

Parental confidence and self-efficacy following a co-delivered model of early intervention for infants at high-risk of cerebral palsy.

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Key finding

Integrating peer support and counselling alongside early intervention recommendations was found very valuable by parents of high-risk infants, especially those with low confidence and self-efficacy.



BACKGROUND

Early identification of infants at high-risk of cerebral palsy (CP) facilitates access to early intervention (EI). Self-perceived competency to engage in parenting activities has been suggested as an important factor in improving future outcome for infants and caregivers.¹

Supporting parental wellbeing and confidence is recognised as integral to EI.² However, early referral of high-risk infants may be delayed due to concerns that it may escalate parental stress.³

The Karitane Parental Confidence Scale (KPCS) is a 15-item self-report questionnaire for parents with infants 0-12 months, using a 4-point scoring scale to rate infant co-occupations, personal stress and perceived support.

A score ≤ 39 is the clinically accepted cut-off for low confidence.⁴

Better Start, Better Future

'Better Start, Better Future' is Cerebral Palsy Cymru's novel model of early intervention service co-delivered by therapists and a family support coordinator, who is a counsellor with lived experience of CP. The fully charitably funded service supports Welsh families with infants at high risk of cerebral palsy and runs in collaboration with and in addition to the NHS.

SUBJECT AND METHODS

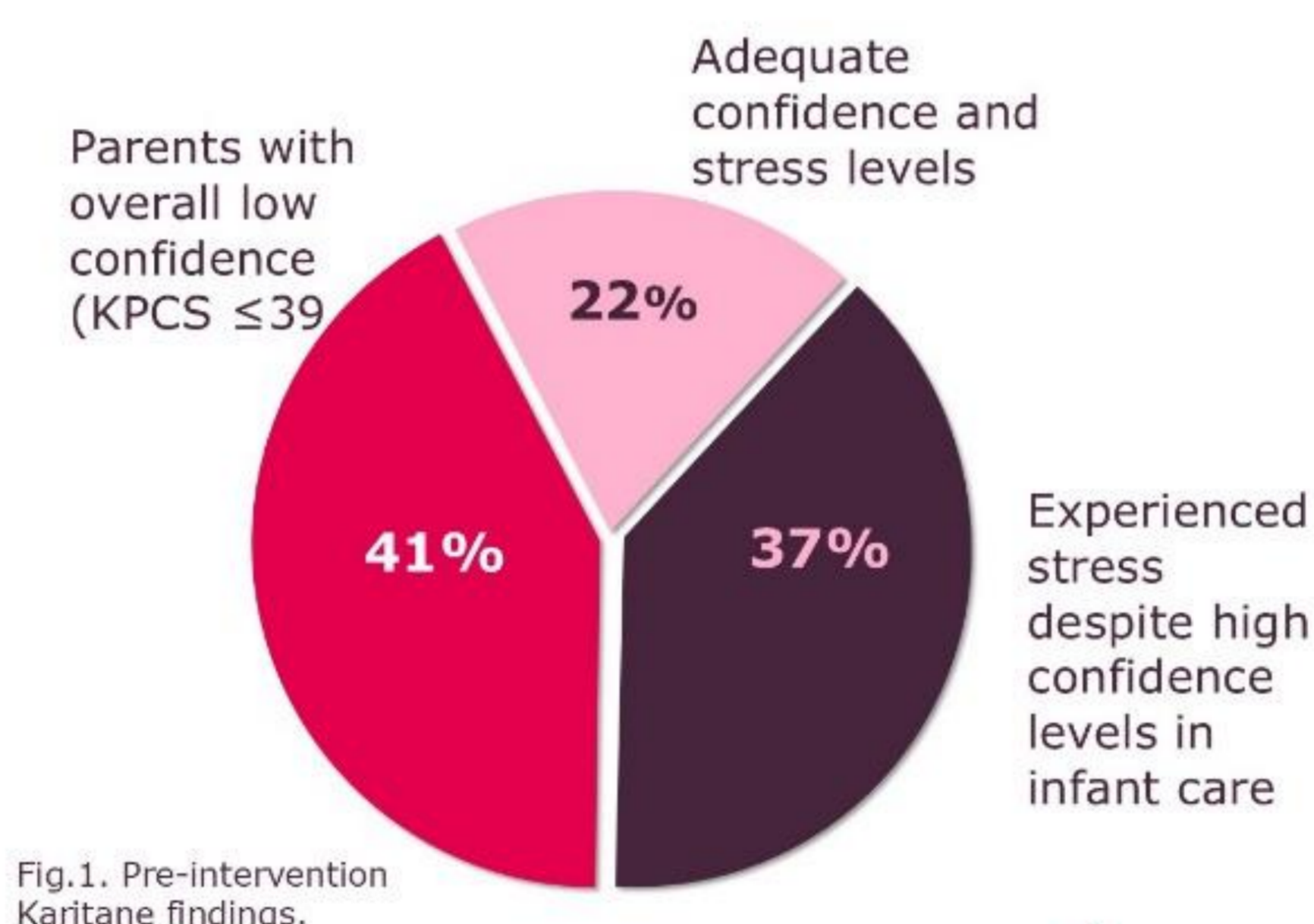
36 parents of high-risk infants (median age=4m) referred to 'Better Start, Better Future' early intervention programme between January 2023-March 2024 completed the Karitane Parenting Confidence Scale prior to attending Cerebral Palsy Cymru (CPC).

Following a 2-hour, individualised intervention session co-delivered by a therapist and a family support coordinator (FSC), all families completed routinely collected feedback questionnaire derived to capture their experiences. A retrospective audit of parents' perceived self-confidence and utility of the novel model at times of high stress was undertaken as part of service development.



RESULTS

- Prior to intervention, only 22% (n=8) reported adequate confidence and low stress levels. 41% (n=15) demonstrated overall low confidence (KPCS ≤ 39) and further 37% (n=13) reported some degree of stress, despite demonstrating high confidence in their infant's daily cares (Fig.1.)
- Play, establishing routine and interpreting their infant's communication were highlighted as most challenging.



"I sometimes feel like I am not doing a good job as a parent"

"I find parenting stressful most or some of the time"

"I don't always understand what my baby is trying to tell me"

- Following intervention, 100% (n=36) of parents reported meeting the peer counsellor as "very valuable".
- All parents with low self-confidence (n=15) identified primary benefits of their first EI session at CPC as: providing practical activities for home, an opportunity to discuss their concerns and reported an increase in confidence (Fig. 2.)

Parents with overall low confidence (KPCS ≤ 39)

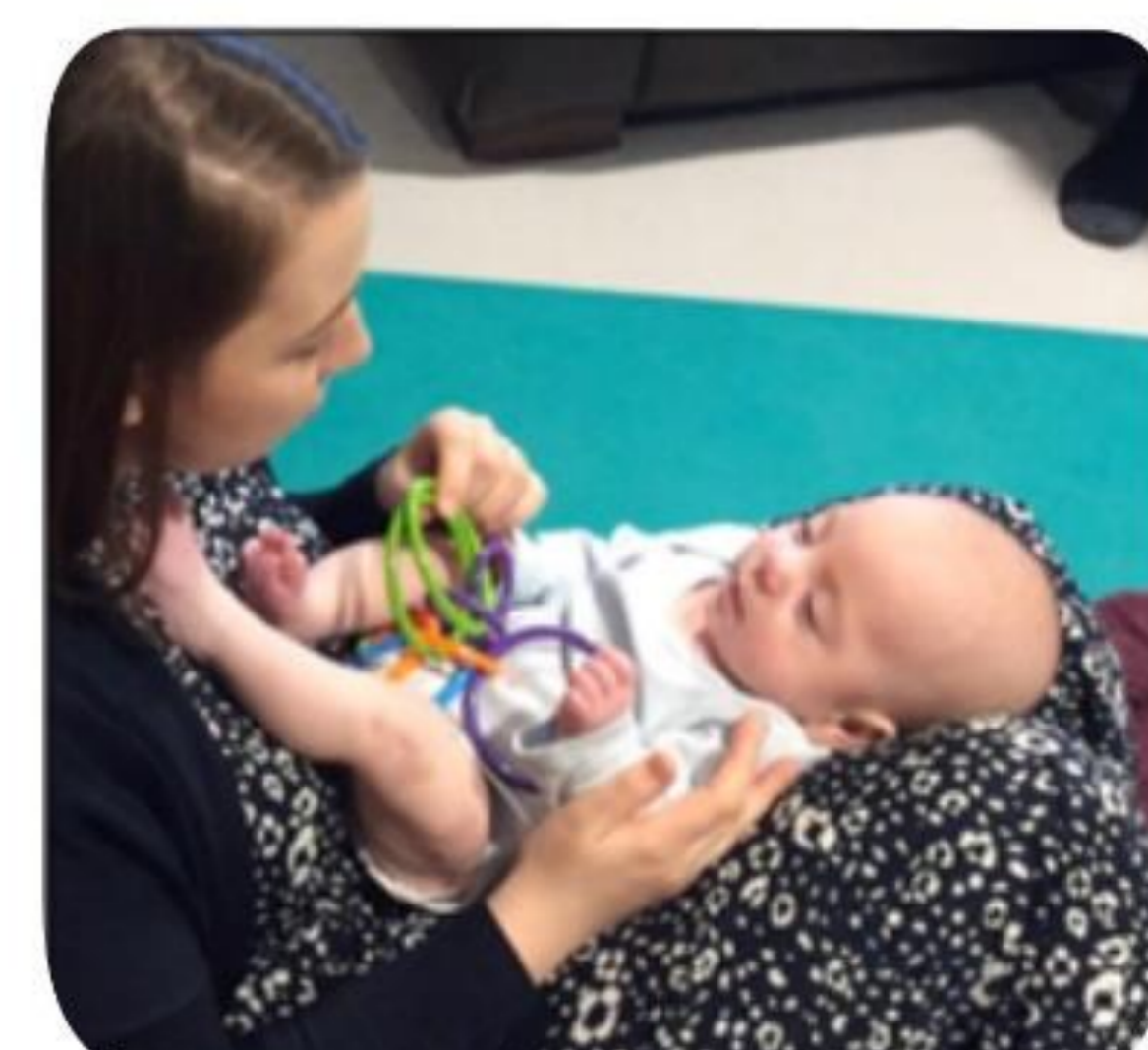
The intervention session:

- Provided practical advice for home
- Increased my confidence
- Provided practical advice for home

CONCLUSION

- Karitane Parental Confidence Scale can be used to identify families with low confidence and self-efficacy.
- 78% parents of high-risk infants referred to 'Better Start, Better Future' reported reduced self-confidence or feeling of stress.
- All parents felt that integrating peer support and counselling alongside EI recommendations was very valuable.
- Early referral for intervention is indicated for all families of infants at high-risk of CP. Further data collection could help establish associations between perceived stress, parental confidence, socio-economic factors and infant's functional abilities.

Fig.2. Post-intervention feedback.



References:

- 1) Albanese A et al. (2018) 'The role of parental self-efficacy in parent and child well-being: A systematic review of associated outcomes.' Childcare Health Development 45:333-363.1.
- 2) Hutchon B et al. (2019) 'Early intervention programmes for infants at high risk of atypical neurodevelopmental outcome.' Developmental Medicine and Childhood Neurology 61: 1362-7.
- 3) Te Velde A et al. (2019) 'Early Diagnosis and Classification of Cerebral Palsy: An Historical Perspective and Barriers to an Early Diagnosis.' Journal of Clinical Medicine 8, 1599.
- 4) Crnčec R, Barnett B & Matthey S (2008). 'Development of an instrument to assess perceived self-efficacy in the parents of infants.' Research in Nursing and Health, Oct;31(5):442-53.





‘Moving on Up’

A co-produced guide to support the move to high school, designed by neurodivergent young people

This co-designed project was initiated by neurodivergent (ND) young people who wished to support other ND pupils.

The aim was to empower neurodivergent young people to share their expertise in a resource that could be used by other ND pupils making the move to high school.

Method: 11 young people, as co-authors, were supported by USW Occupational Therapy students and Volunteers from Dragon’s fun club to plan, design and edit the resource, including commissioning the illustrations.

Outcomes: Despite a better understanding of neurodivergence as ‘difference’ rather than ‘deficit,’ young peoples’ successes are rarely captured as they were in this resource, which has now been distributed widely (~200 copies).

Feedback from the young people commonly identified *pride in being a co-author and a passion for supporting others, by sharing their expertise.*

Occupational Therapy students recognised they gained hands on experience of facilitating groupwork and applying theory to practice

Professionals, whilst still validating peoples’ challenges, could use co-design to help other groups of people with long term conditions, to recognise their expertise and celebrate their assets, whilst producing a resource for the wider community.



Sally Scott-Roberts: Professional/Course Lead for Occupational Therapy
Thanks to USW Civic Activity Fund, Dr Catherine Purcell (Dragon’s FC), Hannah Davies (USW Media Team), Dragon’s volunteers and USW Occupational Therapy students.

Developing consensus-based competency guidelines to identify and explore the role and skills of dietitians working with avoidant restrictive food intake disorder using a modified Delphi process

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Background Avoidant Restrictive Food Intake Disorder (ARFID) is an eating disorder in which patients present with extremely limited food intake but without body weight concerns. Nutritional deficiencies, suboptimal growth and impaired psychosocial functioning are core components of the diagnostic criteria (1).

Dietitians have expertise regarding the identification of malnutrition and micronutrient deficiencies; these skills are fundamental to clinical dietetic practice and beneficial in the assessment and treatment of eating disorders (2).

The aim of this research is to identify and explore the skills, knowledge and experience held by dietitians to assess and treat people with ARFID to produce consensus in competency standards with findings used to inform supportive training and standardisation of dietetic practice.

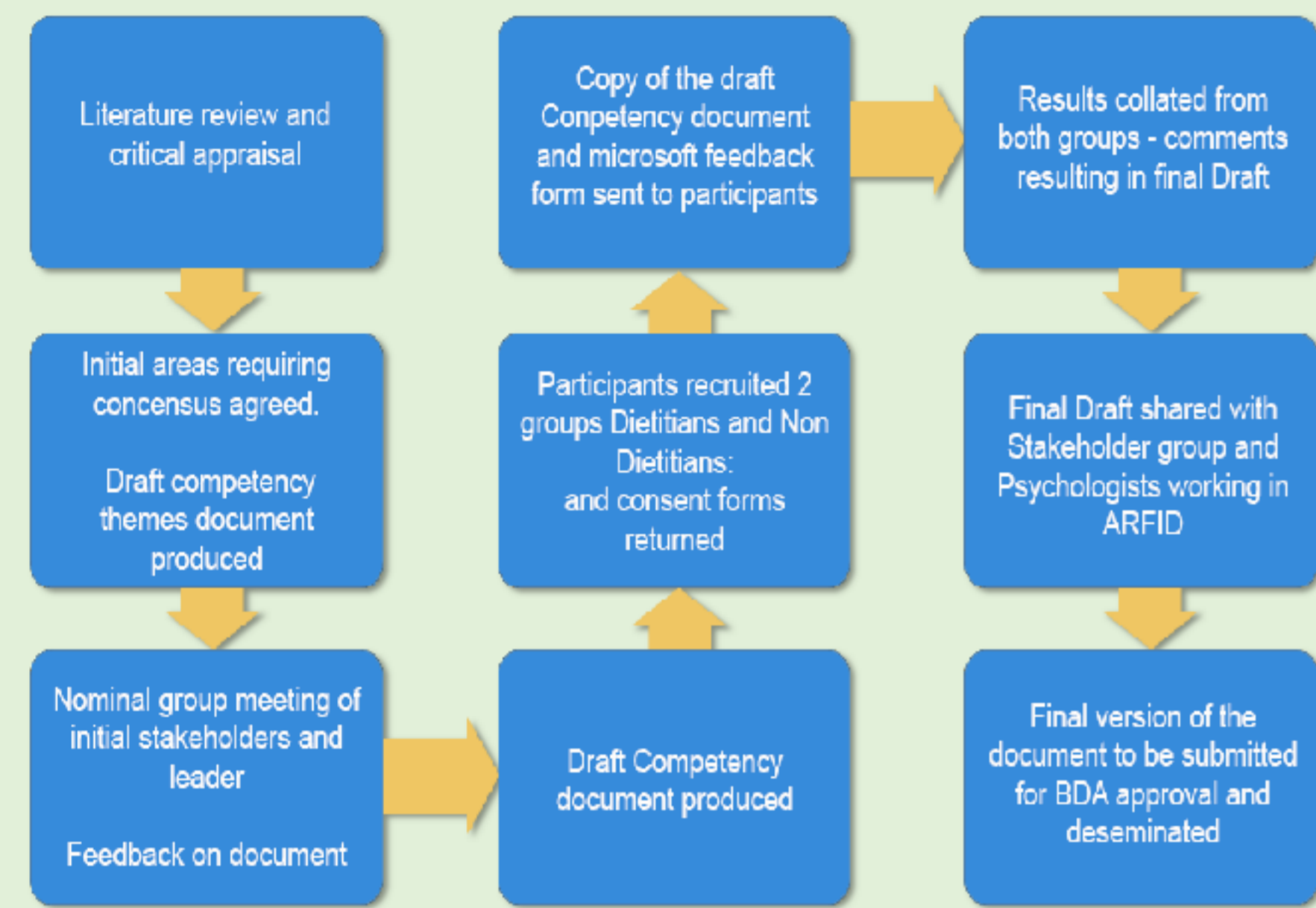


Figure 2 A diagram to illustrate the 9 Stages of a Modified Delphi consensus process leading to the development of the final ARFID Dietetic Competency document.

Methods A modified Delphi (3) design was used to develop consensus using a mixed methods approach. Drafted guidelines and a survey were circulated to clinicians and dietitians recruited by convenience sampling from special interest groups.

Participants included dietitians (n=13) and clinicians (n=9) working with patients with ARFID including dietitians working in physical and mental health and with adult and child patients across the UK.

Consensus was achieved when 80% or more agreed with the statements in each section of the competencies: screening, assessment, dietary assessment, formulation, nutritional intervention, specialist skills, monitoring and evaluation and clinical supervision.

Descriptive statistics were used to identify the differences in proportions in the response. Qualitative data was collated using thematic analysis methods, notes were read, coded and reviewed using a common themes approach clarifying the ratings.

Ethics approval was agreed by Cardiff Metropolitan University and ABUHB research and development department (Reference number PGT-8947).

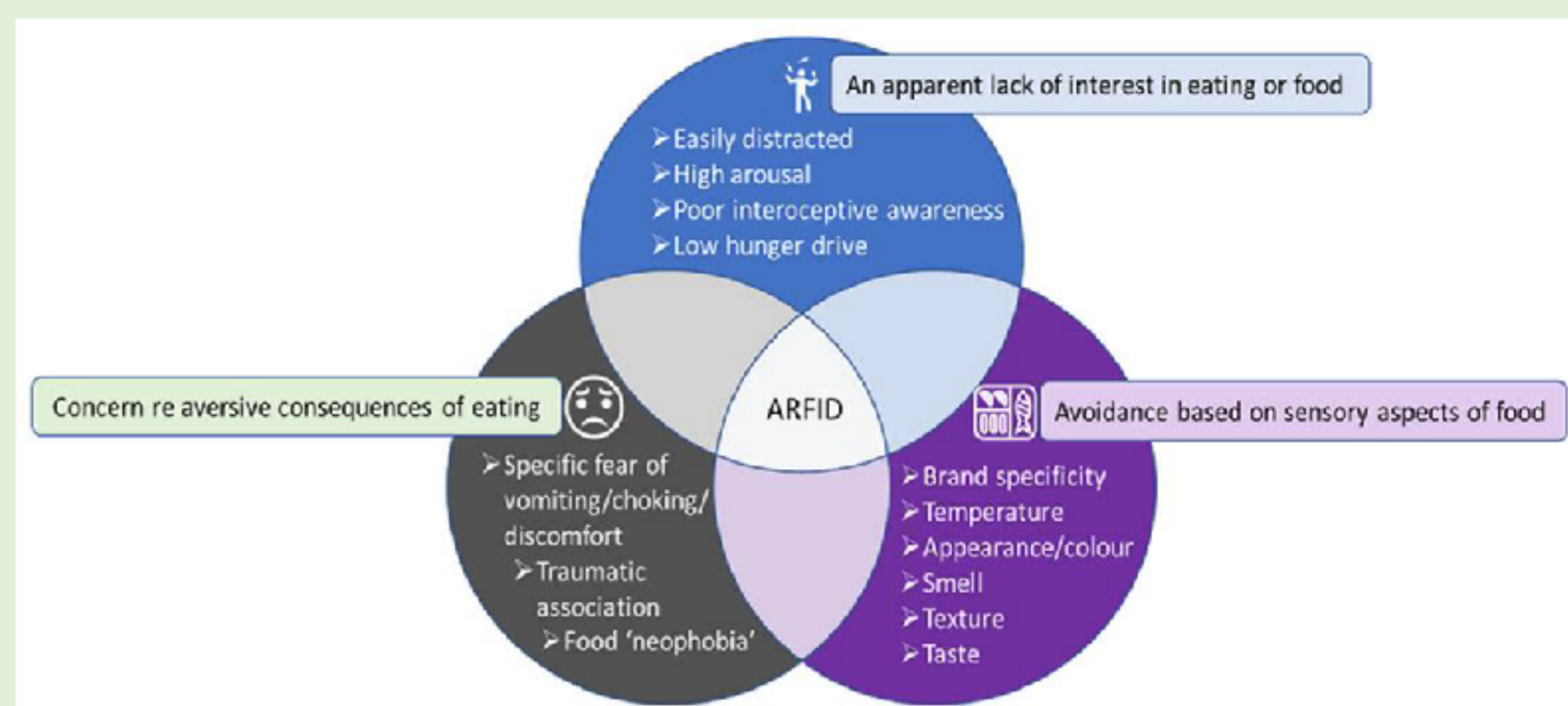


Figure 1 An illustration to show the range of difficulties and presentations in ARFID (Archibald T, Bryant-Waugh R. 2023)(1)

Results Each section of the competency document achieved full consensus from dietitians, the responsibilities of dietitians at different bandings showed large variation (figure 3).

Theme	Sub themes
Core skills of a Dietitian	Screening, Assessment, Treatment/intervention
MDT working	All aspects, Formulation, Role in physical health
Professional practice	Bands and experience
Extended practice	Confidence, Team/context, Training, how and when
Supervision	Dietetic standard practice
standardising practice	General points Value of the document

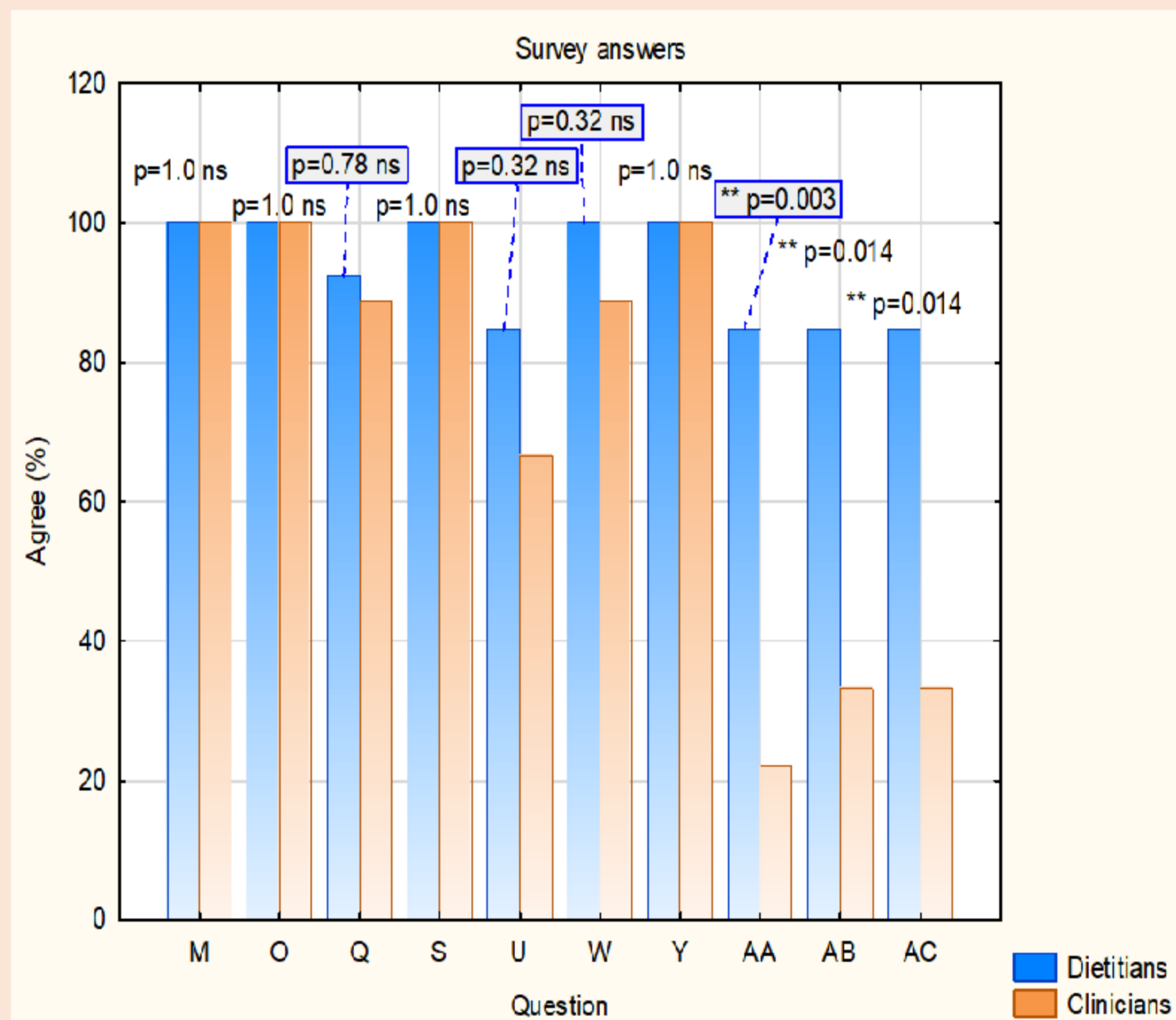
Figure 4 A table to illustrate the themes and subthemes identified in the coding and thematic analysis, clinical experience was used to identify the themes and sub themes.

Dietitians and clinicians commented about the use of core dietetic skills as illustrated by the following examples,

(D10Q9) "Dietitians are very skilled at assessing risk and also understanding the social and environmental impact this assists with a holistic treatment approach".
(C2Q9) "really important to have dietetic input into assessment and ensure areas for targeted intervention".
(C8Q15) "dietitians absolutely essential to support intervention in ARFID eg dietetic psychoeducation – they have more knowledge re macro and micronutrients.."

Clinicians reached consensus for the majority of the competencies bar one, a third were neutral and no one disagreed with dietitians taking extended roles. Themes in the comments being around appropriate training and supervision as highlighted by the following quote.

(C2Q17) "Yes with appropriate therapeutic training and skill - it would be an asset to have the dietetic expertise along with the therapeutic skill. I would not consider this a core competency in all dietitians".



Key Sections of the competency document: M=assessment, O = dietary assessment, Q = formulation, S = nutritional interventions, U = extended skills, W = growth markers. Responsibilities at different dietetic grades AA = band 6, AB = band 7, AC = Band 8.

Figure 3 A graph to show the consensus (agree and strongly agree > 80%) and difference between the dietitians and clinician's groups for each section of the competency document.

Conclusions Despite the broad categories tested, this document has captured the views of experienced dietitians and clinicians and highlights the generic and advanced skill set of dietitians and the value of including dietitians within an ARFID/ED team. Additional training and supervision may be required to ensure all dietitians feel confident using their core skills while working within their scope of practice.

Dietitians have specific skills and knowledge in the, assessment and treatment of malnutrition and ARFID clinician's value these as an essential element of multidisciplinary working. Future research work should include the views of service users regarding the dietitian's role.

ARFID clinicians reported being less able to comment on dietetic grade and roles, this has consequences for practice as many non dietitians are involved in planning services and highlights the importance of dietetic involvement in the strategic design and implementation of ARFID pathways.

The consensus-based competency document will support the BDA Position Paper on ARFID, inform the BDA ARFID training, BDA Toolkit and at a local level support dietitians to create learning standards to support development and increase skills and confidence.



BDA endorsement will be sought via the ARFID subgroup (D5Q25) "Great document – will be such an important resource"

References

1. Archibald, T. and Bryant-Waugh, R. Current evidence for avoidant restrictive food intake disorder: Implications for clinical practice and future directions. JCPP Advances. 2023 June 3 p.e12160.
2. Heruc, G., Hart, S., Stiles, G. et al. ANZAED practice and training standards for dietitians providing eating disorder treatment. J Eat Disord. 2020 8,77.
3. Keller HH, McCullough J, Davidson B, et al. The Integrated Nutrition Pathway for Acute Care (INPAC): Building consensus with a modified Delphi. Nutr J. 2015 Jun 19;14:63. doi: 10.1186/s12937-015-0051-y.

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