OPEN ACCESS

Journal of Obesity and Nutritional Disorders

GAVIN PUBLISHERS

Brief Report

Falcoski P and Haris N. J Obes Nutr Disord 05: 142.
DOI: 10.29011/2577-2244.100042

"My Path to Healing" - My Experiences and Current Support Available for Avoidant Restrictive Food Intake Disorder

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Citation: Falcoski P, Haris N (2020) "My Path to Healing" - My Experiences and Current Support Available for Avoidant Restrictive Food Intake Disorder. J Obes Nutr Disord 05: 142. DOI: 10.29011/2577-2244.100042

Received Date: 16 September, 2020; **Accepted Date:** 21 October, 2020; **Published Date:** 27 October, 2020

Accessible Summary

What is known on the Subject?

- The Avoidant Restrictive Food Intake Disorder - ARFID is a diagnosis in the Diagnostic and Statistical Manual of Mental Disorders - DSM-5 [1] but still not widely known to most mental health professionals
- Although severe physical health consequences can be related to the ARFID restrictive eating patterns most Eating Disorder teams are not commissioned to treat ARFID and/or are not familiar with the treatments available
- ARFID is not driven by body and shape concerns

What the paper adds to existing Knowledge?

- Offering a comprehensive personal history of how important is to have the right diagnosis and which treatments are effective
- To create awareness of how common ARFID is, regardless the age, and what professionals should know to better support these individuals

What are the implications for mental health nursing?

- To be able to identify the early signs of ARFID
- To develop specific skills to deal with ARFID, especially those on impatient both Eating Disorder and general mental health settings and/or general hospitals

Relevance Statement

The Avoidant Restrictive Food Intake Disorder - ARFID is a diagnosis in DSM-5 but still not widely known to most mental health professionals. The paper offers a comprehensive personal history of how important is to have the right diagnosis and which treatments are effective to create awareness of how common ARFID is, regardless the age, and what professionals should know to better support these individuals. We hope that with this paper, clinicians will be able to identify the early signs of ARFID and develop specific skills to deal with ARFID, especially those on impatient both Eating Disorder and general mental health settings and/or general hospitals

Keywords: ARFID; Autism spectrum disorder

What is ARFID?

The Avoidant Restrictive Food Intake Disorder - ARFID is a new diagnosis in the DSM-5 although as it was described as "Selective Eating Disorder" previously. ARFID is diagnosed as: An eating or feeding disturbance (e.g., apparent lack of interest in eating or food; avoidance based on the sensory characteristics of food; concern about aversive consequences of eating) as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following:

- Significant weight loss (or failure to achieve expected weight gain or faltering growth in children).
- Significant nutritional deficiency.
- Dependence on enteral feeding or oral nutritional supplements.
- Marked interference with psychosocial functioning.

In ARFID, the disturbance is not better explained by lack of available food or by an associated culturally sanctioned practice; the eating disturbance does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no evidence of a disturbance in the way in which one's body weight or shape is experienced and the eating disturbance is not attributable to a concurrent medical condition or not better explained by another mental disorder. When the eating disturbance occurs in the context of another condition or disorder, the severity of the eating disturbance exceeds that routinely associated with the condition or disorder and warrants additional clinical attention. Previously, individuals have struggled with ARFID for years but just now clinicians and general population have become more aware of it (Since media reports of patients suffering blindness as a result of nutritional deficiencies) and those with ARFID started to seek help.

ARFID presentation can vary, depending on which maintaining mechanism is present. There is an overlap in eating difficulties, sensory sensitivities and behaviour around food of individuals with ARFID, Autism Spectrum Condition (ASC) and Picky eating [2]. This often includes having a list of “Safe or Preferred” foods, being loyal to brands (As they know what to expect from it) and have specific timetable in an almost ritualist way, as explained below:

“I have a fixed list of “Safe Foods” that I eat from repeatedly every day. I have a fixed routine of time that I eat as well as I eat the same thing (Foods) at the Same time each day therefore routine and familiarity is important to be able to trust my food to be safe. I have difficulty with any unfamiliar steps in my routine of preparing a meal, prioritizing a meal or motivation towards eating. Some day’s im very irritable and struggle with my concentration which adds to the difficulties around my meals. I become very anxious about eating other brands I’m not familiar with, an example of this would be my brand of digestive biscuits. The reason is partly because the biscuits of a different brand are unfamiliar to me but also “Unsafe” as the ingredients of a different brand differ to what I’m now familiar with and feel safe to Consume”. Another element to my eating issues is around contamination and germs, particularly around food preparation which includes handling and storing food. For this reason, I have trouble allowing anyone else to prepare or handle my food. I store my food separately where only I have access to it. What adds to all of the above difficulties is that I feel a disconnect to my body, often only realizing I need food when I become hypoglycemic or extremely tired which means I don’t tend to be motivated by the consequences of NOT eating.

Given that I struggle with issues of interceptions and motivation, working out steps to unfamiliar actions in food preparation and even how I interact with the food is all so overwhelming so it’s even more important for this reason that I maintain a fixed time and routine to meal times, this includes familiarity to everything about my food intake from the brand of food I buy, how I store it, how I prepare it, where I prepare it with whom around me and where I eat the food and what time and in which order using which plate and cutlery I use, how I place it in my plate and what pace I eat it.

ARFID and Comorbid

Research has shown that anxiety is a common comorbidity [3-5]. Nicely, et al. [6] found that anxiety is present almost two times more than Anorexia Nervosa and that the fear of choking is also high which is also anxiety-provoking, making even more difficult to try new foods. This fear or “Panic” can be illustrated by:

“When in private I am able to try any new foods or re-introduce any foods I have been avoiding for a while. I also prefer to sit and eat in private especially on days of emotional overwhelm due to my psychological struggle during meal Consumption where on days or times I struggle with this I place food in my mouth with good intention to “Just Eat” the food but Panic that the food is “Unsafe” so chew the food and struggle to swallow the food so I have to spit the food out. On bad days this struggle with chewing and not swallowing could be very hard get through. The thoughts I struggle with during each bite are that food will harm me by either poisoning me or causing some kind of uncontrollable allergic reaction or just harm me in some unknown way. This psychological struggle plays up more on days I am too Anxious and or emotionally overwhelmed where it all becomes too much so I find it easier to avoid food altogether”.

“There are times when during eating I become particularly Sensitive to tastes, textures and smell of food. An example of this is eating something with a hard or Crunchy texture that could result in a Sore tongue, this could then trigger a panic attack. Certain foods can at times taste different Such as buttered toast That can taste too salty, Orange Juice unbelievably Sour and boiled eggs Can Smell too “Eggy” etc... During these kinds of episodes, I have to be mindful of my Sensory Sensitivities and Retry the Same foods at a later time. Previously this was much harder to do as I didn’t have much awareness or understanding of my own deficiencies around my interaction with food”.

Progression of ARFID and the Importance of the Right Diagnosis

The Importance of the Right Diagnosis Is Essential To Have the Best Treatment Possible

“My relationship with food began to get Complicated quite early in my life, my earliest Memory is of when I was 7 years old when I remember avoiding food and not even so much as thinking about it after a distressing emotional situation. I also remember I was unable to tolerate Certain textures, Smells, Colours of food from this age but as it was never recognised or addressed , I find that this has carried into my adult life and compounded with later experiences to become what most professionals label as ARFID (Avoidant restrictive food intake disorder) with Anxiety disorder and Obsessive Compulsive Disorder - OCD. All of this Means I didn’t really realise anything was really wrong with my relationship with food until a lot later on in My adult life. I now am learning how to manage Certain aspects of this distorted relationship with food. I am currently also on a waiting list to be assessed for Aspergers Syndrome also known as high functioning Autism. I am hoping this will be able to help in understanding the connection between my executive dysfunction issues and disconnection with food”

Consequences of ARFID - When Impatient Admission is needed

Each ARFID is different and everyone will present specific symptoms. However, those who may have all the three domains

(Sensitivities around food, aversive consequence of eating and apparent lack of interest around food) are much more complex and usually present with a very low weight, which in turn may be difficult to regain in community and therefore impatient admission might be necessary. These units tend to be Specialist Eating Disorder Units that are most commonly required to treat Anorexia Nervosa with very rigid rules around meal times (i.e. everyone eating in the dining room, timed meals, no eating behaviours, such as separating food) and general meal plans (i.e. menu rota not chosen by the individuals). Therefore, ARFID individuals tend to struggle to “Fit in”. The illnesses, although sharing some similarities (restrictive eating, anxiety around mealtimes, weight loss rigidity, isolation and impact on family and social situations) should be treated in different ways respecting each individual presentation.

One of the most important aspect is to deliver training to staff about ARFID, so they are familiarized with the specificity of such delicate situation, as most of the times, individuals with ARFID are seen as “Picky eaters” and people normally “Don’t get it” why they are not able to “Just eat”. Because they do not present with body and shape concern and tend to eat foods that most people consider “Fast Food” or “Food that anorectics individuals won’t eat”, can be even more confusing to understand and support these patients.

“My real learning about my eating issues came when I was admitted into an eating disorders hospital at an unbelievably low weight at the point where I almost lost my life. During my time there I Soon learned I didn’t have much in common with other people on the ward in terms of my issues with food. If you looked close enough you could see the difference in the presentation of the eating disorder between me and another person diagnosed differently to me, although the outward Symptoms displayed similarly: Low weight, emaciated and malnourished body and appearance. The psychological differences Such as what drives the thoughts and behaviours towards food could only be determined once you Spoke to a person individually or paid attention their eating behaviours during mealtimes. With close observation you could tell who was binging, restricting, avoiding and having difficulty with OCD etc. “My own experience taught me to keep the difference of my eating issues from those around me a secret in fear of being judged, the only ones that knew anything to be different were my Consultant and Councilor during my time at this hospital. An example of some differences was those eating disorders typically associated with body Image and size would Cause the person experiencing the disorder to become highly Competitive Such as with Anorexia & bulimia, this competitiveness Could be experienced around the dinner table when each person was observing the other and often telling on each other or even looking for opportunities to hide food in pockets etc. This was typical of avoiders and restricters. Bingers could be identified by teaming up and taking food from Friends and buddies (Those who were close enough), these people once Caught would be Searched for food every time they Came on to the ward after time away. I just couldn’t relate to any of these behaviours I was just so scared that food would harm me, and also of any change to the routine of my meal, especially if a brand of food was changed for whatever reason or sitting in a different place and different plates and cups used or even a member of staff I didn’t trust much would all cause me high anxiety which wouldn’t be recognised or understood by staff, but if I didn’t comply there were consequences which further added to my anxiety around meal times. my first meal was the hardest, this was also the day I ended up having a argument with the toughest staff member on the ward, Obviously not a great way to start! I Managed without any medication and eventually gained a healthy Body Mass Index -BMI after almost 8 Months of Hospitalisation”.

Transition to Community Services after Impatient Admission

Although ARFID is a diagnosed Eating Disorder, just very few community teams are commissioned to see ARFID individuals. Therefore, getting help can be very difficult especially after an admission.

“After discharge continued care/ aftercare was the hardest to get. Previous rejections for help and my past experiences meant I wouldn’t get the help I expected and needed. To be discharged without a long- term plan of help in the Community Can really set you back and Make recovery or management pretty hard. Hospitalization doesn’t necessarily mean full recovery this is a misconception. Recovery or even long-term management of ARFID take place with the right kind of help and resources as well as a willingness to acknowledge that change has to take place and then have the Courage to face the thing that needs addressing. As you can imagine this can take time and be different for each individual.

Often individuals being treated in hospital settings are not there of their own free will, this results in witnessing many individuals resisting treatment and recovery. This suggests maybe more should be done in Community settings to educate, address and support these issues by early interventions and more awareness in schools and Community settings on how to spot Symptoms early. More also needs to be done in bringing awareness amongst the public and professionals not just in clinical settings but also professionals in the Community like GP’s, teachers about the different types of eating disorders especially ARFID and it’s possible links to Autism spectrum Condition. And in highlighting that each type carries its complications and can ultimately be fatal. It’s just so unfortunate that many communities’ services are not commissioned to treat ARFID”.

Looking for the Future

“I have successfully been able to introduce additional foods to my" Safe foods "list, this has been possible with the help and guidance from the right people not everyone would be as lucky as me to meet. Ultimately, it's change that will take place over time, but I know I have begun my Journey on this long unknown road".

Key Points for Change

- Patient work with a Registered Dietitian to create meal plan based on what they can manage, respecting their presentation
- Structured meals and snacks time, with visual timetable and written meal plan
- so patients know what to expect and anxiety will be lessen
- Patient starts on preferred foods to emphasize calorie intake, and over time with the right treatment they can introduce more variety
- Use behavioural changes and treatments (i.e. Cognitive Behaviour Therapy - CBT, Sequential Oral Sensory Approach to Feeding - SOS…)
- Interoceptive exposure to body sensations
- Exposure therapy + food hierarchy
- Carers and staff education on ARFID
- Individualized care and pathway, including continued care

- "Patient and patient families should also be educated about the eating disorder (Including nutritional educational, behavioural and sensory management too), this is a must, so that they are better able to support themselves and family members in a healthy way during and after in-hospital admission.
- Patients should be discharged with a in information pack which includes a individualized meal plans for up to 6 months and daily food diaries (which include mood and feelings logging as well as what they found challenging and why) that can be shared with therapist and dietitian to continue on as a way of introducing the patient and their families on how to continue with the system of treatment applied during admission, this will ensure continuation in a familiarised system to lessen any anxiety during transitional period once discharged.
- A online forum set up between patients and staff also for patients to support each other in their recovery. This is not just for purposes of support and mentorship but also for both parties to learn from one another about ARFID and also to help manage expectations of both staff and patients. This method of communication and exchange is also very helpful for patients who struggle with social anxiety or have issues around communication such as selective mutism due to Autistic spectrum diagnosis.
- An induction video to be presented on admission and beginning of treatment that answer frequently asked questions also explaining treatment outline and what's expected from treatment. Audio visual instruction is much better than reading on paper especially for anyone on the Autism spectrum and struggling with a diagnosis of Dyslexia, Dyspraxia, Asperger's etc.
- Patients being treated MUST have flexibility of choice with foods and meal plans as there is a vast difference in presentation of anxiety and tactile interaction and difficulties between patients with different foods, it's not always textbook typical.
- Treatment should also involve regular interaction of avoided food in the form of cooking it or eating out if patients are safe to do so and willing. This will help with normalising the experience around food and eating using exposure therapy for sensory issues as a whole around food. (I struggled with the sensory overload of smell, sound, taste and visual appearance each mealtime. Even who is sitting at the table or around me or during cooking can be anxiety provoking as familiarity and safety are key)"

More Information on Current Treatments - What Has Helped Me So Far

- "Regular contact with a dietitian who is not only familiar with eating disorders but also with Autism spectrum disorders where clinical side of things can be monitored such as weight and diet and suggestions of what can be added or tried in diet (private as the NHS will not provide one in my case of ARFID diagnosis).
- Regular sessions with a Councillor who is trauma informed as well as familiar with working with people on the autistic spectrum using Open Dialogue therapy (This encourages and involves family and social community inclusion in patient recovery) to have a regular platform to explore narratives, emotions and feelings around food and also other areas in life that impact our relationship with food.
- Weekly sessions with a Psychotherapist where the foods discussed and chosen with dietitian are then approached using exposure therapy and CBT. I am given regular homework/ tasks to complete each week and get to discuss the challenges around the thoughts and feelings logged in my food diary ... during the week. This has been with the NHS so only has a set number of sessions to teach and equip u with the tools for change to continue practicing on your own once sessions end".
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My Thoughts on Things That Could Help In My Treatment Right Now

- "It could help greatly if all three of the professionals I am currently working with were able to communicate with each other about my case so to make treatment a smoother more efficient and effective process. Currently I am liaising between all 3, who each are aware of each other, so this is ensuring that there is no overlap in treatment in the 3 different areas of treatment provided. This results in a more comprehensive treatment.
- Weekly tasks to accomplish/homework should be set. family and people who are part of my support system should have a way of knowing how they can support me. This speed up recovery or management training as it ensures regular encouragement and monitoring weekly targets are met. As a result, this would boost confidence in my own abilities and will power to try new things. Mealtimes can feel more like an ordeal than a pleasurable experience, so it's important to have someone trusted and informed about my meal plan and tasks to achieve for the week to sit with me for support. They too should be eating to encourage and support a more normalised pattern of meal hygiene".

Conflict of Interest and Funding Statement

The authors declare that there is no conflict of interest and there has been no financial support for this work.

Acknowledgement

I, Nadya, would like to thank the people who have and continue to help me on my journey of recovery. A special thanks to the professionals who treat children and adults with ARFID, helping many other countless lives, who have helped me to recognise my barriers and challenge myself to try new things and who have been supporting me to make sense of the processes of recovery whilst not losing myself. I, Paola, would like to thank Nadya immensely for the courage to share her history and for being strong during her recovery journey.

Author's Contribution

Paola conceived the presented idea. Paola and Nadya developed the narrative and performed the paper.

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