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| Institution: City, University of London | | |
| Unit of Assessment: Allied Health Professions, Dentistry, Nursing and Pharmacy | | |
| Title of case study: Changing practice in treatment for aphasia: novel measures and interventions that address patient priorities | | |
| Period when the underpinning research was undertaken: 2003 - ongoing | | |
| Details of staff conducting the underpinning research from the submitting unit: | | |
| Name(s): | Role(s) (e.g. job title): | Period(s) employed by submitting HEI: |
| Prof Jane Marshall | Professor, Division of Language and Communication Science | 1990 – present |
| Prof Katerina Hilari | Professor of Acquired Communication Disorders | 2002 – present |
| Dr Madeline Cruice | Reader | 2002 – present |
| Dr Celia Woolf | Senior Research Fellow | 2008 – present |
| Period when the claimed impact occurred: 2013 – 2020 | | |
| Is this case study continued from a case study submitted in 2014? No | | |
| 1. Summary of the impact <p>Over 300,000 people in the UK have language impairment after stroke (aphasia), a figure that is rising with the aging population. Studies undertaken in the Centre for Language and Communication Science Research at City, University of London have made a real difference to the lives of people with aphasia. Our patient-focused outcome measures reveal the impact of aphasia on people's lives and help clinicians choose interventions to improve quality of life. They are advocated as gold standards for use in all aphasia trials. The team's novel intervention studies employ technology-enhanced aphasia treatments that significantly improve functional communication and recover previously lost language activities, with findings that are changing practice, both in the UK and internationally.</p> | | |
| 2. Underpinning research <p>Every year, 100,000 people in the UK have a stroke and one third of these individuals will acquire aphasia. Stroke survivors with aphasia have worse rehabilitation outcomes than those with other effects but no aphasia, resulting in devastating consequences for quality of life and mental health. Our research aims to address this inequality.</p> <p><u>Outcome measures</u></p> <p>It is a major challenge to capture the impact of aphasia on people's lives in order to target rehabilitation more effectively. People with aphasia are typically excluded from stroke studies because they have been considered unable to complete outcome measures. The outcomes research, led by <i>Hilari</i> since 2003, has shown how training interviewers to help people with aphasia understand questions and provide responses, alongside adaptations to the format of outcome measures (such as fewer items per page, key words in bold), can enable people with aphasia to self-report on measures of communication, wellbeing and quality of life. <i>Hilari</i> and her team have developed and/or validated novel outcome measures including the Stroke Specific Social Network Scale and the Scenario Test-UK that can be used to assess the outcomes of even those with severe aphasia. A key contribution has been the Stroke and Aphasia Quality of Life scale, (SAQOL-39g), a quality of life tool specifically tested in both people with aphasia and other stroke survivors so that it can be used as a key outcome in stroke services and stroke outcome research [3.1].</p> <p>The outcomes research has also generated rich evidence that factors such as emotional distress/depression, severity of aphasia, communication disability, activity limitations and diminishing social networks need to be addressed to improve quality of life [3.2]. Studies have</p> | | |

also revealed the status of current clinical practice in relation to quality of life in aphasia [3.3]. These findings subsequently informed our aphasia intervention research.

Intervention research

City has been conducting aphasia intervention research for over 25 years led by *Marshall*, whose contribution to improving the lives of people with aphasia was recognised by the award of an OBE in 2018. Much of our current intervention research grew from an innovative interdisciplinary collaboration between the Centre for Language and Communication Science Research and the Centre for Human Computer Interaction Design, bringing together expertise in aphasia intervention and computer science. The resulting research explored therapeutic uses of digital technologies to benefit people with aphasia. The CommuniCATE project developed new treatments for reading, writing and conversation that repurpose mainstream technologies, such as voice recognition software. Controlled group trials showed that these technology-enhanced treatments can restore functional/ real-life communication activities in aphasia [3.4], and that aphasia therapy can be delivered remotely via video conferencing technologies, with significant benefits for word production [3.5].

The team also developed EVA Park, the first multiuser virtual reality platform designed for people with aphasia. This enables people with aphasia to meet on-line for communication treatments and social support. Our research demonstrated that aphasia therapies delivered via EVA Park can enhance functional communication and improve specific language skills, such as word retrieval [3.6].

3. References to the research

- [3.1] Hilari K, Lamping DL, Smith SC, Northcott S, Lamb A, Marshall J. Psychometric properties of the Stroke and Aphasia Quality of Life Scale (SAQOL-39) in a generic stroke population. *Clinical Rehabilitation*. 2009;23(6):544-57.
<https://doi.org/10.1177/0269215508101729>.
- [3.2] Hilari K, Needle JJ, Harrison KL. What are the important factors in health-related quality of life for people with aphasia? A systematic review. *Archives of Physical Medicine and Rehabilitation*. 2012;93(1):S86-95.
<https://doi.org/10.1016/j.apmr.2011.05.028>.
- [3.3] Hilari K, Klippi A, Constantinidou F, Horton S, Penn C, Raymer A, Wallace S, Zemva N, Worrall L. An international perspective on quality of life in aphasia: A survey of clinician views and practices from sixteen countries. *Folia Phoniatrica et Logopaedica*. 2015;67(3):119-30. <https://doi.org/10.1159/000434748>
- [3.4] Marshall J, Cauter A, Chadd K, Cruice M, Monnelly K, Wilson S, Woolf C. Technology-enhanced writing therapy for people with aphasia: results of a quasi-randomized waitlist controlled study. *International Journal of Language & Communication Disorders*. 2019;54(2):203-20.. <https://doi.org/10.1111/1460-6984.12391>
- [3.5] Woolf C, Cauter A, Haigh Z, Galliers J, Wilson S, Kessie A, Hirani S, Hegarty B, Marshall J. A comparison of remote therapy, face to face therapy and an attention control intervention for people with aphasia: a quasi-randomised controlled feasibility study. *Clinical Rehabilitation*. 2016;30(4):359-73.
<https://doi.org/10.1177/0269215515582074>
- [3.6] Marshall J, Booth T, Devane N, Galliers J, Greenwood H, Hilari K, Talbot R, Wilson S, Woolf C. Evaluating the benefits of aphasia intervention delivered in virtual reality: results of a quasi-randomised study. *PLOS ONE*. 2016;11(8):e0160381.
<https://doi.org/10.1371/journal.pone.0160381>

All outputs were published in prestigious academic journals that apply a rigorous peer-review process prior to acceptance of papers. The outputs were supported by grants from: the Health Foundation ("Assessing health-related quality of life after stroke", *Hilari* PI, 2004-2008, GBP134,000); Barts Charity ("Enhancing communication in aphasia through technology", *Marshall/Woolf* joint PIs, 2014-2017, GBP415,785); Bupa Foundation ("A Pilot Investigation of Aphasia Therapy Delivered via Internet Video Conferencing Technology", *Marshall* PI,

2012-2013, GBP19,926); The Tavistock Trust for Aphasia “Remote Aphasia Therapy: A Feasibility Study”, *Marshall* PI, 2012-2013, GBP53,263; and The Stroke Association, “Evaluating the effects of a virtual communication environment for people with aphasia”, *Marshall* PI, 2012-2016, GBP204,898.

4. Details of the impact

Impact of Outcomes research

The evidence generated by *Hilari* and her team has contributed to a paradigm shift in aphasia rehabilitation. Service providers and clinicians are direct beneficiaries of the research with a resulting impact on people with aphasia. Speech and language therapists are now increasingly addressing quality of life in their rehabilitation; in an international survey, the most commonly used measure to guide clinical practice was the SAQOL-39g [3.3]. The underpinning research has had an impact on National Clinical Guidelines; the Australian Aphasia Rehabilitation Best Practice Statement 5 “Providing Intervention” states that rehabilitation should address the impact of aphasia on quality of life and cite our work as the highest level of evidence [5.1] and one of our systematic reviews on diminishing social networks after stroke and links to depression has been cited in a NICE surveillance review as key evidence for the need to update the Stroke Rehabilitation Guideline, CG 162 [5.2].

Two of our tools, the SAQOL-39g and the Scenario Test-UK, are recommended in the international ROMA consensus statement, and these tools now comprise two of the four essential measures included in the Core Outcome Set (COS) for aphasia, which is endorsed by the Collaboration of Aphasia Trialists and the internationally respected COMET Initiative [5.3]. Of all measures evaluated in the aphasia COS, the SAQOL-39g had the highest selection rate (96% compared to 74-83%). A systematic review by Neumann et al. (2019) found that the SAQOL-39g is the most frequently used quality of life measure in aphasia research. The impact the SAQOL-39g has had on clinical practice is evidenced by the fact that it is validated and currently available for use in 19 different languages [5.4].

The team has developed a bespoke online platform, City Access Resources for Aphasia (CARA), to make the SAQOL-39g and other resources developed at City available to clinicians. CARA officially launched in May 2019 and now has more than 2,475 users from across the world, including Europe, Asia, United States, Canada and Australia. The SAQOL-39g, in particular, has been accessed for use 1,343 times. Testimonials from clinicians in the UK and abroad have highlighted how use of the SAQOL-39g has transformed their practice. This has included facilitating collaborative goal setting for patients with aphasia and their families, being used as the core outcome measure across the stroke rehabilitation team and providing evidence for increased therapy that improves rehabilitation of those with aphasia [5.5].

Impact of Intervention research

Our intervention research, led by *Marshall*, has made a significant contribution to the aphasia therapy evidence base, which in turn guides treatment selection by practising therapists. One study is included in the most recent Cochrane review of speech and language therapy for aphasia [5.6] and there are further citations in international therapy evidence tables, such as Speech Bite (Australia) and Speech Pathology Data Base for Best Interventions and Treatment Efficacy (USA).

Patient benefits have been promoted via extensive training and outreach activities. Over 450 qualified speech and language therapists have been trained in the CommuniCATE treatments, including groups (n = 40) from USA (2015) and Australia (2018). A further 50 speech and language therapy students have been trained through placement opportunities, with a profound impact on their learning and subsequent practice. Manuals for our CommuniCATE and remote treatment approaches are available on our CARA website.

Since the project inception in 2014, at least 200 people with aphasia have directly benefited from the CommuniCATE therapies, delivered by City, the NHS and Australian clinics. Significant improvements have been achieved for those receiving treatment on measures of

everyday reading and writing. Participants also report transformative benefits, such as being able to write in full sentences again and post personal stories on the internet [5.7].

EVA Park has been used at City to deliver therapy to 60 people with aphasia, using interventions that target language, communication and social support. Benefits have been demonstrated on formal measures and in the reports of users [5.8]. At least 200 service providers have benefited from practitioner EVA Park training. Forty-six aphasia services, including users from the USA, Australia, Spain and Bermuda, have been given access to EVA Park. All therapists have been trained in its use and provided with EVA Park treatment resources. To date, 427 user avatars have been created in EVA Park and over 5000 hours of therapy and support have been delivered on the platform. Feedback from service providers and recipients report important and novel benefits [5.9].

Online videos about EVA Park, which describe the intervention and its benefits from the perspective of therapists and those with aphasia, have attracted almost 6,000 views [5.10]. EVA Park has been recognised by the 2015 Tech4Good people's award, which was based on a popular mandate, and by its 2016 nomination as one of the world's 100 most inspiring uses of technology to drive social change (Nominet Trust). The EVA Park and CommuniCATE team was named as one of the 100 Nation's Lifesavers, during the UK Universities MadeatUni Campaign. Since the outbreak of the COVID-19 pandemic in the UK, digital technologies have been at the forefront for delivering primary care. The RCSLT Telehealth Guidance issued in response to the pandemic cites our research as part of the evidence base supporting the virtual delivery of speech and language therapy services [5.11].

5. Sources to corroborate the impact

- [5.1] The Australian Aphasia Rehabilitation Best Practice, Statement 5, p19. (Available from <http://www.aphasiapathway.com.au/flux-content/aarp/pdf/2014-COMPREHENSIVE-FINAL-01-10-2014-1.pdf> accessed 19 March 2021).
- [5.2] NICE Surveillance Review for CG162 the Stroke Rehabilitation Guideline. Appendix A: Summary of evidence from surveillance. p15 and reference 33. (Available from [appendix-a-summary-of-evidence-from-surveillance-pdf-6723786638 \(nice.org.uk\)](https://www.nice.org.uk/appendix-a-summary-of-evidence-from-surveillance-pdf-6723786638) accessed 19 March 2021).
- [5.3] Endorsements by the Collaboration of Aphasia Triallists (CATs) and the COMET initiative of the Research Outcome Measurement in Aphasia (ROMA) Core Outcome Set (COS).
- [5.4] City Access Resources for Aphasia (CARA) web page on SAQOL-39g translations.
- [5.5] Testimonials from clinicians supporting the use of SAQOL-39g, specifically: facilitating collaborative goal setting in patients with aphasia and their families; as the core outcome measure across the stroke rehabilitation team; and the use of SAQOL-39g results in benefits for patients with aphasia.
- [5.6] Brady MC, Kelly H, Godwin J, Enderby P, Campbell P. (2016) Speech and language therapy for aphasia following stroke. Cochrane Database of Systematic Reviews, Issue 6. Art. No.: CD000425. <https://doi.org/10.1002/14651858.CD000425.pub4>
- [5.7] CommuniCATE testimonials; blog posts by patients from the CommuniCATE Clinic.
- [5.8] Amaya A, Woolf C, Devane N, Galliers J, Talbot R, Wilson S, & Marshall J (2018). Receiving aphasia intervention in a virtual environment: the participants' perspective. *Aphasiology*, 32(5), 538-558. <https://doi.org/10.1080/02687038.2018.1431831>
- [5.9] Testimonials for EVA Park from a charity funder (The Stroke Association), patient/carer and therapist.
- [5.10] Video testimonials for EVA Park describing the intervention and its benefits. (Available from <https://www.youtube.com/watch?v=ouF1Nwvo6js> and <https://www.youtube.com/watch?v=k8iJVRFSsxA> accessed 19 March 2021).

[5.11] The Royal College of Speech and Language Therapists Telehealth Guidance web page.