Received: 28 July 2018 | Revised: 21 January 2019 | Accepted: 22 January 2019

DOI: 10.1002/eat.23038

International Journal of EATING DISORDERS

BRIEF REPORT

Long-term follow-up study of low-weight avoidant restrictive food intake disorder compared with childhood-onset anorexia nervosa: Psychiatric and occupational outcome in 56 patients

C.R. André Lange MD[1,2] | Hanna Ekedahl Fjertorp MD[1] | Riitta Holmer[2] | Elin Wijk MD[1] | Ulf Wallin MD, PhD[1,2]

[1]Psychiatry Skane, Child and Adolescent Psychiatry, Eating Disorders Centre, Lund, Sweden

[2]Division of Child and Adolescent Psychiatry, Department of Clinical Sciences, Lund University, Sweden

Correspondence
C. R. André Lange, Psychiatry Skane, Child and Adolescent Psychiatry, Eating Disorders Centre, Lund, Sweden.
Email: andre.lange@med.lu.se

Funding information
Lindhaga Foundation

Abstract

Objective: To compare long term outcome between childhood-onset Anorexia Nervosa (AN) and low-weight Avoidant/Restrictive Food Intake Disorder (ARFID) in regard to psychiatric diagnoses, social and occupational functioning.

Method: A consecutive series of 56 children originally treated for low-weight restrictive eating disorder (ED) were followed up after a mean of 15.9 years. ARFID-diagnoses were assigned retrospectively.

Results: Thirty-seven patients originally had AN and 19 patients were diagnosed retrospectively with ARFID. At follow-up, in the AN-group 21.6% had a current ED, 24.3% had another psychiatric diagnosis, and 54.1% did not have any psychiatric diagnosis. In the ARFID-group, 26.3% had a current ED, 26.3% had another psychiatric diagnosis, and 47.4% had no psychiatric diagnosis. In the ARFID-group ED diagnoses at follow-up were all ARFID, whereas the AN-group showed heterogeneity. Morgan Russell Outcome Assessment Schedule indicated similar outcome in the AN- and ARFID-group. Occupational functioning did not differ significantly between the AN- and ARFID-group.

Discussion: The AN-group showed high rate of ED at follow up. The ARFID-group had a similar outcome to AN. In the ARFID-group, all ED-cases at follow up had ARFID, possibly indicating symptomatic stability. Low-weight ARFID should be treated as seriously as childhood onset AN.

KEYWORDS

anorexia nervosa, avoidant/restrictive food intake disorder, course, feeding and eating disorders of childhood, follow-up studies, restrictive eating

1 | INTRODUCTION

Avoidant/restrictive food intake disorder (ARFID) was introduced as a diagnostic category with DSM-5 (American Psychiatric Association, 2013). ARFID replaced the previous category of feeding disorders of infancy and childhood in DSM-IV and also made the disorder applicable across the entire lifespan. While there is emerging literature reporting the characteristics of ARFID in clinical populations (Norris et al., 2018), its prevalence in clinical settings (Fisher et al., 2014; Nicely, Lane-Loney, Masciulli, Hollenbeak, & Ornstein, 2014) and in a general population (Kurz, van Dyck, Dremmel, Munsch, & Hilbert, 2015), the literature on outcome remains scarce. In a recent study of an adult population, ARFID outcome was compared to anorexia nervosa (AN) outcome over 7 years, which showed a more favorable outcome for ARFID (Nakai et al., 2017). Regarding early-onset AN there are more studies but the literature is still sparse. A review of six outcome studies, concluded that early-onset AN does not differ much from adolescent-onset AN in the intermediate term outcome (Hsu, 1996). In a recent study of early-onset AN, good outcome was seen in only 41% of the patients (Herpertz-Dahlman et al., 2018). To our knowledge, no long-term outcome studies comparing ARFID and early-onset AN have been published. This study explores similarities and differences in the long-term outcome between childhood-onset AN and ARFID in a low-weight sample.

2 | METHODS

In a retrospective chart review based on 102 consecutive patients diagnosed with restrictive low-weight eating disorder (ED) and treated before the age of 13 at the regional ED service of Scania in southern Sweden from 1983 to 2007, 43% of the cases presented with absence of weight- and shape-related psychopathology (Wallin & Råstam, 2016). The former 102 patients were invited to participate in a long-term follow-up study. Fifty-six patients, 53 women and 3 men, consented. The mean age at start of treatment was 11.0 years (range 6.8–12.9). Follow up took place during 2010–2013, with a mean follow up time of 15.9 years (range 7.2–29.3). In this study, we wanted to identify the character of the EDs presented and investigate the course and outcome. We assumed that some would meet diagnostic criteria for ARFID.

Thus, those patients without apparent weight- and shape-related psychopathology were reevaluated in regard to ARFID, using DSM-5 criteria. This was done through a retrospective complete chart review, which was the first procedure of the study. The information available in the medical notes comprised assessment by a child psychiatrist, weight and height, and for most patients a physiotherapist had examined for disturbances in body weight and shape experiences. Diagnostic information about weight and shape concerns and difficulties concerning eating came from the psychiatrist intake interview and from notes during treatment. In addition, audio recordings from the semistructured follow-up interview (Wallin & Holmer, 2009) were used in unclear cases, as they contain sections on the patient's experience of illness onset. Unclear cases were assessed collaboratively by the research team.

At follow up, weight and height were measured. Two interviews were conducted: One was a semistructured interview developed for the follow up (Wallin & Holmer, 2009), the other was the structured clinical interview for diagnosis (SCID, First, Spitzer, Gibbon, & Williams, 2002). Morgan-Russell Outcome Assessment Schedule was administered (Morgan & Hayward, 1988). Subscale D on sexuality aspects was omitted due to its implication of heteronormativity. The self-report questionnaires Symptom Check-List 90 (Derogatis, Lipman, & Covi, 1973), Eating Disorder Examination Questionnaire (Welch, Birgegård, Parling, & Ghaderi, 2011), and Swedish eating assessment of autism spectrum disorders (SWEAA; Karlsson et al., 2013) were used. In this study, SWEAA was used to contribute diagnostic information pertaining to ARFID. As the follow-up procedure had already been completed before the introduction of the ARFID-diagnosis in DSM-5, assessment of ARFID at follow up had to be done retrospectively, and was based on all available relevant information from the follow-up procedure. Only those who had been assigned a retrospective ARFID diagnosis at start of treatment were retrospectively assessed for ARFID at follow up. Unclear cases were assessed collaboratively with authors U.W. and A.L.

Occupational functioning and activity were assessed through Morgan-Russell Assessment Schedule item E 5, the semistructured interview and the SCID overview section. A reference sample was created using data from the national income register. Being in employment or engaging in developmentally appropriate activity was defined as either having your main income from paid employment, being a full-time student, or being on parental leave receiving parent's allowance. People on other benefits were classified as unemployed. Statistics Sweden (Statistiska Centralbyrån, SCB) carried out the calculations, based on a sample of 41,000 women from Scania (same as most study participants) who were matched for age. The above income parameters were taken from the same period during which the follow-up took place. Men were excluded from the reference sample as they made up such a small proportion of the participants, risking to distort data.

Descriptive statistics were used in this study, due to the small sample size and subgroups. Statistical mean, range, and standard deviations (*SD*) are presented. Significance testing was done with *t* test for continuous variables and chi-square test for categorical variables. Drop-out analysis compared baseline age and expected body weight percentage (EBW; Le Grange et al., 2012) between participants and those who did not consent to participate.

The study was approved by the regional ethical review board at Lund University, Reg. No. 2009/619.

3 | RESULTS

At treatment start, 37 cases were assigned a diagnosis of AN and 19 of ARFID. AN-group mean EBW% was 77.6% (range 64.8–91.1; *SD* 7.97), ARFID group mean EBW% was 78.2% (range 68.8–86.9; *SD* 5.17).

At follow-up, there had been no deaths. Table 1 presents descriptive information at follow up. Mean BMI for the AN-group was 21.5 kg/m^2 (range 17.4–28.0; *SD* 2.61) and for the ARFID-group 21.9 kg/m^2 (range 16.5–29.9; *SD* 3.33). AN-group mean age was 28.4 years (range 18.9–42.2; *SD* 6.58), ARFID-group mean age was 25.5 years (range 19.4–40.7; *SD* 5.35).

In the AN-group, 21.6% (*n* = 8) had a current ED, 24.3% (*n* = 9) had another psychiatric diagnosis (but no ED), and 54.1% (*n* = 20) did not have any psychiatric diagnosis. In the ARFID-group, 26.3% (*n* = 5) had a current ED, 26.3% (*n* = 5) had another psychiatric diagnosis, and 47.4% (*n* = 9) had no psychiatric diagnosis (Table 2).

In the AN-group, out of the current eating disorder (ED) cases (*n* = 8), one had AN, six patients had EDNOS (ED not otherwise specified), and one patient had binge ED. Mean body mass index (BMI) for the eight ED-cases was 21.1 kg/m^2 (range 17.4–26.2; *SD* 2.61).

TABLE 1 Descriptive information at follow up

	AN-group (*n* = 37)			ARFID-group (*n* = 19)		
	Mean	*SD*	Range	Mean	*SD*	Range
Age at F-U (years)	28.4	6.58	18.9–42.2	25.5	5.35	19.4–40.7
F-U time (years)	16.5	6.46	7.4–29.3	14.6	5.5	7.2–28.5
BMI at F-U (kg/m^2)	21.5	2.61	17.4–28.0	21.9	3.33	16.5–29.9
Morgan-Russell average score	9.97	2.41	2.3–12.0	10.1	1.9	4.9–12.0

TABLE 2 Occupational level and diagnoses at follow up

	AN-group (*n* = 37) %(*n*)	ARFID-group (*n* = 19) %(*n*)
Occupational level	95%	84%
Diagnoses		
ED	21.6% (*n* = 8)	26.3% (*n* = 5)
Other psychiatric diagnosis	24.3% (*n* = 9)	26.3% (*n* = 5)
No psychiatric diagnosis	54.1% (*n* = 20)	47.4% (*n* = 9)

Sixty-three (*n* = 5) had a co-morbid disorder—depression or dysthymia. In the ARFID-group, all current ED cases met criteria for ARFID (*n* = 5), with mean BMI 22.7 kg/m^2 (range 16.5–29.9; *SD* 5.12). Sixty percent (*n* = 3) had a co-morbid disorder—two cases of dysthymia and one had OCD. Other psychiatric diagnoses were, in the AN-group, depression (8%, *n* = 3), dysthymia (24%, *n* = 9), and anxiety disorder (14%, *n* = 5). In the ARFID-group, other psychiatric diagnoses were depression (11%, *n* = 2), dysthymia (22%, *n* = 4), anxiety disorder (26%, *n* = 5), and obsessive compulsive disorder (5%, *n* = 1). One person in the ARFID-group had an Autism Spectrum Disorder (5%, *n* = 1).

3.1 | Psychological self-rating scales

The Symptom Check-List 90 average index mean score was 0.48 for the AN-group (range 0.02–1.4; *SD* 0.42), and 0.45 for the ARFID-group (range 0.02–1.4; *SD* 0.33). The Eating Disorder Examination-Questionnaire mean score was 1.03 for the AN-group (range 0.0–4.3; *SD* 1.17) and 1.5 for the ARFID-group (range 0.0–3.2; *SD* 1.07).

3.2 | Morgan-Russell outcome assessment schedule

For the Morgan-Russell (M-R) total average score, the AN-group had a mean score of 9.97 (range 2.3–12.0; *SD* 2.41) and the ARFID-group 10.1 (range 4.9–12.0; *SD* 1.90), where 12.0 represents the best functioning. Looking specifically at item E 1–4, which measures aspects of social functioning, the AN-group had a mean score of 10.1 (range 0–12; *SD* 3.04) and the ARFID-group 8.98 (range 1–12; *SD* 3.26).

Looking at the subgroup with no psychiatric diagnosis, the AN-group had a M-R total average score of 11.44 (range 8.9–12.0; *SD* 0.77), and the ARFID-group 11.36 (range 10.2–12.0; *SD* 0.67). In the subgroup with current ED, the AN-group had an average M-R score of 6.72 (range 2.3–9.7; *SD* 2.78) and the ARFID-group 8.74 (range 4.9–12.0; *SD* 2.67). Social functioning, item E 1–4, for the subgroup with no psychiatric diagnosis was for the AN-group 11.75 (range 10–12; *SD* 0.54) and 10.44 (range 7–12; *SD* 2.01) for the ARFID-group. Item E 1–4 score for the subgroup with current ED, was for the AN-group 6.13 (range 0–11; *SD* 3.37) and for the ARFID-group 8.2 (range 1–12; *SD* 4.75).

3.3 | Occupational functioning

In the reference sample, the occupational level was 91%. Results were clear and dichotomous: you were either in or out of age-appropriate occupation. In the AN-group, the occupational level was 95%, and in the ARFID-group 84%. For the subgroup with no psychiatric diagnosis at follow-up, both the AN-group and ARFID-group showed 100% occupational levels. For the subgroup with a current ED, the AN-group had an occupational level of 87%, the ARFID-group 80%. Finally, in the subgroup that had another psychiatric diagnosis at follow-up (but no current ED), the AN-group had an occupational level of 89%, the ARFID-group 60%.

3.4 | Significance testing

No statistically significant differences could be found between the AN- and ARFID-group regarding diagnosis, BMI, psychological self-rating scales, Morgan-Russell Outcome Assessment Schedule or occupational functioning.

3.5 | Attrition

Forty-six persons (45%) did not consent to the study. Participant mean EBW% was 78% (range 64.8–91.1; *SD* 7.1) and mean age was 11.6 years (range 6.8–12.9; *SD* 1.3). Nonparticipant mean EBW% was 80.0% (range 56.9–90.0; *SD* 7.95) and mean age was 11.3 years (range 5.6–12.9; *SD* 1.71).

4 | DISCUSSION

For the AN-group, the results are ambiguous. This study shows a relatively high rate of ED at follow up compared to an 18-year follow-up study of adolescent-onset AN (Wentz, Gillberg, Anckarsäter, Gillberg, & Råstam, 2009). Compared to a recent outcome study of early-onset AN (Herpertz-Dahlman et al., 2018), our study had lower rates of ED at follow up but very similar rates of psychiatric comorbidity. Interestingly, those who appear to recover from their ED, presenting without ED or any other psychiatric diagnosis (more than half), appear to function well both socially and occupationally.

For the ARFID-group, the overall and consistent pattern in the results lies in the similarity with the outcome of the AN-group. As in the AN-group, those who at follow-up had no ED or other psychiatric diagnosis, functioned well socially and occupationally. Compared to a recent ARFID outcome study (Nakai et al., 2017), our low-weight ARFID-group had a poorer overall outcome, perhaps due to the lower age at treatment start in our study.

4.1 | Diagnostic stability of ARFID

This study indicates the possibility of a higher symptomatic stability for ARFID than for AN. In the ARFID-group there was no cross-over to another ED, such that all five patients with a current ED were still suffering from ARFID, however only two had retained low weight. The AN-group showed heterogeneity, consistent with the literature on diagnostic crossover (Eddy et al., 2008).

4.2 | Methodological considerations and limitations

The study sample represents a selected, low-weight group. One should be cautious to generalize these findings. Second, all ARFID-diagnoses were assigned retrospectively, with higher risk of diagnostic uncertainty.

Compared to other recent ARFID-studies with retrospective, chart-based diagnoses, this study has the advantage of also using data gathered from the semistructured recorded follow-up interview (Wallin & Holmer, 2009) to support diagnosis.

Only 55% of the total group of 102 persons originally in treatment participated in the follow up. This incurs a considerable limitation of the representativeness of the study.

The study has a number of strengths: a long follow-up period, the use of structured diagnostic interview, outcome defined not only by BMI and diagnosis, but also by psychosocial and occupational functioning, and a large reference sample in support of the latter.

4.3 | Implications of the study findings

The results indicate that low-weight ARFID may have a similar long-term outcome to that of childhood-onset AN. More research should be directed toward examining the relationship between comorbidity and long-term outcome in ARFID and early-onset AN. Predictors of illness maintenance and recovery should also be explored.

ACKNOWLEDGMENTS

Financial support was provided by Lindhaga Foundation.

ORCID

C.R. André Lange https://orcid.org/0000-0001-5533-6554

REFERENCES

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Association.

Derogatis, L. R., Lipman, R. S., & Covi, L. (1973). SCL-90: An outpatient psychiatric rating scale—Preliminary report. *Psychopharmacology Bulletin*, *9*(1), 13–28.

Eddy, K. T., Dorer, D. J., Franko, D. L., Tahilani, K., Thompson-Brenner, H., & Herzog, D. B. (2008). Diagnostic crossover in anorexia nervosa and bulimia nervosa: Implications for DSM-V. *American Journal of Psychiatry*, *165*, 245–250. https://doi.org/10.1176/appi.ajp.2007.07060951.07060951

First, M. B., Spitzer, R. L., Gibbon, M., & Williams, J. B. W. (2002). *Structured clinical interview for DSM-IV-TR axis I disorders, research version (SCID-I/P)*. New York: New York State Psychiatric Institute.

Fisher, M. M., Rosen, D. S., Ornstein, R. M., Mammel, K. A., Katzman, D. K., Rome, E. S., … Walsh, B. T. (2014). Characteristics of avoidant/restrictive food intake disorder in children and adolescents: A "new disorder" in DSM-5. *Journal of Adolescent Health*, *55*, 49–52. https://doi.org/10.1016/j.jadohealth.2013.11.013

Herpertz-Dahlman, B., Dempfle, A., Egberts, K. M., Kappel, V., Konrad, K., Vloet, J. A., & Bühren, K. (2018). Outcome of childhood anorexia nervosa—The results of a five-to ten-year follow-up study. *International Journal of Eating Disorders*, *51*, 295–304. https://doi.org/10.1002/eat.22840

Hsu, L. K. G. (1996). Outcome of early onset anorexia nervosa: What do we know? *Journal of Youth and Adolescence*, *25*(4), 563–568. https://doi.org/10.1007/BF01537549

Karlsson, L., Råstam, M., & Wentz, E. (2013). The Swedish Eating Assessment for Autism spectrum disorders (SWEAA)-Validation of a self-report questionnaire targeting eating disturbances within the autism spectrum. *Research in Developmental Disabilities*, *34*(7), 2224–2233. https://doi.org/10.1016/j.ridd.2013.03.035

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

Le Grange, D., Doyle, P. M., Swanson, S. A., Ludwig, K., Glunz, C., & Kreipe, R. E. (2012). Calculation of expected body weight in adolescents with eating disorders. *Pediatrics*, *129*, e438–e446. https://doi.org/10.1542/peds.2011-1676

Morgan, H., & Hayward, A. (1988). Clinical assessment of anorexia nervosa: The Morgan-Russell outcome assessment schedule. *British Journal of Psychiatry*, *152*, 367–371.

Nakai, Y., Nin, K., Noma, S., Hamagaki, S., Takagi, R., Teramukai, S., & Wonderlich, S. A. (2017). Clinical presentation and outcome of avoidant/restrictive food intake disorder in a Japanese sample. *Eating Behaviors*, *24*, 49–53. https://doi.org/10.1016/j.eatbeh.2016.12.004

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

Norris, M. L., Spettigue, W., Hammond, N. G., Katzman, D. K., Zucker, N., Yelle, K., … Obeid, N. (2018). Building evidence for the use of descriptive subtypes in youth with avoidant restrictive food intake disorder. *International Journal of Eating Disorders*, *51*, 170–173. https://doi.org/10.1002/eat.22814

Wallin, U., & Holmer, R. (2009). Semi-structured follow-up interview for childhood-onset eating disorder (in Swedish). Unpublished manuscript, Department of Child and Adolescent Psychiatry, University of Lund.

Wallin, U., & Råstam, M. (2016). Childhood anorexia nervosa compared with low weight food intake disorder without weight and shape-related psychopathology: A retrospective study of 102 patients. *European Eating Disorders Review*, *24*(4), 329–333. https://doi.org/10.1002/erv.2447

Welch, E., Birgegård, A., Parling, T., & Ghaderi, A. (2011). Eating disorder examination questionnaire and clinical impairment assessment questionnaire: General population and clinical norms for young adult women in Sweden. *Behaviour Research and Therapy*, *49*(2), 85–91. https://doi.org/10.1016/j.brat.2010.10.010

Wentz, E., Gillberg, C., Anckarsäter, H., Gillberg, C., & Råstam, M. (2009). Adolescent-onset anorexia nervosa: 18-year outcome. *British Journal of Psychiatry*, *194*, 168–174. https://doi.org/10.1192/bjp.bp.107.048686

How to cite this article: Lange A, Ekedahl Fjertorp H, Holmer R, Wijk E, Wallin U. Long-term follow-up study of low-weight avoidant restrictive food intake disorder compared with childhood-onset anorexia nervosa: Psychiatric and occupational outcome in 56 patients. *Int J Eat Disord*. 2019;52:435–438. https://doi.org/10.1002/eat.23038