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CLINICAL CASE ROUNDS

Case Presentations Combining Family-Based Treatment with the Unified Protocols for Transdiagnostic Treatment of Emotional Disorders in Children and Adolescents for Comorbid Avoidant Restrictive Food Intake Disorder and Autism Spectrum Disorder

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Abstract

Avoidant Restrictive Food Intake Disorder (ARFID) is a Feeding and Eating Disorder newly added to the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition*, which presents with high prevalence rates in community and clinical settings. Given its recent diagnostic recognition, validated and standardized treatments for this population are lacking. In addition, given the complexity, heterogeneity of symptoms, and high rates of psychiatric comorbidities in the ARFID population, new models of care are required. The current therapy model combines two evidence-based treatments – Family Based Treatment (FBT) and the Unified Protocols for Transdiagnostic Treatment of Emotional Disorders in Children and Adolescents (UP-C/A) – for young patients with ARFID plus Autism Spectrum Disorder (ASD), which allows clinicians to personalize care based on each patient's unique presenting needs. This paper presents two distinct cases which showcase the use of the FBT+UP for ARFID approach for treating comorbid ARFID and ASD in a clinical setting. Case 1 demonstrates the application and reliance on FBT, while Case 2 draws upon UP to facilitate behavioural change in the patient. Case backgrounds, presenting problems, and treatment approaches combining the two evidence-based treatments are presented and discussed. The cases demonstrate the unique challenges of treating young patients with comorbid ARFID and ASD, along with the proposed benefits of the combined approach with this population.

Key Words*: avoidant restrictive food intake disorder, autism spectrum disorder, evidence-based treatments, child, adolescent*

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Résumé

Le trouble évitant/restrictif de la prise alimentaire (TERPA) est un trouble alimentaire nouvellement ajouté au *Manuel diagnostique et statistique des troubles mentaux, 5e édition*, qui présente des taux de prévalence élevés en milieu communautaire et clinique. Étant donné sa récente reconnaissance diagnostique, il manque de traitements validés et normalisés pour cette population. En outre, vu la complexité et l'hétérogénéité des symptômes, et les taux élevés de comorbidités psychiatriques dans la population TERPA, de nouveaux modèles de soins sont nécessaires. Le modèle de thérapie actuel combine deux traitements fondés sur les données probantes – le traitement basé sur la famille (TBF) et les protocoles unifiés pour le traitement transdiagnostique des troubles émotionnels chez les enfants et les adolescents (PU-E/A) – pour les jeunes patients souffrant de TERPA et de TSA qui permet aux cliniciens de personnaliser les soins, selon les besoins uniques présentés par chaque patient. Le présent article présente deux cas distincts qui démontrent le recours à TBF + PU pour l'approche du TERPA afin de traiter le TERPA et le TSA comorbides dans un cadre clinique. Le cas 1 démontre l'application et la confiance dans le TBF, tandis que le cas 2 puise aux PU pour faciliter le changement de comportement du patient. Les antécédents des cas, les problèmes présentés et les approches de traitement combinant les deux traitements fondés sur des données probantes sont présentés et discutés. Les cas démontrent les difficultés singulières de traiter de jeunes patients souffrant de TERPA et de TSA comorbides, de même que les avantages proposés d'une approche combinée avec cette population.

Mots clés: *trouble évitant/restrictif de la prise alimentaire, trouble du spectre de l'autisme, traitements fondés sur les données probantes, enfant, adolescent*

Introduction

Avoidant/Restrictive Food Intake Disorder (ARFID) is a Feeding and Eating Disorder diagnosis that was newly added to the *Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition* (DSM-5; American Psychiatric Association, 2013), and was developed to encompass and expand the DSM-IV diagnosis of Eating Disorder Not Otherwise Specified (EDNOS) and Feeding Disorder of Infancy or Early Childhood. Given the recent diagnostic recognition of ARFID, appropriate models of care for this population are still emerging. In addition, there have been no standardized and validated treatments to date for individuals with ARFID, particularly for children and adolescents who have been shown to be susceptible to developing the disorder (e.g., Norris et al., 2014). This has led to an urgent call from researchers in the field for validated models of care for ARFID, and for increased guidance for clinicians in the assessment and treatment of the disorder (Magel et al., 2021).

According to the DSM-5, ARFID is characterized by a lack of interest in food, or an avoidance of particular foods due to aversive sensory characteristics, and/or concern over negative outcomes of eating (e.g., vomiting, choking), resulting in significant weight loss (or failure to achieve expected growth), nutritional deficiency, dependence on oral supplements or enteral feeding, and interference with psychosocial functioning (American Psychiatric Association, 2013). Community-based studies estimate that 3.2% of children and adolescents meet criteria for ARFID (Kurz et al., 2015). Other studies demonstrate a mean prevalence of up to 13.8% for children and adolescents in clinical and hospital settings (Fisher et al., 2014). In addition, research has found high rates of psychiatric comorbidities for individuals with ARFID, ranging from 57% to 95% of patients with ARFID in hospital settings (Bryson et al., 2018; Cooney et al., 2018).

Psychiatric Comorbidities

One common psychiatric comorbidity in individuals with ARFID is autism spectrum disorder (ASD; (Bryant-Waugh et al., 2012). Current estimates suggest that between 3% and 13% of patients with ARFID present with comorbid ASD (Lieberman et al., 2019; Nicely et al., 2014). ASD is a neurodevelopmental disorder characterized by deficits in social communication and interaction, as well as restricted and repetitive interests and behaviours (American Psychiatric Association, 2013). Similar to ARFID, ASD is associated with a variety of comorbid conditions that occur more frequently in this population compared to the general population, including: anxiety (van Steensel et al., 2011; White et al., 2009), gastrointestinal problems (Babinska et al., 2020; Kohane et al., 2012) and feeding/eating difficulties (Sharp et al., 2013). When these vulnerabilities are coupled with ASD features such as sensory sensitivity and a strong preference for sameness and predictability, it is not surprising that people with ASD are also more vulnerable to developing ARFID (Lieberman et al., 2019; Nicely et al., 2014).

Evidence-Based Interventions for Comorbid ASD

For young people with ASD, high intensity interventions have shown better outcomes than low intensity interventions across a range of behavioural domains (Smith & Iadarola, 2015). A systematic review identified 27 focused interventions that meet criteria for being evidence based practices (EBPs) for problematic behaviours in young people with ASD (Wong et al., 2015). Examples include: differential reinforcement (provision of positive/desirable consequences for behaviours or their absence that reduce the occurrence of an undesirable behaviour), functional behavioural analysis (systematic collection of information about an interfering behaviour to identify functional contingencies that support the behaviour), extinction (withdrawal or removal of reinforcers of interfering behaviour to reduce the occurrence of that behaviour), scripting (verbal or written information about a specific skill/situation that serves as a model and is usually practiced in advance) and visual supports (any visual display that supports the learner engaging in a desired behaviour or skills independent of prompts). The EBPs were found to produce outcomes across a variety of skill areas and researchers tended to use multiple EBPs to address a specific goal or skill (Wong et al., 2015), including feeding behaviours (Sarcia, 2020).

In addition, the feeding disorder literature has examined interventions for feeding problems for children with and without ASD and other developmental delays. Evidence supports intensive interventions that have used functional behavioural analysis to target problem behaviours such as: aggressive or disruptive behaviours, difficulties remaining seated, eating slowly, and gaging (Margari et al., 2020). The antecedents and consequences for the behaviour are identified and interventions are designed to reduce reinforcement of the problem behaviours and increase reinforcement of the desired behaviour. The techniques with the most empirical support include rewards, planned ignoring, and reducing the young person's ability to avoid the food (escape extinction) (Sarcia, 2020; Williams et al., 2010).

Novel Interventions to Address a Complex Population

Given the breadth and specificity of symptoms/triggers and the high rates of psychiatric comorbidities (Bryant-Waugh et al., 2012; Norris et al., 2016), the suggested treatment course for ARFID typically addresses both malnutrition and underlying comorbidities which lead to food aversions (Bryant-Waugh, 2013; Kenney et al., 2013). For a subset of ARFID patients with comorbid ASD, treatment course may vary and would require complex solutions for this heterogeneous population (e.g., Eddy et al., 2019). The current therapy model, named Family Based Treatment + the Unified Protocol for ARFID, was developed to combine and modify leading evidence-based treatments such as Family-based Treatment (FBT) and the Unified Protocols for Transdiagnostic Treatment of Emotional Disorders in Children and Adolescents (UP-C/A) for ARFID patients. FBT is the leading evidence-based, manualized treatment for adolescents and children with restrictive eating disorders (Lock et al., 2013). It is a multi-phased treatment aimed at empowering parents to address disordered eating by supporting their child in eating and refeeding to achieve a healthy body weight and independent eating (Lock et al., 2013). In the current therapy model, patients and their parents begin with traditional FBT for sessions 1-4, which includes weighing the patient, raising parental anxiety about the dangers of malnutrition in young people, providing psychoeducation material (specific to ARFID patients and their eating problems), separating the eating problem from the child, charging parents with taking control of their child's eating, beginning discussion of rewards that may be helpful, and a family meal. The remainder of this first portion of treatment focuses on discussing the parental alliance and ways to improve the parent's ability to work together on the task of weight gain and related symptoms (food avoidance, anxieties around eating, etc.). Following these four sessions, if patients are underweight but making progress with their weight gain (i.e., at least 85% expected body weight [EBW]) or are at a normal weight, the UP-C/UP-A modules are introduced. If patients remain too underweight, they continue with FBT sessions until making appropriate progress. Once the UP-C/A is added, sessions continue to remain focused on brainstorming any challenges related to eating/weight gain but can also be personalized to address each patient's specific ARFID symptoms (i.e. fear of trying new foods, vomiting/choking fears, emotion avoidance, disgust responses).

The Unified Protocols for Transdiagnostic Treatment of Emotional Disorders in Children and Adolescents: Therapist Guide (UP-C and UP-A respectively; Ehrenreich-May et al., 2018) is a treatment manual developed in concert with the original Unified Protocol for Transdiagnostic Treatment of Emotional Disorders (UP; Barlow et al., 2010), which provides clinicians with an evidence-based treatment model that brings together core cognitive-behavioural techniques into a single treatment in a modular package that flexibly targets high order factors common to emotional disorders (e.g. high negative affect, low distress tolerance, high avoidance, etc.). The protocols were developed for youth ages 6-18 years and offer patients and families a treatment program that provides skills training in cognitive

Table 1 FBT + UP-C for ARFID session content

Session	Content
FBT Session 1	**Psychoeducation** on ARFID, separating the child from their eating problem, advising parents to take control of their child's eating, discussion of utilizing an effective reward system.
FBT Session 2	**Family meal** where the therapist assesses patient's eating, addresses mealtime behaviours that are impeding success, and works to empower parents in their role to help their child with their eating.
FBT Sessions 3+	For severely underweight patients, additional FBT sessions focus on building the parental alliance and improving parent's ability to work together on weight gain and related symptoms (e.g. food avoidance, anxiety with eating). For normal weight patients or those who are gaining weight appropriately, UP-C session content may begin to be added.
FBT+UP-C Chapter 1: C Skill: Consider How I Feel	Introduces child/parents to the treatment model/structure and describes the **CLUES** skills (**C**onsider how I feel, **L**ook at my thoughts, **U**se detective thinking and problem solving, **E**xperience my feelings, **S**tay healthy and happy), discusses the purpose of emotions/helps build emotional awareness, and identifies three top problems and treatment goals. Top problems should focus on ARFID related goals and may also be more wide-range to address additional emotional avoidance and co-morbid diagnoses.
FBT+UP-C Chapter 2: C Skill: Consider How I Feel	Teaches child to identify and rate intensity of various emotions, normalizes emotional experiences, discusses the three parts of the emotional experience and the cycle of avoidance, explains true/false alarms, identifies rewards for "brave" behaviours, and educates child on how to examines what happens Before, During and After strong emotions.
FBT +UP-C Chapter 3: C Skill: Consider How I Feel	Learn about "acting opposite" concept by using science experiments to help with acting opposite/emotional behaviours, explains the connection between activity level and emotion and assigns emotion and activity tracking as an experiment.
FBT+UP-C Chapter 4: C Skill: Consider How I Feel	Describes the concept of body clues and their relation to strong emotions, learn to identify body clues for different emotions, teaches the skill of body scanning to develop awareness of body clues, helps child experiencing body clues without using avoidance/distraction through the use of interoceptive exposures.
FBT+UP-C Chapter 5: L Skill: Look at my Thoughts	Introduces flexible thinking and teach children to recognize common "thinking trap" characters.
FBT+UP-C Chapter 6: U Skill: Use Detective Thinking and Problem Solving	Introduces a new skill called "detective thinking" to help child think in more flexible ways.
FBT+UP-C Chapter 7: U Skill: Use Detective Thinking and Problem Solving	Introduces problem solving and the use of problem solving for interpersonal conflicts or challenges related to eating.
FBT+UP-C Chapter 8: E Skill: Experience My Emotions	Teaches child about present moment awareness, introduces non-judgmental awareness (especially helpful for a child with strong disgust responses).
FBT+UP-C Chapter 9: E Skill: Experience My Emotions	Reviews skills learned to date in the UP-C, reviews the concepts of emotional behaviours and "acting opposite" in preparation for a new type of science experiment named "exposure," demonstrates an exposure, works together with child/parents to begin developing plans for in-session and in-home exposures.
FBT+UP-C Chapter 10: E Skill: Experience My Emotions	Reviews the use of science experiments to face strong emotions, introduces safety behaviours and subtle avoidance behaviours (e.g., distraction), practices a science experiment to face strong emotions (sample situational emotion exposure), makes plans for future science experiments for facing strong emotions (individualized situational emotion exposures).
FBT+UP-C Chapter 11: E Skill: Experience My Emotions	Plans and executes initial situational emotion exposure in session, plans and executes additional situational emotion exposure activities in future sessions and at home.
FBT+UP-C Chapter 12: S Skill: Stay Healthy and Happy	Reviews Emotion Detective skills learned in the UP-C, plans for facing strong emotions in the future, celebrates treatment progress, creates a plan for sustaining and furthering progress after treatment, distinguishes lapses from relapses, and helps family recognize future warning signs of relapse.
FBT+UP-C Chapters 13-17: Parenting modules	Teaches caregivers each of the skills that were taught in session with their child. Provides an overview of the entire UP-C in a format for parents to practice with their child. Explains the four emotional parenting behaviours that are common when parenting a child with an emotional disorder, as well as "opposite parenting" behaviours, how to reinforce positive behaviours, and monitoring of caregiver's responses Before During and After the child's emotional behaviour.

reappraisal, opposite action, problem-solving, and exposure-based paradigms (see Table 1). Additionally, both the UP-C and UP-A provide materials on core emotional parenting behaviours that are frequently present when treating emotional disorders in youth (i.e. modeling of emotion avoidance, criticism, over-control/over protection, and inconsistency) (Ehrenreich-May et al., in press). A major benefit of the UP-C and UP-A is the flexibility they provide when combined with FBT. Specifically, the treatments allow clinicians to personalize care based on each patient's unique presenting needs, while also utilizing a core set of evidence-based strategies that can benefit patients with a wide array of symptom presentations. Additionally, given the significant heterogeneity and psychiatric comorbidities present in ARFID patients, a transdiagnostic approach may be needed and could especially benefit these patients during their treatment course (Duncombe Lowe et al., 2019).

The UP incorporates many of the evidence-based strategies used in the feeding disorder literature to treat food refusal. Problem behaviours are termed 'emotional behaviours' in the UP-C/A and close attention is paid to the antecedents, function, and reinforcers of these behaviours. When treating young people with ARFID and comorbid ASD, however, it is also helpful to draw upon the focused interventions found to enhance skill development in the ASD group, such that the ARFID intervention is tailored to the specific needs of this population. The following case presentations showcase the use of the targeted FBT+UP for ARFID approach with this complex and heterogeneous population. The first case presented demonstrates the application and reliance more on FBT, while second case draws more greatly on the UP to facilitate behavioural change in the young person. It is our hope that that these two cases illustrate the flexibility of FBT + UP for ARFID when working with children with both ARFID and ASD.

Case 1

Background

The authors received written permission from the parent/guardian and the client for this case to be published. Lauren was six years 10mths old when admitted to hospital for medical instability weighing 21.4kg (BMI 14.49 kg/m^2 94%mBMI based on 50th centile for age), following a 3kg weight loss over 3 weeks (Kuczmarski et al., 2000). She has three siblings, including a twin brother, and lives in an intact family. Lauren has previous diagnoses of ASD level 2 and separation anxiety. Her mother said Lauren historically ate a varied and balanced diet, but always refused foods such as pasta and rice.

Presenting Problems

Approximately 12 months prior to the referral Lauren transitioned to primary school. Over her first year of school her mother noted a gradual reduction in Lauren's food variety and a reluctance to eat at school and in front of peers, however her weight remained stable. At the end of the school year, Lauren drastically reduced her oral intake after a viral throat infection. She reported a fear of food 'getting stuck in her throat' and choking and complained of food tasting 'metallic'. A 3kg weight loss over three weeks resulted in a hospital admission for medical instability. Coinciding with her restricted nutritional intake, Lauren displayed increased sensitivity to the sight and smell of food and aggressive, irritable behaviours. Prior to admission her private paediatrician started her on 0.25mg of Risperidone for her aggressive behaviour. Prior to the outpatient referral for FBT + UP treatment for ARFID, the inpatient medical team prescribed 5mg of fluoxetine to reduce Lauren's fear of choking and promote eating. Her mother said the fluoxetine assisted with reducing Lauren's generalised anxiety, however it had minimal impact on her eating related anxiety and she subsequently required a nasogastric tube (NGT) during the admission to ensure adequate nutrition and weight gain. The NGT was effective in achieving weight restoration during the admission, with her weight increasing to 23kg (BMI 16.47 kg/m^2, 101.7%mBMI based on 50th centile for age) (Kuczmarski et al., 2000) at discharge. Her oral intake of food was still poor. Lauren only tolerated small bites of food and sipped some fluids, resulting in her being discharged with the NGT for nutrition and a referral to the Psychology Service in the local public paediatric hospital for outpatient treatment of her eating behaviour.

Treatment

Treatment Structure and Goals

Due to COVID-19 restrictions on face-to-face appointments, the assessment and first three FBT sessions were conducted face to face in clinic and the remainder were delivered via telehealth. Appointments were initially booked weekly and reduced to fortnightly and every three weeks as treatment progressed. Twenty-four sessions were provided over 8 months; 19 sessions attended by Lauren and her mother and four individual parent sessions. Her father worked full time and was unable to take time off work to attend appointments. In the initial session Lauren and her mother identified three Top Problems (an ideographic assessment tool by [Weisz et al., 2011] modified for use in the UP-C and UP-A by Ehrenreich-May et al. [2017]) they wanted to address during treatment; 1) eat enough to no longer need the NGT, 2) eat a greater variety of foods, 3) take fluoxetine

orally instead of via the NGT. The first two goals were primarily addressed with FBT, while the third was addressed using UP-C. Treatment initially focused on improving her eating behaviour to a point where Lauren was no longer reliant on the NGT. Lauren identified this as the priority, as she was self-conscious about returning to school with the NGT and was very fearful of procedures associated with changing the tube. Her mother was concerned that the NGT reinforced food avoidance and Lauren may become 'reliant' on it for nutrition.

Session No	Treatment Modality
1-8	FBT
9-18	UP-C
20-22	FBT
23-24	UP-C

FBT

The initial session focused on gathering a history of the problem, separating Lauren from her illness and labelling it as ARFID, reducing guilt and blame, raising anxiety and reinforcing the seriousness of the illness, and empowering her mother to take control of meals. The family was encouraged to create a clear structure and routine for meals and to increase the volume of tolerated foods. Unlike FBT for Anorexia Nervosa (AN), the introduction of new foods was delayed and Lauren was involved in identifying the foods she was comfortable eating.

Using rewards to motivate action was also discussed with Lauren and her mother in Session 1. Rewards could be earned for 'brave behaviour', which were associated with tolerating strong emotions or feelings in the body when eating more. Ideas for meaningful and realistic rewards were discussed and a reward plan was developed and reviewed over the course of treatment. The plan varied depending on the difficulty of the behaviour being targeted, but it was largely composed of earning ticks on a 'tick chart' that detailed the specific goal being worked on. Ticks could then be exchanged for a small prize from a prize box, or engaging in a special activity with family members. Clear rules were pre-established for the number of ticks required for different rewards to reduce potential for arguments or negotiation at mealtimes. Once a behaviour was no longer associated with an emotional response, the rewards were either faded out or transferred to the next target behaviour.

Enhancing FBT with the UP-C and ASD Interventions

FBT strategies were enhanced using materials from the UP-C parent modules, as well as evidence-based ASD interventions. Materials from the parenting module (refer to table 1) were used to examine how the parents responded to emotional behaviours and the different ways parents reinforced her behaviour. The 'double before, during and after form' (double BDA) was particularly useful. This form was used to record; 1) what was happening for Lauren *before* an emotional behaviour was observed (e.g. Lauren was hiding in her room and refusing to come to the table for dinner); 2) Lauren's thoughts (e.g. 'I'm not coming!'), body clues (e.g. red face, tense body) and behaviours (e.g. yelling, hiding) *during* the emotional behaviour; and 3) Lauren's short and long term responses *after* the initial response (e.g. short term: family ate without her and Lauren calmed down, longer term: Lauren went to her room and shut door when mother called her for next meal). Parallel to this, her mother recorded the same information regarding her own responses to Lauren's emotional behaviour. These techniques were used to increase the mother's awareness of the connection between her emotional responses and Lauren's emotional responses, as well as how her responses impact on the likelihood of Lauren engaging in emotional behaviours in-session and during meals (e.g. hitting, kicking, shouting, and refusing to sit at the table). Reprimanding and reducing food intake expectations reinforced the emotional behaviours. On the other hand, desired behaviours (remaining at the table, taking one more bite, trying a new food, completing meals) were reinforced by decreasing criticism, increasing consistency, and providing immediate verbal praise. It was helpful to combine reward charts with visual supports that contained mealtimes, food volumes, foods to be eaten, and behaviours being targeted.

Eating Progress

Lauren's oral intake improved rapidly. In consultation with the dietitian, her mother ceased overnight NGT feeds just prior to the family meal in the second week of treatment, however the NGT remained in place for her fluoxetine, which was administered as a soluble tablet dissolved in water. Lauren refused liquid fluoxetine, saying she did not like the taste even when disguised in food and drinks. Oral acceptance of fluoxetine was a high priority for Lauren's mother, as she reported noticing a decrease in Lauren's general anxiety and rigidity following commencement of the medication.

During the family meal, her mother chose foods Lauren had been eating without distress and was guided to provide portions required for maintaining a healthy weight. The session was used to trial different ways of responding to resistance to eat. Similar to the strategies used with FBT for AN, planned ignoring of minor disruptive behaviour (e.g. comment such as 'I'm full' or 'this is gross'), meal supervision, and normalising eating by eating with her and having normal mealtime conversations, was found to be effective.

When Lauren was eating well, she was able to introduce 1-2 new foods a week by identifying foods from a food list that she was willing to eat. Her mother included these foods in multiple meals each day until they were fully incorporated in the diet.

Graphing weight progress and reviewing food intake each week was an important part of treatment. Changes in routine or increased stress on the family was noted to significantly impact Lauren's eating behaviour. This was most notable during the two COVID-19 related 'Stay at Home' orders put in place in her city. Coinciding with the first 'Stay at Home' orders, small overnight NGT feeds were reintroduced for two weeks (after six weeks of treatment) and her fluoxetine was increased to 10mg by her private paediatrician. The family was able to quickly correct her eating by creating a routine of six meals a day, increasing the volume of preferred foods, reintroducing rewards and providing meal support as described above.

UP-C

Once regular eating was established and Lauren was comfortable gradually expanding her food variety, focus shifted from FBT to the UP-C to address the goal of taking fluoxetine orally. Lauren found it very hard to concentrate during telehealth sessions focused on teaching UP-C skills, due to frequent disruptions from siblings who were also learning from home. Sessions with Lauren were limited to 15 minutes and focused on introducing her to the concepts of the three parts of the emotional response, the cycle of avoidance, true and false alarms (noticing whether an emotional reaction is a reasonable or unreasonable response to a situation, e.g. a reasonable response to seeing a really steep hill when riding fast on your bike, may be going more slowly or choosing another path, an unreasonable response to worrying about talking in front of the class would be to stop going to school), opposite action and present-moment awareness. Detailed explanations were then provided to her mother and plans were established for practicing them during the week. A ladder was used to break down the exposure steps and identify a reward for achieving each step. She chose to start by dissolving the medication in a preferred drink and dripping it on the tongue, then gradually increased the amount taken by mouth and reduced the amount placed in the NGT. Exposures were practiced in session and at home daily. Distress was managed by allowing Lauren to move at her own pace, noticing her emotional responses, and present moment awareness techniques. Once Lauren had demonstrated an ability to take 100% of her medication orally without distress it was important to develop a regular routine for taking her medication, by setting a time, providing supervision and making access to her enjoyable after school activities contingent on having taken the medication.

Case 2

Background

The authors received written permission from the parent/guardian and the client for this case to be published. Rachel was 11 years and 5 months old and weighed 33.7kg (BMI 18.1 kg/m^2, 101.6%mBMI based on 50th centile for age (Kuczmarski et al., 2000) at time of assessment. She is the second of three children in an intact family. Rachel had a diagnosis of tuberous sclerosis (TS), mild intellectual disability, autism spectrum disorder (ASD) level 2 and a history of epilepsy surgeries. She was referred to the psychology service for outpatient treatment of eating difficulties as she had been reliant on nasogastric feeds for all fluid and nutrition for the previous eight months.

Presenting Problems

Eight months prior to the outpatient psychology referral, Rachel had an inpatient admission at a general medical ward of her local paediatric hospital following three weeks of reduced oral intake progressing from an insistence on soft foods to only tolerating small sips of water and weight loss (weight 29.3kg, BMI 16.3 kg/m^2 33rd percentile for age). Food refusal was triggered by a sore throat, dental pain and a fear of putting things in her mouth. Rachel was reported to be highly sensitive to procedures and discomfort in her head area, due to her history of epilepsy surgeries. While on the ward, expectations regarding eating were increased, resulting in high distress and total refusal to take anything by mouth, including water. The clinical team diagnosed Avoidant/Restrictive Food Intake Disorder (ARFID), and conceptualised the problem as an anxious avoidance of food. She was commenced on 10mg of fluoxetine while on the ward, which was gradually increased to 30mg, and a nasogastric tube (NGT) was inserted for 100% of her nutrition and fluid intake. She was discharged to the local Child and Adolescent Mental Health Service (CAMHS), who disagreed with the ARFID diagnosis and diagnosed a sensory processing disorder. Her parents were offered support to cope with the situation. The family sought help from a private speech pathologist, who attempted graded exposure, but difficulties engaging Rachel in treatment tasks impacted progress. Considering the length of time the NGT had been in place and the lack of treatment progress, a percutaneous endoscopic gastrostomy (PEG) for nutrition and fluids was being considered by the medical team.

Treatment

Treatment Structure and Goals

Due to COVID-19 restrictions on face-to-face appointments, the first session was conducted in person at the hospital and the remainder were delivered via telehealth. Twenty-nine sessions were offered over approximately seven months. Three parent-only sessions were provided, two with both parents at the start of treatment and another with mother alone when reviewing progress with exposure tasks. The remainder were attended by Rachel and her mother, however time alone with mother was provided on five occasions at the start or end of sessions. Appointments were booked weekly and increased to daily near the end of treatment. Similar to Case 1, Rachel and her parents identified three Top Problems in the first session: 1) Improve her awareness of her emotions. 2) Reduce emotional behaviours and eat and drink enough to remove the NGT.

ASD Interventions

Consistent with the ASD literature (Wong et al., 2015), Rachel benefitted from a session 'script' that she was given prior to the next appointment, making her aware of the session structure, topics, and activities in advance. Deviations from script often resulted in high levels of distress/withdrawal and it was better to highlight a change in structure or activity a week in advance. Visual supports were also heavily relied on to represent session content/plans.

FBT

Rachel was entirely dependent on the NGT for nutrition and was in the healthy weight range at the start of treatment. While FBT was not used to increase the amount of food eaten, sessions 1 & 2 focused on FBT principles, including emphasising the seriousness of the illness and difficulty of recovery, parental empowerment, parental unity, externalisation of the illness, and the importance of actively targeting and changing eating behaviour. These techniques were consistently reviewed over the entire course of treatment.

UP-C

Individual Skills. Considering previous failed attempts at food exposure, content from the UP-C was used to improve Rachel's emotional awareness, develop skills for managing strong emotions, and respond to emotional behaviours that had interfered with therapy in the past such as: crying, hitting, raising her voice, and leaving the room. She was introduced to the three parts of the emotional experience, the cycle of avoidance, behavioural experiments and true and false emotional alarms. Interoceptive exposures (running in place/breath holding), present moment awareness and non-judgemental awareness techniques were used to help her notice and tolerate distress (Boswell et al., 2013; Craske et al., 1997). Rachel appeared to respond very well to identifying 'thinking traps', but found the detective thinking skills too complicated. Instead 'thinking traps' became a useful awareness strategy that helped her to stop and notice thoughts linked to unhelpful emotional behaviours.

Caregiver skills. Caregiver modules of the UP-C were used to examine emotional parenting behaviours, and 'how to reinforce your child'. The 'before, during and after' (BDA) and Double BDA forms were used to examine emotional behaviours at home and in session. Emotional behaviours were reinforced by attempting to rationalise with Rachel and by convincing her to eat, reducing demands, and delaying decision-making. 'Brave' behaviour appeared to be promoted by ignoring minor emotional behaviours, clearly identifying 'brave' behaviours, verbal praise and stickers.

After working through the UP-C modules, distress in session was noted to decrease. Her mother reported that the skills had generalised to other behaviours at home and school, with her mother stating she had noted fewer number of emotional outbursts in these settings. Rachel also showed increased capacity to collaborate with her mother in designing exposure tasks for achieving her third goal of eating and drinking again, which she had been highly resistant to discussing at all. Incorporating the FBT techniques of externalisation and parental empowerment, Rachel and her mother used the Double BDA and behavioural experiments to develop the following strategy when emotional behaviours emerged during exposure planning; Rachel was given five minutes to use her self-regulation strategies and re-engage in the conversation. If she was unable to join the conversation because her anxiety was too strong, she agreed her mother would make the decision for her. This strategy was consistently employed throughout the exposure hierarchy. Prior to employing these techniques, 50 min sessions often ended without a goal being set, due to Rachel becoming distressed and hitting her mother, banging the table, or attempting to turn off the telehealth computer monitor. Consistently using the techniques was associated with shorter session times and completion of more at home exposure tasks between sessions.

Combining FBT + UP-C & ASD Interventions to Promote Eating

The exposure hierarchy was completed using a combination of FBT, UP-C and ASD specific techniques. Exposure started in the first session when parents were empowered to set family rules around mealtimes such as all members participating in setting/clearing the table, being at the table at mealtimes, and being served the same meals. An

exposure hierarchy was developed with the end goal being to put food or drink in Rachel's mouth and swallow. When Rachel attempted exposure tasks and tolerated distress, she was positively reinforced with additional device time (five minutes earned per day, to be used on the weekend) or a football collector card. Non-judgemental awareness techniques from the UP-C were used on the lower levels of the hierarchy to help Rachel experience foods with her five senses. While her confidence with four of her five senses grew and she started cooking with her mother and tolerating food being placed in front of her at the table, she maintained her resistance to bringing the food near her mouth and tasting it, despite the rewards.

Progress was slow with one session a week. As intensive interventions have the best evidence for changing behaviour in ASD populations, including feeding behaviours (Lyra et al., 2017; Sarcia, 2020; Smith & Iadarola, 2015), appointments were scheduled daily for one week and rewards were provided for practicing exposure tasks at least five times a day. At the start of the week, Rachel was drinking 30ml of water from a syringe. By the end of the week, she was drinking lemonade from a glass. Without any further sessions, she and her mother continued designing and implementing exposures five to six times a day, and after two weeks Rachel was no longer reliant on the NGT for fluids. After four weeks of family-designed food exposures she was eating soft foods from all food groups and her NGT was removed.

Discussion

The case studies presented demonstrate the unique challenges of working with young people who present with ASD and ARFID in Eating Disorder Programs and suggest potential benefit from the approaches described. The case studies elucidate the application of FBT and specific UP strategies that were implemented with guidance from ASD literature. Our team demonstrated the application of FBT+UP for ARFID plus ASD and the way in which it appeared to contribute towards improving oral intake/food variety consumed and reducing reliance on NGT feeds. Additionally, based on self-report measures (Top Problem ratings), application of FBT+UP appeared to contribute towards improving anxiety symptoms associated with oral intake for the two young people presented here. We chose two case studies that helped illustrate the flexibility of the FBT-UP model in treating complex and diverse populations. These cases were the initial two referrals to the Psychology service between 2020 with a diagnosis of ARFID and comorbid diagnosis of ASD.

Implementation of FBT principles (Lock & Le Grange, 2014) within the initial stage of treatment (eight sessions with Lauren and two session with Rachel), and then consistently throughout treatment while UP skills were delivered, seemed to enable parents to develop a sense of empowerment and unity, and to maintain a sense of urgency in treating the illness. Additionally, FBT strategies enabled the clinician to consistently and repeatedly externalise the ARFID illness from the young person and focus on preparing the family for the difficulty of recovery through a pragmatic focus on mealtime behaviours that may interfere with change. The flexibility of the FBT+UP for ARFID approach enabled the clinician to be able to return to a focus on FBT principles in the case of Lauren when a major disruption to routine prompted decreased intake.

Evident in both case studies was the importance of the clinician considering the role of behavioural strategies to address the ASD in order to implement FBT+UP for ARFID effectively. In the case of Rachel, scripting, visual aids, identification of interfering behaviours and using differential reinforcement to promote extinction were ASD specific strategies employed by the clinician. In the case of Lauren, the use of visual aids (visual schedule and reward chart) and a strong focus on routine were ASD specific strategies that were found to be associated with increased persistence with meals despite the experience of strong emotions, as observed and reported by Lauren and her mother. Careful examination of behaviours to determine if they were primarily ASD or ARFID driven enabled the clinician to implement appropriate strategies and skills, which in turn appeared to contribute to increased oral intake and reduced reliance on nasogastric tubes.

Rachel's long history of anxiety and a fear of aversive consequences appeared to be driven, in part, by sensory sensitivity as well as a history of difficult surgeries. UP content enabled Rachel to improve emotional awareness and management of strong emotions, complete interoceptive exposures to reduce anxiety sensitivity, understand present moment awareness and non-judgemental awareness for distress tolerance, and identify thinking traps to promote cognitive reappraisal (Eckhardt et al., 2019). As reported by Rachel's mother, improvement was observed in other areas of Rachel's life in relation to her ability to self-regulate in anxiety-provoking situations (reported reduction in emotional outbursts and increased participation in collaborating with her mother in relation to goal setting with meals).

Lauren's sudden fear of aversive consequences after a viral throat infection made her a good candidate for FBT+UP for ARFID. Identification of emotional parenting behaviours,

the three parts of the emotional response, the cycle of avoidance, true and false alarms, opposite action and present moment awareness content enabled Lauren to meet treatment goals. The outcomes of both Rachel and Lauren highlights the strength of the UP as a transdiagnostic model that can be applied to varied presentations and treatment goals. Evident in both case studies was the importance of the clinician using an ASD sensitive approach when teaching and using FBT + UP for ARFID skills and techniques.

Central to the successful treatment of both AS and Lauren was the implementation of exposure hierarchies. As observed in both cases, exposure was observed to be successful when it began within the early stages of treatment and was delivered intensively and persistently. In the case of Rachel, swift symptom reduction was observed after having engaged the family in one week of repeated exposures with the clinician and then continued multiple times a day within the home. Similarly, in the case of Lauren, weekly in-session exposures and daily home-based exposure appeared to result in successful reintroduction of foods and introducing oral medication. Frequency and duration of sessions were intensive, with Rachel receiving 30 sessions of 50 minute duration over a period of six months and Lauren receiving 23 sessions of 50 minute average duration over a period of 8 months, with the number of sessions being consistent with evidence based ED treatments such as cognitive behavioural therapy for adults (e.g., (Fairburn, 2008; Linardon et al., 2017).

The heterogeneous nature of ARFID may present challenges for implementing effective treatment. Evident in these case studies was the need for the clinician to consider the presentation of each young person and apply the FBT+UP for ARFID model to the individual. In both case presentations, there was a prior history of eating well and from a wide variety of foods whereas other clients presenting with a history of limited variety might pose an additional treatment challenge, requiring increased exposure tasks with new foods. Similarly, the authors acknowledge the complexity of the cases presented and that less complex case presentations might require fewer sessions and length of overall treatment.

Currently, there are no published randomised controlled trials for the treatment of ARFID in children and adolescents, though several treatments have been explored in pilot studies, case studies, and treatment manuals (Ehrenreich-May et al., 2018; van Steensel et al., 2011; White et al., 2009). The presented cases demonstrate how an evidence-based treatment for eating disorders (FBT) can be combined with an evidence-based treatment (UP-C/A) for the anxiety underlying problematic eating and mealtime behaviours and adapted to young people with ASD.

Limitations of this paper include the lack of objective outcome measures used in the cases of Rachel and Lauren. Although Rachel and Lauren met their treatment goals and were observed to gain weight, objective measures of anxiety and ARFID symptoms were not used before, during or after treatment. It is difficult to determine the mechanism of change within the FBT-UP for ARFID treatment for either of them. In both cases, FBT+UP for ARFID, with consideration of adaptations for comorbid diagnoses of ASD, and including exposure tasks, appeared to be central to change. However, it is still unclear if FBT or UP implemented as a stand-alone treatment would have brought about similar changes. Fluoxetine was prescribed by an external clinical team and commenced by Rachel and Lauren prior to referral to the Psychology Service and commencing FBT+UP. There is little research examining fluoxetine use in young people diagnosed with ARFID and undertaking FBT, though in a case series (Spettigue et al., 2018) examining Family Based Therapy in six young people with a diagnosis of ARFID (median age 12.9, SD 1.13 years) all six were reported to have commenced medication (fluoxetine $n = 5$, Fluvoxamine $n = 1$, oanzapine $n = 6$) during treatment. Within this case study, it is difficult to determine the effect of fluoxetine on treatment progress and outcomes. Further research is required to better understand the role of medication in the treatment of young people diagnosed with ARFID. An additional limitation worth consideration is that exposure tasks as part of the UP appeared to drive change and treatment success; however, if this focus alone would have been sufficient to bring about change, and if either one of these combinations could produce equal or superior treatment outcomes is unclear.

Future research that focuses on determining the best treatment approach for ARFID according to individual client presentation would be highly beneficial to clinicians. Specifically, research into the effectiveness of FBT+UP treatment modules for various presentations will advance the field. Additionally, research investigating the ways in which ASD treatment strategies could be utilized for young people presenting with ARFID with a comorbid ASD diagnosis is needed.

Conflicts of Interest

Dr. Le Grange receives royalties from Guilford Press and Routledge, and is co-director of the Training Institute for Child and Adolescent Eating Disorders, LLC. The other authors declare no conflict of interest.

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