AVOIDANT/RESTRICTIVE FOOD INTAKE DISORDER

ARFID

OVERVIEW OF CURRENT RESEARCH

Dr Hannah Kennedy, Department of Psychological Medicine, University of Otago -Christchurch

Jomine Ayers - Mother of two boys with ARFID

WHO AM I?

PostDoc (cancer genetics)

2009

BSc (Genetics)

2017

PhD (Pathology)

Eating Disorders

2019

2020

ARFID

Now

WHAT IS ARFID?

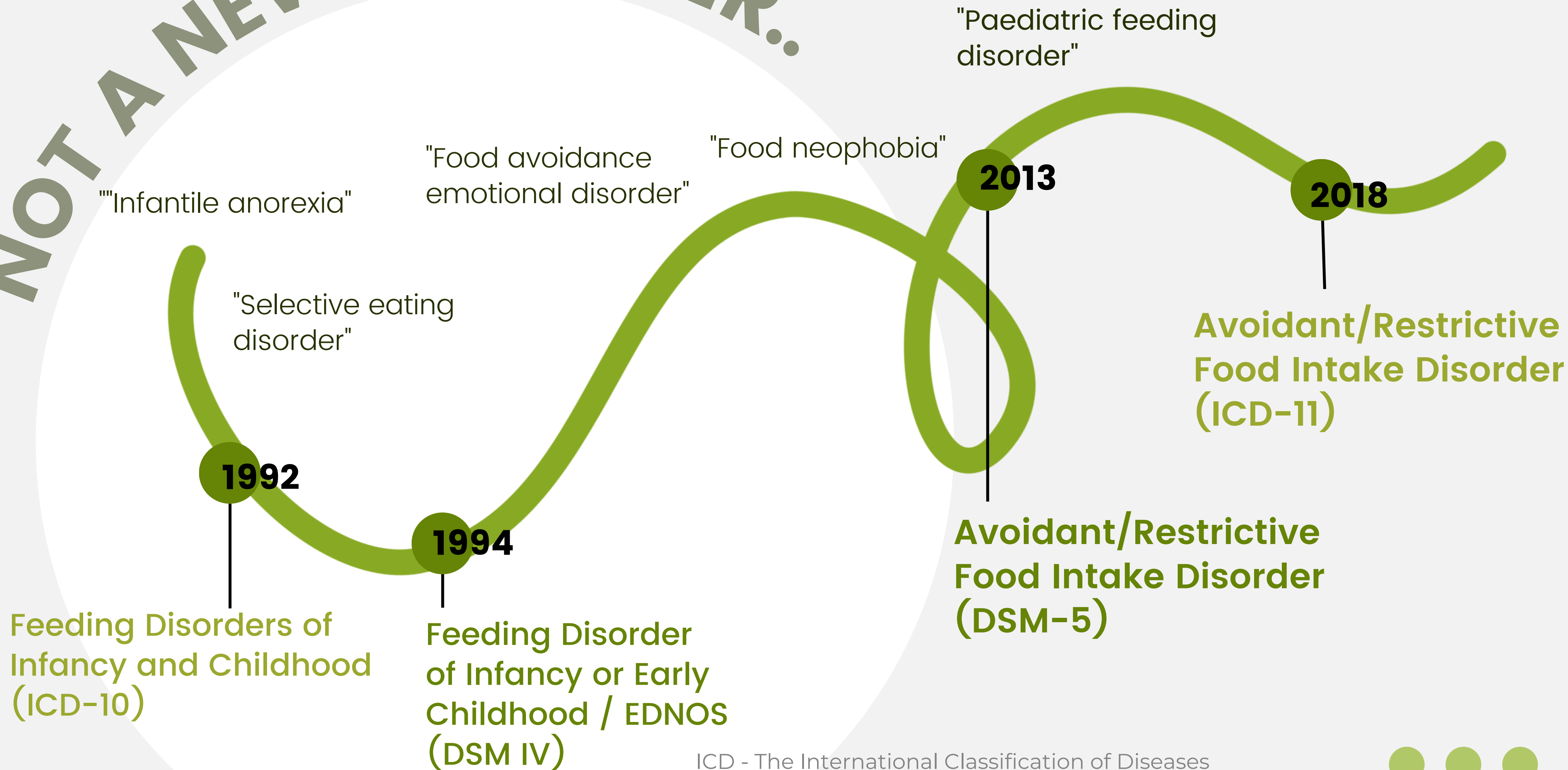
DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS (DSM-5) DEFINITION:

An eating or food disturbance as manifested by persistant failure to meet appropriate nutritional and/or energy needs associated with one or more of the following:

- Significant weight loss (or faltering growth)
- Significant nutritional deficiency
- Dependance on oral supplements or tube feeding
- Marked interference with psychosocial functioning

WHAT IS ARFID NOT?

- No body weight or shape concerns (occurs during Anorexia nervosa or Bulimia nervosa)
- Not better explained by another current condition.
- Cultural practice or lack of available food


NOT A NEW DISORDER..
""Infantile anorexia"
"Selective eating disorder"
"Food avoidance emotional disorder"
"Food neophobia"
"Paediatric feeding disorder"
1992
1994
2013
2018
Feeding Disorders of Infancy and Childhood (ICD-10)
Feeding Disorder of Infancy or Early Childhood / EDNOS (DSM IV)
Avoidant/Restrictive Food Intake Disorder (DSM-5)
Avoidant/Restrictive Food Intake Disorder (ICD-11)
ICD - The International Classification of Diseases
DSM - The Diagnostic and Statistical Manual of Mental Disorders

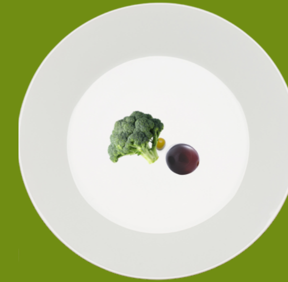
ARFID SUBTYPES

- Three proposed subtypes
- Not mutually exclusive

AVERSIVE

- Commonly acute onset triggered by trauma
- Fear of:
  -choking
  -vomiting
  -pain
  -contamination
- Most frequent adult presentation

RESTRICTIVE

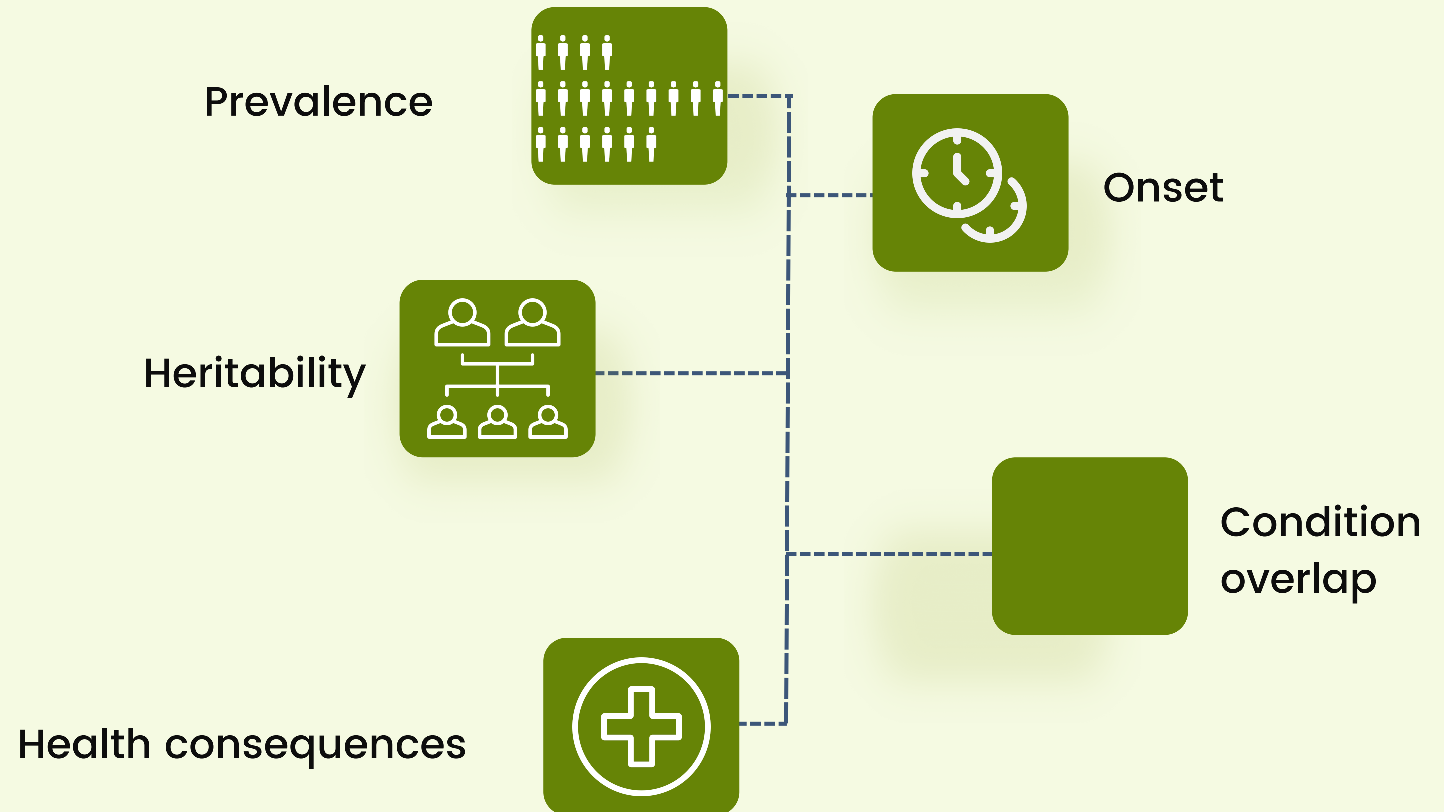


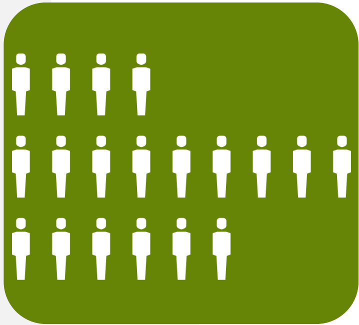
- Low appetite
- Lack of interest in food
- No enjoyment from eating
- Feels full quickly
- Often present from early life

AVOIDANT

- Extreme 'picky eating'
- Limited range of accepted foods
- Sensory sensitivity
- Often comorbid ASD
- Early onset is common

WHAT DO WE KNOW?





Prevalence

Significant variability in prevalence estimates:

- General population: <1%-5.5% (all studies screened for ARFID in a different manner)
- Adults 0.3% (n= ~3000 South Australians) Hay et al., 2017
- Children 2.0% (31%F) (n =>33 000 twins from Swedish longitudinal cohort) Dinkler et al., 2023
- Equal prevalence in males and females in general population.

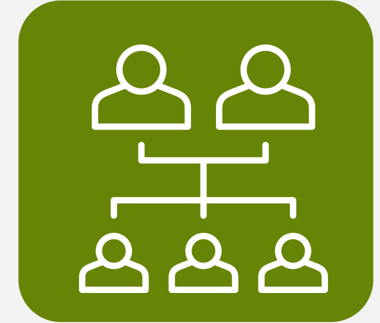
Children ~2%
Adults ~0.3%

Onset

Can be at any age, but childhood onset is common, and younger than in other EDs:

- Median age = 6y ARFID vs 12y Anorexia nervosa (AN) - Thomas et al., 2017
- Median age = 8.7y ARFID - Hameed et al., 2018
- Adult-onset ARFID - Aversive subtype is most frequent, where a traumatic event often precipitates food avoidance.

Heritability



Genetic heritability = the degree to which genetic factors play a role in the development or susceptibility to ARFID.

- "Genetics loads the gun, while environment pulls the trigger"
- First twin study of ARFID (Feb 2023)

JAMA Psychiatry | Original Investigation

Etiology of the Broad Avoidant Restrictive Food Intake Disorder Phenotype in Swedish Twins Aged 6 to 12 Years

Lisa Dinkler, PhD; Marie-Louis Wronski, MSc; Paul Lichtenstein, PhD; Sebastian Lundström, PhD; Henrik Larsson, PhD; Nadia Micali, PhD; Mark J. Taylor, PhD; Cynthia M. Bulik, PhD

- Heritability = 70-85% genetic factors
- More heritable than AN (48-74%) and closer to ASD (79-84%)!

Condition overlap

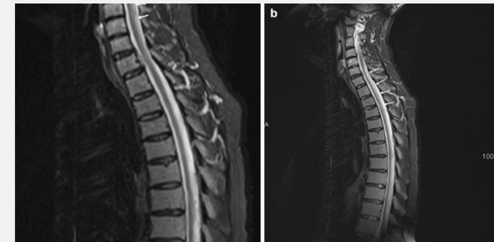
Health consequences

Neurodevelopmental disorders are more common in individuals with ARFID

- Children with significant early neurodevelopmental challenges – 3x increased risk of developing ARFID (Dinkler et al., 2022)
- Specific areas predictive of ARFID were challenges in general development, communication/language, attention/concentration, social interaction, and sleep.
- Anxiety, ASD, ADHD, OCD, & mood disorders also common.

Severe medical consequences secondary to malnutrition and/or low weight:

- Cardiovascular complications
- Osteoporosis and bone fractures
- Organ damage

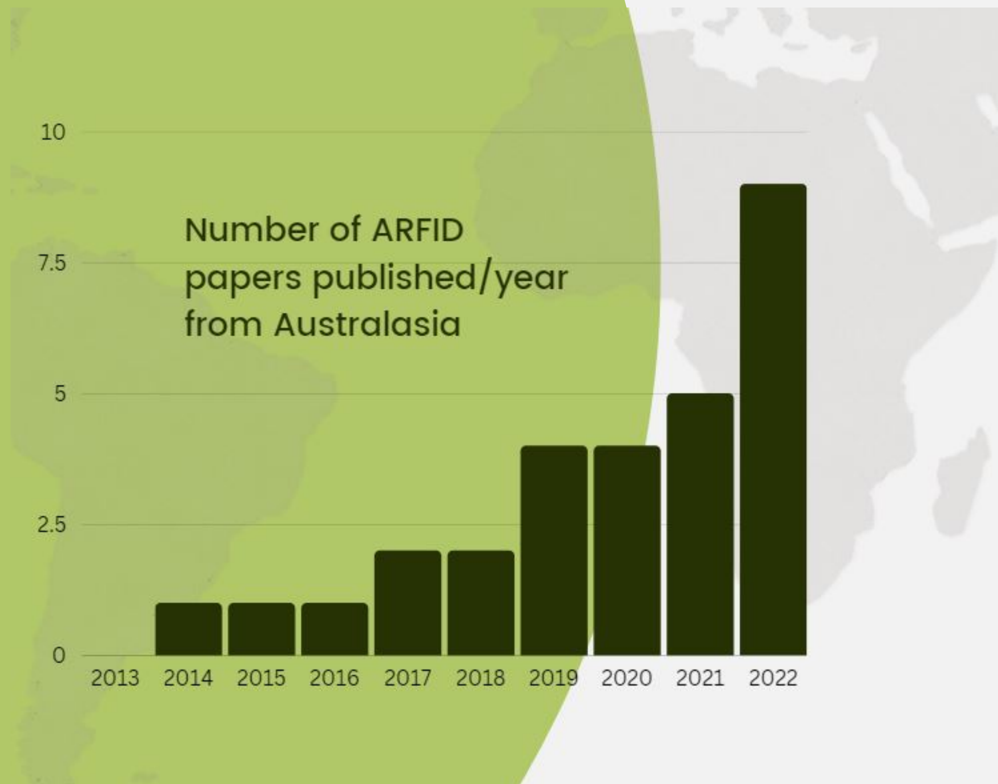


subacute combined degeneration of spinal cord - secondary to B12 deficiency

Optic neuropathy/retinopathy

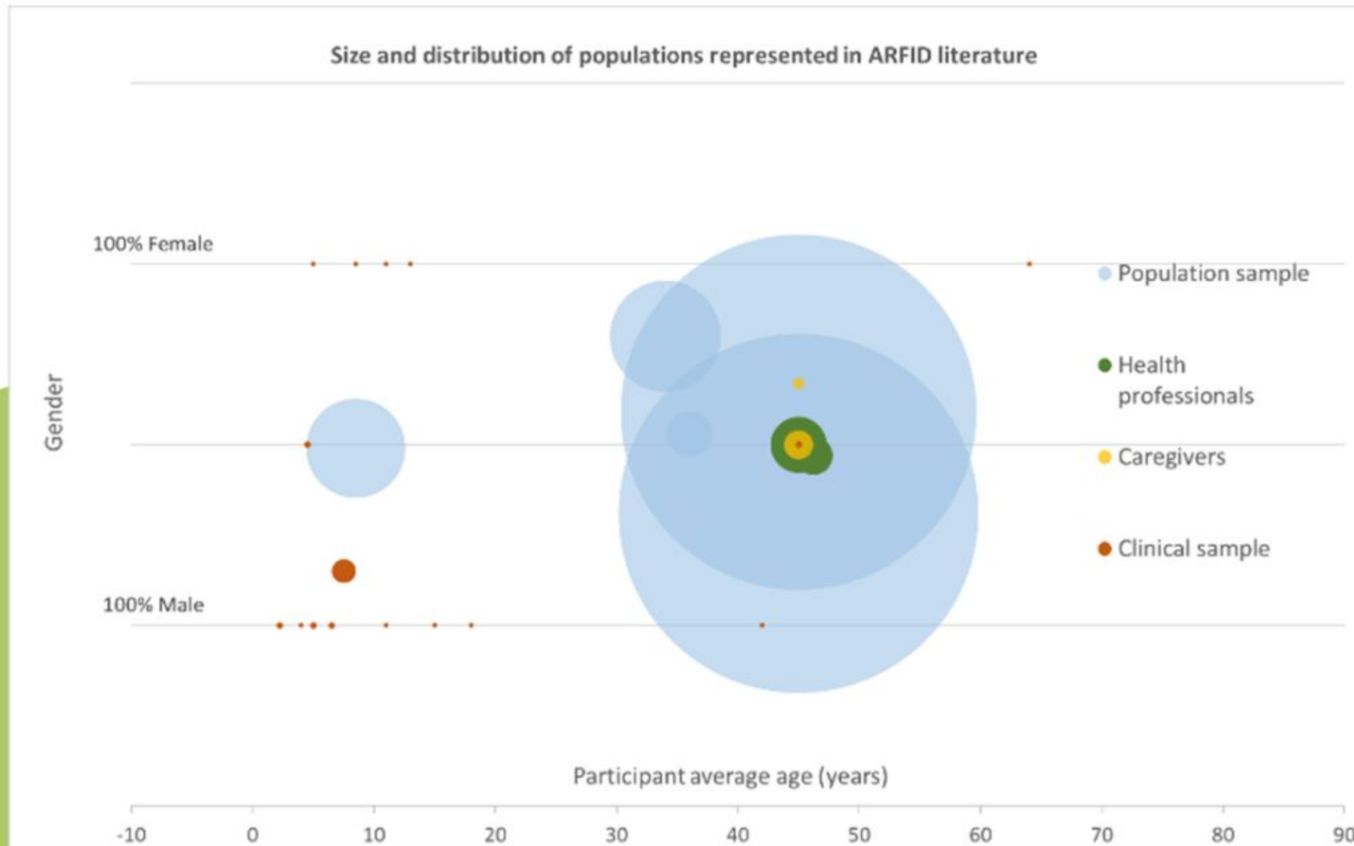
ASD - autism spectrum disorder,, ADHD - attention deficit hyperactivity disorder, OCD - obsessive compulsive disorder

WHAT RESEARCH HAS BEEN DONE IN AUSTRALASIA?



- Systematic review of all published literature from NZ and Australia since 2013 that relates to ARFID
- ~160 papers ---> 30 relevant studies ---> data extraction
- Who? What? Where? How?

Data summary



- Studies grouped by sample type (Population, health professionals, caregivers or clinical).
- Represented here seperated by average age and gender, size of bubble reflects sample number.

Data summary

Have:

- Muliple isolated case reports (1 series)
- Gender balance
- Some population data in adulthood

Missing:

- Larger-scale patient samples in both childhood and adulthood
- Population studies in children that give ARFID prevalence data
- Studies of caregivers

Data summary

- Wide range of health specialties may be expected to recognise and treat ARFID.
- NZ (and international!) data suggests confidence is lacking for many.

"When presented with a typical case vignette suggestive of ARFID, the majority of NZ health professional respondents did not label the case as ARFID in a multichoice answer, and 89.7% said there was "no consensus" on a label"

Five years of Avoidant/Restrictive Food Intake Disorder: no consensus of understanding among health professionals in New Zealand

Bianca N. Jackson, Léa A. T. Turner, Georgina L. Kevany & Suzanne C. Purdy

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To link to this article: https://doi.org/10.1080/2050571X.2021.1926620

"Experience and confidence in diagnosing and treating ARFID are generally low in Swedish clinicians, and many individuals with ARFID do not receive treatment."

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BRIEF REPORT

WILEY

Self-reported expertise and confidence in diagnosing and treating avoidant restrictive food intake disorder among Swedish clinicians

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[1]Department of Medical Epidemiology and Biostatistics, Karolinska Institutet, Stockholm, Sweden

[2]Department of Psychiatry, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA

Abstract

Objective: To assess self-reported knowledge and confidence regarding avoidant restrictive food intake disorder (ARFID) diagnosis and treatment in Swedish clinicians from various disciplines.

Recommendations

- Continuing education of heath professionals
- Move towards standard screening and assessment instruments
- Increased studies on clinical samples - What are the characteristics of ARFID in Australasia?
- Large-scale studies in the general population for more accurate prevalence estimates - Adults AND Children
- Further research to understand ARFID in non-European populations
- Treatment trials -Effectiveness of treatment interventions
- Inclusion of individuals with lived experience in co-desgining research

STEPS TO EATING

EATING

- chews and swallows whole bolus independently
- chews, swallows whole bolus with drink
- chews, swallows some and spits some
- bites, chews "x" times & spits out
- bites pieces, holds in mouth for "x" seconds & spits out
- bites off piece & spits out immediately
- full tongue lick
- licks lips or teeth

TASTE

- tip of tongue, top of tongue
- teeth
- lips
- nose, underneath nose
- chin, cheek
- top of head
- chest, neck
- arm, shoulder
- whole hand
- fingertips, fingerpads
- one finger tip

TOUCH

- leans down or picks up to smell
- odor in child's forward space
- odor at table
- odor in room

SMELLS

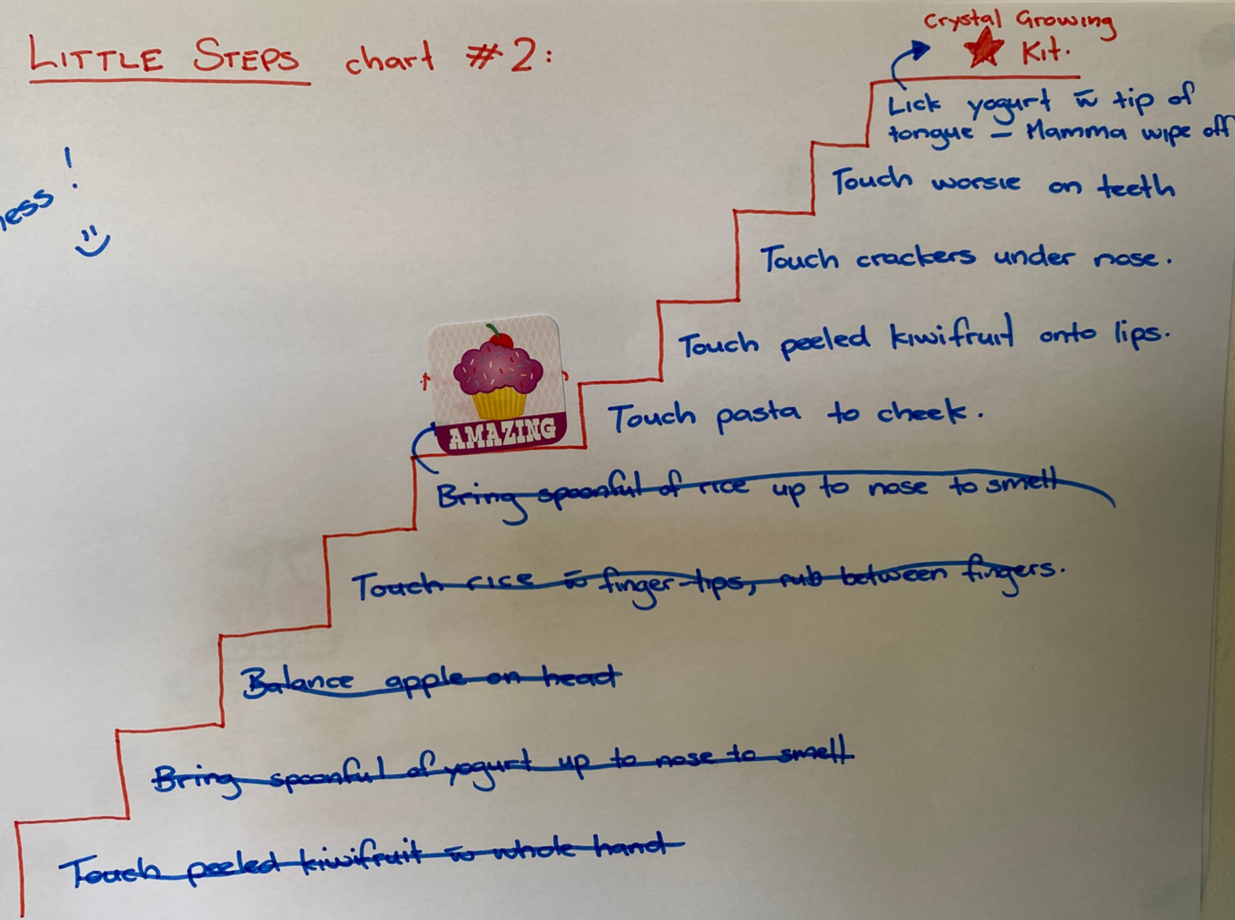
- uses utensils or container to serve self onto own plate/space
- uses utensils or a container to stir or pour food/drink outside of own space
- uses utensils or a container to stir or pour food/drink for others
- assists in preparation/set up with food

INTERACTS WITH

- looks at food when directly in child's space
- being at the table with the food just outside of child's space
- being at the table with the food ½ way across the table
- being at the table with the food on the other side of the table
- being in the same room

TOLERATES

Dr Kay A Toomey, PhD Toomey@starcenter.us Copyright 200

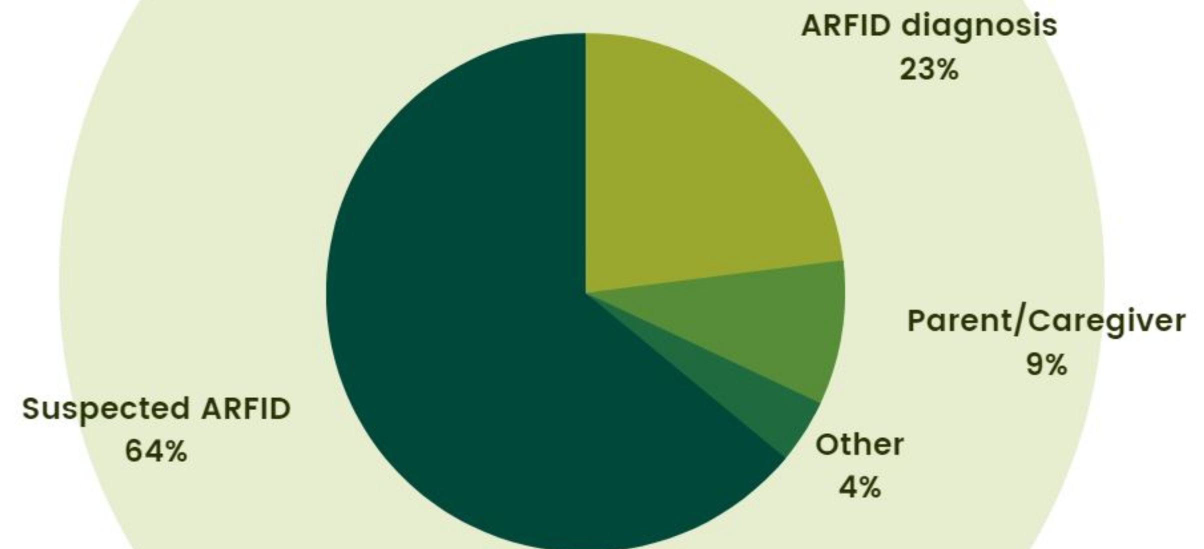


Gian's LITTLE STEPS chart #2:
! Mindfulness !
Crystal Growing Kit.
Lick yogurt w tip of tongue – Mamma wipe off.
Touch worsie on teeth
Touch crackers under nose.
Touch peeled kiwifruit onto lips.
Touch pasta to cheek.
Bring spoonful of rice up to nose to smell
Touch rice w finger-tips, rub between fingers.
Balance apple on head
Bring spoonful of yogurt up to nose to smell
Touch peeled kiwifruit to whole hand

AMAZING

NZ ARFID SURVEY

Understanding the research priorities of those most affected by ARFID



- ~500 respondents completed an online survey
- Demographic and ARFID symptomology questions
- Asked to rate importance of 34 ARFID research areas
- Suggest any additional priorities

- Only 23% have a clinical ARFID diagnosis (self-reported)
- Majority believe they have ARFID but have never recieved a dx

TOP PRIORITIES – INDIVIDUALS WITH ARFID

- Impacts of other co-existing conditions (eg. anxiety, ASD, ADHD)
- Onset of ARFID (how/when/why)
- Understanding ARFID across the lifespan (childhood-adulthood)
- Exploring combined mental health prevention programs
- Availability and accessibility of evidence-based treatment guidelines

TOP PRIORITIES – PARENTS AND CAREGIVERS

- Increasing recognition of ARFID by health professionals
- Interventions (enchance existing, develop new)
- **Impacts of other co-existing conditions (eg. anxiety, ASD, ADHD)**
- Availability and accessibility of evidence-based treatment guidelines

WHERE TO NOW?

OUR ARFID PRIORITIES

- Elevate the profile of ARFID for health professionals that may encounter it
- Encourage a community of researchers, clinicians, and individuals with lived experience of ARFID in NZ to engage in planning future research
- Conduct first large-scale study of ARFID in NZ

--> observable behaviour and traits (phenotype) data

--> genetic sample

- Understand the drivers of ARFID (Genetic background + environmental impacts)
- Long term aim of better treatment and prevention options!

THANK YOU!

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