BACD Newsletter

Safe, Efficient and Enjoyable Mealtimes for children who need mealtime assistance – not as easy as it may SEEM – A multi-method PhD study

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Children with neurodisability can experience difficulties with eating, drinking and swallowing, termed oropharyngeal dysphagia. This area of difficulty has a limited research-evidence base (1, 2) and there are minimal guidelines for this very varied group. These children have a wide range of diagnoses with research sometimes focussing on specific diagnoses; Cerebral Palsy (3), Down Syndrome (4), neuromuscular conditions (5), and within the adult field the wider term 'Learning Disabilities' (6). NICE guidelines for children and young people with Cerebral Palsy (7) suggest that there should be a focus on three areas: Safety, Efficiency and Enjoyment. There is small amount of current research exploring interventions to improve children's eating and drinking and swallowing skills. However, while this emerges families need to feed their child several times a day balancing these three priorities.

Speech and Language Therapists (SLT) work with families to provide recommendations for the meal. The FEEDS study (8) explored the potential targets they; other professionals and families might focus on. There is often a cost and balance to each target. For example, one target recommendation could be a smoother texture for meals, a compensatory strategy. This may improve safety (less risk of coughing and choking), efficiency (meal eaten more quickly) and enjoyment (less stress for the parent not anticipating a choke). However, it could reduce safety long-term (the child is not learning to eat more textured food and at risk if given lumpier food), reduce enjoyment (a single-texture meal), and this could lead to reduced efficiency (less consumed). SLTs often recommend multiple mealtime recommendations and carers are known to not always follow them (9, 10).

My research project aims to create a toolkit to guide this complex decision making between the family-carer and SLT. The focus is on children with neurodisability who have oropharyngeal dysphagia with a particular level of need, rather than diagnosis. The focus is children with that require adaptations to the mealtime e.g., different position, pacing and/or food texture and that also require mealtime assistance (EDACS rating: 'Requires Assistance' or 'Totally dependent'(11)). We know that people who require mealtime assistance are at a greater risk of emergency hospitalisation (12). This project focuses on school-aged children as previous studies have mainly focussed on pre-school (9) and younger children (2) or adults (10).

My project is using various implementation science frameworks to consider how to develop the toolkit, but the simplest description would be an evidence-based practice model. Evidence based practice has three aspects (13) and my project considers those three elements.

1. *Best research-evidence: Systematic Literature Review*

I am completing a Prospero registered systematic literature review of mealtime recommendation interventions provided to carers of school-aged children who have oropharyngeal dysphagia (14). I am completing data extraction with findings so far indicating many studies are from low-middle income settings compared to other literature, and many different participant approaches; child, carer and/or child-carer dyad.

2. *Clinical expertise: Survey of current clinical practice*

In summer 2021 I completed a survey of SLT clinical practice when working with school-aged children with neurodisability, oropharyngeal dysphagia and requiring mealtime assistance. I am still analysing some qualitative data including the written resources SLTs use to provide recommendations e.g., mealtime mats (15). Findings so far describe the negative impact of Covid19 on practice but with some positives also that have been maintained; telehealth and closer family contact (16). SLTs also describe much greater use of a wide range of mealtime recommendations when compared with the wider health care professional participants of a previous survey (2).

3. *Patient and/or carer values and preferences: Qualitative observational study of mealtimes of family-carers and children*

I am currently completing the ethics application for this next stage of my research project where I will explore family-carers and children's experiences of an assisted mealtime. My small 'parent expert group' has been invaluable in planning this part. I worked clinically with children and families for 19 years before starting a teaching role and this research, but I continue to learn more from them.

I am also guided and supported by my supervisors, Professor Katerina Hilari, Dr Kathleen Mulligan and Dr Kelly Weir, alongside my SLT stakeholder group and specialist SLT advisors.

I look forward to sharing my results further as the project progresses. If you want to read more and access my current conference abstracts and future journal articles for free, they are/will be on my University profile: https://www.city.ac.uk/about/people/academics/sally-morgan#publications-link

If you are a parent or family carer of a child with neurodisability with oropharyngeal dysphagia who needs mealtime assistance, and you might be interested in increasing the diversity of my 'parent expert group' then I'd love to hear from you: sally.morgan.2@city.ac.uk

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