Rediscovering missing voices in aphasia patients

**Professor Elizabeth Armstrong** is a speech pathologist with a keen interest in acquired communication disorders following brain injury. She describes her innovative research in the field and the challenges still to overcome.

What are acquired communication disorders (ACD) and how do they affect an individual’s daily life?

Acquired communication disorders are difficulties with communication following a neurological event, such as stroke or traumatic brain injury, which damage areas of the brain that control language and the motor aspects of speaking. If the area of the brain that is involved with motor control is damaged, then speech can be slurred and the vocal tone can be nasal or husky. If the area of the brain controlling language features such as vocabulary and grammar is damaged, the person may forget words, use incorrect words or get the order of words wrong in sentences. Their ability to understand conversations, read and write can also be affected.

Traumatic injury to the frontal lobe of the brain can cause difficulty with social communication in everyday interactions in that the person may not know when to start talking, when to stop talking or may not abide by rules of communication such as politeness. Any of these disorders can severely impact on an individual’s family relationships, social life, employability and ability to organise one’s life in the way they did before the event.

Can you reveal what led to your passion for studying aphasia and speech recovery following brain injury?

I have always been interested in communication and gained qualifications in speech pathology and linguistics to pursue this passion. Working clinically for many years in acute hospital and rehabilitation settings highlighted to me the need for a greater understanding of communication and brain function, and what happens to a person with aphasia and their family after a life changing event such as a stroke or traumatic brain injury.

We are just beginning to understand which areas of the brain contribute to complex human functions, such as thinking, talking, writing and reading, and how different areas interact in complex ways to produce these sophisticated human behaviours. To assist in recovery of communication skills following brain damage, and to better inform clinicians, researchers and families of the issues involved and ways to assist the person’s ongoing quality of life, we need much greater knowledge in this area.

What are the best methodologies for research in the area of ACD?

Both quantitative and qualitative methodologies are relevant to the area of ACD. We need to know incidence patterns of disorders, we need strong standardised outcome measures to be able to compare the effects of different treatment methods, and we need standard treatment protocols so that studies can be replicated to build a strong evidence base. Our current study on early aphasia intervention uses a randomised control trial methodology, which is the current gold standard in the quantitative methodology sphere. We also need to use qualitative research methods such as interviews to explore the experiences of people with ACD and their families. This is so that treatment protocols can incorporate relevant aspects that are important for the consumers of services themselves.

Could you outline the main challenges facing cross-cultural research such as your work with Indigenous and non-Indigenous patients in Australia?

Establishing links with communities and ensuring cultural security for partners and participants are the primary challenges. This involves authentic relationships and partnerships that can take years to develop. Designing research frameworks that incorporate ongoing consultation and collaboration with partners and feedback to participants involves working closely with collaborators at the outset.

The project planning and preparation should ideally be driven by community needs and when a community may not be aware that anything can be offered in an area like brain injury, providing detailed information and discussion on the area is essential before a project can even begin to gain momentum. Language difference is also an important challenge in this area. For example, there are approximately 120 distinct Aboriginal languages in Australia, but access to Aboriginal interpreters for research and/or clinical purposes is low.

How important is it to form the right teams and maintain cohesion to achieve successful collaboration?

Teamwork is essential in all research, and finding the right people with the relevant areas of expertise is crucial. In my experience, multidisciplinary teams add richness and value to a project as they provide different perspectives on the issue at hand. Where teams are not physically co-located, extra effort is needed to ensure that ongoing channels of communication are maintained through face-to-face meetings, teleconference and electronic forms of communication. In the case of research investigating Aboriginal health issues, Aboriginal team members and leaders are essential.
Almost one-third of stroke patients have acquired communication difficulties. Research at Edith Cowan University, Australia, is leading the development of rehabilitation therapies to give these individuals back their voice.

ACQUIRED COMMUNICATION DISORDERS (ACD) typically arise after damage to the brain from a stroke or head injury. The resulting conditions, including aphasia, mean sufferers have difficulty communicating, often using incorrect words or grammar, slurring their speech or failing to respond to social situations properly.

People with aphasia rarely fully regain full independence, and often suffer from social and emotional isolation. Less than 23 per cent of aphasia patients who are employed before developing the condition return to work. Aphasia devastates the lives of affected individuals by limiting their independence and employability, and acting as a barrier between the patient and their family, as well as the wider community.

At Edith Cowan University, Australia, Professor Elizabeth Armstrong leads a multidisciplinary team investigating communication disorders such as aphasia. Despite 30 per cent of stroke victims having ACD, there is still little understanding of the condition by the general public and there is a lot to be learned about the condition in the scientific field. Armstrong explains: “Rehabilitation services are currently under-resourced for providing services to people with ACD, and those with the condition are often left out of stroke research because of their lack of ‘voice’”. Her pioneering work aims to highlight the importance of ACD and investigate potential approaches to enhance the recovery of ACD patients.

EARLY TREATMENT OF ACD
After a stroke, the brain quickly establishes new neurological pathways to repair itself. A key component of aphasia treatment is speech therapy, with recent research suggesting that the sooner this treatment starts, the better the chance of recovery. Armstrong and colleagues established the Very Early Rehabilitation in Speech (VERSE) project, which investigates the efficacy and cost-effectiveness of very early aphasia therapy. Beginning language rehabilitation during this early phase may enable the brain to strongly incorporate language into its new circuits. Moreover, daily aphasia therapy has been shown to significantly improve communication independence when implemented immediately after a stroke.

Unfortunately, this approach is rare in practice, with fewer than 30 per cent of patients receiving very early aphasia treatment in hospital.

Despite the promising potential of early therapy, Armstrong explains that more research is needed: “To date, the results of the few studies in this area have been equivocal, with methodological issues ranging from low numbers of participants restricting conclusions to inferior experimental design. VERSE is aiming to recruit 246 patients. The largest study to date in this area, it conforms strictly to international standards for randomised control trials and includes a cost-benefit analysis, following patients on their recovery journey for six months after the stroke”. The VERSE project aims to prove that very early aphasia therapy is both beneficial and cost effective over a longer period, ultimately influencing healthcare policy to improve the services for aphasia patients and their families.

TIMING IS CRUCIAL
The time immediately following a stroke is believed to be the period in which extensive recovery occurs. However, the team’s
ACQUIRED COMMUNICATION DISORDERS

OBJECTIVES

- To highlight the importance of acquired communication disorders (ACD) and research novel approaches to improve the recovery of ACD patients
- To improve services offered to survivors of stroke and traumatic brain injury and, ultimately, improve recovery outcomes
- To investigate the effects of very early intervention for aphasia after stroke and explore the experiences of Aboriginal Australians with communication difficulties following stroke and traumatic brain injury

KEY COLLABORATORS

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PROFESSOR ELIZABETH ARMSTRONG is Foundation Chair in Speech Pathology at Edith Cowan University, Australia. She publishes widely in the field of aphasia and leads large multidisciplinary research teams focused on speech recovery following brain injury. Cross-cultural implications for services with a focus on Aboriginal populations constitute an important part of the research programme.

Armstrong’s research surrounding both Aboriginal ACD patients and the importance of early treatment is undoubtedly benefiting the lives of those affected by communication disorders.

earlier studies have already highlighted that stroke patients with aphasia are not receiving equivalent communicative activity in hospitals as those without aphasia. Upon observation of the very early recovery of twenty stroke survivors, half of which had aphasia, Armstrong’s team found that the patients with aphasia were left alone for significantly longer periods of time than those without aphasia, and were less likely to be engaged in communication at any given time. Another of the team’s studies found that nurses generally asked closed questions, which potentially led to communication breakdown and encouraged the development of learned non-use of language in aphasia patients.

Communicating with aphasia patients is certainly challenging; however, such isolation during this critical early period may well be inhibiting recovery. Armstrong and colleagues are now investigating potential approaches to enhance communication with aphasia patients in hospitals, such as, for example, specific training of staff as conversation partners, which may improve communication abilities in early stroke recovery.

MISSING VOICES: CULTURAL DIFFERENCES IN ACD REHABILITATION

Another of Armstrong’s key research foci is to investigate the issues facing Aboriginal people with ACD. This is due to strokes and traumatic brain injury being two to three times more common in Aboriginal people than non-Aboriginal people in Australia, and often occurring at a younger age. “Representation of Aboriginal people in rehabilitation services is low, and long-term outcomes for the individuals are unknown. This situation is true for Indigenous peoples internationally,” Armstrong explains. “We hope to highlight the number of people suffering from ACD, current services available to them, attitudes of health professionals providing these services to working with Aboriginal communities and, most importantly, experiences of Aboriginal people with ACD and their families.” Through this work, Armstrong and her team aim to improve services provided to Aboriginal people with ACD.

The Missing Voices project has already elucidated some of the reasons behind the low number of Aboriginal patients receiving rehabilitation services. These include Aboriginal people having competing health and social needs that prevent them from accessing services immediately after discharge from hospital, as well as a lack of awareness of being able to re-enter the rehabilitation services at a later stage, and inflexibility of systems in this regard. In addition, the team found that rehabilitation services are often only being offered far away from the person’s ‘country’ and there is limited availability of such services even in the better resourced metropolitan areas. Breakdown in communication between multiple services involved in the person’s medical conditions as well as limited care coordination have also been highlighted as key issues. Furthermore, general medical practitioners were shown to be not referring to rehabilitation services later down the track because of perceptions that the person has already ‘had rehab’, which is often not the case, and under-identification of the effects of stroke and brain injury as a chronic condition was also a problem.

REHABILITATION REVAMP

Cultural and linguistic differences between patients and therapists in rehabilitation treatments can present challenges. Patients often feel isolated, while therapists vary significantly in their level of confidence when working with Aboriginal patients with ACD, particularly in finding ways to engage patients across a language barrier. The Missing Voices project builds on and provides evidence for the recommendations of the National Rural Health Alliance of Australia, highlighting the need for rehabilitation workers to be located within local Aboriginal health services and specific cultural competence training to be developed for clinicians working with Aboriginal and Torres Strait Islander patients with brain impairment. Service delivery models must also be developed to provide accessible and culturally appropriate therapy for all patients, both in urban and rural locations.

Armstrong’s research surrounding both Aboriginal ACD patients and the importance of early treatment is undoubtedly benefiting the lives of those affected by communication disorders. By helping service providers better understand the needs of Aboriginal people with brain impairments, the Missing Voices project will improve the care provided to patients within Aboriginal communities. Furthermore, by establishing early intervention projects such as VERSE to improve language rehabilitation during a critical time for recovery, Armstrong and her team are helping to bring back the lost voices of affected individuals.