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CLINICAL ROUNDS

Development of an inpatient protocol for adolescents with avoidant/restrictive food intake disorder: a case study

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Abstract

Introduction: Avoidant/restrictive food intake disorder (ARFID) is an eating disorder characterised by a pattern of eating that leads to failure to meet appropriate nutritional and/or energy needs. **Method:** In the absence of evidence-based inpatient guidelines for adolescents with ARFID, we set out to develop and pilot an inpatient protocol for adolescents with ARFID. Identification of the key differences between managing inpatients with ARFID and anorexia nervosa (AN) led to modification of an existing AN protocol with the goals of better meeting patient needs, enhancing alignment with outpatient care, and improving outcomes. A case report of an adolescent with ARFID who had three hospital admissions is presented to highlight these changes. Interviews with this patient and her family were undertaken, together with key staff, to explore the challenges of the AN protocol for this patient and the perceived benefits and any limitations of the ARFID protocol for this patient and others. **Results:** The new ARFID protocol supports greater choice of meals, without the need for rest periods after meals and bathroom supervision. The similarities with the AN protocol reflect the need to promote timely weight gain through meal support, including a staged approach to nutritional supplementation. The protocol appears to have been well accepted by the patient and her family, as well as by staff, and continues to be used in cases of ARFID. **Conclusion:** Further evaluation would help identify how well this protocol meets the needs of different adolescents with ARFID.

Key Words: *eating disorder, avoidant restrictive food intake disorder, malnutrition, refeeding, clinical protocol*

Résumé

Introduction: Le trouble évitant/restrictif de la prise alimentaire (TERPA) est un trouble alimentaire caractérisé par un modèle d'alimentation qui entraîne une incapacité à répondre aux besoins nutritionnels et/ou énergétiques appropriés. **Méthode:** En l'absence de lignes directrices fondées sur des données probantes en milieu hospitalier pour des

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adolescents souffrant de TERPA, nous avons entrepris de développer et de piloter un protocole en milieu hospitalier pour les adolescents souffrant de TERPA. L'identification des principales différences entre la prise en charge des patients hospitalisés souffrant de TERPA et d'anorexie mentale (AM) a mené à une modification d'un protocole d'AM existant dans le but de mieux répondre aux besoins des patients, d'accroître l'alignement avec les soins des patients ambulatoires, et d'améliorer les résultats. Un rapport de cas d'une adolescente souffrant de TERPA qui a eu trois hospitalisations est présenté pour souligner ces changements. Des entrevues avec cette patiente et sa famille ont été réalisées, de même qu'avec le personnel principal, afin d'explorer les difficultés du protocole d'AM pour cette patiente ainsi que les avantages perçus et toute limite du protocole TERPA pour cette patiente et d'autres. **Résultats:** Le nouveau protocole TERPA supporte un plus grand nombre de repas, sans le besoin de périodes de repos après les repas et une supervision de la salle de bain. Les similitudes avec le protocole AM reflètent le besoin de promouvoir une prise de poids rapide grâce à un soutien aux repas, y compris une approche par étapes de supplémentation nutritionnelle. Le protocole semble avoir été bien accepté par la patiente et sa famille, ainsi que par le personnel, et continue d'être utilisé dans les cas de TERPA. **Conclusion:** Une évaluation plus poussée aiderait à identifier dans quelle mesure ce protocole répond aux besoins de différents adolescents souffrant de TERPA.

Mots clés: *trouble alimentaire, trouble évitant restrictif de la prise alimentaire, malnutrition, réalimentation, protocole clinique*

Introduction

Avoidant/restrictive food intake disorder (ARFID) is an eating disorder where food avoidance leads to failure to meet nutritional and/or energy needs as evident by significant nutritional deficiency, weight loss or failure to gain adequate weight, reliance on oral supplementation or tube feeding, and/or marked interference with psychosocial functioning (1). In contrast to anorexia nervosa (AN), ARFID is not due to a drive for thinness or fear of weight gain, and patients lack the body image preoccupation that accompanies AN. Rather, food restriction may result from lack of interest in food, avoidance of food due to its sensory characteristics, or fear of aversive consequences of eating such as nausea or vomiting (1,2). As with AN, the complications of underweight and malnutrition in children and adolescents (e.g., nutritional deficiencies, cardiovascular compromise, poor growth, secondary amenorrhoea and poor bone health) can be sufficiently severe to require hospital admission (3,4).

There are no evidence-based guidelines to manage children and adolescents with ARFID (5) and there is considerable variation around the inpatient care of this heterogeneous population (6,7). Currently in the USA, the majority of eating disorder treatment programs adapt AN protocols to manage this diverse group, including inpatient refeeding protocols (8). Not surprisingly, there have been calls to develop specific inpatient guidelines to improve treatment outcomes (8), reinforced by evidence that patients with ARFID rely more on enteral nutrition than those with AN (3) and require more individualised, behaviourally oriented approaches than generally provided when managing adolescents with AN (9).

In this paper, we present a case study of an adolescent with ARFID to illustrate some of these challenges and describe the development of a new ARFID inpatient protocol that was successfully implemented with this patient, and that has subsequently continued to be used. To understand the experience of these different protocols, we interviewed the patient and her mother, as well as ward staff. In this brief report, we interweave quotes from the patient, her mother, and multidisciplinary staff to highlight the issues that were particular to this case, framed within wider staff concerns about managing adolescents with ARFID using the AN protocol.

Case report

Anna (pseudonym) was a 14-year-old girl with autism spectrum disorder and mild intellectual disability who was referred to the hospital's eating disorder program in a children's hospital in Australia by her community paediatrician following two years of poor weight gain. Anna lived at home with her mother, step-father, and four younger stepbrothers. She attended a mainstream high school where she was attempting Year 8. Her siblings had medical and developmental concerns requiring high levels of parental support.

Anna was first seen by a specialist adolescent physician within the program who encouraged her parents to develop a regular routine of supervised meals of Anna's preferred

foods, and to use various approaches to help Anna better tolerate her emotional and physical discomfort associated with eating more. Six months later, despite regular review where these messages were reinforced, her paediatrician referred Anna for multidisciplinary assessment within the program due to poor weight gain and primary amenorrhea. At that time, she weighed 31.75 kg (73% median body mass index [BMI]) and both height and weight were deviating from past trajectories. She was cardio-vascularly stable. There was no evidence of nutritional deficiencies based on bloodwork.

At this time, Anna and her family were experiencing a range of psychosocial stressors within the broader family system that were impacting Anna's wellbeing. Anna's mother and step-father reported Anna could eat well, but tended to reduce her intake when she was anxious and upset. At these times, eating became associated with physical discomfort and she became preoccupied by worries and 'forgot to eat'. Her diet included some vegetables but predominantly comprised carbohydrates, high energy foods such as cereals, pizza, pasta, and soft drinks. Anna denied binges, compensatory behaviours or concerns with body image. Anna's mother reported that she had had some concerns regarding Anna's disinterest in eating and low formula intake as an infant. In early childhood, her mother considered Anna's weight gain consistent with age expectations, but she appreciated that around six years of age, her physique was noticeably thinner compared to her peers.

On assessment, Anna was diagnosed with ARFID, secondary to generalised anxiety about a range of issues including the health of family members, school, and difficulty tolerating noisy environments, on the background of a mild intellectual disability. Her presentation appeared consistent with lack of interest and avoidance of physical discomfort associated with eating when emotionally distressed. Anna and her mother provided written informed consent to publish her case anonymously.

Treatment Overview

Following assessment, Anna commenced Family-Based Treatment (FBT) with a clinical psychologist but failed to gain weight. Indeed, both height and weight continued to deviate from a healthy pattern. Over the next 14 months, Anna required three elective admissions to the hospital's adolescent medicine ward (Table 1). Each of the admissions occurred in the context of psychosocial stress and associated loss of weight. The goals of each admission were weight gain and to establish a routine around eating. As an outpatient, Anna received a total of 24 sessions of FBT and three booster sessions.

Challenges with the AN protocol

Anna's first admission was structured around the hospital's usual protocol for managing adolescents with AN. Consistent with clinical guidelines (10,11), this protocol prescribes set meals and snacks, a schedule of social and educational activities, and bathroom supervision. Meal replacements with high energy nutritional supplement drinks are provided immediately at the completion of a meal if food and drinks are not fully consumed within a defined period.

Longstanding sensitivities with taste and texture made it difficult for Anna to eat the prescribed meals. This led to anxiety and associated vomiting, prescription of anxiolytic medication, and placement of a nasogastric tube for feeding. Anna became too distressed to leave her mother to participate in the structured elements of the eating disorder program, such as school. In this context, the first admission felt counterproductive. At the very least, the set meal plan was considered to be inappropriate as Anna was happy to eat high calorie food to gain weight yet refused to eat many specific foods on the AN protocol meal plans.

> *"She doesn't mind eating as long as it's something that she wants to eat."* ***(Anna's mother)***
>
> *"It was so clear that if you gave her food that she liked she'd eat it, if you presented her with food that she didn't like she wouldn't eat it and then you got into the whole difficulty of putting in tubes and giving her boluses."* ***(Adolescent physician)***
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> *"I'm just really trying to get them back onto food and feeling comfortable with eating enough to keep them safe at home."* ***(Dietician)***
>
> *"Treating [patients with ARFID] on the normal eating disorder protocol was challenging them in ways that they didn't necessarily need to be challenged."* ***(Clinical Nurse Consultant)***

Nursing staff had also become concerned that the AN protocol was not meeting the needs of this particular patient. They were especially challenged about how to justify the strict approach to Anna and her parents, particularly the requirement for supervision in the toilet and shower, as Anna had never engaged in any compensatory activities (her vomiting was considered to reflect anxiety rather than being self-induced). This became more distressing when Anna experienced enuresis on more than one occasion. The challenges raised for this particular patient were in the context that more widely, ward nurses were concerned that the AN protocol was inappropriately restrictive for inpatients

Table 1. Characteristics of the three admissions. Admission 1 used the AN protocol and admission 3 used the ARFID protocol. During Admission 2, the AN protocol was used for day 0-12, and the ARFID protocol was used for day 12-15.

	Admission 1	Admission 2	Admission 3
Context of admission			
Time since commencing FBT (months)	2	10	15
Medically stable on admission	No	Yes	Yes
Goal weight (kg)	None	39	41
Daily intake requirements*			
Minimum (kcal)	1900	1900	2300
Maximum (kcal)	2700	2700	2300
Minimum (kJ)	8000	8000	9200
Maximum (kJ)	11,400	11,400	9200
Outcome data			
Length of admission (days)	12	15	8
Admission weight (kg)	33.2	36	39.8
Discharge weight (kg)	35.4	39.9	41.6
Total weight gain during admission (kg)	2.2	3.9	1.8
Week one weight gain (kg)	1.3	1.2	1.8
Average daily weight gain (kg)	0.18	0.26	0.23
Vomiting frequency (days)**	4	7	1
Days with any vomiting** (%)	25	46	12.5
Medication frequency (days)***	11	15	0
Medication frequency (% days)***	92	100	0
Discharge Plan			
FBT follow-up	yes	booster session	no
Paediatrician follow- up	yes	yes	yes

* daily intake requirements were increased in incremental steps
**Vomiting was considered to be due to anxiety rather than self-induced
***Medications were for nausea (Ondansetron, Metoclopramide, Nitrous Oxide), laxatives (Docusate Sennosides), sleep (Melatonin) and distress (Lorazepam)

with ARFID, and that strictly implementing the protocol for these patients was not an efficient use of staff time.

> *"[The nursing staff were] definitely feeling uncomfortable with enforcing rules that they didn't really think these kids needed."* ***(Clinical Nurse Consultant)***
>
> *"If they [patients with ARFID] didn't necessarily need to be supervised then you had more time to focus on other things."* ***(Ward Nurse)***
>
> *"There seemed to be quite a few complaints from families questioning why we were keeping the bathrooms locked for these kids when potentially we didn't need them to be and when we looked at it, it kind of made sense."* ***(Clinical Nurse Consultant)***
>
> *"You basically pressed the buzzer and sometimes if you were bursting you basically wet yourself."* ***(Anna)***

Development of the ARFID protocol

Initial reluctance was expressed by the specialist eating disorder program team about developing a separate ARFID inpatient protocol due to the concern that two protocols would be confusing for staff. However, in light of the challenges faced by Anna, a working group was formed (dietician, paediatric fellow and clinical nurse consultant [advanced clinical nursing position, equivalent to a Clinical Nurse Specialist in the United States of America]) to review the existing

Table 2. Key differences and similarities between the AN and ARFID inpatient protocols

	AN Protocol	ARFID Protocol
Differences		
Choice of meals	No	Yes
Supervision required in bathroom/toilet	Yes	No
Stabilisation phase*	Yes	No
Rest period after meals	Yes	No
Diet code **	Full ward	High energy
If unable to tolerate meal replacements during the day, provided as overnight continuous nasogastric tube feed	No	Yes
Similarities		
Choice of snacks	No	No
Time limit of meals and snacks	Yes	Yes
High energy supplement drink provided if meal or snack not eaten in time	Yes	Yes
High energy supplement drink (200ml) added to meal plan if bi-weekly weight target of minimum 500g not achieved	Yes	Yes
Nasogastric tube inserted if patient is unable to drink high energy supplement drink	Yes	Yes

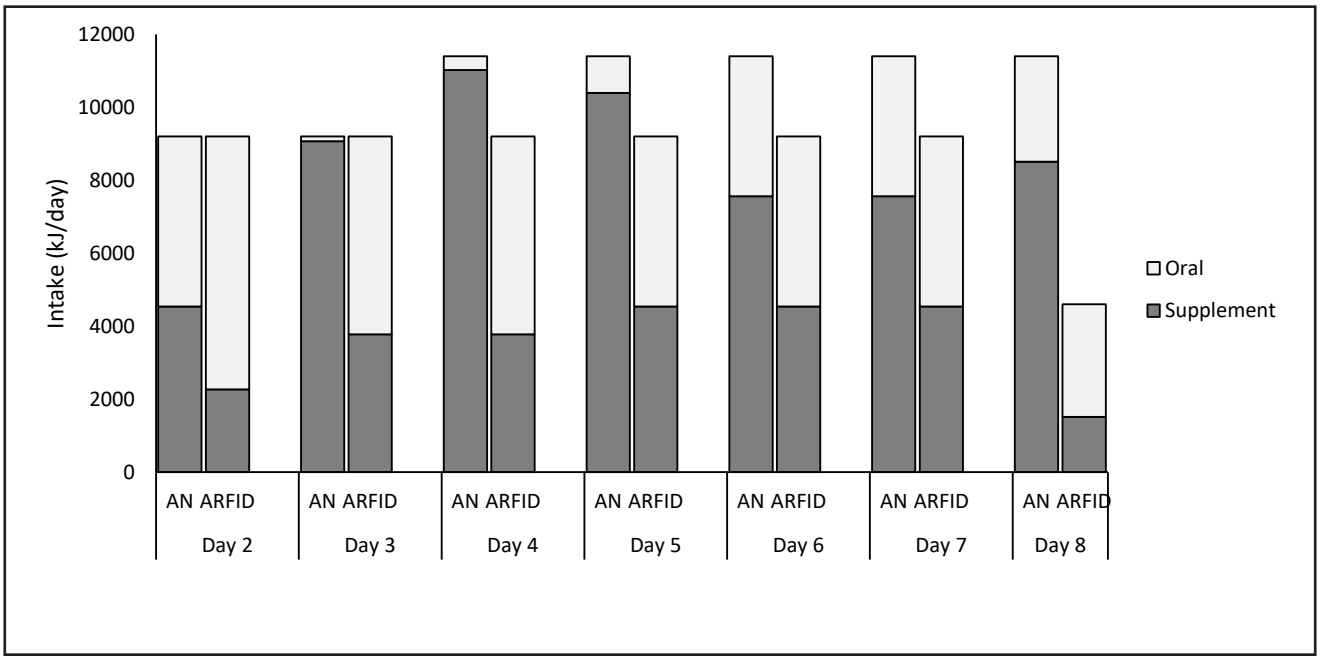
*Stabilisation phases specify the amount of activity and ward leave a patient is permitted.
** Full ward diet code refers to the standard hospital menu, while a high energy diet code refers to the provision of energy dense foods, used for weight gain.

AN protocol and identify the key issues for Anna and other patients with ARFID. A literature review was undertaken and various eating disorder service and research leaders were contacted with the goal of identifying any ARFID inpatient protocols. The absence of any specific protocols led us to develop a new ARFID protocol that was intended to address the major challenges identified in applying the AN protocol to this cohort. Around this time (between Anna's first and second admissions), the team had started to transition from offering standard FBT to combined FBT+ Unified Protocol for Transdiagnostic Treatment of Emotional Disorders in Children (12,13). This outpatient treatment focuses on use of preferred foods for weight gain and establishment of regular meal routines, and we wanted the inpatient and outpatient treatments to be more consistent. The major similarities and differences between the AN protocol and the ARFID protocol are shown in Table 2.

Implementing the ARFID protocol

The AN protocol was used for Anna's first admission which lasted for 12 days (see Table 1). During Anna's second admission the AN protocol was used until day 12, following which the new ARFID protocol was implemented due to her high levels of distress. This proved successful; less anxiety and distress were immediately evident and weight gain improved. The ARFID protocol was also used for her third admission which was not only briefer, but also characterised by less distress, as shown by reduced frequency of vomiting (Table 1) and a higher proportion of caloric intake from food compared to meal replacements (Figure 1). The removal of the requirement for bathroom supervision prevented episodes of enuresis and reduced the amount of supervision required by nurses. The patient, her mother, and staff were all positive about the modified protocol.

Figure 1. Energy provided by supplement drink (Fortisip) and oral intake across Admission 1 (column 1, AN protocol) and Admission 3 (column 2, ARFID protocol).



NB: Anna had a grace period during day 0 and 1 of Admission 1, during which the supplement drink was not provided to meet daily caloric intake. Data from Admission 2 are not shown as the changeover of protocols occurred during this admission. The figure only focuses on the first eight days of Admission 1 and 3 to enable comparison as Admission 3 only lasted 8 days. The supplement drink was delivered orally or via a nasogastric tube, according to Anna's preference. Overall, Anna chose the supplement drink to be delivered via a nasogastric tube on three days in Admission 1, and six days in Admission 3.

> *"It was so much easier on her. After a while, she didn't need me to be around as much, she goes, 'Mum, go home! You need to rest, look after yourself'."* ***(Anna's mother)***
>
> *"We were able to show that if she was given the opportunity to eat the food that she liked she could manage it fairly well without the need for a nasogastric tube. It's clearly been less distressing for her, she's been able to eat more, her weight gain has still been good, admission was shorter and we didn't have the problems with vomiting, enuresis or urinary incontinence."* ***(Adolescent physician)***
>
> *"Families have definitely made comments that the patients find it a lot less stressful for them and I think they can see that we are supporting them a bit more rather than trying to force feed them with foods that we want them to eat."* ***(Dietician).***

As a result of this experience, we have continued to provide both protocols. Clinical staff have not experienced confusion in managing concurrent protocols on the ward, and there have been no subsequent issues raised by other patients about the different protocols. Specifically, patients with AN have not reported any distress at observing patients with ARFID consuming high calorie food during meals where they eat together. Similarly, no concerns have been raised by patients with AN that their counterparts with ARFID had choice over their meals. To the contrary, patients with AN have expressed distress at being given a choice of food due to the difficulties they face in identifying the lowest calorie food. Within the ARFID protocol, the same set of snacks are offered as to patients with AN due to the acceptability of these foods for patients with ARFID. There were no comments made about differential access to bathrooms which may reflect that patients with AN were not aware that those with ARFID had access to bathrooms, as each patient's room has a private bathroom.

Discussion

This case report highlights the difficulties of applying an inpatient eating disorder protocol that was specifically developed to support weight gain in adolescents with AN to

adolescents with ARFID, whose restricted food intake is shaped by very different features such as lack of interest in food, fear of aversive consequences, or sensory sensitivities (2). Patient, family, and staff feedback were consistent about the limitations of using the AN protocol for adolescents with ARFID, which was recognised to be counterproductive on some occasions due to the prominence of vomiting and the reliance on nasogastric feeds. The new ARFID protocol was developed with the intention of addressing these issues. Its implementation appeared highly beneficial in this patient, and it continues to be used.

Our specialist eating disorder service delayed developing a distinct protocol for adolescents with ARFID due to the potential confusion of having two separate inpatient protocols for adolescents with restrictive eating disorders. We also appreciated that a patient's response to the AN protocol can help inform the diagnosis of AN, especially when the adolescent denies the drive for thinness (14). We now use the ARFID protocol for all patients with a confirmed diagnosis of ARFID, regardless of presentation, provided that AN is not suspected as a differential diagnosis. We continue to use the AN protocol when there is diagnostic uncertainty, and observation by ward nurses of meal times and behaviour on the ward has been helpful in confirming either diagnosis (AN or ARFID). For example, attempts at exercise, refusing foods previously claimed to be preferred, or exhibiting concerns about shape and weight as consumption demands are increased may support an AN diagnosis and ongoing use of the AN protocol. An absence of these behaviours, in combination with caregiver affirmation, would support consideration of a diagnosis of ARFID and a switch to this protocol. In our experience, the patient's preferences become apparent quickly. We recognise that use of the AN protocol carries a risk of causing unnecessary difficulties for patients with a missed diagnosis of ARFID. However, on balance, we have found it preferable to commence using the stricter AN protocol before changing to the ARFID protocol, rather than starting with the less stringent ARFID protocol. We are yet to formally evaluate the extent to which the protocol benefits the range of patients with ARFID, and whether it might be more or less effective for certain groups, such as those with neurodevelopmental disabilities which commonly accompany ARFID (15).

In patients with AN, inpatient protocols are beneficial in setting expectations that align with the outpatient treatment. In our service that mostly offers FBT for adolescents with AN, the inpatient AN protocol is consistent with the parents (rather than the patient) taking responsibility for refeeding (16). There is currently no evidence-based treatment for ARFID (5). Many programs offer an FBT-informed approach, and emerging outpatient treatment includes Cognitive Behavioural Therapy for ARFID (17,18) and combined FBT+ Unified Protocol for Transdiagnostic Treatment of Emotional Disorders in Children (12,13). The ARFID protocol provides greater flexibility with choice of meals in the inpatient setting that aligns with cognitive-behavioural oriented outpatient treatment expectations.

While Anna's outcomes and the team's response to the new protocol appear to have been positive, this study reports a single case. The interviews were not part of an in-depth qualitative research study and the lack of experimental design means that Anna's outcomes cannot be confirmed to have been caused by the changes to the protocol. Notwithstanding these caveats, the inpatient team continues to use this protocol due to its perceived benefits. Further research is needed to formally assess the value of targeted ARFID inpatient protocols.

In summary, this case report highlights the challenges of applying an AN protocol to adolescents with ARFID and showed that implementing a specific ARFID protocol was associated with less emotional distress, improved eating, better weight gain, and less vomiting. It also proved acceptable for the patient, parents and staff and is more consistent with outpatient ARFID treatment. Given the diversity of ARFID presentations, further evaluation is needed to identify how well it meets the needs of different groups of patients with this heterogenous eating disorder.

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Conflicts of Interest

The authors have no conflict to declare.

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