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A living experience proposal for the co-occurring diagnosis of avoidant/restrictive food intake disorder and other eating disorders

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Abstract

The eating and feeding disorder section of the *Diagnostic and Statistical Manual of Mental Disorders 5 Text Revision* (DSM-5-TR) is organized by a diagnostic algorithm that limits the contemporaneous assignment of multiple eating disorder diagnoses. Avoidant/restrictive food intake disorder (ARFID) is a disturbance in food intake typically associated with lack of interest in food, food avoidance based on sensory characteristics, and/or fear of aversive consequences from eating. According to the DSM-5-TR, an ARFID diagnosis cannot be made when weight or shape disturbances are present, and ARFID cannot be co-diagnosed with other eating disorders characterized by these disturbances. However, emerging evidence from both clinical and lived experience contexts suggests that the co-occurrence of ARFID with multiple other types of eating disorders may be problematically invisibilized by this trumping scheme. The diagnostic criteria for ARFID can contribute to inappropriate diagnosis or exclusion from diagnosis due to excessive ambiguity and disqualification based on body image disturbance and other eating disorder pathology, even if unrelated to the food restriction or avoidance. This harmfully limits the ability of diagnostic codes to accurately describe an individual's eating disorder symptomatology, impacting access to specialized and appropriate eating disorder care. Therefore, revision of the DSM-5-TR criteria for ARFID and removal of limitations on the diagnosis of ARFID concurrent to other full-syndrome eating disorders stands to improve identification, diagnosis, and support of the full spectrum of ARFID presentations.

Keywords Avoidant/Restrictive food intake disorder, Lived experience, Co-occurring diagnoses, Body image, Diagnostic algorithm

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Main text

This correspondence presents a living experience critique of the Diagnostic and Statistical Manual of Mental Disorders 5th Edition Text Revision (DSM-5-TR) [1] eating disorder (ED) diagnostic criteria for avoidant/restrictive food intake disorder (ARFID), especially the limitation of co-occurring diagnosis of ARFID with other eating disorders (EDs)[1]Informed by a review of the literature and my own experience of ARFID, I will outline two major critiques of the DSM-5-TR diagnostic algorithm and criteria for ARFID, provide examples of how ARFID can present alongside other EDs, and conclude with recommendations for augmenting the diagnostic criteria to better encompass the full spectrum of ARFID presentations.

As an adult who developed ARFID during the course of and while in treatment for a pre-existing ED, I was able to gain context for the new symptoms I was experiencing primarily through learning about the experiences of other individuals with ARFID in virtual ED support spaces. The categorization of my cognitions and behavioral manifestations as consistent with ARFID has been subsequently validated by ED specialist clinicians. However, when I initially became aware of these symptoms, my communications about them to my clinicians at the time did not result in modification of my treatment, which, while helpful in many ways, did not adequately accommodate and support healing from these co-occurring features of ARFID. I believe the limitations on co-diagnosis of ARFID with other EDs contributed to this delayed recognition, misaligned care, and iatrogenesis, which could have been mitigated without these barriers to accurate diagnosis and treatment.

My living experience perspective is shaped both by the features of my own EDs and the broader social milieus in which I have experienced and contextualized them. While there is no singular or official ARFID or ED "community," through my work and involvement in ED peer support spaces, social media communities, and expert by experience research collaborations over the last several years, I have interfaced with hundreds of other adults living with ARFID and other EDs. Previous research has also affirmed the extent to which an individual's experience of EDs can occur relationally in orientation to peer ED support communities [2, 3], and although I cannot speak for an entire community, my understanding of my own ARFID and my awareness of the spectrum of ARFID presentations and etiologies reflect these shared narratives and connections.

Disclaimer regarding limitations and potential harms of clinical mental health diagnoses

My critiques and recommendations for the DSM-5-TR ARFID diagnostic criteria are based in recognition that many people may be aided in accessing support, community, accommodations, and self-understanding through clinical diagnosis. These critiques and recommendations are intended to help prevent individuals with ARFID from receiving inappropriate diagnoses or going undiagnosed, and may assist clinicians in providing clients with supportive and effective care.

I also understand, respect, and support that many people seek healing outside of clinical systems of diagnosis and treatment, and, as a member of transgender, intersex, and disability communities, I recognize how my own life history and those of my peers have been marked by pathologizing, invasive, and damaging interactions with these systems. The medical and scientific history of ascribing disorder to bodies and minds is intertwined with eugenic and supremacist projects and has frequently functioned in service of fomenting pre-existing social prejudices with supposed scientific justification [4, 5]. While I hope these proposed revisions will aid in improving access to appropriate care and support for individuals with ARFID, I am aware that no proposed amendment to the DSM or clinical interpretation thereof can resolve these systemic problems. I encourage all clinicians and individuals seeking care to proceed with a pragmatic and critical perspective on the derivation of diagnoses and the practice of their assignment.

Critique 1: Subjective assessment of disorder and distress

Criterion A for ARFID in the DSM-5-TR ARFID diagnosis describes the most common profiles associated with ARFID (avoidance or restriction of foods due to sensory distress, fear of aversive consequences from food/eating, or lack of interest in food/eating) and the consequences of this disorder (weight loss or failure to gain weight, nutritional deficiencies, dependence on supplements or enteral feeding, and/or psychosocial distress) [1]. These broad ARFID diagnostic criteria appropriately enable the diagnosis of a range of ARFID presentations; however, recent literature reviews have identified potentially excessive ambiguity in the operationalization of these criteria for assessments of clinical and research samples [6–8]. In their review, which evaluated operational definitions of criterion A within existing ARFID literature, Harshman et al. found 33 different methods used to evaluate ARFID symptomology across 26 articles [7]. While ARFID is known to have highly heterogeneous presentations [9], the use of inconsistent diagnostic parameters means that

[1] This correspondence focuses on the co-occurrence of ARFID with anorexia nervosa, bulimia nervosa, and subtypes of other specified feeding or eating disorder that include weight and shape disturbance such as atypical anorexia nervosa (it is already possible to concurrently diagnose ARFID and binge eating disorder). It does not specifically consider co-occurrence with Pica or Rumination Syndrome, as these diagnoses and their co-occurrences with ARFID fall beyond the scope of this paper.

a substantial percentage of individuals who would meet diagnostic criteria as defined by one research study or clinic would not meet another study or clinic's criteria [7]. These inconsistencies in operational use of ARFID diagnostic criteria can hamper appropriate diagnosis and [6] and impede the development of a rigorous and replicable knowledge base for this under-studied condition [8].

Additionally of note is the wording for criterion A4, which describes "marked interference with psychosocial functioning" [1, p. 376], in contrast to the use of "clinically significant distress or impairment" in the DSM-5-TR criteria for other specified feeding or eating disorder (OSFED), which some have argued should include "sub-threshold" presentations of ARFID [10]. This criterion was noted by Harshman et al. as both one of the most commonly endorsed and one of the most subjectively assessed across the articles they surveyed [7]. While clinicians may infer the implication of distress in criterion A4 as written, defining this criterion as "psychosocial" situates assessments of patient functionality relative to heterogeneous external contexts which may complicate assessments of distress. These contexts may include parental concern about a child's selective eating that results in increased and aversive pressure around food [11], the development of psychosocial strategies which mask but do not eliminate internal distress [12, 13] and inconsistent interpretations of external function and internal distress between clinician assessments and self-reports of ARFID symptoms [7, 8]. Adopting similar language to the OSFED criteria explicitly specifying "clinically significant distress or impairment" in the ARFID diagnostic criteria could increase consistency in assessment of personal impairment across ED diagnoses.

Critique 2: limitation of co-occurring diagnoses and body image disturbance

Body image disturbance and ARFID

The DSM-5-TR requires evaluation of 3 exclusion criteria (B, C, and D) [1] in order to diagnose ARFID, which can helpfully clarify that some individuals meeting at least one of criteria A1-4 do not indeed have ARFID. However, these exclusion criteria as written may prevent some individuals from receiving a clinically appropriate diagnosis which would facilitate better access to care. A recent published case study discusses a patient with ARFID who later developed weight and shape concerns and avoidance of high calorie foods [14]. As this patient no longer met ARFID criterion C, she would not be considered to have "full syndrome" ARFID anymore, and under a non-co-diagnostic schema would be diagnosed with OSFED- atypical anorexia nervosa (AAN) subtype, though her significant fear of choking remained [14]. While some clinicians, including the authors of the case study, provide concurrent treatment for co-occurring ARFID symptoms even when ARFID is algorithmically trumped by another diagnosis [14], others advise treatment approaches "targeted toward the core psychopathology of the relevant ED" [15, p. e40] as distinguished through differential diagnosis, even for patients with co-occurring features of other EDs [15, 16].

The role of body image disturbance in evaluation and diagnosis of ARFID also encompasses further complexities. According to DSM-5-TR criterion C for ARFID, any "evidence of a disturbance in the way in which one's body weight or shape is experienced" will preclude a diagnosis of ARFID [1, p. 376]. While it is important to differentiate ARFID from restriction or avoidance of food driven by a desire for thinness, a recent publication noted that criterion C "…may be a high threshold for diagnosis. Individuals with ARFID are not immune to societal influences of shape/weight and, even individuals without eating disorders express body image concerns" [17, p. 3] High percentages of adults experience some level of body image disturbance [18–21], and existing research has found that women without EDs may endorse unrealistic and detrimental weight goals [22], "disruptions in body image" [23, p. 12], and "body checking and avoidance" behaviors [24, p. 588].

Additionally, body image is increasingly understood as "a multidimensional construct" and common operationalizations of DSM-5-TR body image criteria may be inadequately inclusive [25]. Understandings of excessive preoccupation with perceived weight and shape in criteria for anorexia nervosa (AN), AAN, bulimia nervosa (BN), and Body Dysmorphic Disorder [1, 26, 27] based on a narrowly defined drive for thinness or dysmorphic perceptions of a thin body as being much larger than it is have primarily been evaluated in populations of cisgender women and girls [25]. It is therefore unclear how this criteria should be interpreted in relation to growing recognition of body image as multifaceted [25, 28], with variable manifestations in cisgender boys and men and transgender individuals [29–31], individuals experiencing stigma or bullying for being seen by others as too big, too small, or insufficiently muscular [25, 29, 32–35], or individuals subjected to systemic oppression due to anti-fat bias [33].

Underexplored facets of body image may be particularly significant in ARFID. As ARFID can be highly sensory and often co-occurs with autism and sensory processing differences [36–38], sensory input related to changes in body shape or size may be acutely noticeable and result in substantial distress and disturbance. Although proprioception and interoception are not typically considered part of body image, they play an important role in providing sensory information that contributes to the construction of a person's mental "image" of their body as it relates to its internal and external environments. For

some individuals with ARFID, changes in this proprioceptive and interoceptive "image" due to shifts in weight, bloating, or water retention may be highly distressing and dysregulating and increase food restriction or avoidance to prevent these unpleasant consequences. Understanding the impact of these unique types of body image concerns on individuals with ARFID is important for providing appropriate support and care.

Co-occurrence of ARFID with other eating disorders

Research on ARFID co-occurrence with other ED diagnoses has been limited. While some researchers have argued that ARFID is clinically distinct with minimal crossover to other EDs [39, 40], other researchers have in fact documented crossover from ARFID to other ED diagnoses [41–43]. Observance of crossover rates between ARFID and other EDs may be impacted by research methodology, as some studies may utilize eligibility criteria excluding individuals with body image disturbance from ARFID study populations [11, 44, 45]. Similarly, individuals found to have "crossed over" from ARFID to another ED diagnosis may still have equal ARFID symptomatology before and after their diagnostic transition but would be unable to retain their ARFID diagnosis per the DSM-5-TR [14, 41, 43]. A more comprehensive assessment of co-occurrence and diagnostic crossover for ARFID and other EDs would likely require a more holistic screening methodology de-emphasizing exclusion from ARFID diagnosis based on criterion 3, an approach which has not always been utilized [11, 44, 45].

Lived experience perspectives on ED symptoms and nosology notably differ from the focus on trumping schemes and disqualifying criteria within the DSM-5-TR diagnostic algorithm. Individuals with an ED or disordered eating generally describe and identify their experiences based on the behaviors, cognitions, and disturbances *present* in their lives, rather than based on the *absence* of disqualifying criteria. Operationally, the presence of body image disturbance, binging and purging, and other ED behaviors may exist contemporaneously to and fail to cancel out lack of interest in food, avoidance of food due to sensory characteristics, or fears of aversive consequences [41, 43]. Nor does the presence of non-ARFID ED symptomatology inherently render ARFID symptoms as less severe or prominent relative to these other eating disturbances. For example, an individual who meets full criteria for AN and ARFID criteria A1-4 may be more impaired and face more barriers to recovery due to their inability to tolerate the sensory characteristics of most foods than by their fear of gaining weight.

My experience of developing ARFID during the course of a pre-existing ED was characterized by a growing awareness of new cognitions surrounding food and eating that were clearly different from but did not replace or negate my extant ED cognitions. Previously, I had always liked food and my ED cognitions and behaviors had been identifiably in service of the goals, narrative, and internal logic of the ED. The ARFID cognitions were distinct in that they rendered food itself uninteresting and undesirable, resulting in previously enjoyed foods becoming repulsive in their smell, taste, or texture. A turning point in recognizing these distinct new symptoms was a particular day when I sincerely wanted to be able to eat but could not think of a single food with a tolerable taste and texture. This had never happened before. It took so long to think of a food I could tolerate that by the time I began cooking, I was shaking so much that I accidentally knocked a glass out of the cabinet. The glass shattered, providing a visceral and visual symbol that I was dealing with something new and very wrong. I eventually identified this persistent lack of interest in food and sensory distress as congruent with avoidant and restrictive ARFID. While nutrient deficiency can impact the taste and perception of certain foods [15], my negative sensory responses to previously enjoyed foods and overall lack of interest in food persisted even after nutritional rehabilitation.

Becker et al. also notes these types of concurrent ED presentations, stating, "In our clinical experience, it is not unusual for adolescents who present with frank ARFID to simultaneously report or subsequently develop traditional eating-disorder psychopathology" [14, p. 209]. Expanding the ability to simultaneously diagnose ARFID concurrently with other EDs stands to better facilitate assessment and treatment of these ED presentations.

Examples of co-occurring ARFID and other ED etiology

Multiple trajectories of simultaneous or sequential development of co-occurring ARFID with other EDs have been named in the literature or described by individuals with lived experience. Below are some examples.

Development of AN or AAN in a person with ARFID

Initial development of ARFID due to idiopathic causes, sensory sensitivities, digestive problems, or surgery [46] may result in a negative energy balance, a hypothesized trigger for AN in those with a genetic predisposition [47, 48] and/or social valuation of thinness in a person who loses or fails to gain weight due to ARFID [49] may result in overidentification and overvaluation of this trait, progressing to AN cognitions and behaviors [14]. It has also been hypothesized that gastroesophageal and gastrointestinal conditions early in life may directly contribute to the development of AN as well as ARFID [50].

Treatment of individuals with ARFID in general ED treatment settings where co-patients may be highly focused on weight and body image, competitive and

comparative dynamics between patients may be prevalent, and programming may enforce expectations about (non-ARFID) ED presentations may also contribute to the subsequent development of AN or other ED symptomatology [41].

Development of BED or BN in a person with ARFID

In an individual with ARFID, limited availability of tolerated or preferred foods (even if total availability of food is not restricted) may trigger responsive binging episodes when preferred foods are available [14]. This may result over time in a restrict/binge or restrict/binge-purge cycle.

Development of ARFID due to a traumatic incident in a person with a pre-existing ED

Traumatic incidents related to food and eating (such as choking, vomiting, or an allergic reaction) are a known precipitant of ARFID [9, 51–53]. This type of ARFID onset may also occur in people with pre-existing EDs and would not necessarily result in the spontaneous remission of other ED symptomatology.

Development of ARFID in a person with AN or AAN

Gastroesophageal and gastrointestinal conditions, symptoms, and pain are known risk factors for ARFID [46, 54] and common sequelae of AN [50]. Fear of and desire to avoid these symptoms (which may become worse during or after eating for individuals who are malnourished or undergoing refeeding) may lead to avoidance, aversion, or lack of interest in food distinct from restrictive cognitions and behaviors driven by desire for thinness.

Development of ARFID due to iatrogenic harm in treatment for another ED

For some individuals in ED treatment, protocols which do not accommodate personal dislikes [39, 55, 56], unpalatability of institutional food [57], repeated nasogastric tube insertion [9, 45, 58, 59], punishing physical discomfort due to the physiological healing process and the quantity of food that must be consumed [60, 61, p. 131–133], or the entire experience of mandated eating in treatment [62] may have traumatic effects [58, 63–65]. Given existing evidence that traumatic experiences involving food, pain, and/or medical procedures can precipitate ARFID development [9, 46, 51, 53, 56], it is possible that such experiences may produce long-lasting avoidance, aversion [53], or lack of interest in food for certain individuals. My own experiences of iatrogenic contributions to ARFID etiology are shared in the next section.

Implications for treatment

Access to ED treatment is generally predicated on obtaining a clinical ED diagnosis. While clinicians will ideally holistically consider all behavioral and cognitive symptoms in assigning a diagnosis, many clinicians, including emergency room and primary care doctors who are frequently the first point of contact for individuals with EDs seeking care, have limited knowledge or training in EDs [66–69]. Non-ED-specialist clinicians may be less familiar with the full diagnostic criteria for each ED, more likely to accurately diagnose EDs with more extreme or stereotypical presentations (i.e. white women, very low weight patients), and more variable in how they interpret and apply ARFID criteria [70–72]. This ambiguity and generally low clinician knowledge about non-stereotypical ARFID presentations [72] may reduce access to appropriate diagnosis for individuals with ARFID who have other co-occurring EDs or co-occurring body image disturbance. Some clinicians do treat ARFID symptoms in individuals who do not have an ARFID diagnosis [14] but this type of specialized care is often inaccessible due to geographic, financial, and insurance-related barriers.

Effective treatment modalities for ARFID remain under-explored [73], but some approaches utilized in the treatment of other EDs may be contraindicated [9, 41, 45, 74]. While individualized care has become increasingly recognized as crucial in effective ED treatment, some programs utilize standard AN treatments [45, 75] for individuals which ARFID which may require increases in volume and variety of food simultaneously or provide no accommodations for "disliked" foods in a mandated meal plan [39, 55, 56]. These types of non-individualized protocols may result in increased food aversions [45], negative outcomes such as panic attacks and vomiting [9], and consequences for perceived non-compliance (such as loss of privileges, contingencies, or premature discharge; [57, 62, 76–81] for individuals with ARFID (with or without co-occurring ED diagnoses). Collaborating with ARFID patients or their parents to select tolerated foods from an existing menu to meet target energy needs can be more effective [9] but may not be permitted in facilities that require all patients to consume the same menu [82], have specific rules about food variety [56], or consider menu selection a privilege that has to be earned [83, 84].

Shortly after the onset of my ARFID symptoms, I received treatment from an outpatient dietitian who provided me with a meal plan for nutritional rehabilitation. I was highly motivated to address the unpleasant symptoms caused by my pre-existing ED, and consistently adhered to the meal plan despite considerable physical and psychological challenges. Like many people with avoidant ARFID, the foods that produce sensory distress for me shift over time, and previously tolerated foods may be "dropped"/"lost" and become distressing [85, 86] due to eating them too often, negative associations with stressful events, or undiscernible reasons. Due to the stress of nutritional rehabilitation and the meal plan's specification to consume certain foods daily, I

developed negative sensory responses to yogurt and muffins. I knew if I took a break from eating these foods, they would likely becoming tolerable again within weeks to months. I expressed this to my dietitian, who told me that substitution of other items of equivalent caloric value would be too difficult and directed me to continue with the prescribed meal plan. Because of my considerable motivation to comply with the meal plan, I continued to eat these foods. This exacerbated the negative sensory responses, resulting in involuntarily gagging and spontaneous emesis when eating them. Two years later, I am still unable to eat these foods. In contrast, when working with a different dietitian who better understood and accommodated my co-occurring ARFID, I have been supported in substituting foods that begin to cause negative sensory responses, and as a result, I have subsequently regained the ability to eat them within a few months.

Other components of standard ED treatment may also reduce treatment efficacy for individuals with ARFID if their ARFID is not recognized or if modifications are not allowed. Some facilities utilize enteral feeding through a nasogastric tube supplementary to oral intake or as a consequence for not completing meals or complying with treatment expectations [45, 58]. For some individuals with ARFID, enteral feeding may be highly beneficial [87], while others may experience the insertion and sensory sensations of a nasogastric tube as acutely distressing [9, 45, 59]. In one case study, the authors observed that "prolonged nasogastric tube insertion, multiple hospitalizations, and other iatrogenic harms may have been avoided with the implementation of a patient-centered protocol allowing flexible nutritional choices" [9, p. 10]. This underscores that there is no single gold standard approach for treating ARFID, and that flexibility and responsiveness to each individual's needs and ARFID presentation are crucial.

ARFID patients may also be required to participate in all therapy groups and activities designed for non-ARFID populations, even when some of these activates may not be relevant for some ARFID patients and risk contributing to the development of new ED symptomatology due to mirroring of normalized/peer behavior in treatment milieus [41]. While further studies on treatment approaches for ARFID are needed, existing research indicates that attentiveness to individualized care and appropriate ARFID accommodations, including for individuals with co-occurring diagnoses, may improve outcomes and decrease iatrogenic harm (which has been shown to negatively impact ED recovery, quality of life, and receptiveness to seeking future ED care if necessary [63, 88–101]).

Recommendations

Identification of ARFID in individuals with other co-occurring EDs and/or body image disturbance stands to improve appropriate diagnosis, increase access to support, and reduce harmful, inappropriate, or inadequate treatment. While some ambiguity in diagnostic criteria is necessary to allow for clinical discretion [7], based on my living experience and review of the ARFID literature, I believe several criteria changes can reduce excessive ambiguity and misdiagnosis. I propose the following modifications to the DSM-5-TR criteria for ARFID (F50.82) [1] to be considered for review, consultation, and testing.

Criterion A

For criterion A4, remove "interference with psychosocial function" and replace with "significant distress or impairment in social, occupational, or other important areas of functioning." This will bring the assessment of personal distress due to ARFID symptomology into alignment with considerations of distress in other ED diagnoses. As has been recommended by previous authors [6–8], ongoing research is necessary to develop more precise methods of assessment and operationalization of this criterion.

Criteria B-D

Remove "there is no evidence of a disturbance in the way in which one's body weight or shape is experienced" from criterion C. Include language under "Diagnostic Features," stating that interpretation of criteria B-D must be holistic in the context of overall causes and impacts of avoidant and restrictive behaviors and the possible and non-disqualifying presence of other co-occurring EDs. This could be facilitated by developing more comprehensive and sensitive questions to assess overall food restriction or avoidance/restriction of specific foods in terms of cognitions, motivations, multifaceted body image considerations, and co-occurring symptoms.

Diagnostic algorithm for ED diagnosis

Allow concurrent diagnosis of ARFID with AN, BN, and OSFED subtypes with body image disturbance when there is substantial evidence of the presence of relevant and impactful symptoms that cannot fully be encompassed by a single diagnosis. This should involve comprehensive consideration of current and past ED cognitions and behaviors, timing and causes of symptom onset, evaluation of distress or impairment caused by each type of symptoms, and the option to prioritize the presence of ED-specific symptoms over the absence of disqualifying criteria in determining which diagnosis or diagnoses to assign.

Conclusions

As overall understanding of and treatment for ARFID progress, there is considerable need and opportunity to continue refining its conceptualization and criteria. Adjusting the diagnostic criteria for ARFID and reducing the limitations on co-occurring diagnoses with other EDs stand to substantially improve access to support and quality of life for individuals across the full spectrum of ARFID presentations. This can be facilitated through ongoing research, greater incorporation of lived and living experiences, and increased education for clinicians and the general population about better supporting and accommodating individuals with ARFID.

Abbreviations

AAN	Atypical anorexia nervosa
AN	Anorexia nervosa
ARFID	Avoidant/restrictive food intake disorder
BED	Binge eating disorder
BN	Bulimia nervosa
DSM-5	Diagnostic and Statistical Manual of Mental Health Disorders, fifth edition
DSM-5-TR	Diagnostic and Statistical Manual of Mental Health Disorders, fifth edition, text revision
ED	Eating disorder
EDs	Eating disorders
OSFED	Other specified feeding or eating disorder

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Competing interests

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