AN MDT APPROACH TO COMPLEX FEEDING DIFFICULTIES IN CHILDREN

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There is no uncertainty that multidisciplinary models of care across a number of dietetic, nutrition and health treatment modalities are gold standard and strived for amongst professionals. With a lack of robust guidelines for this area of paediatrics and due to the wide spectrum of disorders more frequently documented, a multidisciplinary (MDT) approach is essential.

Multidisciplinary working is widely referenced throughout NHS literature, including regular acknowledgment of its importance in provision of patient-centred care. The NHS defines the following:

"A multidisciplinary approach involves drawing appropriately from multiple disciplines to explore problems outside of normal boundaries and reach solutions based on a new understanding of complex situations."[1]

Within paediatric dietetics, multi-disciplinary team (MDT) working is a well-established framework for management of certain conditions and referenced across guidelines for diagnoses such as cystic fibrosis, diabetes and food allergy. There are, however, certain pockets of paediatric dietetics that are currently yet to have such robust guidelines in place, largely due to the complex and heterogenous nature of clinical presentation, variability in management or treatment strategies, and/or lack of evidence-based treatment pathways.

One such area relates to children presenting with feeding difficulties. Evidently, the term itself is broad in its reach, encompassing what may be considered 'mild' feeding difficulties such as fussy/picky eating, to more 'severe' feeding difficulties such as Avoidant Restrictive Food Intake Disorder (ARFID). The frequency of feeding difficulties is documented to be as high as 30-50% of children;[2,3,4] however, this is likely to represent a spectrum between normal feeding behaviours, misperceived feeding problems, milder feeding difficulties up to severe difficulties or 'feeding disorders'.[2] Studies report figures as high as 80% incidence for feeding difficulties in children with developmental delays due to chronic medical conditions,[4] with interactions between medical, behavioural, developmental, social and/or psychological factors more likely to be present in children with more complex or severe feeding difficulties.[4]

In practice, complex or severe feeding difficulties are likely to encompass, but not be limited to, children presenting with:

- ARFID (fitting DSM V criteria);
- feeding challenges, food refusal, oral aversion and/or highly restricted diets associated with developmental and/or motor delay, complex medical history, past feeding experiences, diagnoses such as food allergy, autism, sensory processing disorder or developmental disorders;
- children requiring enteral nutrition to meet nutritional needs ('tube dependency') in the absence of dysphagia or with feeding skills +/- dietary modifications which can be adapted to meet nutritional requirements without requirements for enteral nutrition;
- paediatric feeding disorders.

REFERENCES Please visit the Subscriber zone at NHDmag.com

At present, practice-based evidence would suggest that individual clinicians, including dietitians, are being increasingly confronted by the more severe end of the spectrum, where support goes beyond the scope of management by a single individual or speciality. Whilst parents and clinicians alike are starting to benefit from improved understanding and definitions of feeding difficulties such as ARFID, recent literature identifies that 'severe or resistant' cases require interdisciplinary feeding teams.[5] In the interim, suggestions for first-line clinical settings include using a progressive approach to managing feeding difficulties such as identifying red flags, screening for oro-motor dysfunction and address feeding practices.[5]

PRACTICE-BASED EXPERIENCE

A reflection on working outside or without an MDT for children with complex feeding difficulties

For children with complex feeding difficulties, it is not uncommon for a paediatric dietitian to already be involved, or to be one of the first professionals referred to for advice. Whilst there is certainly scope of practice for dietitians to support, with factors including growth requirements, nutritional optimisation, food allergy management, first-line behavioural advice and appropriate use of supplementation, further strategies for management can be variable based on practitioner experience, additional training and resources. Within practice, managing a child with more complex feeding difficulties can feel isolating, particularly in circumstances where the following occur:

- Parents have already trialled and exhausted common behavioural management strategies for feeding difficulties.
- You are unable to meet parents' expectations of feeding support, or there is misunderstanding about the scope of dietetic input or remit.
- Parents are evidently frustrated with inconsistency of advice, lack of availability of specialist services and/or time lags between input with differing professionals.
- Resources are limited in terms of frequency or availability of further review, onward treatment pathways, evidence-based advice.
- Further assessment has not yet been considered or carried out by other members of the MDT.
- There is a lack of MDT working and either practitioners work in isolation at given times, or services are not commissioned for input of certain specialities such as occupational therapy or psychology for children with complex feeding conditions.

Why is an MDT approach essential for this group of children?

Complex feeding difficulties by their nature are multifaceted in presentation and, thus, management. Feeding is a highly complex task and unpicking each child's journey is essential to management. In fact, understanding feeding difficulties in practice requires an understanding of multiple factors including, but not limited to the following:

- the nutritional requirements of the child, taking into account any additional considerations such as food allergy or disease specific requirements;
- alternative feeding options, eg, enteral nutrition;
- infant and child development;
- sensory processing;
- motor development, including oro-motor development;
- dysphagia;
- the aetiology of medical conditions or diagnoses and their interaction with feeding;
- pharmacology;
- emotional and social development;
- parenting styles;
- early feeding experiences.

Understandably, all of which cannot be unpicked from contact with a single professional!

Research and literature widely acknowledge that an MDT approach is required for managing more complex and severe feeding difficulties, defining or outlining the essential need for:

- a group or collective of specialists from multiple disciplines providing recommendations and treatment;
- clinical feeding programs which include 'multidisciplinary specialists involved using variations in assessment modalities and intervention strategies'.[4,6]

A recent systematic review and meta-analysis,[6] which focused primarily on management of

paediatric feeding disorders, indicated that, 'intensive, multidisciplinary treatment holds benefits for children with severe feeding difficulties', with those treated as such noted to have outcomes including increased oral intake, reduced parenting stress and improved mealtime behaviours.[4,6] It does remain widely acknowledged, however, that there is still a need for further evidence and literature surrounding methodology, case definitions and examination/standardisation of treatment.

Considerations of parental stress and health-related quality of life outcomes for this group of children can also not be ignored. As detailed above, often parents have tirelessly trialled a number of interventions with minimal success and the burden of feeding cannot be escaped, remaining a non-negotiable part of everyday life. Research has noted that parents and individuals involved in the care of children with complex feeding difficulties feel personally responsible for their child's disorder.[7] There may also be medical issues coexisting, or contributing to the feeding challenges, with families adopting a 'therapeutic' parenting role already. A repetitive cycle between stress and anxiety around feeding, which in turn leads to food refusal or 'failed' mealtimes, can exacerbate food avoidance by the child alongside concurrent increases in parental frustration, anger and stress.[8] Multiple studies highlight a negative correlation between high levels of parental stress and positive parent-child interactions for children with severe feeding disorders.[8]

Research identified that parental stress surrounding a child with feeding difficulties is better managed if their child is seen within an MDT feeding team and they are provided with a specific and specialised plan, receiving support from multiple disciplines on how to implement advice.[8]

Conversely, from a clinicians' perspective, this group of children can be difficult to diagnose and treat – often challenging and multifaceted in presentation. The support of an MDT for each team member involved can be invaluable in managing the burden of patient care, coping with parental stress and expectations, dissecting the child's complexity surrounding feeding and developing individual treatment goals. Ultimately, working with a supportive and specialised team reinforces practitioner confidence, experience and their own stress management!

AN MDT MODEL FOR MANAGING CHILDREN WITH COMPLEX FEEDING DIFFICULTIES

A service example: transdisciplinary feeding clinic and outcomes data

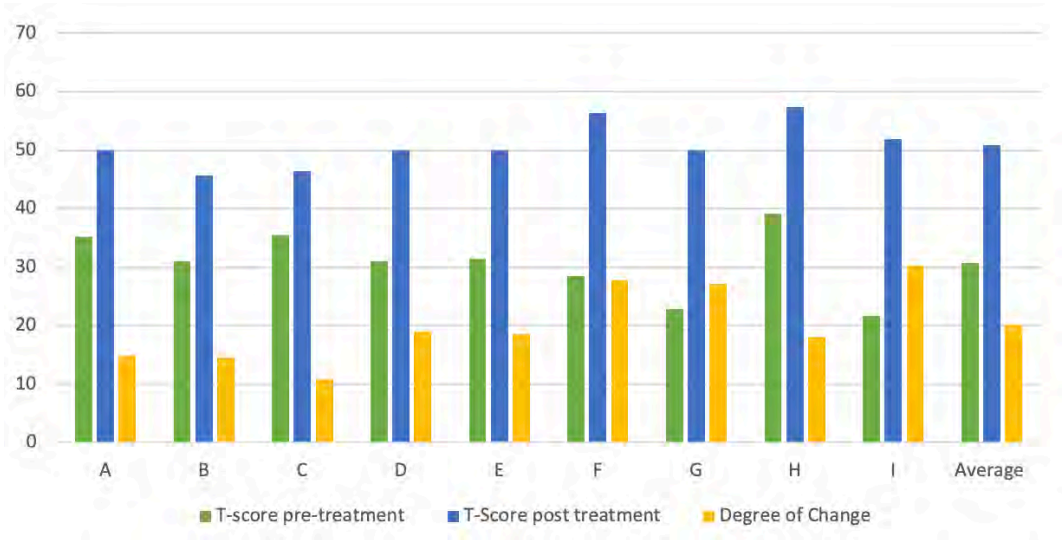
Whilst a multidisciplinary model for managing complex or severe feeding difficulties is evidently crucial, there remains variability and flexibility in how this can be delivered, often resource allowing. Whilst there are a range of approaches and methodologies to delivering support and treatment for complex feeding difficulties, multicomponent interventions including use of factors such as behavioural support, learning theory, operant conditioning, systematic desensitisation and changes to environment and familial practices, have all been reported as effective.[9]

Within the UK, there are a number of specialist feeding clinics and teams already working within hospitals and trusts, such as Great Ormond Street Hospital, Evelina London and Addenbrookes Hospital. There are, however, evident disparities in service availability across the country and it is likely that there will be increasing pressure on the resources currently available, in light of increasing patient demand.

Within the West Midlands (and in the absence of any local NHS specialised feeding teams), Lucy (Upton) has been fortunate to gain experience within a private paediatric feeding team for the past five years run through Integrated Therapy Solutions. Since 2012, the team has used the globally recognised transdisciplinary Sequential Oral Sensory (SOS) approach for assessing and treating children.[10,11] The team consists of speech and language therapy, occupational therapy, nutrition and dietetics and clinical psychology. Close liaison with any NHS managing clinicians, including paediatrician are outlined as a requirement when families are enrolled.

The MDT has so far supported children with a range of conditions including ARFID, autism, feeding difficulties associated with reflux and other gut problems, sensory-based feeding difficulties, food fear and refusal, tube weaning

Figure 1: MDT feeding clinic outcomes



and motor-based feeding difficulties associated with neuro-developmental disability.

The approach and delivery of support allows for key aspects of identified paediatric feeding teams[4,5,9] including:

- MDT assessment and input;
- following an evidence-based approach for managing feeding difficulties, with pragmatic adaptation to a child's individual needs;
- consistency with delivery of advice/approach and treatment protocol, agreed by all members of the team;
- intensive support (including weekly contact if required), and intermediate contact via email or phone with families;
- parental (and extended family) education to support confidence and ongoing delivery of therapy at home environment;
- support with home, nursery, or school visits as required to ensure consistency of delivery and management;
- modification or adjustments to the approach or treatment plan, alongside specific adjunctive therapy, with one or multiple therapists as required depending on the individual needs and/or presentation of the child.

Following a detailed assessment, completed by all members of the MDT, treatment blocks last 12 months and incorporate:

- education to help parents understand and treat feeding problems;
- systematic desensitisation of underlying sensory issues;
- achievement of normal developmental feeding milestones;
- food hierarchies to explore new foods through therapeutic play;
- set routines in sessions including perceptual preparation;
- positive social reinforcement;
- a child is progressed through a detailed 32-step programme of eating hierarchy with each new food;
- daily repetition to transfer the programme outside of the clinic environment.

OUTCOME DATA

As part of running a feeding clinic, practice-based evidence and family feedback is gathered as part of standard care. We complete a yearly retrospective cohort analysis of our outcomes to evaluate the effectiveness of the service. In order to do this, we use Goal Attainment Scaling (GAS)[12,13] with bespoke goals for each child set at the outset of therapy, which are later subject to review. GAS allows for cohort comparability irrespective of individualised functional goals and differing diagnosis.[12,13] Goals are weighted to take account of the relative importance of

the goal to the individual and the anticipated difficulty of achieving it. A client goal set is converted into a summary score reflecting pre- and post-treatment goal attainment (T-score) – with the results summarised in Figure 1.

Whist, evidently, this data reflects a small sample set, the majority of our children achieve a statistically significant post treatment T-score of 50, meaning the goals are achieved as expected.

When our outcome data was broken down to provide further details and insight, we were able to extrapolate the following information:

- Treatment goals are achieved within 12 months.
- Our families attended an average of nine appointments and follow advice daily.
- Children increase the variety of foods they eat after the programme.
- All of the children and young people were discharged and were eating at least 30 foods including 10 starches, 10 fruits or vegetables and 10 proteins.
- Our data reflects published research that children consume an additional 200 calories per day, on average, after the programme.
- Our families report less mealtime battles, increased confidence with managing their child's needs and helping their child make progress, plus a self-identified reduction in parental stress and anxiety.

This initial data collection is highly encouraging, supporting both the efficacy of the service and also the recommendation for use of a transdisciplinary approach for managing children with complex or challenging feeding difficulties.

We noted that two children failed to achieve a T-score of 50, so further investigated the reasons behind this. The first child had progressed well with exploring and interacting with new foods. However, he was experiencing specific anxiety and intrusive thoughts regarding eating these foods: "My tummy wants to eat them, but my head says they will hurt me." Parents had not been able to access clinical psychology support due to financial constraints, which affected further progression. He would have benefited from additional clinical psychology support around these specific anxieties. The second child had a diagnosis of Down syndrome. He moved up the lower steps of feeding hierarchy at an equivalent pace to the other children, but had difficulty progressing further. Post treatment, he went onto receive a secondary diagnosis of autism and in view of this he would have benefited from undertaking the adapted SOS feeding approach for autism, which takes a more gradual approach over a longer time.

At present, families identify charitable or private funding sources to access transdisciplinary feeding therapy. This means that, despite an exceptionally high referral rate, not all families are able to access a full block of feeding therapy. Some families follow a modified educational approach as their financial circumstances allow, as such, this data was excluded on the rationale that they followed a different treatment approach.

THE FUTURE

Given the success of the service so far, and recognising the teams desire to be able to provide treatment for families unable to access private or charitable funding, we have just launched 'The Feeding Trust'; a not-for-profit enterprise, offering treatment for children and young people who have complex feeding difficulties.

By setting up The Feeding Trust we hope to support more families and increase the quantity of our practice-based evidence. By data capturing on a larger scale, we can evaluate the effectiveness of direct therapy against some of our other models of feeding therapy, such as; intensive therapy blocks, parent and child groups, school-based groups and parent education groups.

We hope that this model of care, alongside similar MDT models across the country will continue to provide the specialist input this group of children benefit from, based not only on suggestions from literature around best practice, but from practice-based evidence too.

If you would like any further information about The Feeding Trust, please do not hesitate to contact us:

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