

RCSLT/ NIHR Dysphagia research priorities

Current member research and quality improvement projects

Hazel Warren

Project summary

Hazel undertook a service evaluation exploring patient and staff perceptions of using computers to provide biofeedback in intensive dysphagia therapy. This was a single case-study with one patient and the team around them (the patient, his wife, a speech and language therapist and a therapy assistant) with semi structured interviews. Data were analysed with thematic analysis, which resulted in recommendations for service and future practice in the setting.

Implications for clinical practice

- This therapy requires high levels of effort and commitment and should be made clear to service users when considering intervention options
- Members of staff delivering therapy need to have relevant skills including technological skills, making appropriate adaptations, building a therapeutic relationship and responding to needs of service users.
- Staff members need to adapt their approach to meet individual physiological and psychological needs of service users
- An individualised approach to staff development is essential. Building confidence requires access to resources, opportunities for discussion, observation and experiential learning. Face to face contact was a supportive factor for staff in meeting logistical requirements of the therapy
- Flexibility in timing and location was important in reducing care-giver stress

Contact Hazel to find out more: hazel.warren@nhs.net or @HazelWarrenSLT / @ncitycare_SLT

Rachael Kasch

Project summary

“What are the experiences of adults with intellectual disabilities and dysphagia? An exploratory study”

Implications for clinical practice

- Now offering to eat lunch with patients
- Considering impact of ‘cutting up food’ recommendations on emotional wellbeing and looking at how service user independence can be increased
- Providing advice on eating out socially with dysphagia

Contact Rachael to find out more: Rachael.kasch@bhamcommunity.nhs.uk

Anna Robinson

Project summary

This MRes research study was a qualitative study exploring the experiences of family members living with a loved one with post stroke dysphagia. Within the findings, themes came out around priorities:

4. Are caregivers aware of how to identify eating/drinking difficulties and the potential risks and consequences of dysphagia?
and

7. What is the impact of shared-decision making (patient, carer and health professionals) for the modification of food textures and fluids on health and wellbeing outcomes when compared with decisions made by health professionals alone?

My study wasn't specifically looking at this areas but the findings may give some insight into family members awareness of swallowing problems and their views on decision making

Implications for clinical practice

- Early stages of dissemination but the results may impact on how a 'living with dysphagia' community group is run.

Contact Anna to find out more: anna.robinson7@nhs.net or @robbo_ak

Gemma Clunie

Project summary

What are the changes in voice and swallowing outcomes of adults with airway stenosis pre- and post-reconstructive airway surgery?

This touches on the priority number 4 of the adult list (What is the prevalence and nature of dysphagia in adults with respiratory conditions over time?) as I will be measuring outcomes pre-surgery, 2 weeks and 6 months post-surgery. It also touches on priority number 3 of the general list (What is the impact of reflux on swallowing function and health outcomes (including pneumonia) for children and adults who have dysphagia?) as one of my outcomes is the Reflux Symptom Index.

Implications for clinical practice

- Partly designed by patients, the project will allow SLTs to offer the best possible service to a group of vulnerable, chronically ill patients
- Gives clinicians the confidence to be able to back up their clinical practice with patients who have airway stenosis with some evidence specific to swallowing and voice problems.

Contact Gemma to find out more: g.clunie@imperial.ac.uk or @gemmaclunie

Sabrina Eltringham

Project summary

How does variation in assessment and management of dysphagia in acute stroke affect the development of stroke-associated pneumonia?

The primary aim of the research is to find out how do methods of dysphagia assessment and clinical management during the first 72 hours of admission to hospital affect the risk of patients developing stroke-associated pneumonia (SAP). A second aim is to find out what care processes and interventions systemic to patients with dysphagia affect the risk of stroke patients developing SAP during the acute phase.

Contact Sabrina to find out more: Sabrina.eltringham@sth.nhs.uk or @SabrinaEltringh

James Faraday

Project summary

Improving mealtimes for people with dementia: a training intervention for care home staff.

The aim of the project is to develop a training package for care home staff, helping them care for people with dementia at mealtimes. The project will test the training in care home settings to see if it is acceptable

Implications for clinical practice

- Hopefully in time the work will help clinicians provide effective and sustainable training to care staff working with people with dementia. The aim is that this will result in better mealtimes for people with dementia – safer, and more enjoyable.

Contact James to find out more: j.faraday@newcastle.ac.uk or @JamesHFaraday

Joanne Patterson

Project summary

Joanne is supervising a number of studies that fit the RCSLT research priorities for dysphagia in the North East of England.

- An MSc project looking at fluid intake and thickened drinks in older frail patients.
- A PhD project looking at pulmonary fibrosis and dysphagia- using instrumental assessments (VF and FEES) and patient recorded outcomes.
- An NIHR intern for expiratory muscle strength with head and neck cancer patients with structured standardised outcome measures
- A project on evaluating the patient experience after running workshops with Ryan Riley from Life Kitchen
- Development of a carer questionnaire for head and neck cancer patients with dysphagia.

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Diane Sellers

Project summary

Diane is involved in a range of studies that are nearing completion:

- 1.) The FEEDS review (Focus on Early Eating Drinking and Swallowing review) at Newcastle University aims to find out about the services currently offered to families of children with eating, drinking and swallowing difficulties by NHS services. We then want to gather information in order to plan a future study of one or more potentially worthwhile treatments.
- 2.) Diane Sellers and the team at Chailey Clinical are building on a previous development of the Eating and Drinking Ability Classification System (EDCAS) for people with cerebral palsy, aged 3 years and over. They are developing the mini-EDCAS, suitable for use with children aged 18-36 months. The mini-EDCAS will provide a universal way of classifying and communicating eating and drinking abilities of young children with cerebral palsy, suitable for use with families to aid their understanding of associated risks. The abstract for Mini-EDACS has been selected for an oral presentation at the forthcoming European Academy of Childhood Disability conference in Paris May 2019.
- 3.) The G-PATH psychological support study led by Dr Gill Craig at Hertfordshire University is a programme of work to consider the question: "How do different neurodisability services meet the psychosocial support needs of children/young people with feeding disabilities and their families: a national survey and case study approach to mapping and costing service models, care pathways and the child and family experience?".

Contact Diane to find out more: diane.sellers@nhs.net

Lisa Everton

Project summary

Lisa is analysing Videofluoroscopy Swallowing Studies in acute stroke patients. The main aim of the research is to assess how sensitive outcomes are in detecting change in swallowing function following an intervention. She is comparing the Penetration Aspiration Scale with other measures of swallowing (timing measures and clearance measures) to see which measure, if any, is more sensitive to detecting change in swallowing following an intervention. The second part of the paper is looking into correlations of disordered swallowing features and how they are related to severity of aspiration.

Clinical implications

- This research will contribute to better outcomes for adults with dysphagia as it examines the important area of outcome measurement in dysphagia rehabilitation and also helps to improve our understanding of disordered swallowing.

Contact Lisa to find out more: Lisa.Everton@nottingham.ac.uk or @lisa_everton

Bernadette Clifford

Project summary

Bernadette ran a project which helped to develop The Lung Group. The Lung Group was developed to address and improve the respiratory health of people with learning disabilities and vulnerable respiratory health. The lung group is based on the active cycle of breathing technique, widely used by respiratory physiotherapists. The technique was

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adapted to be accessible and enjoyable for this target population. Their project was published in the [Learning Disability Practice](#) journal.

Clinical implications

- It has increased the recognition of the effectiveness of joint working between physiotherapy and speech and language therapy.
- It has enabled the active cycle of breathing technique to reach an audience to whom it is beneficial, but who did not find existing respiratory health groups accessible.
- We have presented our findings to Trust audit and clinical effectiveness day.

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Sally Morgan

Project summary

Sally's MSc research project found that healthcare professionals' reported that gastrostomy feeding improved health and wellbeing for children & parents including psychosocial improvements (emotions). However they viewed physical health as more important than other values e.g. social aspect of mealtimes. The abstract for the poster presenting this work at EACD 2014 can be found [here](#). Sally has also worked with colleagues on a review looking at this area in relation to blended tube feeds (Breaks et al. [2019](#)). These relate to paediatric dysphagia research priority 7.

Sally has also worked on projects addressing the non-age specific dysphagia research priorities 1 and 4, including looking at the use of mealtime mats in clinical practice in special schools. The project found that mealtime mats were not consistently in use, and have multiple names and are not accessible to family/carers so suggesting they may not refer to these when they support at mealtimes. Sally's paper can be found [here](#). Work with colleagues Charpentier et al. ([2018](#)), Sally also researches parent adherence to dysphagia management guidelines.

Clinical implications

- The work around healthcare professionals' awareness of gastronomy has led to a trust clinical guideline regarding support for gastrostomy decision making.
- New project on the development of a Service User Reference Group for making mealtimes safer and more enjoyable for people with learning disabilities and dysphagia.

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Examples of patient and public involvement in the projects:

- Speaking to service users and families about the study idea prior to proposal development
- Making links with established PPI groups
- A working group of people with dysphagia involved throughout the project in developing easy-read resources and questionnaires and involvement in analysis.
- A PPI advisory group to ensure work is in line with patient and public priorities
- Involving service users in the project design

- Qualitative information gathered from service user participants in research studies
- Consulting with service users and their carers before setting up a group
- Gathering weekly feedback throughout a programme's implementation and afterwards.

The RCSLT research priorities project is a test-bed for the [new national patient involvement standards](#)

If you have been working on a research or quality improvement project related to the RCSLT/ NIHR dysphagia research priorities and would like it featured on this document, please email lauren.longhurst@rcslt.org