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Comparison of clinical presentation and management of children and adolescents with ARFID between paediatrics and child and adolescent psychiatry: a prospective surveillance study

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ABSTRACT

Objective To compare the clinical presentations, management and outcomes of avoidant/restrictive food intake disorder (ARFID) across paediatric and child and adolescent (C&A) psychiatric settings.

Study design Prospective surveillance study.

Methods Data were collected during a 13-month prospective surveillance study of children and adolescents with ARFID in the UK and Republic of Ireland. Paediatricians reported cases via the British Paediatric Surveillance Unit and psychiatrists through the Child and Adolescent Psychiatry Surveillance System. A follow-up questionnaire was sent at 12 months after a case of ARFID was reported.

Results 319 cases were included, 189 from paediatricians and 130 from C&A psychiatrists. Patients presenting to paediatricians were younger (9.8 years vs 13.7 years), more often male (62.4% vs 43.1%), and had more chronic symptoms (80.4% vs 67.0%), selective eating (63.7% vs 46.6%) and comorbid autism (67.6% vs 50.0%) than to psychiatrists. Psychiatrists saw patients with more fear of aversive consequences from eating (13.1% vs 3.2%), weight loss (76.7% vs 65.0%) and comorbid anxiety (78.2% vs 47.4%). Patients presenting to paediatricians more often received medical monitoring (74.6% vs 53.1%), dietetic advice (83.1% vs 70.0%) and nutritional supplements (49.2% vs 30.0%). At follow-up, both cohorts improved in nutritional status. However, the psychiatric cohort improved more regarding disordered eating behaviours.

Conclusions The presentation and management of ARFID differs across clinical settings. Findings suggest the need to develop clinical pathways for ARFID assessment and management across paediatrics and mental health. Our findings highlight the potential benefits of psychiatric input for some patients with ARFID.

BACKGROUND

Avoidant/restrictive food intake disorder (ARFID) is a persistent eating disturbance resulting in inability to meet nutritional or energy needs.¹ Unlike anorexia nervosa, food restriction is not driven by concerns about weight or body image; instead, three primary rationales behind food restriction in ARFID have been proposed, including: sensitivity to sensory aspects of food; lack of interest in eating;

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Avoidant/restrictive food intake disorder (ARFID) is an eating disturbance which leads to: weight loss; nutritional deficiency; dependence on enteral feeding/nutritional supplements; or psychosocial impairment.
- ⇒ ARFID is an umbrella term covering a number of clinical presentations. Existing descriptions of ARFID presentations have drawn from specific clinical settings, limiting their generalisability.
- ⇒ Clinical guidance on the management of ARFID is limited by a lack of research evidence.

WHAT THIS STUDY ADDS

- ⇒ This is the first study to examine the presentation and management of ARFID across different clinical settings.
- ⇒ It highlights the potential benefits of collaborative working and availability of psychological interventions in improving outcomes for children and young people with ARFID.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ This will guide the development of evidence-based pathways for ARFID assessment and management to ensure they are tailored to the specific needs of each patient.

and fear of aversive consequences (eg, choking, vomiting).^{1,2} These presentations may occur independently or coexist, and differ by age and sex, among other factors.³ Prevalence estimates range from 0.3% and 15.5% in non-clinical settings up to 64% in specialist eating disorder clinics.⁴

ARFID frequently presents together with various medical and psychiatric comorbidities, including anxiety,⁵ autism spectrum disorder (ASD)⁶ or obsessive-compulsive disorder (OCD).⁷ Medical sequelae of ARFID can be severe, with multiple potential complications due to low weight and malnutrition.⁸

As a relatively new diagnosis, research on ARFID remains limited. Current management strategies are formulated using clinical experience rather than research evidence due to lack of randomised

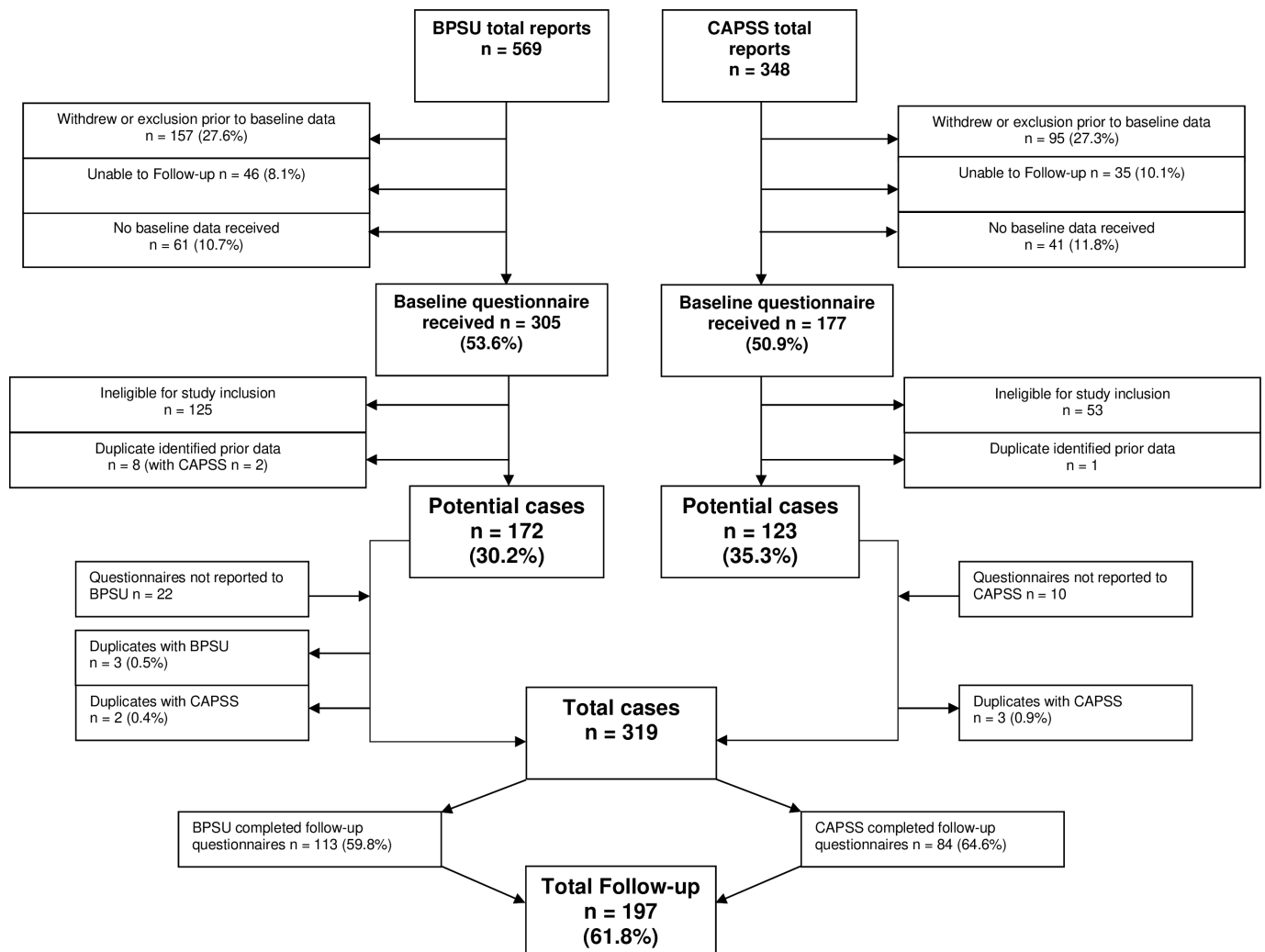


Figure 1 Flow diagram of case ascertainment. This figure shows the flow of individuals from notification to case validation: after reporting a case to BPSU or CAPSS, clinicians were contacted to complete a questionnaire. Reporting errors (such as prevalent cases or confirmed diagnosis of anorexia nervosa) were excluded prior to baseline questionnaire completion after contacting the clinician. Unable to follow-up cases were those excluded due to clinicians stating that they did not wish to be included in the study (due to retirement, shortage of reporting capacity and so on). Cases were excluded if no response was obtained after multiple attempts to contact the notifying clinician or their team (no baseline data received). Completed questionnaires by reporting clinicians were examined to confirm cases were eligible for inclusion. Duplicates were identified and excluded. Additional cases from other sources that met inclusion criteria were added. A 1-year follow-up questionnaire was sent to clinicians reporting confirmed cases. BPSU, British Paediatric Surveillance Unit; CAPSS, Child and Adolescent Psychiatry Surveillance System.

controlled trials.^{7,9} Patients with ARFID require assessment and treatment using a multimodal multidisciplinary approach.¹⁰

Existing literature characterising ARFID is highly heterogeneous depending on the clinical setting. Studies have been conducted in paediatric settings^{11–15} but, to our knowledge, no previous research has compared clinical presentations and management of ARFID between paediatric and psychiatric settings. We aimed to characterise ARFID presentations in children and young people (CYP) and the care received in each setting. We hypothesised differences in demographic and clinical characteristics, medical symptoms, psychiatric comorbidities, management approaches and outcomes between cases seen in paediatric and psychiatric services.

METHODS

Study design

Data were from a prospective surveillance study of CYP with ARFID in the UK and the Republic of Ireland (ROI) presenting

to secondary care. The study was undertaken over 13 months, 1 March 2021 to 31 March 2022, with 1-year follow-up. Cases were identified through the British Paediatric Surveillance Unit (BPSU) and the Child and Adolescent Psychiatry Surveillance System (CAPSS), which employ active surveillance methodology to facilitate research into rare paediatric conditions.¹⁶ Surveillance report cards were emailed monthly to 4298 consultant paediatricians and 695 child and adolescent psychiatrists, requesting notification of new cases meeting ARFID reporting criteria. A 1-year follow-up questionnaire was then sent to clinicians reporting confirmed cases.

Study population

Participants were CYP newly diagnosed with ARFID attending secondary care. A surveillance case definition (online supplemental table 1) based on modified Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition criteria¹ was approved by BPSU and CAPSS committees. Paediatricians

Table 1 Demographics

	Paediatrics n (%) / Median (IQR)	Child and adolescent psychiatry n (%) / Median (IQR)
Sex (male)**	118 (62.4)	56 (43.1)
Age**	9.8 (6.51, 13.24)	13.7 (10.5, 15.1)
Age groups**		
5–9	97 (51.3)	29 (22.3)
10–14	73 (38.6)	66 (50.8)
15–18	19 (10.1)	35 (26.9)
Ethnicity*		
White British	129 (72.1)	98 (84.5)
Other white	16 (8.9)	4 (3.4)
Mixed ethnicity	13 (7.3)	9 (7.8)
Asian	6 (3.4)	5 (4.3)
Black	8 (4.5)	0 (0.0)
Other	7 (3.9)	0 (0.0)
ARFID subtype**		
Combined	79 (41.8)	43 (33.1)
Sensory	53 (28.0)	41 (31.5)
Lack of interest	51 (27.0)	29 (22.3)
Fear*	6 (3.2)	17 (13.1)

*Significant at $p < 0.05$; **significant at $p < 0.005$.
†Post hoc tests with Bonferroni correction revealed that the Fear subtype was different from the others.
ARFID, avoidant/restrictive food intake disorder.

reported cases from 5 to 16 years as indicated in BPSU guidelines.¹⁷ Psychiatrists reported cases from 5 to 18 years. Clinicians reporting a suspected case received a questionnaire requesting more information. A detailed analytical case definition was used by the study team to confirm cases based on the questionnaire data (online supplemental table 2).

Data

Data were collected using initial and follow-up questionnaires developed for this study by the authors. All data were depersonalised using Research Electronic Data Capture (REDCap),¹⁸ a secure, web-based software platform, and stored in a protected environment at Imperial College London. Questionnaires included items on demographic, presentation, clinical features and management of each case using yes/no questions supplemented with free text or multiple-response options. Additionally, clinicians were asked to report their overall clinical impression regarding the patient's eating behaviours at follow-up. We compared responses between paediatricians and psychiatrists.

Body mass index (BMI) was calculated and z -scores for height, weight and BMI were determined using UK 1990 growth reference data.^{19 20} BMI z -score cut-offs were: obesity $> +2$ SD; overweight $> +1$ to $\leq +2$ SD; normal weight $\leq +1$ SD to > -2 SD; underweight ≤ -2 to > -3 SD; and severe underweight < -3 SD.²¹

We classified cases using four mutually exclusive ARFID subtypes defined elsewhere (Combined, Sensory, Lack of interest, Fear).³

Statistics

Data were coded and analysed with IBM Statistical Package for Social Sciences (SPSS) V.29.0. For continuous outcomes, Mann-Whitney U test and t -tests were used. Categorical outcomes were evaluated with χ^2 and McNemar's tests. Statistical significance was set as two-sided $p < 0.05$. As the age range for paediatric cases

Table 2 Clinical presentation

	Paediatrics n (%)	Child and adolescent psychiatry n (%)	Test statistic	P value
Duration of symptoms (≥ 1 year)*	131 (80.4)	73 (67.0)	6.25	0.012
Weight loss	119 (65.0)	99 (76.7)	4.93	0.026
Absence of food groups†	116 (63.7)	55 (46.6)	8.57	0.003
Nutritional deficiency	90 (52.9)	51 (47.7)	0.73	0.392
Nutritional supplements	92 (50.0)	46 (37.4)	4.73	0.030
Tube feeding	22 (11.7)	12 (9.3)	0.46	0.498
Distress with eating	134 (75.7)	95 (77.2)	0.09	0.759
Inability to eat with others	95 (57.9)	58 (55.8)	0.12	0.728
Avoidance of social	100 (67.6)	77 (75.5)	1.83	0.176
Lack of appetite	90 (53.3)	59 (50.9)	0.16	0.691
Lack of interest in food/eating	134 (77.0)	78 (61.9)	8.05	0.005
Difficulty with practicalities	88 (52.4)	51 (45.9)	1.11	0.293
Sensory characteristics	132 (76.3)	89 (76.7)	0.01	0.934
Fear of consequences	45 (30.6)	64 (54.2)	15.09	<0.001
Rigid eating	122 (70.5)	72 (66.1)	0.62	0.431
Arrhythmia/ECG changes	2 (1.1)	1 (0.8)	0.07	0.793
Dizziness	20 (10.6)	36 (27.7)	15.58	<0.001
Syncope	10 (5.3)	12 (9.2)	1.86	0.172
Dehydration	6 (3.2)	4 (3.1)	0.01	0.961
Constipation	53 (28.0)	17 (13.1)	10.07	0.002
Muscle wasting	18 (9.5)	8 (6.2)	1.17	0.280
Gastro-oesophageal reflux	6 (3.2)	6 (4.6)	0.44	0.506

In bold, results were statistically significant at a p value < 0.05 .
*Chronic symptoms were defined as those lasting longer than 1 year.
†Selective eating was defined as the absence of whole food groups (fruits and vegetables, carbohydrates, protein or dairy products).

and psychiatric cases differed, a sensitivity analysis excluding individuals ≥ 16 years was performed.¹⁸

RESULTS

319 cases of ARFID fulfilled analytical case definition and were included in this study. Of those, 189 cases were reported by paediatricians and 130 by psychiatrists. 265 cases were reported from England, 7 from Wales, 13 from Scotland, 7 from Northern Ireland, 6 from ROI and one each from Jersey and the Isle of Man. Four confirmed cases were reported to both BPSU and CAPSS (duplicates, figure 1). Follow-up data were available for 197 (61.8%) participants (113 from paediatricians and 84 from psychiatrists).

Demographics

Table 1 summarises demographic characteristics. 174 (54.5%) male and 145 (45.5%) female cases were reported. Paediatricians were significantly more likely to see males than psychiatrists ($\chi^2(1, n=319)=11.64, p=0.001, \phi=0.19$). The median age of participants was 11.9 years (IQR 7.6, 14.4). Individuals in the psychiatric cohort had a higher median age (13.7 years; IQR 10.5, 15.1) compared with the paediatric cohort (9.8 years; IQR 6.5, 13.2; $U=17\,103, z=5.95, p<0.001, r=0.33$). Paediatricians more often managed children aged 5–9 years, whereas psychiatrists more so treated CYP aged 10–14 and 15–18 ($\chi^2(2, n=319)=31.97, p<0.001, \phi=0.32$). Psychiatrists were more likely to see white British CYP, while paediatricians saw more

Table 3 Management strategies

	Paediatrics n (%)	Child and adolescent psychiatry n (%)	Test statistic	P value
Medical monitoring	141 (74.6)	69 (53.1)	15.87	<0.001
Dietetic advice	157 (83.1)	91 (70.0)	7.60	0.006
Psychoeducation	77 (40.7)	87 (66.9)	21.14	<0.001
Medication	42 (22.2)	32 (24.6)	0.25	0.619
Tube feeding	16 (8.5)	4 (3.1)	3.81	0.051
Nutritional supplements	93 (49.2)	39 (30.0)	11.71	0.001
Individual psychological therapy	36 (19.0)	48 (36.9)	12.69	<0.001
Family therapy	28 (14.8)	29 (22.3)	2.95	0.086
Input from another specialty	66 (34.9)	29 (22.3)	5.86	0.015

In bold, results were statistically significant at a p value <0.05.

from African, Caribbean, black British and other ethnic backgrounds ($\chi^2(5, n=295)=14.46, p=0.013, \phi=0.22$). Duration of symptoms at presentation ranged from 0 to 16 years, with a median of 3.0 years (IQR 0.9, 6.0). CYP with longer duration of symptoms more frequently presented to paediatricians ($\chi^2(1, n=272)=6.25, p=0.012, \phi=0.15$).

Subtypes

Paediatric cases (79 (41.8%)) were more likely to present with Combined subtype than psychiatric cases (43 (33.1%)). Psychiatrists reported a higher proportion of CYP with Fear subtype (17 (13.1%)) than paediatricians (6 (3.2%); $\chi^2(3, n=319)=13.00, p=0.005, \phi=0.20$).

Clinical presentation

Clinical characteristics are shown in table 2. 53.4% participants were normal weight, 34.2% underweight and 12.3% overweight or obese at presentation. Paediatricians were more likely to report overweight CYP (18 (13.0%)) than psychiatrists (2(2.1%); $\chi^2(4,$

$n=234)=10.29, p=0.036, \phi=0.21$) and mean SD BMI z-scores were lower in psychiatry settings ($-1.70 (1.76)$) than in paediatrics ($-0.99 (1.79)$; $t(232)=3.02; p=0.003; \eta^2=0.037$). A higher proportion of cases presented with weight loss in the psychiatric cohort (99 (76.7%)) than the paediatric cohort (119 (65.0%); $\chi^2(1, n=312)=4.93, p=0.026, \phi=0.13$). Paediatric cases (92 (50%)) were more frequently prescribed nutritional supplements than psychiatric cases (46 (37.4%); $\chi^2(1, n=307)=4.73, p=0.030, \phi=0.12$), most commonly for iron and vitamin D deficiencies. The paediatric cohort also exhibited a higher tendency to exclude whole food groups ('selective eating') (116 (63.7%)) compared with those presenting to psychiatry (55 (46.6%); $\chi^2(1, n=300)=8.57, p=0.003, \phi=0.17$).

Constipation (70 (21.9%)) was the most prevalent medical symptom/sign, followed by dizziness (56 (17.6%)), bradycardia (15 (14.4%)) and muscle wasting (26 (8.2%)). The psychiatric cohort (36 (27.7%)) experienced dizziness significantly more than the paediatric cohort (20 (10.6%); $\chi^2(1, n=319)=15.58, p<0.001, \phi=0.22$). The paediatric cohort (53 (28.0%)) had

Table 4 Outcomes at 1-year follow-up

	Paediatrics			Child and adolescent psychiatry		
	Baseline n (%)	Follow-up	P value	Baseline n (%)	Follow-up	P value
Absence of food groups	116 (63.7)	47 (48.5)	0.005	55 (46.6)	18 (23.7)	0.025
Nutritional deficiency	90 (52.9)	31 (32.0)	0.001	51 (47.7)	18 (25.4)	0.022
Tube feeding	22 (11.7)	15 (14.2)	0.999	12 (9.3)	4 (4.9)	0.480
Distress with eating	134 (75.7)	68 (69.4)	0.377	95 (77.2)	31 (43.1)	0.001
Reported weight loss	119 (65.0)	41 (41.0)	<0.001	99 (76.7)	27 (39.1)	<0.001
Inability to eat with others	95 (57.9)	45 (54.9)	0.999	58 (55.8)	24 (36.4)	0.022
Avoidance of social	100 (67.6)	48 (62.3)	0.239	77 (75.5)	31 (50.8)	0.001
Lack of appetite	90 (53.3)	42 (45.7)	0.216	59 (50.9)	16 (26.2)	0.022
Lack of interest	134 (77.0)	68 (73.1)	0.999	78 (61.9)	26 (41.3)	0.080
Difficulty with practicalities	88 (52.4)	35 (46.7)	0.453	51 (45.9)	10 (16.7)	0.002
Sensory characteristics	132 (76.3)	71 (81.6)	0.606	89 (76.7)	31 (57.6)	0.006
Fear of consequences	45 (30.6)	16 (22.5)	0.190	64 (54.2)	16 (25.8)	0.024
Rigid eating	122 (70.5)	58 (69.9)	0.502	72 (66.1)	21 (35.0)	0.001
	Mean (SD)		P value	Mean (SD)		P value
SDS height	-0.35 (1.67)	-0.41 (1.59)	0.541	-0.29 (1.20)	-0.36 (1.23)	0.244
SDS weight	-0.95 (1.83)	-0.83 (1.91)	0.058	-1.63 (1.28)	-1.55 (1.25)	0.123
BMI	16.14 (3.51)	16.82 (3.90)	0.001	15.43 (2.36)	15.87 (2.40)	0.005
SDS BMI	-1.02 (1.72)	-0.78 (1.90)	0.027	-2.14 (1.48)	-1.90 (1.48)	0.004

In bold, results were statistically significant at a p value <0.05.
BMI, body mass index; SDS, SD score.

Table 5 Overall clinical impression regarding the patient's eating behaviours at follow-up

	Paediatrics n (%)	Child and adolescent psychiatry n (%)
Improved	51 (53.7)	57 (81.4)
Changed in presentation	1 (1.1)	4 (5.7)
Persisted unchanged	37 (38.9)	9 (12.9)
Worsened	6 (6.3)	0 (0.0)
Not reported	15 (13.6)	17 (19.5)

In the follow-up questionnaire, clinicians were asked in a multiple-response question to report their impression regarding the patient's eating behaviours.

higher rates of constipation than the psychiatric cohort (17 (13.1%); $\chi^2(1, n=319)=10.07, p=0.002, \phi=0.18$). Menstrual status was reported in 28 of 145 females (19.3%). Of these, 10 (35.7%) had documented secondary amenorrhoea, 5 (33.3%) in the paediatric and 5 (38.5%) in the psychiatric cohort.

Mental health

The psychiatric cohort were more likely to be reported as having comorbid anxiety (79 (78.2%)), depression (24 (25.5%)) or OCD (14 (15.7%)) than the paediatric cohort (72 (47.4%); $\chi^2(1, n=253)=24.00, p<0.001, \phi=0.31$; 9 (6.3%); $\chi^2(1, n=237)=17.51, p<0.001, \phi=0.27$; 8 (5.8%); $\chi^2(1, n=226)=6.01, p=0.014, \phi=0.16$) and more likely to show deliberate self-harm (16 (17.6%)) than the paediatric cohort (12 (8.4%); $\chi^2(1, n=234)=4.46, p=0.035, \phi=0.14$). More children with ASD (96 (67.6%)) and intellectual disabilities (ID) (55 (33.1%)) were reported by paediatricians than psychiatrists (43 (50.0%); $\chi^2(1, n=228)=6.98, p=0.008, \phi=0.18$; 10 (10.2%); $\chi^2(1, n=264)=17.46, p<0.001, \phi=0.26$).

Management

Median time to diagnose ARFID was significantly higher in paediatric (1.1 months—IQR 0, 17.2) than psychiatric settings (0.5 months—IQR 0, 2.9; $U=7568, z=-2.21, p=0.027, r=0.13$). Management strategies are described in table 3. Paediatricians were more likely to provide dietetic advice (157 (83.1%)) and medical monitoring (141 (74.6%)) and to prescribe nutritional supplements (93 (49.2%)) and tube feeding (16 (8.5%)) than psychiatrists (91 (70.0%); $\chi^2(1, n=319)=7.60, p=0.006, \phi=0.15$; 69 (53.1%); $\chi^2(1, n=319)=15.87, p<0.001, \phi=0.22$; 39 (30%); $\chi^2(1, n=319)=11.71, p=0.001, \phi=0.19$; 4 (3.1%); $\chi^2(1, n=319)=3.81, p=0.051, \phi=0.11$). Paediatricians drew input from other health professionals more frequently (66 (34.9%)), including dietitians and occupational therapists, than psychiatrists (29 (22.3%); $\chi^2(1, n=319)=5.86, p=0.015, \phi=0.14$). Psychiatrists used more psychoeducation (87 (66.9%)) and individual psychological therapy (48 (36.9%)) than paediatricians (77 (40.7%); $\chi^2(1, n=319)=21.14, p<0.001, \phi=0.26$; 36 (19.0%); $\chi^2(1, n=319)=12.69, p<0.001, \phi=0.20$). Paediatricians referred 75 cases (39.7%) to a psychiatrist or psychologist; psychiatrists referred 11 cases (8.5%) to a paediatrician.

Outcomes

Table 4 displays the changes in nutritional status and eating behaviours after 1-year follow-up. SD BMI z-scores increased from baseline (-1.50 (1.71)) to follow-up (-1.26 (1.81); $t(111)=-3.46, p=0.001, \eta^2=0.10$) for the whole sample. CYP receiving psychiatric care were reported as having greater

improvement in overall eating behaviour (57 (81.4%)) than paediatric patients (51 (53.7%); $\chi^2(3, n=165)=21.89, p<0.001, \phi=0.36$) (table 5).

Duplicates

Four cases were reported to both BPSU and CAPSS: two girls and two boys. Median age was 12.8 years (IQR 11.4, 15.3) and median duration of symptoms was 2.4 years (IQR 1.0, 6.8). Three cases (75%) were from England. Three cases (75%) presented with weight loss (mean SD BMI z-score -2.5 (1.5)).

Sensitivity analysis

All results remained statistically significant in the sensitivity analysis except for comorbid OCD and input from other health professionals (online supplemental material).

DISCUSSION

To our knowledge, this is the first study to characterise and compare how ARFID presents in CYP between paediatric and psychiatric services. Our findings reveal that presentations varied by specialty, with distinct cohorts treated in the two settings. Significant differences between specialties included symptom duration, eating behaviours, clinical features, comorbidities, management approaches and long-term outcomes. Our findings serve as a key step towards developing evidence-based management pathways for this patient group.

Compared with psychiatry, the paediatric cohort consisted of more males and younger patients with longer symptom duration and more selective eating, nutritional deficiencies, constipation and higher BMIs. Literature suggests that lacking food diversity over long time periods predisposes individuals to malnutrition, altered bowel habits and weight gain, particularly with exclusion of fruits and vegetables.²²⁻²⁴ Results suggest that psychiatric teams manage cases with shorter duration of symptoms, often a more acute clinical picture, characterised by anxiety, weight loss and dizziness. This presentation is consistent with prior research on manifestation of acute malnutrition in ARFID, including dizziness and fainting due to dehydration, hypotension or bradycardia²⁵ which correlates with the rate of weight loss.²⁶ The age difference between cohorts may be explained by distinct referral pathways, presenting symptoms and comorbidities. The distribution of comorbid psychiatric and neurodevelopmental disorders differed in each setting; cases seen by psychiatric teams reported as having higher rates of comorbid anxiety and depression, while more CYP with ID and ASD are treated within paediatrics. These profiles are consistent with prior research.^{6 25 27 28}

Despite consensus supporting a multidisciplinary approach, there was little overlap in cases presenting to paediatrics and psychiatry in our sample. Duplicates were more underweight than the general sample, suggesting more acuteness and therefore seen by both specialties; however, firm conclusions cannot be drawn from this small sample. Our data suggest clinicians in each specialty had distinct management approaches and both cohorts improved in rate of reported weight loss, nutritional deficiencies and exclusion of food groups. The psychiatric cohort additionally exhibited significantly greater improvements in disordered eating behaviours. Moreover, more psychiatrists reported case improvement at follow-up by clinical impression. To note, however, paediatricians and psychiatrists may have different perceptions of clinical improvement.

Patients with ARFID presenting to paediatric settings may also benefit from psychiatric services and psychological interventions, and it is important that clinicians identify these CYP.

A multimodal medical and mental health approach to ARFID assessment and treatment on an ARFID-specific referral pathway²⁹ that facilitates access to and close collaboration between paediatrics and psychiatry would improve care of CYP with ARFID.

Strengths and limitations

This is the first study comparing the clinical characteristics of ARFID in CYP accessing paediatric and psychiatric services. Active surveillance methodology enabled ascertainment of national prospective data from paediatricians and psychiatrists in the UK and ROI. This large sample included CYP of different ages and geographical areas, ensuring data were representative. However, in our prospective research design, loss to follow-up may introduce bias in data analysis. The design of the study meant we were unable to compensate for missing data in analyses. Age criteria for paediatric surveillance (5–16) differed from psychiatric surveillance (5–18), possibly accounting for differences between cohorts. A sensitivity analysis, excluding patients ≥ 16 years, showed our results were robust. We asked clinicians to report their overall clinical impression of patients' eating behaviours at follow-up but did not ask them to report this at baseline. We may have introduced reporting bias as no comparisons could be made between cohorts at follow-up regarding medical conditions.

CONCLUSION

This study reveals variations in the presentation and management of newly diagnosed ARFID cases in different clinical settings. CYP in paediatrics presented more frequently with complications of chronic symptoms due to lack of food variety, often associated with comorbid ASD or ID. Psychiatric teams managed more acute presentations of food restriction, with more weight loss, fears of aversive consequences from eating and mental disorders such as anxiety. Patients managed by psychiatrists responded well to psychological interventions, suggesting that all ARFID CYP should be assessed for suitability for this. Results from this study add support to multidisciplinary management of ARFID and collaborative working across paediatrics and psychiatry.

X Javier Sanchez-Cerezo @JaviSanCer1 and Dasha Nicholls @DashaNicholls

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Contributors DN conceptualised the study. DN, JS-C, JN, RL and LDH contributed to the design and development of the study. EH and JS-C performed the analysis and drafted the manuscript. JS-C, JN and DN accessed and verified the data underlying the study. EH and JS-C contributed equally to this paper. All authors edited and approved the final version of the article. All authors confirmed that they had full access to all the data in the study and accepted responsibility to submit for publication. JS-C is the guarantor of this manuscript and accepted full responsibility for the work and conduct of the study, had access to the data and controlled the decision to publish.

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Ethics approval This study involves human participants and was approved by the West Midlands–Black Country Research Ethics Committee (Integrated Research Application System ID 273665; REC 20/WM/0256). Due to the nature of the study, using surveillance methodology, patient and parental consent was not required. As consent was not sought and minimal identifier data were required, approval under England and Wales Section 251 via Confidentiality Advisory Group of the Health Research Authority (20/CAG/0120) was obtained. Data were collected in Scotland following advice from the Public Benefit and Privacy Panel for Health and Social Care (HSC-PBPP) (2021-0113). Northern Ireland Privacy Advisory Committee requirements were met to collect data.

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Supplement Table 1. Instructions to clinicians for notification of potential cases:

Any child or adolescent aged 5 to 16 (5 to 18 for child and adolescent psychiatrists) years with persistent restriction of quantity and/or range of food intake, associated with one or both of the following:

- Nutritional deficiency that requires additional clinical investigation or treatment (e.g., anaemia, micronutrient deficiency, weight loss or poor growth, reliance on nutritional supplementation) that is not fully accounted for by poverty or neglect, cultural practice or an existing medical condition or another mental disorder*
- Interference with day-to-day functioning due to eating behaviour (e.g., unable to eat at school or with peers, needs to take preferred foods when out of home, extreme and frequent distress about eating).

Not explained by ANY of the following:

- Lack of available food (e.g., from poverty, famine, or neglect)
- Culturally sanctioned practice (e.g., endorsed religious and cultural practice)
- Other known diagnosis
 - e.g., Allergy to specific food group (e.g., dairy)
 - Gastrointestinal disorder
 - Constipation
 - Swallowing difficulties
 - Other eating disorder e.g., anorexia nervosa, bulimia nervosa
 - Other medical or psychiatric disorder that fully explains food restriction (not requiring additional clinical attention) e.g., depression, anxiety, OCD, malignancy, diabetes mellitus, inflammatory bowel disease, thyroid disease.

*If the eating disturbance occurs in the context of another condition/disorder, then to meet case definition for ARFID, the severity of eating disturbance should exceed that routinely associated with the particular condition/disorder - and warrant additional clinical attention.

Supplement Table 2. Analytic criteria for inclusion or exclusion of cases:

Any child or adolescent aged 5 to 18 years with persistent restriction of quantity and/or range of food intake, associated with one (or more) of the following:

Lack of appetite
 Lack of interest in food
 Logistics of feeding/eating behaviour not consistent with age and development (e.g., small bites/slow eating)
 Limited variety of food intake
 Rigid eating behaviour (e.g., brand-specific, food items on a plate cannot touch)
 Unfounded fear of aversive consequences of eating (e.g., fear of choking/vomiting)

And resulting in **ANY** one or more of the following bullet points:

	As evidenced by any one of:
Anthropometric evidence of significant weight loss or growth impairment	<ul style="list-style-type: none"> • Weight-for-age <-2 SD from the international reference median value • Weight-for-height <-2 SD from the international reference median value • Height-for-age <-2 SD from the international reference median value • >10% body mass loss
Nutritional deficiency	<p>As evidenced by any one of:</p> <ul style="list-style-type: none"> • Absence (or near absence if other criteria definitely present) of entire food groups from diet (fruit and vegetables / carbohydrates and grains / protein / dairy products) • Nutritional blood investigation abnormalities (e.g., anaemia, micronutrient deficiency) • ≥50% daily caloric intake via prescribed nutritional or food supplementation • Use of any tube feeding not required by a concurrent medical condition.
Interference with psychosocial functioning	<p>As evidenced by any one of:</p> <ul style="list-style-type: none"> • Extreme and frequent distress about eating (tearfulness, tantrums, refusal to eat)

	<ul style="list-style-type: none"> • Inability to eat except only in certain situations (e.g., only alone/only with family members) • Other impairment of social and emotional development or functioning secondary to eating behaviour (e.g., poor school attendance, limited peer relationships, excessively long mealtimes impacting on self/family)
Not explained by ANY of the following:	
Lack of available food	e.g., from poverty, famine, or neglect
Culturally sanctioned practice	e.g., endorsed religious and cultural practice
Other known diagnosis*	<ul style="list-style-type: none"> • Allergy to specific food group (e.g., dairy) • Gastrointestinal disorder • Constipation • Swallowing difficulties • Other eating disorder e.g., anorexia nervosa, bulimia nervosa • Other medical or psychiatric disorder that fully explains food restriction (not requiring additional clinical attention) e.g., depression, anxiety, OCD, malignancy, diabetes mellitus, inflammatory bowel disease, thyroid disease.

*If the eating disturbance occurs in the context of another condition/disorder, then to meet case definition for ARFID, the severity of eating disturbance should exceed that routinely associated with the particular condition/disorder - and warrant additional clinical attention.

Sensitivity analysis (excluding ≥ 16 years old)

Demographics

Male (paediatrics: 115 [63.9%]; psychiatry: 49 [46.7%]); $\chi^2[1, N=285]=8.051$; **p=.005**

Female (paediatrics: 65 [36.1%]; psychiatry: 56 [53.3%]); $\chi^2[1, N=285]=8.051$; **p=.005**:

Median Age (paediatrics: 9.6 years; IQR 6.4, 13.1; psychiatry: 12.7; IQR 9.8, 14.3); $U=12489$; $z=4.53$; **p<.001**

Age category: 5-9 years (paediatrics: 97 [53.9%]; psychiatry: 29 [27.6%]); 10-14 years (paediatrics: 73 [40.6%]; psychiatry: 66 [62.9%]); 15-18 years (paediatrics: 10 [5.6%]; psychiatry: 10 [9.5%]); $\chi^2[2, N=285]=18.60$; **p<.001**

Ethnicity: White British (paediatrics: 123 [71.5%]; psychiatry: 77 [79.4%]); Other White (paediatrics: 16 [9.3%]; psychiatry: 5 [5.2%]); Mixed ethnicity (paediatrics: 14 [8.1%]; psychiatry: 8 [8.2%]); Asian (paediatrics: 6 [3.5%]; psychiatry: 7 [7.2%]); African, Caribbean, Black British (paediatrics: 7 [4.1%]; psychiatry: 0 [0.0%]); (paediatrics: 6 [3.5%]; psychiatry: 0 [0.0%]); $\chi^2[5, N=269]=11.00$; **p=.051**

Duration of symptoms > 1 year (paediatrics: 127 [79.9%]; psychiatry: 57 [64.0%]) $\chi^2[1, N=248]=7.47$; **p=.006**

Subtype

Combined subtype (paediatrics: 78 [43.3%]; psychiatry: 37 [35.2%]); Sensory subtype (paediatrics: 52 [28.9%]; psychiatry: 34 [32.4%]); Lack of Interest subtype (paediatrics: 45 [25.0%]; psychiatry: 20 [19.0%]); Fear subtype (paediatrics: 5 [2.8%]; psychiatry: 14 [13.3%]); $\chi^2[3, N=285]=13.46$; **p=.004**

Presentation

Weight status: Obese (paediatrics: 5 [3.9%]; psychiatry: 4 [5.1%]) Overweight (paediatrics: 18 [14.0%]; psychiatry: 2 [2.5%]) Normal weight (paediatrics: 67 [51.9%]; psychiatry: 48 [60.8%]); Thinness (paediatrics: 23 [17.8%]; psychiatry: 10 [12.7%]); Severe thinness (paediatrics: 16 [12.4%]; psychiatry: 15 [19.0%]); $\chi^2[1, N=208]=9.75$; **p=.045**

Weight loss (paediatrics: 110 [63.2%]; psychiatry: 79 [75.2%]); $\chi^2[1, N=279]=4.33$; **p=.037**

Mean BMI z scores (paediatrics: -.92 [1.81]; psychiatry: -1.49 [1.8]); $t[232]=2.23$; **p=.027**

Reliant on nutritional supplements (paediatrics: 89 [50.9%]; psychiatry: 39 [38.2%]); $\chi^2[1, N=277]=4.13$; **p=.042**

Excluding whole food groups (paediatrics: 114 [65.5%]; psychiatry: 48 [49.5%]); $\chi^2[1, N=271]=6.66$; **p=.010**

Clinical features

Dizziness (paediatrics: 18 [10.0%]; psychiatry: 28 [26.7%]); $\chi^2[1, N=285]=13.61$; **p<.001**

Constipation (paediatrics: 51 [28.3%]; psychiatry: 15 [14.3%]); $\chi^2[1, N=285]=7.35$; **p=.007**

Mental Health

Anxiety (paediatrics: 70 [49.0%]; psychiatry: 60 [75.0%]); $\chi^2[1, N=223]=14.32$; **p<.001**

Depression (paediatrics: 6 [4.4%]; psychiatry: 16 [21.3%]); $\chi^2[1, N=210]=14.66$; **p<.001**

OCD (paediatrics: 8 [6.2%]; psychiatry: 9 [12.7%]); $\chi^2[1, N=200]=2.47$; **p=.116**

Deliberate self-harm (paediatrics: 11 [8.0%]; psychiatry: 14 [18.9%]); $\chi^2[1, N=212]=5.55$; **p=.018**

ASD (paediatrics: 92 [69.2%]; psychiatry: 34 [50.7%]); $\chi^2[1, N=200]=6.49$; **p=.011**

Intellectual disabilities (paediatrics: 53 [33.8%]; psychiatry: 9 [11.7%]); $\chi^2[1, N=234]=12.92$; **p<.001**

Management

Median time taken to diagnosis (paediatrics: 1.1 months (IQR 0, 17.2), psychiatry: 0.5 months (IQR 0, 2.7)); $U=5518$; $z=-2.22$; **p=.027**

Dietetic advice (paediatrics: 149 [82.8%]; psychiatry: 76 [72.4%]); $\chi^2[1, N=285]=4.31$; **p=.038**

Medical monitoring patients (paediatrics: 133 [73.9%]; psychiatry: 55 [52.4%]); $\chi^2[1, N=285]=13.66$; **p<.001**

Nutritional supplements (paediatrics: 88 [48.9%]; psychiatry: 31 [29.5%]); $\chi^2[1, N=285]=10.23$; **p=.001**

Input from other health professionals (paediatrics: 65 [36.1%]; psychiatry: 27 [25.7%]); $\chi^2[1, N=285]=3.28$; **p=.070**

Psychoeducation (paediatrics: 71 [39.4%]; psychiatry: 72 [68.6%]); $\chi^2[1, N=285]=22.51$; **$p<.001$**

Individual psychological therapy (paediatrics: 28 [15.6%]; psychiatry: 37 [35.2%]); $\chi^2[1, N=285]=14.59$; **$p<.001$**

Outcomes

	Paediatrics			Child and Adolescent Psychiatry		
	Baseline	Follow-up	<i>p</i> value	Baseline	Follow-up	<i>p</i> value
	n (%)			n (%)		
Absence of food groups	114 (65.5)	47 (49.0)	.008	48 (49.5)	14 (21.9)	.014
Nutritional deficiency	86 (53.1)	30 (31.6)	.001	44 (49.4)	16 (26.2)	.015
Tube feeding	22 (12.2)	15 (14.4)	.999	12 (11.5)	4 (5.8)	.480
Distress with eating	130 (77.4)	66 (68.8)	.281	80 (79.2)	26 (41.9)	.001
Reported weight loss	110 (63.2)	40 (40.8)	<.001	79 (75.2)	22 (37.3)	<.001
Inability to eat with others	92 (59.0)	44 (55.0)	.999	50 (57.5)	20 (35.7)	.010
Avoidance of social	96 (68.6)	47 (62.7)	.332	62 (73.8)	25 (48.1)	.002
Lack of appetite	83 (51.9)	41 (45.6)	.281	43 (45.7)	11 (22.0)	.039
Lack of interest	127 (76.5)	67 (73.6)	.999	61 (59.8)	18 (34.6)	.061
Difficulty with logistics	88 (55.3)	35 (47.3)	.453	41 (43.6)	7 (14.3)	.001
Sensory characteristics	130 (78.8)	70 (81.4)	.606	72 (75.8)	24 (48.0)	.006
Fear of consequences	43 (30.9)	16 (22.9)	.190	50 (51.5)	11 (21.6)	.006
Rigid eating	119 (72.1)	57 (69.5)	.502	62 (68.9)	14 (29.8)	<.001
	Mean (SD)		<i>p</i> value	Mean (SD)		<i>p</i> value
SDS Height	-.31 (1.65)	-.39 (1.59)	.393	-.22 (1.24)	-.31 (1.28)	.103
SDS Weight	-.90 (1.83)	-.79 (1.92)	.086	-1.45 (1.31)	-1.34 (1.29)	.087
BMI	16.11 (3.53)	16.83 (3.93)	.001	15.24 (2.64)	15.77 (2.71)	.007
SDS BMI	-1.02 (1.74)	-.75 (1.90)	.015	-2.04 (1.64)	-1.76 (1.65)	.005

Overall clinical impression: improvement (paediatrics: 50 [53.8%]; psychiatry: 48 [81.4%]); changed presentation (paediatrics: 1 [1.1%]; psychiatry: 3 [5.1%]); persisted unchanged (paediatrics: 36 [38.7%]; psychiatry: 8 [13.6%]); worsened (paediatrics: 6 [6.5%]; psychiatry: 0 [0.0%]); $\chi^2[3, N=152]=18.16$; **$p<.001$**