Knedgen and Starr
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A tradeoff between safety and freedom: Adults' lived experiences of ARFID

Megan M. Knedgen[1,2*] and Rachel A. Starr[3]

Abstract

Background Avoidant restrictive food intake disorder (ARFID) is characterized as a pattern of restrictive eating leading to significant medical and/or psychosocial impairment (American Psychiatric Association in Diagnostic and statistical manual of mental disorders, American Psychiatric Association, Washington, D.C., 2013). Most existing research on ARFID utilizes quantitative methodologies to study children and adolescents. As a result, the experiences of adults with ARFID have been underrepresented in research. To fill this gap, the current study examines the lived experiences of adults with a DSM-5 diagnosis of ARFID.

Method Participants (n = 9) included adult women aged 20–42 (M = 27, SD = 6.2) recruited from social media advertising. Open-ended, semi-structured interviews were conducted. Data were analyzed using interpretative phenomenological analysis (IPA).

Results One of three overarching themes identified by IPA will be discussed in this study: "A tradeoff between safety and freedom," which consists of two subthemes: (a) Ensuring safety from food unknowns and (c) Longing for Freedom. This overarching theme explores the influence of ARFID on an individual's sense of safety and freedom.

Discussion This study is one of few to qualitatively examine ARFID, and the only to do so using IPA. Findings offer novel insights relevant to researchers and clinicians who treat adults with ARFID and who wish to increase consideration and understanding of patient lived experience in their work.

Plain English Summary

Avoidant Restrictive Food Intake Disorder (ARFID) is an eating disorder (ED) with serious medical and psychological consequences. There is little research that tries to understand the experiences of people with ARFID. We carried out a qualitative study on adults with ARFID to improve our understanding.

We interviewed 9 adult women with ARFID who we recruited from social media. We asked them open questions meant to get them to reflect and share about what it is like for them to live with ARFID. We then looked at the transcripts from these interviews and identified major topics (or themes) that were talked about the most. This study examines 1 of the 3 total themes that we found. This theme is about how food restriction makes participants feel safe but also limits their freedom to go places and do things. Participants are caught between an impossible choice between safety and freedom.

Overall, this study improves our understanding of what it is like to live with ARFID as an adult. All participants had difficulty tolerating uncertainty, something that people with other psychiatric disorders also experience. Therefore,

*Correspondence:
Megan M. Knedgen
mknedgen@antioch.edu
Full list of author information is available at the end of the article

general treatments that target core issues (like intolerance of uncertainty) may help people with ARFID, people with other psychiatric conditions, or people with both ARFID and other psychiatric conditions.

This study also offers insights about the thoughts and feelings of people with ARFID which is new and unique. Qualitative research tends to form a baseline understanding of new or underexplored topics, and so findings from this study can contribute to the development of new assessment measures that ask people what they are thinking and feeling to help diagnosis them and eventually treat them.

Lastly, this study helps clinicians and researchers to better understand people with ARFID and what they may be experiencing. This can lead to better outcomes for people with ARIFD.

Keywords Avoidant restrictive food intake disorder, Interpretative phenomenological analysis, Adults, DSM-5, Qualitative research

Introduction

Avoidant Restrictive Food Intake Disorder (ARFID), introduced in the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; [3]), is characterized as a pattern of restrictive eating leading to significant medical and/or psychosocial impairment. Individuals with ARFID typically adhere to a diet lacking in adequate volume and/or variety, which can lead to malnutrition, low weight, growth faltering, nutritional deficiencies, supplement and/or enteral feeding dependence, and psychosocial impairment [3]. Distinct from classical eating disorders (EDs) such as anorexia nervosa or bulimia nervosa, body image and/or weight concerns do not underlie restrictive eating in ARFID.

Prior to DSM-5 publication, the DSM-IV diagnosis of *Feeding Disorder of Infancy or Early Childhood* included diagnostic criteria that captured avoidant/restrictive eaters [4]. However, this diagnosis was conditioned on onset prior to age six; as a result, there is a historical lack of empirical research among a wide range of individuals struggling with clinically significant avoidant/restrictive eating with adolescent or adult onset. Due to lack of large-scale epidemiological studies, it is unclear if ARFID is more prevalent among children compared to other EDs, as some existing research suggests [9, 14, 21, 30], or if older cohorts are simply underrepresented in research. Indeed, existing research is predominantly focused on pediatric populations [33], as reflected by a current lack of validated assessment measures and evidence-based interventions for adults with ARFID [11, 31].

The few studies exploring ARFID in adults have indicated the presence of high anxiety symptoms [20], impaired quality of life [20], and suicidal ideation [26]. Fitzgerald and Frankum [13] advocated for better understanding of ARFID in adults, particularly as differences between child and adult populations have been observed with respect to demographic, physical and psychological presentation. These differences potentially necessitate different approaches to assessment and treatment [22, 35].

When a phenomenon appears complex or is new or under-explored (as is the case in adult ARFID), qualitative research can offer an important avenue to further understanding [2, 12]. However, the limited qualitative research that exists on ARFID includes mixed samples across different age groups, roles (carers, clinicians and patients) and EDs (e.g., [1, 25]). To date, limited qualitative research has examined how adults with ARFID describe their experience. Interpretative Phenomenological Analysis (IPA; [28]) is a qualitative methodology that focuses study on individual people through detailed, in-depth, case-by-cases analysis. It is also an inductive approach allowing researchers to explore, clarify, expand, and contextualize experiences and meaning-making, unrestricted by the potential impedance of a priori understandings. Fox et al. [15] used IPA to explore self-identified adult picky eaters without a formal diagnosis of ARFID. IPA allowed the authors to develop a nuanced account of the meaning of 'safe foods' for their participants, revealing a range of determinants that arguably could not have been identified using predefined measures.

To begin to address the gaps which limit comprehensive understanding of ARFID, this study employed IPA to investigate the experiences of adults with ARFID with the aim of adding their voices and sense making to understandings of the condition. It is hoped that the findings will help develop a more comprehensive account of ARFID and in turn inform a potential range of clinical assessments and interventions that directly impact diagnosed adults.

Method

Design

This study used semi-structured interviews to explore the lived experiences of adults with ARFID. In IPA, capturing lived experience is achieved by using a *double hermeneutic*, an interpretive process in which the researcher attempts to make sense of the subject's attempt to make sense of their experiences [28]. As such, no claim is made

to objectivity, as would be associated with experimentation. Instead, subjective understanding is considered inherently part of how researchers and participants make sense of the world. According to Smith et al. [28], interpretation is crucial to move beyond description and provide new insights to a phenomenon.

Participants and procedure

This study included nine adult women aged 20–42 (M = 27, SD = 6.2) from various geographical locations across the United States, consistent with the IPA requirement for a small homogenous sample to allow for in-depth, case-by-case analysis. This sample size is also aligned with the recommendation of Turpin et al. [34] and is commensurate with published IPA research on EDs (e.g., [16, 29]). Inclusion criteria were: age 18 or above, DSM-5 diagnosis of ARFID, fluent in English, and past and/or current experience with treatment for ARFID. Criteria included individuals who had sought treatment at any time point due to a higher likelihood of having an ARFID diagnosis and viewing ARFID as personally impactful. This study was approved by the local Institutional Review Board. No incentives were offered to participants and there were no consequences for declining participation.

To obtain a homogenous sample required for IPA, participants were purposefully recruited through social media groups (i.e., Facebook, Reddit) for individuals with ARFID and their supporters. All responders identified as women, which may be an artifact of the proportion of women who subscribe to ARFID-focused social media groups. In keeping with the homogeneity requirement in IPA, additional male participants were not sought. Prospective participants contacted the researcher via email to schedule a brief pre-screening call where the first author collected demographic data including age and gender, confirmed inclusion criteria, and answered questions related to the study. Subsequently, eligible individuals provided written informed consent to the study prior to scheduling an interview. Participants provided additional verbal consent to audio and visual recording prior to each interview. Finally, participants were offered the opportunity to select a pseudonym to maintain both their privacy and the personability of extracts. Some participants selected their own pseudonym while others indicated no preference and were thus assigned a pseudonym by the researcher. These pseudonyms are used throughout this paper.

Semi-structured interviews ranging from 40 min to 1 h were conducted virtually through a teleconferencing platform (i.e., Zoom), and were recorded and transcribed verbatim. The interview schedule was developed based on Smith et al. [28] and piloted by the research team. Open non-directive questions covered areas such as the nature and impact of participant's eating behavior, with prompts used only as necessary. Upon completing the interview, participants were offered a handout with mental health resources.

Data analysis

Transcripts were analyzed using IPA following the 7-step guide by Smith et al. [28]. Each transcript was analyzed individually and independently. This involved first reading the transcripts several times (step 1) and recording exploratory notes concerning early impressions, areas of interest, use of language, suggested meanings and potentially important passages (step 2). Notes were then condensed into experiential statements that summarized meaningful aspects of the text (step 3). The experiential statements for the whole transcript were then studied for patterns and connections (step 4). Statements were gradually clustered and condensed into groups that were named according to the experiential concepts they represented to form a structure of personal experiential themes, or PETs (step 5). Once this had been completed for all cases (step 6), it was possible to compare across PETs and explore connections and patterns at a group level. These group level clusters came to represent group experiential themes, otherwise known as GETs (step 7).

The importance of evaluating qualitative research using appropriate criteria, distinct from the measures typically applied to quantitative work, is well documented [5, 36]. Accordingly, we evaluated this work against validity criteria developed for IPA as described in Smith [27] (Table 1), and additional recent criteria [23, 28]. The first author conducted the analysis with feedback and sense-checking provided by the second author to facilitate reflexivity, another quality marker of IPA [23].

Results

Three GETs and their subthemes were developed during analysis. In keeping with Smith's [27] recommendation that it is preferable to present fewer themes in depth versus "all themes... superficially" (p. 24), one GET is highlighted in this paper (Table 2). This GET, "A tradeoff between safety and freedom," consists of two subthemes: (a) Ensuring safety from food unknowns and (b) Longing for freedom. This GET is highlighted because it evokes aspects of autonomy less likely to be expressed by the pediatric participants who have informed much previous ARFID research and has therefore has value in describing and distinguishing adult ARFID experiences.

Subtheme 1. Ensuring safety from food unknowns

This subtheme illustrates how uncertain or unknown food is perceived by participants as a visceral threat of

Table 1 Evaluative criteria for IPA (summarized from [27], p. 10)

Criterion	Examples in this research
The paper should have a clear focus	The research concerns ARFID and the experiences of adults specifically
The paper will have strong data	The data included consists of verbatim extracts that include detailed descriptions of cognitions and emotions associated with ARFID
The paper should be rigorous	The GET is well evidenced with extracts from all participants, demonstrating this theme represents the group. We provide a transparent account of the analytic process (Method)
Sufficient space must be given to the elaboration of each theme	The focus on a single GET allows for in-depth presentation of the theme
The analysis should be interpretative not just descriptive	In *Ensuring Safety from Food Unknowns*, we offer interpretations of the fear and disgust associated with novel foods and the extent to which these feelings transcend eating behaviors
The analysis should be pointing to both convergence and divergence	In *Longing for Freedom* we explore diverging forms of control (physical, mental) as well as convergence between participants such as the sense of threat associated with lack of control

Table 2 Summary of group experiential theme 1 (GET)

Theme	Subtheme	Participant' pseudonyms
A tradeoff between safety and freedom	Ensuring safety from food unknowns	Fiona, Reagan, Shannon, Quinn, Elizabeth, Janice, Grace, Holly, Spencer
	Longing for freedom	Fiona, Reagan, Shannon, Quinn, Elizabeth, Janice, Grace, Holly, Spencer

bodily harm. Elizabeth conveys what it was like to face food unknowns:

> *it's super scary not being able to see what I'm gonna eat. Like, that's that's the thing with Gushers. I hate biting into it, and then like liquid comes—ugh—so gross. Hate that. Even though I love fruit snacks. Um. So, I think like, um, not being able to see things is super scary and like not knowing what's in it all—like, what's in everything. And I think that's what's scary about like, um, casseroles or anything like that where there's like lots of things hidden on the inside.*

Elizabeth's experience of unknown or mysterious foods is conveyed through her dramatic and evocative language. Her feeling of "hate" for liquid-filled gushers[1] despite her overall "love" of fruit snacks conveys the powerful emotional impact of being surprised by "hidden" aspects of food. Elizabeth's use of the terms "gross" and "scary" conjures images of the gristly and grotesque lurking beneath the surface of casseroles or hidden in the center of chewy fruit snacks. For Elizabeth, to be afraid involves "not being able to see things" and "not knowing." Janice echoed Elizabeth's fear of the unknown or unexpected:

> *my brain just like saying like you don't know what that will do to you. Uh. It will make you gag. You'll embarrass yourself. Um. It won't taste right. Um. And I think a lot of it is a survival thing…everyone has, like, has parts of that in them. Like, if they see a piece of rotting food, they're not going to eat it. But I see everything as rotting food.*

Janice seems to view her emotional responses to food unknowns as a biologically ingrained means of "survival." Her reference to rotting food is reminiscent of Elizabeth's mention of the plague; both analogies depict the disgust participants experience.

To ensure their safety, most participants control their eating environment as well as the amount and kind of food they consume. Shannon shares how she exerts control to keep safe from having an allergic reaction:

> *what if I have this and I'm home by myself and this allergic reaction happens. So, when I—I'm trying something—if I try something new there, when I'm trying it out to practice it here a few times, I always make sure like my husband is home, or like my mom's 5 minutes away.*

[1] Gushers are a soft chewy fruit snack with a liquorice like exterior and a liquid juice center.

Shannon controls her eating environment by assuring she is not alone while trying new foods. This seems to provide her with a sense of safety from the risks of having an adverse reaction with no one present to help. Like Shannon, Holly is concerned with bodily threats which she attempts to mitigate by controlling her environment. She was particularly fearful after learning she has a genetic mutation that predisposes her to cancer:

> *I like to control my environment. It was the perfect storm for me to suddenly just become afraid of food. Like my motivation at this point is—I was not like, you know, wanting to lose weight? I wasn't hating on my body. I'd had those things. I just was like, afraid to eat. Will this give me cancer? Will I develop an allergic reaction? Is this going to make me throw up? And intuitively… I knew that, like most of the foods I eat, I eat a lot of like—or I did eat a lot of like beans and vegetables and dried fruits and wholegrains and all these things that like, can it be protective at least against spontaneous cancers?*

In this passage, Holly describes controlling her environment amidst a host of eating unknowns, particularly as they relate to potential bodily harm. The threat of the unexpected is emphasized by her use of the words "suddenly" and "spontaneously." Similarly, her reference to a "perfect storm" can be interpreted as an analogy for both her felt sense of chaos and for the way chaos manifested-through a powerful combination of life events, including a previously reported history of mental health concerns and medical risk factors, that make for an especially bad situation. This stormy instability appears intensified by the conflicting risks and unknowns involved in eating as Holly struggles to untangle her fears of food from what she "intuitively" feels will protect her health. Holly's preference for controlling her environment "I like to," is expressed with a simplicity that starkly contrasts with the sense of chaos she otherwise feels.

Spencer provides a similar account of confusion and contradiction when describing the arbitrary way she has come to regard some foods as safe and others not:

> *no like rhyme or reason ever for my safe foods. It's like my brain just picks them, and then I keep them. And then, like I always have three safe foods, and if I get a new safe food, then one of them gets kicked off the list, like I always have three.*

In this passage, Spencer highlights how she feels as though she lacks full control over her eating. Her use of the phrase "[no] rhyme or reason" explicitly exemplifies the same sense of chaos and lack of control conveyed by Holly. Furthermore, Spencer uses a passive voice when describing her role in how safe foods are selected, including "if I get a new safe food" rather than *when I choose* one, which further emphasizes a lack of agency in relation to food and eating. Whereas Shannon and Holly describe physically controlling their environments, Spencer's systematic selection and rotation of food in her diet suggests a very controlled mental environment; a list which always consists of three items. These rules appear to help Spencer assert, or at least partially retain, some control over her eating experience.

Participants describe feeling disgusted and/or afraid of uncertain or unknown foods. In contrast, familiar or previously eaten foods provide participants with a sense of safety and security as their properties and effects are known and certain. Although the means of control and degree of felt agency varies, participants commonly acknowledged the role of control in responding to their fears. Through efforts to control, they can feel safe from the potential negative consequences of eating.

Subtheme 2. Longing for freedom

In addition to their attempts to exert control in response to feared unknowns of eating, participants describe the significance of the known. Staying within the realm of the familiar is experienced as simultaneously safe and limiting. Avoidance of threat could also involve a loss of freedom. Reagan discusses restrictions in the domain of social life:

> *New—new events that are circled around food are very difficult—networking, conferences, um. Banned. It's definitely been a stressor in my life, and it definitely prevents me from, er, being able to um, socialize as I normally would because I'm very on edge.*

In this passage, Reagan expresses feeling restricted from participating in social events. Her abrupt use of the term "banned" is absolute and punitive. This social restriction is certain (i.e., "definitely"), persistent (i.e., "in my life") and acutely felt (i.e., "on edge").

Fiona also discusses the impact of her restricted diet on her ability to go places and socialize:

> *It's also affected my ability to travel, and you know, my partner and I really enjoy traveling and we've had to cancel a few trips.*

Like Reagan, Fiona voices a sense of social restriction caused by her eating because she finds herself unable to share certain experiences, like taking trips, with her partner. Fiona also conveys a sense of physical confinement that is devoid of pleasure, as her ability to "enjoy" travel is being restricted by her eating. Shannon echoed the same sense of physical confinement:

your world gets smaller when you don't want to like go out and eat, and you don't wanna do like, anything social. Um. So, I just like, I was getting very frustrated and then I think like…I'm gonna be stuck in this house, like forever kind of feeling.

Shannon conveys her feeling of being captive in her home and isolated from others. Her reference to being "stuck" in a house conjures images of being isolated in a prison. Further, her use of the word "forever" suggests the perpetual nature of her sense of entrapment and separation from others who "go out" into the world. Shannon's frustration with her current situation suggests she longs for the ability to "go out and eat" with others. Presumably, Shannon's world is not literally getting smaller; instead, her words can be interpreted figuratively as a representation of how her sense of personal autonomy is limited by her restricted diet. The restriction she experiences seems to extend to all aspects of her life as evidenced by her reference to its impact on her entire "world."

Quinn reflects on her ability to access preferred foods at the grocery store due to supply chain shortages:

I was really scared about like, what was gonna happen if those foods aren't on the shelf. Like, it's not like I can just pick another option… not like—someone else who goes to the grocery store and like, they're out of one thing and they can just pick out another.

In this passage, Quinn appears to have a fixed idea of how freely other people shop and choose food. Comparing herself to others seems to highlight her lack of freedom to choose foods and exacerbates her sense of entrapment. Quinn's description of limited options at the grocery store seems to relate to Shannon's world getting smaller. Both accounts involve dwindling resources as personal autonomy becomes more restricted. Given this restriction, most participants, including Grace, express a desire to have more freedom in their lives:

raw chicken is like a big fear of mine. Um. But it's like, the only meat I eat, so it's hard because I've never like - I can't really cook chicken without being like terrified that I'm not gonna like, cook it correctly, and I'm gonna get sick. So that's kinda hard because I would love to make different types of chicken for dinner all the time.

In this passage, Grace conveys her desire for the freedom to prepare different types of foods. Elizabeth similarity shares her dream involving freedom to order at restaurants:

I want to be able to go to a restaurant and order something off the menu and not have to change anything about it. I just want to say can I get this and then like that's it. Like, it—that's like, it's just—that's like a dream.

Both Grace and Elizabeth both seem to desire what is most difficult for them to do. They appear to equate the ability to engage in acts such as food preparation and ordering from a restaurant with being free.

In sum, participants often feel threatened by food unknowns and tend to control their mental and physical environments to keep themselves safe. Although participants avoid the threat of harm, they feel restricted in their social life and personal autonomy. They must then confront a "tradeoff" between feeling safe or feeling free, as the price of one often comes at the cost of the other.

Discussion

The GET "A tradeoff between safety and freedom" describes how participants ascribe importance to both safety and freedom, and the dilemma of sacrificing one in pursuit of the other. This study inductively explored the experience of ARFID from an adult perspective and was not grounded in existing theory about the underlying mechanisms of ARFID. Interestingly, however, the results generated through this process align with some of the proposed mechanisms for ARFID. For example, Shannon and Holly conveyed their fear of bodily harm, such as illness or allergic reaction, resulting from consumption of unknown or mysterious foods. Indeed, food avoidance due to a fear of negative consequences is one of the three prototypical presentations of ARFID identified by Thomas et al. [32]. Likewise, Elizabeth and Jancie conveyed surprise and disgust resulting from the sensory characteristics of unknown or mysterious foods. This is consistent with another known mechanism of ARFID, food avoidance due to sensory sensitivity [32]. A third ARFID mechanism, food avoidance due to lack of interest in eating [32], was not represented in this participant sample. This may be due to factors unique to the adult ARFID experience. While this sample considered only adult women, future work of this type involving men or older adults, could help extend the knowledge base without sacrificing experiential detail. Finally, all participants in this study emphasized a loss of freedom, specifically in their personal autonomy and/or ability to participate in social life.

The tradeoff discussed by participants as a component of their ARFID is surprisingly intuitive. The apparent underlying psychological process of ARFID (i.e., tradeoff) experienced by participants in this study appears to align with widely recognized human instincts for self-preservation and free will. These processes may become

pathological for anyone given the right combination of events, otherwise described by Holly as a "perfect storm." Indeed, participants' experiences of ARFID in this study parallel those seen in other EDs and psychiatric conditions. Despite differing emotions and feared or expected outcomes, all participants expressed a similar intolerance of uncertainty. This process has been identified as a characteristic feature of other psychiatric conditions, including anxiety and obsessive–compulsive disorders [6] and anorexia nervosa [7]. Since these processes appear to underlie other related or comorbid conditions, a unified approach may be indicated. Transdiagnostic treatments offer universal approaches to address a wide range of mental health conditions, facilitating dissemination and clinical application of core therapeutic elements [10]. Targeting transdiagnostic processes may increase treatment access for this undertreated population. Future research could examine whether intolerance of uncertainty is similarly and significantly endorsed as a transdiagnostic process across different ARFID presentations.

This study is one of few to qualitatively examine adults with ARFID, and the only published IPA study on this topic to date. Peer validation is recommended over member checking in IPA, due to amalgamation of accounts, interpretation by the researcher, and the passage of time [19, Chapter 8]. Therefore, this study utilized peer validation with fellow researchers and adherence to principles outlined in Table 1 to establish validity. Although findings have limited generalizability due to both the inherent nature of IPA and a homogenous sample consisting of only self-identified women, the loss of ability to project summarized findings to a larger population is countered by potential to gain deep understanding of how participants make meaning of their experience and to uncover previously unknown aspects of a phenomenon. Indeed, due to its value in generating new understandings, qualitative findings have historically proven useful as a first stage in developing self-report measures [18, 24]. All existing ARFID measures focus on characterizing the nature of food restriction [8, 17, 37]. As a result, existing measures may not accurately discriminate between ARFID and other EDs or capture symptom change from session to session. Themes generated from this study and future qualitative work could form the basis of factors measuring cognitions, emotions, and domains of psychosocial impairment associated with ARFID, which have yet to be developed.

In conclusion, the "tradeoff" experienced by participants in this study offers insights about the emotions and cognitions experienced by adults with ARFID. This preliminary information on the adult ARFID experience may be expanded upon in future work, particularly through the development of novel assessment measures and unified treatment approaches ultimately to better serve adults with ARFID.

Author contributions

MK contributed to conceptualization, data curation, formal analysis, investigation, methodology, validation, writing the original draft and editing and revisions. RS contributed to formal analysis, validation, writing the original draft and editing and revisions. Both authors reviewed the manuscript and approve the submission in its current form.

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Availability of data and materials

De-identified data that support the findings of this study are available from the corresponding author upon reasonable request.

Declarations

Ethical approval and consent to participate

This research was approved by the Antioch University Seattle Institutional Review Board. All participants provided verbal and written consent to participate.

Competing interests

The authors declare no competing interests.

Author details

[1]Department of Psychology, Antioch University Seattle, Seattle, WA, USA. [2]Department of Child and Adolescent Psychiatry and Behavioral Sciences, Children's Hospital of Philadelphia, Philadelphia, PA, USA. [3]Department of Psychological Sciences, Birkbeck, University of London, London, UK.

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