Research Newsletter from the Royal Hospital for Neuro-disability

## brainwaves

Summer 2019

## RHN speech therapist starts PDOC PhD at UCL

In September I started a part time PhD at University College London (UCL) in the Department of Language and Communication Science. I am researching how we assess functional communication in patients emerging from a Prolonged Disorder of Consciousness (PDOC). At UCL I have been developing the skills to carry out a research project based at the RHN. So far, I have reviewed what we already know about assessing emergence and where the gaps are. I have also devised and sent out an online questionnaire to specialist clinicians working with PDOC patients. I am about to start analysing the results and I am looking forward to finding out what they show.

It is fantastically exciting and I feel very lucky as I am the first person to benefit from the RHN PhD Fellowship fund, which has been set up to help therapists carry out research relevant to our patients. I am Clinical Lead Speech and Language Therapist on the Brain Injury Service and I have worked at the RHN for 14 years. My experience working with this complex population has enabled me to identify a clinically relevant research question that will directly benefit patients in the future.

At the RHN we often work with patients in a vegetative state or minimally conscious state. I am looking at how we assess if patients can communicate reliably to show they have emerged from this state. Accurate diagnosis is vital for patients, and their families, to make sure they get the correct care and therapy, and to support complex decision making about ongoing treatment.



My project has three stages

- 1. A survey of therapists and doctors across England to find out what currently works, what doesn't and how therapists work with families.
- 2. Working with patients from the RHN trying some different tasks with them to find out which they find easier. For example, I will look at different types of yes/no questions about themselves, or about objects, and I will compare if there is any difference if a family member asks the question rather than a therapist
- 3. Using Eye Gaze technology, I will try a completely different task that doesn't involve language where a person looks at a point on a computer screen to show their answer.

Although it's strange being a student again and starting at the bottom, it has been really exciting starting at UCL and meeting other PhD students. I am learning how to juggle work, studies and a family. By the end of my PhD I hope to have found out what works and what doesn't, which will help our patients.

### **Amy Pundole**

Clinical lead speech and language therapist



## Memory and learning after brain injury

Our memory is a crucial part of our life; if we think about times that we forget important information, it is easy to bring to mind how distressing this can be and what consequences it can have. In people who have an acquired brain injury – some sort of damage to the brain through a stroke, or head injury, for example – memory problems are very common.

While there are many different types of memory, our verbal memory is perhaps one of the most important for functioning day-to-day. Verbal memory is our memory for words – either from things we, or that we have read. After a severe brain injury, people typically have trouble remembering really important things such as information about their diagnosis, or the pros and cons of what life may be like if they are discharged back to their own home compared to going to a care home. While our rehabilitation service currently uses a number of techniques to help people with their memory difficulties, there is a need to develop these further to ensure we can help patients as much as possible.

This study will investigate whether giving patients a brief rest after they have learnt some information helps them to hang on to more of that information than if they are asked to engage in another activity directly after learning something. The existing research suggests that some people with memory disorders show remarkable improvements in the amount they remember under these 'wakeful rest' conditions. The researchers have suggested that when the brain is left to think naturally, distraction free, after learning something, it is able to strengthen the memory for the information. On the other hand, if we have to do another task straight after learning something, the brain's resources are competing against each other making it harder to strengthen the memory. As you can imagine, when someone has brain damage, this task becomes very tricky.

The existing research on this topic is very convincing but hasn't until now been looked at in a more practical setting such as in a neuro-rehabilitation ward with patients presenting with more varied problems in their thinking skills, such as the people we see at the RHN. Our study is therefore plugging this gap by comparing the effects of rest versus distraction for patients in our rehabilitation service on Drapers ward, who are able to consent to take part. The potential benefits of the study are that we can refine the ways that we support patients with their memory difficulties based on their patterns of performance and thus help them to learn and remember information that is important to them.

#### **Dr Sarah Crawford**

Consultant clinical neuropsychologist

## Dr Nathan Illman

Clinical psychologist

## **Reflective practice**

Della Warren is a registered nurse, Queen's Nurse and specialist community public health nurse and health visitor. She is doing a PhD and has just completed her first year part-time which she combines with her quality assurance role at the RHN.

Della's PhD is looking at the impact of reflection in nursing on patients and residents. This research is particularly important as it is mandatory for every nurse to undertake reflection on their practice in order to maintain their registration on the National Professional Nursing and Midwifery Register with The Nursing and Midwifery Council (NMC).

The reason for this research is because there is very little known about the impact of reflective practice from experienced nurses in clinical environments with complex patients. Della has completed an extensive international literature and policy review. She presented her findings at this year's National Queen's nurse meeting through the Queen's Nursing Institute (QNI).

She is currently refining her methodology and will be actively engaging in data collection over the next year. Della is hoping to fill the gap in the available evidence to support how reflection in nursing impacts on the experience of patients and residents and how to best implement it in clinical practice.



## The assessment of mood and wellbeing in severe brain injury

Severe brain injury affects cognitive, physical, social and emotional facets of a patient's life. One area that can be particularly challenging to address is mood difficulties such as depression and anxiety. Accurate diagnosis and treatment is essential as mood disorders could potentially impact on a patients' functioning and their abilities to meet their goals.

In the general population, mood disorders are identified using clinical interviews and/or selfreport questionnaires. However, these methods do not work with most patients at RHN because they may not have the necessary attention span, language, memory and abstraction skills to engage with a clinical interview. They may not be able to understand and answer complex questions accurately. Current national clinical guidelines suggest alternative methods such as inferring a patient's mood from observations, but these could have more than one possible meaning and could be difficult to attribute to mood alone.

The risks of inaccurately diagnosing someone as having depression when they do not (false positive) or mistakenly concluding that someone is not depressed when they are (false negative) are high. False negative diagnoses can result in patients not receiving the support they need and potentially failing to make as much progress as they could. False positive diagnoses can result in patients being prescribed unnecessary medication that could have a wide range of negative side-effects. As a clinical psychologist specialising in neuropsychology, I identified this is an area of possible health care inequality and am endeavouring to improve the assessment of mood and wellbeing in this population. My PhD project will evaluate current measures for assessing mood by applying these assessments and detailing their limitations. I will also use these measures with non-brain-injured people; first, to evaluate the benefits and drawbacks of repeated assessments of mood and wellbeing; and secondly, to explore whether asking positive questions about wellbeing is more useful than asking negative questions about low mood.

The study will broaden our understanding of how staff and families understand mood and mood disorders in our patients, as this is something which often concerns them. The overall aim from these studies will be to develop an alternative methodology for measuring mood and wellbeing for people with severe brain injury. It is anticipated that the findings will help the RHN to contribute to revisions of national clinical guidelines, in order to ensure that vulnerable patients with severe brain injury receive more accurate diagnosis and appropriate treatment in the future.

#### Alexandra Rose

Principle clinical psychologist



# Augmentative and alternative communication training

The development of a care staff training programme in augmentative and alternative communication (AAC) based on the views of users and carers in a long-term care setting.

For many people with communication difficulties as a result of a head injury, stroke or progressive condition, communication aids, or AAC, are their only means of communicating. These can be paper-based letter and picture charts, or computer systems which have a synthesised voice output (Communication Matters, 2018). Worldwide the numbers of people using these devices has risen and is likely to rise further because of increased life expectancy and people with complex conditions living longer due to medical developments (Department of Health, 2014). At any one time in the RHN we have approximately 25 people depending on a communication aid to communicate.

Everyday, nurses and HCAs set up and use AAC devices for communication with patients who have communication difficulties. To do this they require training. Currently there is no evidence base on what that training should be. We know that communication breakdowns occur between care staff and adults who have communication difficulties. These breakdowns can be more frequent if the individual is using a communication aid, such as a chart or a computer which the carer does not understand how to use or to set up.

This mixed-methods study will interview adults who use AAC and invite five to eight nursing staff to be

part of a focus group to discover how both of these groups feel about their communication with each other, and their views on training. Following analysis of this data, a training intervention will be developed.

The research has now started with interviews with three residents about their views on nurse training. These findings will feed into the training, as will the information we get from the nursing staff in their focus groups. Both the focus groups and the interviews will use Talking Mats (www.talkingmats. com) an evidence-based interactive resource that uses picture communication symbols to establish the views of another person.

The training intervention will be evaluated through in-depth semi-structured interviews with the people who use AAC, and post-training, surveys to capture knowledge and satisfaction with communication interactions will be taken by care staff.

It is hoped that the training intervention developed is successful and can be used at the RHN to help staff learn about how to use AAC. The training could then be disseminated to other nursing homes, rehabilitation units and other settings where people with communication difficulties live.

### **Helen Paterson**

Advanced specialist speech and language therapist

- Communication Matters (2018) What is AAC? [Online] Accessed 30/05/2018: <u>https://www.communicationmatters.org.uk/page/whatis-aac</u>
- 2. Department of Health (2014) Transforming primary care. London: Department of Health.

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