems like quite a lucky thing really."*

"We literally made the postcode by two roads. We've been so lucky and I'm just so thankful for the place."

For one parent, however, whose child had experienced an acute onset of symptoms resulting in sudden and severe weight loss, referral to the clinic was immediate:

"Her calorie levels had dropped drastically, and she was only eating a piece of toast, a bread roll, around 300-400 calories a day, and barely any water so we were at risk of dehydration and obviously weight loss. We were very lucky that we saw the ARFID team incredibly quickly, possibly because it was very drastic."

Such a rapid response ensured that the situation could not worsen, and that fast action was taken to work towards recovery:

"We were having weekly meetings with the psychology team there, who were amazing, and the paediatric doctors were saying she'd have to be tube fed soon. She started on some medication at the time and received some really intensive support from the ARFID team, and I also had support for parents, to know how to talk to her. So, we had to be very regimented to get the amount of energy into her that she needed and fortunately over months of this intense support, we managed to get to a place where things started to turn around a little bit. She started to gain weight."

Subtheme 3b: Validation and professional input

Upon receiving support, participants expressed the value of useful and relevant input from professionals at the clinic. This input came in several forms, first by recognising the value of

a diagnosis, not only for self-validation, but as a tool to educate others and challenge judgemental views:

> *"It was helpful for the clinic to tell us that we were doing the right thing. That feeling at the start of feeling really lost and not knowing what the right thing to do was, and that we'd done everything we can".*

Input also came by way of suitable, ARFID-specific advice such as reduced mealtime pressure, the introduction of multivitamins, and nutritionist interventions aimed at increasing caloric intake:

> *"The clinic said very early on that she just needs to eat, and it's helpful to have that very clear message from the professionals as sometimes you don't know if you're doing the right thing…they explained that it was really important for her to feel safe when encouraged to eat, but that it's not threatening. And that's a really important safety mechanism for her because she knows that her mum and dad are not going to let her not eat."*

Theme 4: Looking ahead

The final theme captures parents' views of the journey that lies ahead. This refers both to their child's own journey and what they expect from recovery, and also their view of the future of ARFID clinical management more generally, and a keenness to contribute to the improvement of access to care.

Subtheme 4a: Views of recovery

There was a general sense that discharge from the clinic, and/or the loss of the ARFID diagnosis did not equal recovery, but rather, having had input from ARFID specialists, parents felt empowered to support their child on the road ahead:

> *"Indirectly what supported her was that I got the support as a parent to know what the narrative was, what I needed to do."*

> *"It's helpful to have that very clear message from the professionals as sometimes you don't know if you're doing the right thing."*

> *"We just feel as though we know how to handle it now, even if things get bad again."*

For all participants, hopes for the future were modest and centred around general happiness, reasonable health, and reduced fear around food and eating:

> *"Just him being happier would be nice. We've been coping with this his entire life, we're doing well at coping, but him being happier."*

> *"It would just be lovely for her to not have that fear and that anxiety. I would just like her to find one food, something common, so she could eat with others. I wouldn't even want her to eat everything, just to eat enough so her health wasn't at risk."*

"I think that magic wand would take those worries away for her so she could live her life socially, interact, eat, and drink when she can. Not having to have that background worry."

Subtheme 4b: "Opening the doors for others"

For many, a view of the future also involved creating awareness of ARFID by educating healthcare professionals, reducing stigma around restrictive eating, and improving access to services:

"…the paucity of service, I feel for other people who don't have that understanding of what ARFID is or its severity and where it can lead. It is an eating disorder in its own right, and I just want to ensure that others are able to access the support and services that we were able to."

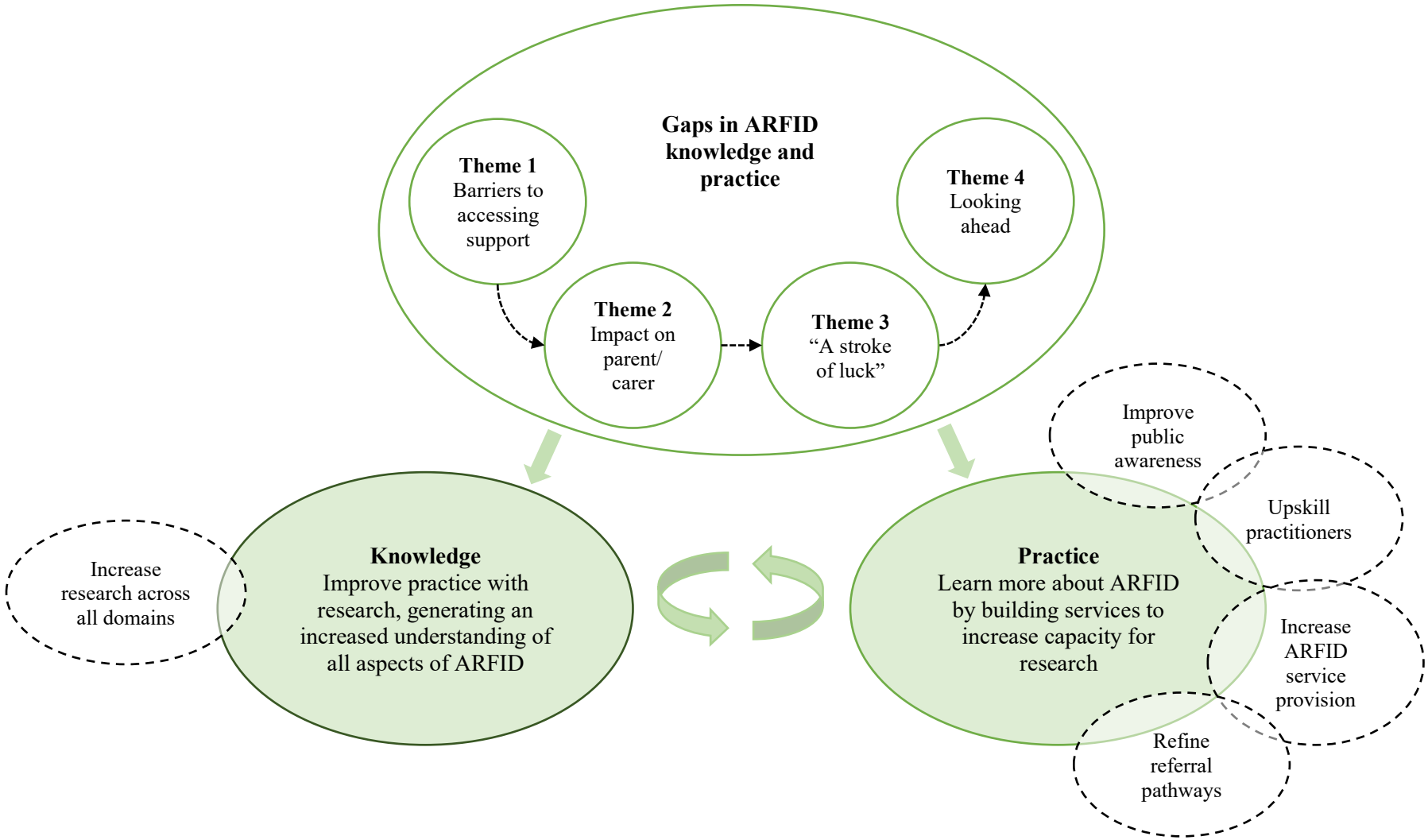
"I'm constantly challenging the authorities and working with the community hospital, because they need to understand that there's a fussy eater and then there's an eating disorder."

Several parents made active attempts to exact these changes and improve awareness. One parent described how they had spoken to teachers at their child's school and reflected on the school's keenness to learn more and "upskill themselves on ARFID". Another parent contacted their GP with an update on their child's ARFID diagnosis:

"Afterwards actually I did write to the GP to let them know that there's a clinic down the road that deals with this exactly, you know, if another child is having issues like

this, then this could be helpful. Because even if they've not got space in the clinic, it might be that they can give the right advice or guidance."

Figure 8. Conceptual map of thematic analysis with implications for knowledge and practice



Discussion

The aim of this qualitative study was to explore the experiences of ARFID caregivers who were successfully able to access support for their child's eating difficulties. One overarching theme was found to underlie all participant accounts: Gaps in ARFID knowledge and practice. Four further themes were found sit within this landscape: (1) Barriers to accessing support, (2) The impact on the parent/carer, (3) "A stroke of luck" - finally achieving appropriate ARFID support and, (4) Looking ahead. The themes depict a journey from initially seeking help, to ultimately sourcing and benefiting from appropriate ARFID care.

Overall, caregivers spoke negatively of their experiences. Participants described the challenges associated with approaching healthcare professionals, the struggle to be taken seriously, and the fight to accessing support. This is in line with Eilender (2022) who reported similar barriers, including a lack of knowledge and healthcare professionals underestimating the impact of reported difficulties. Harrison (2021) explored this issue from another angle, using mixed methods to question practitioners on the current management of ARFID in England. A distinct lack of confidence was reported by healthcare professionals in identifying ARFID and referring patients on for assessment due to a number of factors, including a lack of knowledge and a lack of training. Systematic barriers were also noted, such as the lack of a clear pathway or specific guidance for managing this cohort of patients, which further supports our finding about the scarcity of support available and goes some to explaining why caregivers were dismissed and left to deal with the issue. Elsewhere, the literature suggests that many primary care providers are not recognising the symptoms of ARFID as consistent with an eating disorder, which highlights another possible reason for patients falling between the cracks (Cooney et al., 2018).

The findings of this study contribute to the existing research and highlight several implications for both knowledge and practice. First, the findings highlight gaps in ARFID knowledge. Further research is warranted across all domains, but in particular, work is needed to better characterise and formulate ARFID and to distinguish clinically significant ARFID symptomology from food fussiness which is considered a normal phase of childhood development. Caregivers spoke about difficulties in accessing care because practitioners failed to recognise the severity of ARFID and instead, dismissed symptoms as a phase of picky eating. Such an understanding will ensure that healthcare professionals can be educated to identify those presentations which require clinical input and upskilled to assess and manage significant eating difficulties. This will also reduce the burden on caregivers who described feeling forced to seek out their own answers and fight for the necessary help. Relatedly, work to validate assessment and diagnostic measures and to implement them into practice will ensure that clinicians are better equipped to assess patients and evaluate the need for specialist input.

The findings also emphasise important gaps in ARFID practice. Participants spoke about judgements from others, and the need to manage opinions and unwanted advice, with many assuming that such behaviours were a direct result of their parenting practices, or simple food fussiness. It is clear that public understanding is lacking, and that work is needed to raise awareness of ARFID. Further, since research suggests that onward referrals are currently unpredictable and treatment plans disjointed (Norris et al., 2016), referral pathways need to be developed and refined, and specialist ARFID service provision increased to facilitate timely and optimum care.

It is necessary to consider the findings of this study in the context of several limitations. Although not uncommon in qualitative research, we drew participants from one outpatient eating disorder service in England over a relatively short period of time. Since the

participants in our study represent a small portion of the population who had received recognition and support for ARFID, it would be useful to conduct the interviews in non-clinical populations, and with adults whose eating difficulties preceded the introduction of the diagnosis and thus, never managed to acquire professional support as children and young people. Further, since experiences of seeking support for ARFID will arguably be very different in years to come, a longitudinal exploration would be valuable. Despite these limitations, the study addresses a key gap in the literature and to our knowledge, is the first to explore experiences of accessing care for ARFID and engaging with services, from the perspective of caregivers. Further, the sample itself is diverse, in terms of background, ethnicity, age, gender and neurodiversity, and covers a range of ARFID presentations.

Overall, this study indicates that children and young people with ARFID are struggling to access appropriate care. The findings point towards a need to address various gaps in both ARFID knowledge and practice. Importantly, efforts to fill these gaps will be mutually constructive. ARFID practices can be improved by generating a better understanding of all aspects of ARFID from research, and conversely, an increased capacity for research can be built by establishing clear service pathways and optimal care.

Chapter 8: General Discussion

Chapter Overview

Specific features of each of the six studies comprising this thesis have been discussed throughout, including the main findings, implications, and strengths and limitations. The current chapter provides a global summary and general discussion of this thesis.

First, a vision of optimal care for ARFID is proposed. The key findings and implications of this research are then discussed together with avenues for further work, with a view to achieving this vision over the coming years. Overall strengths, limitations and methodological decision are then reflected upon, and conclusions drawn.

Thesis Aims

This thesis aimed to contribute to the current ARFID literature in order to support evidence-based practice for this heterogeneous disorder. Specifically, a multi-method approach was taken to address the following aims:

1. Evaluate the best available research evidence by synthesising and appraising the current literature relating to ARFID and identifying key gaps in the evidence base.
2. Enhance understanding of ARFID and contribute to best current research evidence by considering the overlap between clinically severe restrictive eating, as is captured by the diagnosis of ARFID, and picky eating, and investigating risk factors and outcomes associated with different trajectories of food pickiness in childhood.
3. Increase the prominence of patient voices by systematically investigating how those with ARFID and their families understand and experience ARFID, including their experiences of seeking help for the condition.

What's Next for ARFID? Key Findings, Implications, and Future Focus

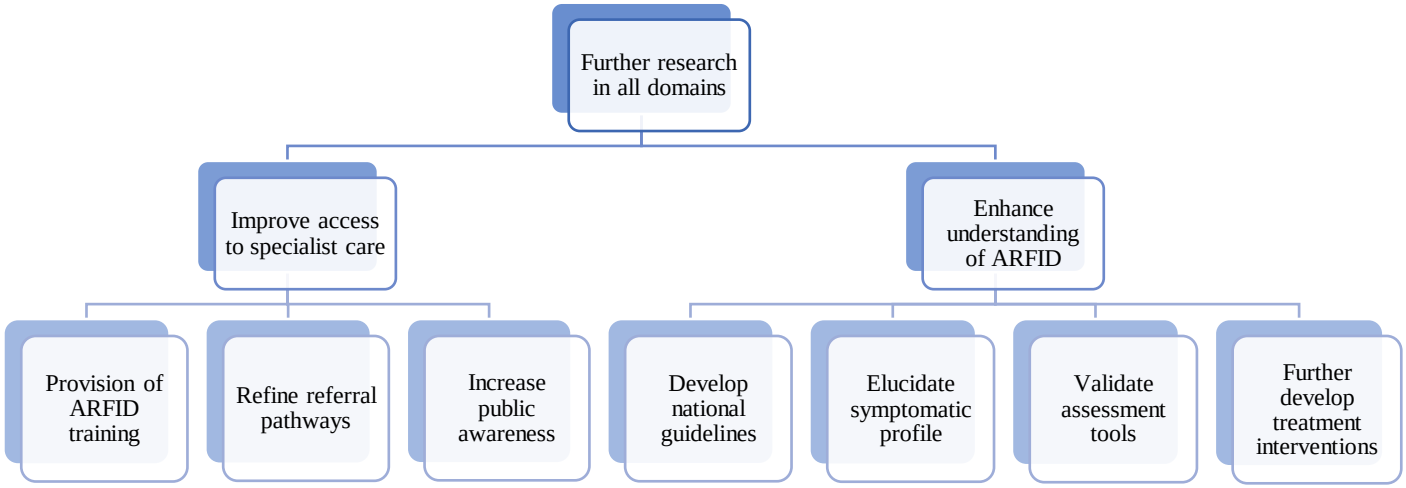
Since ARFID was established as a diagnostic entity in 2013, it has generated welcome clinical attention and a burgeoning body of research. While the last 10 years have seen steady advancements in our understanding of ARFID psychopathology, the current evidence base is still limited and there is vast scope for further investigation.

In the 10 years ahead, there is hope that we will see significant improvements in our understanding of ARFID which will inform service provision and support evidence-based practice that responds to the varying clinical needs of this heterogeneous population. An optimal vision for the future of ARFID management is depicted in **Figure 9**. This starts with further research across all domains to develop a robust understanding of ARFID, address gaps and uncertainties in the literature, and reinforce the three-legged stool of evidence-based practice.

Increased research will first improve access to specialist care, by focusing on the development and provision of training and the refinement of referral pathways. This will ensure that GPs and other frontline healthcare professionals are able to identify clinically significant eating difficulties and can be guided by clear clinical referral pathways to specialist services.

Further research will also enhance understanding of ARFID and its causes, symptom presentation, risk factors, comorbidities, and outcomes. From this, national evidence-based guidelines can be developed to deliver consistent, high quality, evidence-based care which promotes the adoption of standardised practices. Relatedly, an improved picture of ARFID will promote the development of validated, gold-standard measures of assessment which will foster consistent diagnostic practices that contribute to reliable epidemiological data, and effective treatment interventions with multidisciplinary input from various specialists and services.

Figure 9. A vision of optimal ARFID management



The following section proposes avenues for further work, with respect to the findings of this thesis and the resulting implications, which will contribute to achieving this vision for the future. To note, Chapters 2 and 3 of this thesis presented a view of the literature at the time. This section will include research which has since been published and thus, offers a more recent picture of the ARFID literature.

Improve Access to Specialist Care

The findings of this thesis emphasise the need for improvements in accessing care. Chapters 6 and 7 highlighted significant challenges faced by parents and carers in seeking and achieving support for ARFID. Such barriers to support have also been well cited in the literature, largely due to a lack of awareness of ARFID and a lack of training, resulting in the dismissal of symptoms, the provision of conflicting advice, and/or the misdiagnosis of other eating disorders (Bryant-Waugh, 2020; Coglan & Otasowie, 2019; Harrison, 2021).

As such, there is a need for dedicated ARFID training, particularly for healthcare professionals on the frontline, providing key information regarding the delivery of best

practice care to those presenting with severe food restriction. Such training will equip practitioners with the requisite skills and confidence to identify and assess ARFID symptomology, to conduct appropriate medical monitoring, and to refer to appropriate onward care. Further work should therefore focus on designing suitable training programmes and disseminating appropriate information to healthcare professionals. Given the public health interest in preventative and early intervention initiatives for eating disorders (Allen et al., 2020; Hyam et al., 2024; NHS Health Innovation Network, 2023), improved knowledge, and timely access to support would also deliver financial benefits for ARFID service provision.

Relatedly, Chapter 7 highlighted difficulties in accessing support for ARFID which were related to systematic gaps in the provision of care. Currently, onward referrals for ARFID are unpredictable and inconsistent, largely due to the lack of any clear guidance or established decision-making frameworks (Bryant-Waugh et al., 2021; Cardona Cano et al., 2015a; Harrison, 2021; Norris et al., 2016). Indeed, in Chapters 6 and 7, participants described how they were actively refused care, offered unhelpful advice and/or referred to inappropriate healthcare professionals and services because of the absence of any standardised care pathways or national consensus for the clinical management of ARFID.

Since ARFID often requires co-ordinated input from any number of clinical specialists and services (Archibald & Bryant-Waugh, 2023; Katzman et al., 2019), multidisciplinary care pathways will need to be refined to ensure that practitioners have a clear view of appropriate avenues for onward clinical referral. A specific outpatient care pathway for children and young people with ARFID has been conceptualised and proposed for guiding practice (Bryant-Waugh et al., 2021), although further testing is required to assess its usefulness and feasibility. Such initiatives are key, however, for the future of ARFID care, to provide effective referrals, both in terms of cost and practicality, and to ensure the delivery of appropriate and timely care.

Finally, the findings of this thesis pointed towards a general lack of public understanding and knowledge of ARFID. This was found to contribute to feelings of judgement, widespread misconceptions, and stigma. Indeed, stigmatising attitudes towards eating disorders have been evidenced elsewhere in the literature (Brelet et al., 2021; Foran et al., 2020; O'Connor et al., 2021). In a large-scale survey examining public views of ARFID, Ellis et al. (2020) found it to be perceived as significantly less pathological than anorexia nervosa or binge eating disorder, possibly because of a lack of familiarity with the condition leading to assumptions about the severity of ARFID symptomology. For participants in Chapters 6 and 7, negative attitudes and judgement resulted in a reluctance to seek support and diagnosis. Thus, stigmatisation can act as a barrier to seeking help, hinder the recovery process and lead to self-stigma (i.e., where the individual or their parent feels they are responsible for their condition; Brelet et al., 2021).

Therefore, there is a need to improve public awareness of ARFID, with efforts focused on reinforcing the possible causes of severe restriction and tackling misconceptions, for example, related to developmentally expected picky eating and parental responsibility. Further research in the realm of ARFID stigma may also be warranted, to better understand the reasons behind such attitudes and the consequences they elicit.

Enhance Understanding of ARFID

Each of the six studies comprising this thesis have established that further work is highly warranted in order to enhance understanding of ARFID and deliver the gold standard of evidence-based practice, conceptualised by Sackett (1996) as a three-legged stool.

Chapters 2 and 3 make important contributions to the ARFID literature by delivering structured, rigorous, and comprehensive summaries of the state of research at the time they were conducted (searches performed in 2019 and 2021 respectively) across various settings and populations. The reviews also highlight critical gaps in understanding and key directions for future work. In particular, widespread validation of assessment tools is highly warranted.

Since its introduction as a diagnostic construct in 2013, several promising screening tools, clinical interviews, and self-report measures have been developed to assess and diagnose ARFID (i.e., Bryant-Waugh et al., 2019; Hilbert & van-Dyck, 2016; Zickgraf & Ellis, 2018). These tools are, however, yet to be validated and as such, there are no standardised assessment instruments to reliably capture ARFID symptomology (Richmond et al., 2023). Validated screening and diagnostic tools are also key to supporting the gathering of accurate epidemiological data, which will inform resource planning and guide service provision.

The two qualitative studies included in this thesis also make a valuable and distinctive contribution to the literature and help to strengthen the patient values leg of Sackett's stool. They also, however, emphasise the dearth of qualitative research in the field. Further work in this area is key to ensuring that the patient voice is appropriately represented in the evidence base. Insights from those living with the condition can help to address the "how" and "why" questions which explore attitudes, behaviours, thoughts, and feelings, thus providing unique and real-world perspectives on patient needs and experiences. This will inform quantitative work in the field by helping to generate hypotheses and may contribute to elucidating the varied mechanisms of ARFID.

A growing understanding of what causes and maintains ARFID will also feed into treatment development, and in particular, may inform early and preventative intervention work, such as school-based programmes and parent training workshops. Since the qualitative work within this thesis highlights poorer health outcomes and increased parental stress associated with delayed intervention, early recognition and preventative action will ensure that more patients can avoid significant mental and physical health complications.

This thesis evidenced ARFID as a distinct and heterogeneous condition with substantial variation in presentation. There is, however, a pressing need to further explore the phenotype of ARFID and elucidate its varied profile. There is some discourse in the literature around the conceptualisation of ARFID and specifically, the possibility of delineating descriptive

subtypes defined by underlying causal processes (Kennedy et al., 2022; Sanchez-Cerezo et al., 2024). In the most part, studies tend to evidence presentations that loosely cluster into those which resemble the three examples as per the DSM-5 diagnostic criteria (Norris et al., 2018; Sanchez-Cerezo et al., 2024). The work in this thesis largely supports this view, with most presentations approximating one or more of the three examples provided. Nevertheless, drivers are rarely seen in isolation (Watts et al., 2023) and there is often significant overlap, with unique variation in the combination and severity of such presentations observed. Thus, discrete subtypes may provide too limited a view of ARFID.

This was further explored in Chapter 6, which explored the presentation and onset of ARFID via discussions with caregivers. A tentative conceptual model of development was proposed based on the findings of this study, indicating the possibility of two pathways; one relating to a longer-term restriction underpinned by inherent differences which impact eating, and a second stemming from a trigger incident which prompts a sudden onset of food restriction. This has been considered elsewhere in the literature. From a clinical standpoint, Fisher et al. (2023) posits that patients tend to present in "one of two major ways". For some, in fact for the minority, this is as a result of an acute onset of symptoms which is precipitated by a traumatic event or allergic reaction. A much larger proportion of patients, however, present with long-standing restriction relating to innate differences in sensory processing, appetite, mood, or attention. While each patient presents with his or her own needs, the former presentation is more likely to necessitate significant medical intervention or hospitalisation, with a strong possibility of achieving partial or complete recovery, while the latter is likely to persist into adulthood and may require ongoing support to maintain a 'good enough' diet. Further research is required to determine whether ARFID would be better conceptualised as a subtype disorder, and indeed, whether subtypes can reliably describe its varied presentation. While such findings may aid clinical diagnosis and capture differing

trajectories, outcomes, and prognoses, it is important that the complex heterogeneity of this condition is not oversimplified by discrete categories.

An enhanced understanding of ARFID will also rely on further exploration of its correlates and risk factors. Such insight is crucial, both in highlighting transdiagnostic constructs that may pose a potential risk to the development of ARFID and pointing to shared mechanisms which could be targeted in treatment. One approach to capturing this information is via the inclusion of an ARFID measure in prospective longitudinal cohort studies. This will ensure that we can accurately capture ARFID in the population and use this to glean mechanistic insights through the observation of exposure to risk factors and the effects of certain exposures.

This thesis underscored the high occurrence of comorbid psychopathology associated with ARFID. While a number of physical and mental health conditions were found to cooccur alongside ARFID, there was a notable overlap with neurodevelopmental conditions, particularly autism. This has been frequently evidenced elsewhere in the literature (Farag et al., 2021; Keski-Rahkonen & Ruusunen, 2023; Watts et al., 2023) and has important implications for practice. Since a large proportion of those with ARFID are autistic, or exhibit high autistic traits, efforts are needed to ensure that appropriate adaptations are put in place for those with neurodiverse needs during the treatment of ARFID. Such adaptations for family-based therapy have been endorsed in the literature, albeit with a specific focus on treating anorexia nervosa (Loomes & Bryant-Waugh, 2021). While the authors do consider whether such adjustments could be helpfully applied to ARFID, further work is warranted to test this.

Relatedly, Chapters 4 and 5 can contribute to an understanding of the overlap between ARFID and picky eating. The findings provide some insight into potential aetiologies of clinically significant eating difficulties, although further work is required to differentiate between picky eating and ARFID. Specifically, there is a need to elucidate pathways between

the two, to better understand how and why such behaviours develop into those which significantly impair health and day-to-day functioning. Such knowledge could inform early identification and contribute to preventative efforts, for example, in primary care services or schools. Indeed, qualitative data from Chapters 6 and 7 also touched upon this issue, with caregivers mentioning a lack of awareness amongst healthcare professionals in regard to differentiating between picky eating and ARFID. Importantly, an enhanced understanding of this will rely on the development of a valid measure of picky eating behaviours and a universal definition or more specific delineation of the variations in eating behaviours it covers. Such understanding will enhance all areas of understanding, from building a reliable epidemiological picture, to informing successful intervention.

Strengths, limitations and methodological discussion

This thesis employed a rigorous and varied methodological approach to address the research aims. This integrated, multi-method design provided a comprehensive and cohesive understanding of the topic and compensated for potential biases that may have emerged with the use of a single method (Denscombe, 2008). Since ARFID is still a relatively new diagnosis, much of the work comprised within this thesis relied on inductive, exploratory methods to gain insight and develop theories. These methods offered flexibility and the opportunity to gain a broad view of ARFID, to lay the foundations for future work.

Chapters 2 and 3 present two separate literature syntheses, one systematic review evaluating the scope and nature of the current ARFID evidence base and another scoping review assessing the extent of the literature relating to ARFID and severe food selectivity in autistic children and young people. Both provide valuable and much needed contributions to the field, by way of synthesising the current literature and identifying key gaps in understanding. Since publication, both reviews have been frequently downloaded and well cited, highlighting their utility and relevance in the field.

A key limitation with the reviews included in Chapters 2 and 3 is an issue characteristic of newly defined diagnoses. While ARFID was recently recognised as a formal diagnostic entity in 2013, it is not a new condition. Prior to this, ARFID symptomology was captured by various terms and diagnostic entities and there would have been significant research interest and clinical attention relating to this symptomatic profile. The search criteria for the systematic review in Chapter 2 were limited to studies presenting primary data explicitly relating to ARFID as a distinct diagnosis. As such, it is highly likely that useful information could have been gleaned from studies pre-dating the introduction of the diagnosis. This matter resurfaced again in Chapter 3. Since very few studies were found to report on ARFID and autism specifically, the search parameters were extended in order to include those with severe feeding and eating difficulties who were likely to have met diagnostic threshold for ARFID. This was, however, a challenging and subjective process and raised doubts about the validity of the findings in relation to the diagnostic entity of ARFID.

Chapters 4 and 5 employed quantitative techniques to explore potential risk factors and outcomes of different picky eating profiles using the Growing up in Scotland (GUS) dataset. A considerable strength of these studies was the use of secondary data from a large-scale longitudinal cohort study. This allowed for ease of access to vast amounts of data to measure numerous and varied outcomes (Caruana et al., 2015) and to observe relationships and evaluate change over time.

Variables were taken from the GUS dataset across various study sweeps, which meant that the cohort was affected by attrition and a significant amount of data lost. To address this, multiple imputation was used to account for missing data, reduce bias, and to increase statistical power. To interpret the strength of the associations in each regression model, 95% confidence intervals as well as *p*-values were used. Since classifying a result as a dichotomous inference of significant versus not significant according to an arbitrary cut off of p=0.05 can minimise findings, *p*-values were instead interpreted on a continuum of

probability. This is supported and recommended by the literature (i.e., Andrade, 2019; Sterne & Smith, 2001). *P*-values close to 0.05 were deemed as strong evidence against the null hypothesis, whereas higher *p*-values were seen to indicate increasingly weaker evidence. Once *p*-values approach 0.2, the chance of identifying a true finding rather than a false positive is just 80%, and therefore, such results were interpreted with caution. Nevertheless, thoughtful language was used to indicate a relatively weak association, and therefore, the need for further exploration to prove or disprove this finding. Further, the analyses were based on a moderate sample size. Since some of the exposures were quite rare, it is unlikely that the study would have been powered to detect a small difference with $p<0.05$. Thus, the *p*-values were interpreted in the context of the sample size.

There are several limitations to note. First, while large-scale cohort studies are an invaluable resource as discussed above, researchers are fundamentally limited by the scope of the dataset. In particular, investigation is limited by the items posed to respondents, and the time points at which they are asked. No longitudinal studies were found with data pertaining to the screening or assessment of ARFID symptoms specifically, and so the picky eating outcome was operationalised using three separate items in the dataset relating to picky eating behaviours and therefore, deemed to capture such difficulties. A particular issue related to the question posed to respondents at sweep 8: "At the main meal, is [child] served different food from adults?". While this question has been used previously to indicate the presence of picky eating behaviours (Dubois et al., 2007), there are many reasons why a child may be served a different meal to adults; because of family schedules, finances, or simply due to dietary preferences, for example. While the prevalence figures were consistent with previous estimates (Cardona Cano et al., 2015b; Mascola et al., 2010), it is possible that picky eating behaviours were not reliably measured at this study sweep.

Other elements of the analyses were also limited by the constraints of the available data. The picky eating categories used in Chapter 4 were decided a-priori in order to address a

specific research question, namely, to establish whether there are meaningful differences between those who experience short term, developmentally normal picky eating behaviours, and those which persist into later childhood. These categories were also based on previous research (Cardona Cano et al., 2015b) which uses similarly defined groups to capture picky eating trajectories. As the same measure did not appear at three time points in the GUS dataset, it would have been difficult to capture the categories differently, for example, using a statistically driven approach, such as growth mixture modelling. If future data were to become available, an alternative approach may reveal new and important findings on the nature and timing of picky eating, including identifying different groups based on their trajectories. Nevertheless, an a-priori approach was appropriate to the data available, reflected the nature of the research question, and ensured that the findings were relatable to the existing literature. Relatedly, the study presented in Chapter 5 was conducted to gain further insight into the previously defined picky eating groups and in particular, to establish whether outcomes in later childhood are meaningfully different for those belonging to different groups. Given this specific research question, the categories used in Chapter 4 were maintained. While the decision to maintain this category approach was appropriate to the current study and its aims, it would be interesting to explore the outcomes differently, for example, with continuous or time point predictors.

A final consideration relates to the nature of data collection. Chapter 4 sought information on the study child from the parent, whereas the study in Chapter 5 took such information from the children and young people themselves. This inconsistency was largely due to the nature of the variables of interest. Parent report was necessary for the study in Chapter 4, to measure factors relating to pregnancy, birth and early childhood, whereas self-report was more suitable for the study in Chapter 5, since outcome variables were concerned with peer relationships, anxiety, body image, etc. As above, there were also limitations to the data available, for example, several of the variables measured in the second study were not

available via parent report. There are some limitations to using self-report data, not least social desirability bias, exaggeration and possible lack of interest or disengagement from adolescents. Nevertheless, the young people undoubtedly possess greater insight into their own thoughts, feelings and relationships than their parents. It would, however, be interesting to compare findings from parent reported data.

The final two studies comprising this thesis used qualitative research techniques to evaluate interviews with parents and carers of children with ARFID. Chapters 6 and 7 used an iterative, data-driven approach which yielded rich insights into living with and caring for a child with ARFID and captured the complexity and diversity of this experience via open discussion. This would not have been possible with short form qualitative data methods, such as questionnaires, and structured interviews would likely have been restrictive. Further, open forums such as focus groups may have impeded frank and honest dialogue. Given the sensitive nature of such discussions, anonymity and confidentiality protections were strictly maintained throughout. It is likely that this would have reduced social desirability bias and fostered a sense of trust in participants, encouraging openness and honesty. A further unique strength of using this methodology was the meaningful and novel contribution that both studies offer to the field. While quantitative ARFID research is burgeoning in all domains, to date, very little attention has been paid to the qualitative exploration of ARFID. This is likely due, at least in part, to its relatively recent introduction as a diagnostic category and the time taken to explore different avenues of research. A considerable amount of information was gleaned from the interviews, and as such, analysis of the data yielded two studies, each with their own themes and topics. The resulting studies address two distinct, albeit related, research questions, which make unique contributions to our understanding of ARFID, and offer insights into its impact, course, nature, causal and maintaining factors, and experiences of accessing care.

Reflexive thematic analysis was used to analyse the interview data. This technique was adopted as it is flexible and allows the researcher to interpret the data at both a semantic and latent level, and to identify common patterns or themes. Other techniques were considered. For example, Grounded Theory would have afforded the same flexibility and opportunity to generate insights into the data, but it is a specific methodology for developing theories. While a conceptual model was derived from the data, this was not the intention of the study initially, and thus, thematic analysis was deemed more appropriate for gaining a broad view of participant voices. Reflexive thematic analysis was also selected because the reflexive element ensures considered engagement with the data which is interrogated by reflexive thought and journalling, thereby acknowledging the weight of personal experience and prior knowledge in shaping interpretation of the data.

Whilst the qualitative section of this thesis provides a unique and valued contribution to the field, the findings must be interpreted with caution. The interviews were conducted with a relatively diverse cohort of parents and carers with experiences reflecting varied presentations of ARFID, however, participants were recruited from one outpatient eating disorder service in England. Furthermore, there was a prerequisite that only those living close to the service could be accepted for care. To some extent therefore, participant experiences were likely to align, for example, because of commonalities in cultural and socioeconomic background, and geographical location. Also, similarity of experience could have been related to the level of care. Recruiting from more intensive inpatient or day patient services, where factors such as symptom severity, patient motivation, and medical stability are likely to vary, would provide useful insight into the complex and multifaceted nature of the ARFID experience. At the time of the interviews, participants were either actively receiving support or had recently completed treatment. It is therefore important to recognise that the experiences and attitudes of the current sample may have been shaped by their treatment journey and are likely to differ from those who are yet to receive treatment. Thus, there

would be value in recruiting from non-clinical environments, to seek the views and experiences of both those who are not treatment seeking, and those are treatment seeking but are yet to access professional support.

Conclusions

ARFID is a complex and severe eating disorder with significant and widespread impact. Despite steady progress in our understanding across all domains and increasing clinical interest in the last 10 years, the evidence base is lacking, and as a result, ARFID is currently excluded from the NICE accredited eating disorder guidelines. Thus, there is a fundamental drive to generate robust empirical evidence from rigorous research studies which progresses our understanding of ARFID and informs the development of universally acknowledged clinical guidelines to assist practitioners in the assessment and management of symptoms. While ARFID is commissioned for treatment, it is not a priority. Further work and training will aid mobility of care, ensuring that services throughout the UK recognise and respond to patients with ARFID.

The current thesis contributes to the ARFID evidence base by delivering two high-quality and well cited reviews which appraise and synthesise the literature, offering a clear, comprehensive, and accessible overview of what is currently known. The psychopathological profile of ARFID is also explored, with work contributing to understanding potential risk factors and vulnerabilities, longer term outcomes of restriction, comorbidities, and the overlap with picky eating, which gives some insight into the possible mechanisms of restriction. The findings also offer a rich and much-needed insight into the experiences of those living with the condition, highlighting patient needs, preferences, and perspectives.

Crucially, this thesis emphasises the importance of enhancing ARFID awareness and understanding, and underscores necessary avenues for further research, providing a real-world vision for the future of ARFID management.

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Appendix 1

Items taken from the Depression, Anxiety and Stress Scales - 21 (Lovibond & Lovibond, 1995) to measure maternal mental health

GUS Variable Name	Variable Description
MbHdas01	I found myself getting upset by quite trivial things (stress)
MbHdas02	I found it difficult to relax (stress)
MbHdas03	I felt that I had nothing to look forward to (depression)
MbHdas04	I felt sad and depressed (depression)
MbHdas05	I found that I was very irritable (stress)
MbHdas06	I was unable to become enthusiastic about anything (depression)

1 = Did not apply to me at all

2 = Applied to me to some degree, or some of the time

3 = Applied to me a considerable degree, or a good part of the time

4 = Applied to me very much, or most of the time

Appendix 2

Summary of measures taken from Growing up in Scotland birth cohort study

Variable Description	GUS Variable Name	GUS Sweep
Does child eat variety of foods	MbFvar01	2
Does child eat variety of foods	M2Fvar01	5
At the main meal is child served different food from adults	MhFsam02	8
Sex of study child	MaHGsx1	1
Ethnicity of child	DaEthGpC	1
Highest education level of respondent	DaMedu01	1
Age of natural mother at birth of cohort child	DaHGmag5	1
Total income band of your household from all sources before tax - including benefits, interest	MaWinc09	1
During your pregnancy with child did you smoke cigarettes	MaHcig01	1
Thinking back to when you were pregnant with child, which of these best describes how often you usually drank then (alcohol)	MaHalc04	1
What type of delivery did you have	MaBdel01	1
Was child born early, late or on time	MaBtim01	1
Birth weight in grams	DaWgGr	
Did child spend any time in a Special Care Baby Unit (SCBU) or a Neo-Natal Unit after he/she was born	MaBneo01	1
DASS Stress Score (0-9)	DbHdas01	2
DASS Depression Score (0-9)	DbHdas02	2
In the first 3 months how much of a problem was - getting child to feed	MaTfed01	1
In the last 3 months how much of a problem is - getting child to feed or eat	MaTfed02	1

How many months old was child when he/she first started solid food	MaFsol02	1
Do you have any concerns about child s development, learning or behaviour	MaHdev01	1
Has child additional support needs?	MePSan01	5
- Add needs - autistic disorder	MePSan09	5
Has child additional support needs?	MfPSan01	6
- Add needs - autistic disorder	MfPSan09	6
Has child additional support needs?	MgPSan01	7
- Add needs - autistic disorder	MgPSan09	7
Has child additional support needs?	MhPSan01	8
- Add needs - autistic disorder	MhPSan09	8
Has child additional support needs?	MiPSan01	9
- Add needs - autistic disorder	MiPSan09	9
Thinking about your pregnancy with [child] as a whole, would you say you generally kept…	MaPGht01 **(AUXILIARY)**	1
Thinking about the first six weeks or so after child was born, how well do you think you and [child's] mother/father, as a couple, dealt with the arrival of your child?	MaPcop01 **(AUXILIARY)**	1
How is child s health in general?	MaHgen01 **(AUXILIARY)**	1
Does child have any health problems or disabilities that have lasted or are expected to last for more than a year?	MaHlsi01 **(AUXILIARY)**	1
In general, would you say your health is excellent, very good, good, fair, or poor	MaHpgn01 **(AUXILIARY)**	1

Appendix 3

Comparison of sample characteristics for participants with complete data (*n* = 2604) and those with missing outcome and/or exposure data *(n* = 2540) among the total sample of Growing Up in Scotland Children with birth mother as main respondent

	Complete cases	Some missing exposure and/or outcome data
	***n* (%)**	***n* (%)**
Total	2604 (50.6%)	2540 (49.4%)
Child sex		
Male	1329 (50.2%)	1317 (49.8%)
Female	1275 (51.0%)	1223 (49.0%)
Child ethnicity		
White	2532 (51.5%)	2384 (48.5%)
Other ethnic background	72 (32.0%)	153 (68.0%)
Mother's highest education level		
Compulsory	481 (33.8%)	940 (66.2%)
Non-compulsory	2123 (57.2%)	1588 (42.8%)
Maternal age (at birth of cohort child)[xxi]		
Under 20	85 (24.4%)	264 (75.6%)
20-29	904 (43.6%)	1168 (56.4%)
30-39	1523 (60.0%)	1017 (40.0%)
40 or older	92 (50.5%)	90 (49.5%)
Household income[xxii]		
Up to £11,999	376 (36.4%)	657 (63.6%)
£12,000 - £22,999	628 (55.2%)	509 (44.8%)
£23,000 - £31,999	534 (61.7%)	331 (38.3%)

[xxi] Categorical variable used for the purpose of presenting clear sample characteristics. A continuous measure is used in the regression analyses

[xxii] Categorical variable used for the purpose of presenting clear sample characteristics. A continuous measure is used in the regression analyses

£32,000 - £42,999	672 (67.8%)	319 (32.2%)
£50,000 or more	394 (66.7%)	197 (33.3%)
Smoking pregnancy		
No	2139 (55.2%)	1737 (44.8%)
Yes (occasionally/always)	465 (37.7%)	767 (62.3%)
Alcohol pregnancy		
No	1847 (49.7%)	1869 (50.3%)
Yes (occasionally/always)	757 (56.0%)	595 (44.0%)
Type of delivery		
Vaginal delivery	1551 (49.1%)	1608 (50.9%)
With medical intervention	1053 (53.9%)	900 (46.1%)
Child's gestational age		
On time	355 (50.2%)	352 (49.8%)
Early	1072 (50.4%)	1053 (49.6%)
Late	1177 (51.1%)	1126 (48.9%)
Low birth weight[xxiii]		
No	2448 (51.0%)	2354 (49.0%)
Yes	156 (46.4%)	180 (53.6%)
Feeding problems 9-12 months		
Not a problem	2263 (51.0%)	2180 (49.0%)
A problem (a bit or big)	341 (48.6%)	360 (51.4%)
Age at introduction of solid food (months)		
0-3	329 (42.3%)	448 (57.7%)
4-7	2244 (53.2%)	1974 (46.8%)
8-10	31 (44.3%)	39 (55.7%)
Concerns about child's development, learning and behaviour?		
No concerns	2441 (51.2%)	2327 (48.8%)
Yes (some or a lot)	163 (43.7%)	210 (56.3%)

[xxiii] Categorical variable used for the purpose of presenting clear sample characteristics. A continuous measure is used in the regression analyses

Does child have additional needs?		
(Autism spectrum disorder; ASD)		
No	2553 (74.0%)	899 (26.0%)
Yes	51 (63.6%)	28 (35.4%)

Appendix 4

Prevalence of picky eaters at each study sweep (sample including non birth mothers as a sensitivity analysis)

	Count	Percent
Sweep 2 (age 2) (*n* = 4507)	610	13.5
Sweep 5 (age 5) (*n* = 3829)	847	22.1
Sweep 8 (age 10) (*n* = 3143)	205	6.5

Appendix 5

Univariable and multivariable logistic regression model results for the association between picky eating status and child and maternal variables using complete case analysis as a sensitivity analysis (*n* = 2604)

	Picky eating status			
	Transient	**Persistent**	**Transient**	**Persistent**
Variable	**Univariable model, Relative Risk Ratio (95% CI); *p*-value**		**Multivariable model, Relative Risk Ratio (95% CI); *p*-value**	
Child sex				
Male	Reference	Reference	-	-
Female	0.89 (0.73-1.09); 0.263	0.73 (0.47-1.15); 0.168	-	-
Child ethnicity				
White	Reference	Reference	-	-
Other ethnic background	1.50 (0.87-2.58); 0.143	2.17 (0.78-6.09); 0.136	-	-
Highest education level	Reference	Reference	Reference	Reference
Compulsory	0.69 (0.55-0.86); 0.001	0.48 (0.28-0.80); 0.006	0.77 (0.60-0.98); 0.036	0.52 (0.29-0.92); 0.026
Non-compulsory				
Maternal age (at birth of cohort child)	0.97 (0.95-0.98); 0.000	0.96 (0.93-0.99); 0.021	0.97 (0.95-0.99); 0.001	0.98 (0.95-1.01); 0.186
Household income (std)	0.80 (0.73-0.88); 0.000	0.67 (0.52-0.85); 0.001	0.87 (0.78-0.98); 0.026	0.72 (0.52-0.99); 0.042

Smoking pregnancy				
No	Reference	Reference	Reference	Reference
Yes (occasionally/always)	1.44 (1.16-1.79); 0.001	2.92 (1.87-4.57); 0.000	1.18 (0.94-1.48); 0.161	2.41 (1.43-4.06); 0.001
Alcohol pregnancy				
No	Reference	Reference	Reference	Reference
Yes (occasionally/always)	0.89 (0.70-1.13); 0.314	0.77 (0.46-1.27); 0.298	0.97 (0.76-1.23); 0.771	0.80 (0.47-1.35);0.398
Type of delivery				
Vaginal delivery	Reference	Reference	Reference	Reference
With medical intervention	0.95 (0.80-1.13); 0.545	1.48 (1.04-2.12); 0.030	1.06 (0.88-1.27); 0.557	1.67 (1.14-2.46); 0.010
Gestational age				
Early	0.79 (0.60-1.05); 0.108	1.01 (0.49-2.06); 0.988	0.80 (0.59-1.08); 0.136	0.96 (0.46-2.01); 0.912
On time	Reference	Reference	Reference	Reference
Late	0.74 (0.57-0.96);0.026	0.65 (0.33-1.25);0.190	0.74 (0.57-0.97); 0.032	0.65 (0.33-1.27); 0.206
Birth weight (std)				
	0.92 (0.83-1.02); 0.128	0.80 (0.64-0.99); 0.043	0.94 (0.83-1.05); 0.265	0.93 (0.75-1.16); 0.521
Special care baby unit				
No	Reference	Reference	Reference	Reference
Yes	1.11 (0.82-1.52); 0.490	0.72 (0.28-1.82); 0.481	1.02 (0.71-1.46); 0.920	0.43 (0.17-1.12); 0.082
DASS Stress				
	1.07 (1.01-1.13); 0.024	1.18 (1.01-1.37); 0.033	1.04 (0.98-1.10); 0.207	1.11 (0.92-1.34); 0.290
DASS Depression				
	1.10 (1.03-1.17); 0.004	1.22 (1.08-1.37); 0.002	1.03 (0.96-1.11); 0.421	1.05 (0.89-1.24); 0.561
Feeding 0-3 months				
Not a problem	Reference	Reference	Reference	Reference
A problem (a bit or big)	1.35 (1.05-1.73); 0.019	1.00 (0.59-1.71); 0.989	1.39 (1.07-1.80); 0.014	1.01 (0.59-1.74); 0.969

Feeding 9-12 months				
Not a problem	Reference	Reference	Reference	Reference
A problem (a bit or big)	2.36 (1.84-3.03); 0.000	2.08 (1.16-3.72); 0.015	2.42 (1.85- 3.16); 0.000	2.13 (1.22- 3.73); 0.009
Months old - solid food				
	0.95 (0.88-1.02); 0.143	0.99 (0.83-1.19); 0.930	0.97 (0.90-1.04); 0.397	1.04 (0.87-1.25); 0.623
Concerns re development				
No concerns	Reference	Reference	Reference	Reference
Concerns (some or a lot)	1.08 (0.74-1.59); 0.672	1.75 (0.86-3.55); 0.122	1.05 (0.72-1.55); 0.784	1.51 (0.78-2.92); 0.215
Autism spectrum disorder				
No	Reference	Reference	Reference	Reference
Yes	1.23 (0.62-2.46); 0.546	3.82 (1.44-10.13); 0.008	0.97 (0.49-1.92); 0.931	2.38 (0.92-6.15); 0.073

Appendix 6

Univariable and multivariable logistic regression model results for the association between picky eating status and autism (coded as at least one record of autism, even with a subsequent contradictory response, as a sensitivity analysis)

Autism spectrum disorder				
No	Reference	Reference	Reference	Reference
Yes	1.32 (0.77-2.27); 0.301	4.10 (1.94-8.66); 0.000	1.10 (0.62-1.94); 0.735	2.81 (1.36-5.81); 0.006

Appendix 7

Summary of measures taken from Growing up in Scotland birth cohort study

Variable Description	GUS Sweep
Variables used to derive exposure	
Does child eat variety of foods?	2
Does child eat variety of foods?	5
At the main meal is child served different food from adults?	8
Outcome variables	
BMI	10
SDQ emotional symptom	10
SDQ conduct problems	10
SDQ hyperactivity/inattention	10
SDQ peer relationship problems	10
GAD-7 total score	10
Body image: How do you feel about the way you look?	10
Confounding variables	
Sex of study child	1
Ethnicity of child	1
Highest education level of birth mother	1
Age of natural mother at birth of cohort child	1
Total income band of your household from all sources before tax - including benefits, interest	1
DASS Stress Score (0-9)	2
DASS Depression Score (0-9)	2
Child SDQ total difficulties score (parent/carer reported)	4
In the last 3 months how much of a problem is - getting child to feed or eat	1

Has child additional support needs?	5
- Add needs - autistic disorder	5
Has child additional support needs?	6
- Add needs - autistic disorder	6
Has child additional support needs?	7
- Add needs - autistic disorder	7
Has child additional support needs?	8
- Add needs - autistic disorder	8
Has child additional support needs?	9
- Add needs - autistic disorder	9
Auxiliary variables	
Does child take any medication for mental health?	10
Have you (parent/carer) ever experienced any emotional or mental health difficulties to the extent that you have received a diagnosis or sought help for it?	10
Do you (parent/carer) currently take any medication for an emotional or mental health condition?	10

Appendix 8

Comparison of sample characteristics for participants with complete data (*n* = 1724) and those with missing outcome and/or exposure data (*n* = 3420) among the total sample of Growing Up in Scotland Children with birth mother as main respondent

	Complete cases	Some missing exposure, outcome and/or confounder data
	***n* (%)**	***n* (%)**
Total	1724 (33.5%)	3420 (66.5%)
Child sex	2498	
Male	855 (32.3%)	1791 (67.7%)
Female	869 (34.8%)	1629 (65.2%)
Child ethnicity		
White	1663 (33.8%)	3253 (66.2%)
Other ethnic background	61 (27.1%)	164 (72.9%)
Mother's highest education level		
Compulsory	284 (20.0%)	1137 (80.0%)
Non-compulsory	1440 (38.8%)	2271 (61.2%)
Maternal age (at birth of cohort child)[xxiv]		
Under 20	44 (12.6%)	305 (87.4%)
20-29	567 (27.4%)	1505 (72.6%)
30-39	1045 (41.1%)	1495 (58.9%)
40 or older	68 (37.4%)	114 (62.6%)
Household income[xxv]	212 (20.5%)	
Up to £11,999	404 (35.5%)	821 (79.5%)
£12,000 - £22,999	369 (42.7%)	733 (64.5%)

[xxiv] Categorical variable used for the purpose of presenting clear sample characteristics. A continuous variable is used in the regression analyses

[xxv] Categorical variable used for the purpose of presenting clear sample characteristics. A continuous variable is used in the regression analyses

£23,000 - £31,999	464 (46.8%)	496 57.3%)
£32,000 - £42,999	275 (46.5%)	527 (53.2%)
£50,000 or more		316 (53.5%)
Feeding problems 9-12 months		
Not a problem	1484 (33.4%)	2959 (66.6%)
A problem (a bit or big)	240 (34.2%)	461 (65.8%)
Does child have additional needs?		
(Autism spectrum disorder; ASD)		
No	1693 (49.0%)	1759 (51.0%)
Yes	31 (39.2%)	48 (60.8%)

Appendix 9

Univariable and multivariable linear regression model results for the association between picky eating status and physical and mental health correlates using complete case analysis (*n* = 1724)

	Picky eating status					
	Transient	**Persistent**	**Transient**	**Persistent**	**Transient**	**Persistent**
Variable	**Model 1 - Univariable**		**Model 2 - Multivariable**		**Model 3 - Multivariable**	
	Coefficient (95% CI); *p*-value		**Coefficient (95% CI); *p*-value**		**Coefficient (95% CI); *p*-value**	
BMI	-0.01 (-0.16,0.13); 0.856	-0.06 (-0.31,0.19); 0.644	-0.03 (-0.15,0.10); 0.689	-0.10 (-0.37,0.18); 0.477	-0.02 (-0.15,0.10); 0.703	-0.13 (-0.42,0.16); 0.383
BMI (males)	-	-	-0.19 (-0.37,-0.02); 0.033	-0.08 (-0.50,0.34); 0.707	-	-
BMI (females)	-	-	0.15 (-0.04,0.34); 0.113	-0.16 (-0.47,0.14); 0.286	-	-
Anxiety (GAD-7)	0.30 (-0.40,0.99); 0.392	0.11 (-1.23,1.45); 0.870	0.31 (-0.34,0.96); 0.346	0.10 (-1.17,1.37); 0.875	0.25 (-0.40,0.90); 0.442	-0.22 (-1.48,1.05); 0.736
Body image	-0.03(-0.11,0.05); 0.461	-0.01 (-0.23,0.20); 0.895	-0.02(-0.10,0.06); 0.539	0.001(-0.22,0.22); 0.991	-0.01 (-0.09,0.07); 0.788	0.03 (-0.18, 0.25); 0.762
SDQ emotion	0.29 (-0.02,0.61); 0.068	0.26 (-0.46,0.98); 0.473	0.30 (0.004,0.60); 0.047	0.24 (-0.46, 0.94); 0.496	0.27 (-0.03,0.57); 0.079	0.11 (-0.61,0.83); 0.769

SDQ conduct	0.08 (-0.08,0.25); 0.322	0.37 (-0.15,0.88); 0.158	0.01 (-0.15,0.18); 0.881	0.23 (-0.27,0.73); 0.362	-0.02 (-0.19,0.15); 0.821	0.10 (-0.41,0.62); 0.694
SDQ hyper	0.11 (-0.20, 0.42); 0.469	0.65 (0.02,1.29); 0.045	0.04 (-0.27,0.34); 0.800	0.50 (-0.14,1.14); 0.121	-0.002 (-0.29,0.29); 0.989	0.28 (-0.39,0.96); 0.401
SDQ peer	0.17 (-0.008,0.35); 0.061	0.60 (0.12,1.07); 0.014	0.12 (-0.06,0.31); 0.196	0.50 (0.02,0.98); 0.042	0.08 (-0.12,0.27); 0.425	0.29 (-0.16,0.75); 0.203

Appendix 10

Interview schedule

During this interview, I will be asking you questions about your child's eating difficulties. These include questions about the nature of the issue, what you think started it and what keeps it going. I will also be interested in your hopes for treatment and recovery, any concerns that you have and the impact that this has on you and your family. At the end, I will check with you to see if there are any other topics that you think we might have missed and would like to discuss. It's important to know that you do not have to answer any questions that you do not feel comfortable with and can stop the interview at any point. There are no right or wrong answers, only your answers. This interview will last around 45 minutes.

TOPIC

Main questions

- Follow up questions/prompts

BACKGROUND

Could you tell me about your child's eating? (Description of the problem)

- Do you think your child consumes an adequate amount of food?
- Do you think your child consumes an adequate variety of food?
- Is your child dependent on any supplementation (i.e., oral nutritional/enteral)?

Why do you think your child's eating is like this? (Understanding of the problem)

- Could you tell me about how these difficulties developed? (What do you think triggered the problem?)

- What do you think maintains the problem, what causes it to keep happening?
- Since you have been seeking treatment, has your understanding of your child's eating difficulty changed? (Do you now think there may be different reasons as to why the problem began and continues to be an issue?)

Prior to your current treatment, had you sought help with these difficulties?

- What did that involve?
- Did it have any effect on the issue, either positive or negative?
- Did it have an impact on you as a parent/carer? (increased burden, worry, for example)

What do you think makes the problem worse?

- Why?

What do you think makes the problem better?

- Why?
- (if nothing) do you think there is anything that can be done (that isn't already being done) which may improve the problem?

<u>CONCERNS</u>

What are your main concerns about your child's eating difficulties?

- Are you concerned about your child's physical development?
- Are you concerned about your child's nutritional intake?
- Are you concerned about your child's personal life or social relationships as a result of this issue?
- Does this issue raise concerns about family life?

IMPACT

What impact does this have on your child's life?

- Is there anything that it stops him/her doing?

What impact does this have on your life?

- Does it affect other family members or those close to you?

[If it doesn't or has very little impact] are there any ways that you or your family have adjusted things to accommodate your child's eating difficulty?

- Do you do anything differently to make things easier or possible for your child? i.e., ringing in advance of a playdate to ensure that suitable food is on offer, obeying rules about what, when and where specific foods are eaten.

COVID-19

Has the Covid-19 pandemic affected your child's eating difficulties?

- How?
- Has it improved/worsened the situation?
- Have you found it difficult to buy/get access to the foods that your child is willing to eat?

Have your usual support services met your/your child's needs during Covid-19?

- How have things changed (i.e., online clinics)

TREATMENT AND RECOVERY

Suppose you had a magic wand and by waving that wand, you could make things better, what would you notice that's different?

- What do you hope to achieve from treatment?
- What does recovery look like for you?

FINAL REMARKS

Is there anything else you'd like to mention that we have not had a chance to discuss?

Do you have any questions?

Appendix 11

Reflexive Journal Excerpts

"Engagement with the data is a fascinating process, but also extremely frustrating and overwhelming. I recognise that my tendency to organise or even fix things can be counterproductive in qualitative research. I'm finding myself creating links that perhaps don't exist, just so I can feel as though the data is being grouped or tidied into neat categories. I'm having to force myself to allow things to get messy to ensure that I'm not diminishing or diluting too much of the information."

"I'm approaching this process as a researcher who has been engaging with the ARFID literature for several years now. Therefore, I am conscious of the need to keep in mind my own understandings and biases of what it means to live with ARFID. This is a key principle that I must adopt throughout the interview and data analysis process - to reflect on participants' own attitudes and opinions as faithfully as I can and to consider the influence of my own interpretations and preconceptions."

"There is no specific formula for analysing qualitative data, and no fixed destination for me to focus on. This is in some ways frustrating, as I feel I could be omitting important details. In another sense, however, it is also freeing and liberating (and at odds to much of the other research I've done). Though Braun and Clark lay out some guidelines to Reflexive Thematic Analysis, there is a lot of flexibility and variability, with choices to be made throughout the process. One of those choices is deciding when to stop so you're not over-analysing the data, but also not creating shallow codes and themes."

“The process has led me to reflect on my own relationship with food. I do not identify as a picky eater, but I am wondering if certain behaviours and habits could be considered picky. In fact, attitudes towards pickiness and behaviours that classify someone as a picky eater are extremely subjective. How do we know that our eating habits are ‘normal’? If parents or carers describe behaviours that I consider to be ‘normal’, am I discrediting or discounting them? Conversely, am I wrongly pathologising behaviours that I deem unusual, just because they are different to ‘my normal’? It is helpful to consider my positioning and why I have chosen to interpret the data in this way, and grounds me in thinking about the data from a more objective standpoint.”

“I have also been reflecting on my own toddler’s eating habits, and in particular, how it feels when he eats well or doesn’t eat well. It is comforting and, in some ways, rewarding when he enjoys his food or tries new foods, and frustrating when he doesn’t. In fact, at times, it can be a real concern. I can only imagine the stress that the parents and carers in this study are under to manage such difficulties with food and eating. Their emotional response has a real impact on me as I feel connected to this and can relate to simply wanting the very best for your child.”