Institution: City University London

Unit of Assessment: 3 Allied Health Professions, Dentistry, Nursing and Pharmacy

Title of case study: Reducing the consequences of aphasia: Improving intervention and outcome measurement

1. Summary of the impact

Aphasia is a language disorder, typically caused by stroke. It affects about 250,000 people in the UK and numbers are likely to grow with the ageing population. Research at City University London has had a major impact on the treatment of aphasia and on the way that treatment outcomes are assessed. Specifically, our research has:

- generated therapies that significantly enhance language and communication skills
- created measures of quality of life that can be self-reported by people with aphasia and used to assess rehabilitation outcomes.

Our therapy approaches and assessment tools are widely used across the world and are recommended in National and International Clinical Guidelines. As a result, we have enabled people with aphasia to express the impact of aphasia on their lives and helped practitioners to address the language needs that arise from aphasia. We have also helped to establish quality of life as a primary focus for intervention.

2. Underpinning research

Research in Language and Communication Sciences has been a major strength at City University London for over 25 years. The research underpinning the impacts presented here addresses both treatment of aphasia and the quality of life and outcome measurement for people with aphasia.

Treatment of Aphasia

Several innovative aphasia therapy approaches have been pioneered and evaluated under the leadership of Professor Marshall (at City since 1992). The work has shown that word finding problems, virtually ubiquitous in aphasia, can be alleviated and sentence production improved.[1,2,7,10] Treatment benefits have been demonstrated in bilingual populations[13] and findings have shown that people with severe aphasia can learn compensatory communication strategies such as drawing and gesture.[8,11] Treatments were informed by our theoretical work, e.g., relating to the processing impairments underpinning aphasia[3] with the results of treatments contributing to further theoretical work. All studies used experimentally-controlled evaluations which delineate the degree and limitations of change. Many also incorporated novel assessments of communicative impact, so that changes in everyday language could be evaluated (a factor that is often neglected in aphasia therapy research). In all cases therapy was described in sufficient detail to be replicable within routine clinical contexts.

In addition to Marshall, the research was undertaken by Pring (at City since 1983), Chiat (at City 1983 to 2000 and since 2006), Cruice (at City since 2002), Byng (at City 1993 to 2001), Pound (at City 1994 to 2001), Robson (at City 1995 to 2002), Cocks (at City 2005 to 2012) and Hickin (at City 2005 to 2012). One collaborator (Best) is based at UCL and one (Marsello) at the Royal London Hospital. The work was supported by one grant from the Medical Research Council, four from The Stroke Association and one from The Barts and The London NHS Trust (details in section 3).

Quality of life and outcome measurement for people with Aphasia

Research led by Drs Hilari and Cruice (both at City since 2002) has explored quality of life and its measurement in people with aphasia. The work has provided evidence on how patient-reported outcomes can be elicited from people who have aphasia and factors influencing quality of life.

A key achievement is the development of a new quality of life tool (the Stroke and Aphasia Quality of Life scale – 39 item, SAQOL-39g) that can be used with all stroke survivors, including those with aphasia.[4] Evidence has been provided on the relevance and application of existing quality of life measures for people with aphasia; and we have demonstrated how interviewer training and other adaptations can enable people with aphasia to complete quality of life measures.[4, 5] For those who

experience difficulties with self-reporting, we have provided evidence on the direction and magnitude of bias in proxy responding and on how to interpret proxy ratings on quality of life measures.[6] We have examined factors that affect quality of life in stroke survivors with aphasia.[4, 5]

Prior to our work, people with aphasia were typically excluded from stroke outcome studies because of their language difficulties. We have shown that this group can self report, in line with the current emphasis on patient reported outcome measures (PROMs), and have thus generated new insights about the impact of aphasia on quality of life. For example, people with aphasia report worse quality of life than people without aphasia after stroke, even when their physical abilities, wellbeing and social support are comparable. They also participate in fewer activities, have lower mood and reduced physical functioning. These findings have underscored the importance of aphasia rehabilitation for stroke outcomes.

Dr Hilari's work was supported by grants from the Stroke Association, the Dunhill Medical Trust, the Health Foundation (Consortium for Healthcare Research) and the NIHR Service Delivery and Organisation (SDO) programme. Collaborators are based at London School of Hygiene and Tropical Medicine (Lamping, Smith), the Institute of Education (Wiggins), Brunel University (Scriven), Auckland University of Technology (McPherson) and City (Devlin, Lawrenson, Needle, Petchey). Other key academic contributors at City were Byng and Law (employed 1989 to 2004) and Weinberg (1999 to 2007). Clinical collaborators include Consultant Physicians Drs Ames and Chataway from St Mary's Hospital, Imperial College Healthcare NHS Trust; and Speech and Language Therapist Alice Lamb from Royal Free London NHS Foundation Trust. Dr Cruice's work was supported by an Australian Postgraduate Award (1998 to 2001). Her main collaborators (Worrall and Hickson) are based at the University of Queensland, Australia.

3. References to the research

More than 30 peer-reviewed articles have been published in each of the two areas of work. The selected outputs are published in highly-regarded journals in the relevant fields and outlets with a wide international and clinical readership.

1. Marshall J., Pring T. & Chiat S. (1998). Verb retrieval and sentence production in aphasia. *Brain and Language*, 63, 159-183 10.1006/brln.1998.1949
2. Robson J., Marshall J., Pring T. & Chiat S (2001). Enhancing communication in jargon aphasia: a small group study of writing therapy. *International Journal of Language and Communication Disorders*, 36, 471-488. 10.1080/13682820110089371
3. Marshall, J. (2006). Jargon Aphasia: what have we learned? *Aphasiology*, 20, 387 – 410. 10.1080/02687030500489946
4. Hilari K., Byng S., Lamping D.L., & Smith S.C. (2003). Stroke and aphasia quality of life scale-39 (SAQOL-39): evaluation of acceptability, reliability and validity. *Stroke*, 34 (8), 1944-1950 10.1161/01.STR.0000081987.46660.ED
5. Cruice, M., Worrall, L., Hickson, L., & Murison, R. (2003). Finding a focus for quality of life with aphasia: Social and emotional health, and psychological well-being. *Aphasiology*, 17(4), 333-353. 10.1080/02687030244000707
6. Hilari K., Owen S. & Farrelly S.J. (2007). Proxy and self-report agreement on the Stroke and Aphasia Quality of Life scale (SAQOL-39) *Journal of Neurology, Neurosurgery and Psychiatry*, 78, 1072-1075 10.1136/jnnp.2006.111476

Related funding has been provided as follows:

7. Pring, T., Marshall, J., & Chiat S. The Investigation and Treatment of Jargon Aphasia, Medical Research Council, 1993 to 1996, £153,479.
8. Byng S., Marshall, J., & Pound, C. Alternative Communication Strategies in Severe Aphasia: An Evaluation of Therapy for Drawing. The Stroke Association, 1996 to 1997, £30,000.
9. Marshall, J., Robson, J., Pring, T., & Chiat, S. Communicative Writing in Jargon Aphasia: A Therapy Investigation. The Stroke Association, 1998 to 1999, £29,433.
10. Marshall, J., Robson, J., Pring, T., & Chiat, S. The production and comprehension of proper

nouns in aphasia. The Stroke Association, 1999 to 2000, £32,423.
11. Marshall, J., Pring, T., Cruice, M., Cocks, N., Hickin J., & Best, W. Enhancing communication in aphasia through gesture. The Stroke Association, 2006 to 2009, £117,292.
12. Marshall, J., Pring, T., & Marsello, S. Word finding difficulties in bilingual aphasia: implications for speech and language therapy. The Barts and The London NHS Trust. 2003 to 2006, £117,759.
13. Byng, S., Marshall, J., & Pring, T. Doctoral Fellowship: Quality of life in aphasia, The Stroke Association, 1999 to 2001, £40,000. (Award recipient: Hilari, K.)
14. Byng, S. & Law, J. Assessing health related quality of life in people with chronic aphasia, The Dunhill Medical Trust, 2001 to 2002, £31,500 (Award recipient: Hilari, K.)
15. Hilari, K. Assessing health-related quality of life after stroke. The Consortium for Healthcare Research of the Health Foundation, 2004 to 2008, £134,000.
16. Petchey R., Needle J., Lawrenson J., Hilari, K., Devlin N., Scriven A., Weinberg J., & McPherson K. The role of Allied Health Professionals in health promotion. NIHR SDO Programme (Public Health Limited Open Call Scheme), 2007 to 2010 £150,000.

4. Details of the impact

The key beneficiaries of our aphasia research are people with stroke and aphasia, along with the healthcare practitioners who support them. The impact has occurred via changes in the administration of speech and language therapy (SLT) and via the use of the tools we have developed for assessing quality of life, targeting treatment and measuring treatment outcomes.

We have developed therapy approaches that are well-evidenced and widely-recommended to practitioners both in the UK and abroad. This is demonstrated by Clinical Guidelines and Evidence Tables from across the English-speaking world. For example, our therapy papers are cited in the UK Royal College of Speech and Language Therapists Clinical Guidelines[17], the American Speech Hearing Association Evidence Maps (accessed 2012)[18], the Academy of Neurologic Communication Disorders and Sciences (Aphasia Treatment Evidence Tables)[19], the Speech Bite Data Base of Best Interventions and Treatment Efficacy (Australia, accessed 2013)[20] and the Evidence-Based Review of Stroke Rehabilitation (Canada, accessed 2013)[21]. These resources document best practice and the associated evidence base and in many contexts define treatments that can be reimbursed by funders. The Evidence Maps of the American Speech Hearing Association, for instance, state that word finding treatments are efficacious for people with aphasia; their meta-analysis supporting this claim includes studies from City.

Our treatment studies are taught on speech and language therapy training courses, both in the UK and abroad, and are widely referenced in clinical texts. For example, there are 29 references to therapy studies conducted at City University London in R. Chapey (ed) 'Language Intervention Strategies in Aphasia and Related Neurogenic Communication Disorders', 2008. This standard text is on the reading lists of all speech and language therapy courses in the UK. The quality of our therapeutic research was recognised by the award of a Fellowship of the Royal College of Speech and Language Therapists in 2009 to Professor Marshall. Findings were presented to policy-makers at the All Party Parliamentary Group on Medical Research Summer Reception, July 2010. This was attended by the Secretary of State for Health and the Universities and Science Minister. A booklet which included a summary of the showcased City project was produced from the event and Ministers indicated that this would be passed to the Treasury. The findings from our aphasia treatment research have also been disseminated through keynote presentations at practitioner conferences (e.g., in the UK, Australia, Denmark, Germany, Greece and Russia) and through study days for practising clinicians in the UK, Ireland, Greece, Russia and Denmark.

A further impact has been in the domain of technology. Our research into gesture therapy has resulted in the development of a novel computer gesture therapy tool (GEST) with funding from the Engineering and Physical Sciences Research Council. This tool has been piloted with aphasic participants and has been shown to bring about significant gains in the use of communicative gestures. The tool has been made available to a larger group of aphasic participants in a follow-up PhD study. The wider stroke population has been informed via an accessible online video (see https/vimeo.40081415) and via user involvement days at the University.[22]

The quality of life measures and methodologies developed at City University London allow clinicians to assess the impact of stroke and aphasia on people's lives and to make interventions more tailored to their patients' needs. Our tools, particularly the SAQOL-39, are becoming an international gold standard, evidenced by Clinical Guidelines. The SLT resources referred to above all cite our quality of life work. In addition there are citations in generic stroke guidelines, such as the StrokeEngine (Canada) website which offers advice to practitioners based on best available evidence.[21] The uptake of the tool in clinical practice provides further evidence of the reach of the impact. For example, the SAQOL-39 is used for six-month reviews in Camden (Central and NW London NHS Trust) to see whether the quality markers of the National Stroke Strategy are being met.[23] This illustrates the use of the tool as a primary evaluation measure for a major stroke service.

Uptake is not confined to the UK. The SAQOL-39 has been requested for use by over 300 practitioners around the world and has been or is being translated and culturally adapted for use in over 30 countries. In 2013, the International Association of Logopedists and Phoniatrics (IALP) surveyed Speech and Language Therapists from 17 countries (including 8 from Europe, USA, Australia, New Zealand and South Africa) on their assessment of quality of life in clinical practice. The 535 respondents worked in a range of clinical settings (acute-subacute, inpatients, outpatients, community) and at all stages of stroke rehabilitation. The SAQOL-39 was in the top three most commonly used measures of quality of life. The methodologies of Cruice contributed to an international Think Tank on social approaches in aphasia (Toronto, 2007) which has developed into ongoing project to extend international collaboration in social approaches to aphasia treatment.

Dissemination of our quality of life research during the REF period has included 13 international keynote and invited presentations at practitioner conferences (e.g., in the UK, Denmark, Greece, Norway and Slovenia), presentations to user groups, such as Connect, the Communication Disability Network for people living with aphasia, and to general public audiences (e.g., the ESRC Festival of Social Sciences held at City in 2011). The work has also provided a model for other areas of practice, e.g., in stammering. Our work has been taken up in publications for service users. For example, the user publication 'Feeling overwhelmed: The emotional impact of stroke' (The Stroke Association, 2013) cites City research (Hilari) to make the point that emotional distress and depression are more common in stroke survivors with aphasia than those without.[24]

City's research has had significant and wide-reaching impact on speech and language therapy practice for people with aphasia and has provided clinicians with new tools for assessing that practice. We have helped to place self-reported quality of life at the heart of rehabilitation.

5. Sources to corroborate the impact

17. Taylor-Goh S. (2005) RCSLT Clinical Guidelines: 5.12 Aphasia www.rcslt.org/members/publications/clinicalguidelines
18. American Speech Hearing Association, The National Center for Evidence-Based Practice in Communication Disorders www.ncepmaps.org/
19. Academy of Neurologic Communication Disorders and Sciences (Aphasia Treatment Evidence Tables) http://aphasiatx.arizona.edu/
19. SpeechBite: an open access catalogue of **B**est **I**nterventions and **T**reatment **E**fficacy across the scope of Speech Pathology practice www.speechbite.com/index.php
20. The Evidence-Based Review of Stroke Rehabilitation (EBRSR) www.ebrsr.com
21. Stroke Engine Information about Stroke Rehabilitation, Canada http://strokengine.ca/
22. http://www.city.ac.uk/news/2013/nov/school-of-health-sciences-brings-londons-aphasia-research-community-together
23. http://arms.evidence.nhs.uk/resources/qipp/116737/attachment
24. www.stroke.org.uk/involved/feeling-overwhelmed-report