Lost in interpretation: reflections on the challenges associated with completing a cross-cultural cognitive rehabilitation intervention

Alice Storey^{a*} & Nicolò Zarotti^{a,b}

^a Department of Clinical Neuropsychology, Manchester Centre for Clinical Neurosciences, Salford Royal Hospital, Salford, UK.

^b Division of Health Research, Faculty of Health and Medicine, Lancaster University, Lancaster, UK.

This is a pre-publication version of the following article: Storey, A., & Zarotti, N. (2024). Lost in interpretation: Reflections on the challenges associated with completing a cross-cultural cognitive rehabilitation intervention. *Clinical Psychology Forum*, *376*. https://doi.org/10.53841/bpscpf.2024.1.376.22

^{*} Corresponding author. Email: alystorey788@hotmail.co.uk. Address: Department of Clinical Neuropsychology, Manchester Centre for Clinical Neurosciences, Salford Royal Hospital, Salford, UK

This article shares the reflections on carrying out a cross-cultural cognitive rehabilitation intervention with a person not proficient in English. The aim is to highlight some of the challenges experienced throughout the process, along with lessons learnt with regards to improving accessibility for these specific populations. The reflections are shared from the perspective of an Assistant Psychologist (AS), who carried out the intervention under the supervision of a qualified Clinical Psychologist (NZ).

The UK is becoming increasingly more diverse. For instance, the 2021 Census Data reported that slightly less than three fourths of the current residents of England and Wales (74.4%, 44.4 million) identify as White English, Welsh, Scottish, Northern Irish, or British (Office for National Statistics, 2021). This number has seen a consistent decrease over the past two decades, falling from 80.5% (45.1 million) of residents in 2011 (Office for National Statistics, 2011) and 87.5% (45.5 million) in 2001 (Office for National Statistics, 2001).

With a more diverse population also comes the reasonable expectation to see people from all backgrounds being able access free care through the NHS. By working in one of the largest neuropsychology departments in the country, which provides neuropsychological assessments and interventions for inpatient and outpatient hospital-based referrals as well as community patients, I was curious to see whether this expectation was met. However, this did not appear to be the case; a recent retrospective evaluation of referrals within my service has shown that, compared to the 2021 UK census data for the region, all ethnic minorities were underrepresented in both outpatient and inpatient settings (Teager et al., 2023). Sadly, these (Harwood et al., 2023) data appeared to be consistent with other reports across the UK highlighting how, within the NHS, people from ethnic minority backgrounds can experience poorer health outcomes (Hackett et al., 2020), unmet needs (Hayanga et al., 2023), and sparser healthcare provision (Office for National Statistics, 2018). With specific regard to clinical psychology, the current literature shows that ethnic minorities tend to access psychological therapies less (Bhavsar et al., 2021), have worse outcomes following treatment (Arundell et al., 2024), and are less likely to be assessed and offered psychological treatment in general compared to white British people (Harwood et al., 2023).

While I remember feeling surprised to learn about these issues, it was not until I found myself caring for Muhammad[†], a patient who was not proficient in English, that I started to realise fully the challenges involved with this type of cross-cultural work, and why they may prevent people from ethnic minorities from accessing care in the first place.

Muhammad was a Pakistani man in his 50s referred to me for cognitive rehabilitation following an acquired brain injury. His main difficulties involved memory and processing speed, which often translated into problems with orientation and communication, as well as understandable feelings of frustration. After reviewing Muhammad's case record and the assessment carried out by my supervisor with the help of an interpreter, I proceeded to look for the current evidence on doing cross-cultural cognitive rehabilitation. And that is when the problems started.

Challenge 1: Lack of evidence

A quick search of the current literature revealed little to no evidence on referrals or outcomes for cognitive rehabilitation in patients who are not proficient in English. Similarly, there was no evidence considering the impact of cultural values within cognitive rehabilitation models. This was quite a concerning eye-opener and highlighted the abovementioned inequalities in accessing healthcare for

[†] The name has been changed to preserve anonymity. Written informed consent for publication purposes was obtained from the patient.

these population. In fact, I felt an element of discomfort about it – while I was aware of the existence of equality issues in healthcare, this was perhaps the first time I could see their actual impact on my daily clinical activity. Consequently, I also felt keen to use this experience to learn how to make cognitive rehabilitation more accessible.

Therefore, I went back to the drawing board. As we know, cognitive rehabilitation is an intervention which aims to improve cognitive functioning with the goal of changing behaviour, supporting everyday activities, and restoring independence (Nejati, 2023). This often involves finding ways not only to strengthen spared functions, but also to compensate those affected by brain injury (IOM, 2011). Throughout this process, another aim is also to increase an individual's understanding of their difficulties to elicit feelings of empowerment and reduce feelings of failure (Nejati, 2023).

While planning my intervention, I recognised that both the adopted model and the rehabilitation process not only needed to address and meet Muhammad's cognitive rehabilitation goals, but also respect and integrate his cultural values. As I had often been taught, a potential way to achieve this was to adopt flexible rehabilitation materials which could be easily tailored around a patient's specific needs, values, and difficulties. However, those materials would need to be available in the first place.

Challenge 2: Lack of resources

An extensive search across my department's resources was unsuccessful in providing me with any materials to carry out a cross-cultural cognitive rehabilitation not only with Urdu speakers, but also most of the other languages. As it turned out, this was by no means specific to my service, since an attempt to broaden my search by reaching out to external clinicians and academics also proved unfruitful. Therefore, I started to consider creating a custom set of resources. This, I thought, would need to be equal in quality to what we normally offer to English-speaking patients and be delivered just as effectively.

When I first started working in my department, assistant psychologists were pulling together the same resources for each cognitive rehabilitation referral before sharing them with the patients. After a few months, I began to feel this was not the most effective use of our time. More specifically, I would often observe that, whilst rehabilitation elements such as psychoeducation may be similar, the actual strategies implemented with individuals may differ from person to person and depend on several factors. Thus, following discussions with my supervisor and other senior clinicians, I created a cognitive rehabilitation booklet to help inform cognitive rehabilitation sessions within my department, enabling a person-centred approach. This was made to provide fairly standardised resources which could also be tailored around patients' requirements in line with the principles of the Functional Model of Cognitive Rehabilitation (FMCR; Lee et al., 2001). FMCR aims to be a person-centred approach which aims to address rehabilitation goals by considering clinical presentations alongside socioenvironmental factors (such as relationships and social contexts) and personal characteristics (e.g., values and cultural background). Within this perspective, compensatory strategies are built around the need to restore a person's function in activities relevant to them.

Based on the lack of resources in Urdu, I decided to adapt the booklet to Muhammad's specific needs and have it translated into his language by a professional translation service, which ensured the same standard of quality we used for English-speaking patients. In Muhammad's case, the rationale for using FMCR was to support the development of strategies which would be useful for his daily activities within his specific community. More specifically, the materials developed for him consisted of

psychoeducation on a range of cognitive domains (such as memory and attention), along with a list of strategies which could target his most valuable and important activities.

My initial appointment with Mohammad covered the aim of the sessions for him, ensuring that he had a clear understanding of what we were planning to address together through the support of an interpreter. Each week then focused on psychoeducation for the specific cognitive domains in which Muhammad had difficulties. Following this, we moved onto considering strategies. As mentioned above, this was done by exploring Muhammad's values and what activities were most important and valuable to him, in order to offer flexible and meaningful functional and compensatory strategies. For example, Muhammad was very religious and was not working. Therefore, our strategies tended to focus around his religious needs (e.g., navigating routes to the mosque and remembering prayers) rather than professional ones.

Challenge 3: Bridging cultural values

As mentioned, Muhammad's initial assessment had to be carried out with the help of an Urdu interpreter. As I cannot speak Urdu myself, I also found it vital to have an interpreter with me in each session. This enabled both me and Muhammad to build a good rapport and create a safe environment where he felt able to ask any questions freely. The interpreter was the same person who supported Muhammad's earlier assessment with my supervisor, which allowed for consistency and familiarity across Muhammad's care. Indeed, lack of familiarity with care providers has been highlighted as a barrier to open dialogue for people with cognitive impairments (Tang et al., 2019), while enabling a sense of familiarity in the clinical setting has been shown to be beneficial for rehabilitation purposes (O'Donoghue et al., 2022).

As previously mentioned, the FMRC model of cognitive rehabilitation aims specifically to develop person-centred interventions. Working with people from the same cultural background as myself (i.e., white British), it can feel easier to be person-centred, as many of the linguistic, cultural, and social values tend to be similar. However, working with Muhammad and noticing the differences in culture and values between us allowed me to understand that, up until that point, I had perhaps been taking for granted that my characteristics would be similar to most service users'. For instance, I do not consider myself a religious person. On the other hand, not only was Muhammad religious, but his religious values sat at the very core of most of his daily activities and social interactions. Having a lack of interest in religion in my personal life, I felt I also lacked some knowledge around Muhammad's cognitive and functional needs within the context of his spirituality.

This was where I found supervision, as well as the adoption of an interpreter (also a Pakistani man), instrumental in helping me bridge my and Muhammad's cultural values. On one side, supervision helped me reflect further on my values, how they may differ from Muhammad's, and the potential impact such differences could have during our clinical work, particularly when topics such as spirituality and religiousness are involved. On the other, working with the interpreter helped me gain a better understanding of Muhammad's culture and link the use of compensatory strategies to real life applications which were relevant to him. For example, I was able to discuss with the interpreter how to translate common memory strategies (e.g., visualisation) into specific tips to help Muhammad remember his prayers. Without an interpreter, I would have definitely not been able to address this aspect of Muhammad's life. This also allowed me to recognise a need to improve my general cultural sensitivity in my clinical work.

Challenge 4: Cultural Sensitivity

When we deal with language, we deal with culture (Imai et al., 2016). As mentioned above, this appeared to be an issue at times during my work with Muhammad, as he came from a culture whose fundamental elements could sometimes be very far from my own. However, being aware of this also proved to be instrumental in understanding the reasons behind some of his attitudes towards interventions. For instance, in Pakistani culture the collective family identity is frequently placed above personal ones (McGoldrick et al., 2005). With this in mind, I felt that it was essential to collaborate with the interpreter to explore Muhammad's views within the context of his family system, while being sensitive to his values and costumes. Throughout this process, I also had to be aware of my own cultural beliefs, being careful not to apply them implicitly to him.

With regards to this, I found that having open conversations between myself, the interpreter, and Muhammad allowed for the intervention to be equally patient-focused and evidence-based. However, in the past I also found that bringing a family member to the session may be helpful for rehabilitation purposes, as this can allow for a wider view into an individual's cultural context and may also facilitate the adoption of strategies outside of the clinical setting. Since Muhammad was happy to have his family around during the intervention, his daughter started joining us early on and eventually attended all of our sessions. This proved to be quite reassuring for him, as it helped further develop the abovementioned sense of familiarity. Moreover, having Muhammad's daughter with us allowed for the intervention to have an element of continuation outside of the sessions, as she helped ensure he would regularly practice his newly developed functional and compensatory strategies.

Challenge 5: Session Planning

Finally, a further challenge I found myself facing when carrying out a cross-cultural cognitive rehabilitation was a greater need to plan and organise sessions efficiently. Upon receiving Muhammad's referral, I had booked a series of consecutive weekly appointments with him in advance, as I would normally do with people proficient in English. However, having to translate standard or tailored materials between sessions also meant having to (re)schedule each session around the translators' delivery times, while also keeping the interpreter aware of any changes to the appointments. At times, this created some scheduling conflicts, since the translation service could take up 10 working days to complete a job during busy periods. On reflection, I found that allowing for a further 1-week gap between each appointment where materials needed to be translated was helpful to avoid disruptions.

A Note on Supervision

As I worked with Muhammad, I sometimes sat with feelings of guilt while reflecting on my own privilege of having no barriers when it comes to accessing healthcare. If I needed cognitive rehabilitation, there would be no need for additional wait time while session materials are translated, and would not have to be concerned about whether my clinician understands my cultural perspective. During my experience as assistant psychologist, I have often worked on cases which induced strong emotions. However, when I witnessed the differences in accessibility for Muhammad compared to English-speaking patients, I felt a sadness unlike any before, and I found supervision invaluable to explore these feelings.

More specifically, I am aware that I have a tendency to be a perfectionist, and in Muhammad's case I felt this translated into wanting him to have the exact same intervention experience as my English-

speaking patients. Speaking with my supervisor helped me realise that achieving this was at least partially out of my control due to the systemic barriers (e.g., lack of literature and materials) already in place before Muhammad was referred to our service. This sat uncomfortably with me and at times created a sense of helplessness. However, supervision also helped me refocus on the elements I could actively work on, such as increasing my cultural sensitivity and self-reflective skills. In fact, exploring this with my supervisor enabled me to become more aware and accepting of the iterative nature of self-improvement — a process which is never fully complete or 'perfect'. In addition, I feel that recognising that I am not solely responsible for systemic change, but that I can and should help promote it when possible, has helped shaped my future practice as I apply self-compassion while continuing to address inequalities in clinical psychology.

Conclusions

My experience working with Muhammad was seminal in making me realise that, despite the UK's increasing cultural diversity, there is still a long way to go to ensure that healthcare is equally accessible for everyone. Moreover, it has further taught me the importance not only to recognise the impact of language and culture, but also to explore their facets by maintaining a curious mind and avoiding preconceptions. It also helped me understand the importance of learning about cultures through those who are experts on them: having open conversations with the people we work with can help us get educated about diversity and facilitate the delivery of the type of tailored, personcentred support that everyone deserves. Ultimately, as someone who has the privilege of not experiencing any barriers accessing healthcare, Muhammad's case allowed me to understand the importance of always holding in mind those who may face these barriers on a daily basis.

References:

- Arundell, L. L. C., Saunders, R., Buckman, J. E. J., Lewis, G., Stott, J., Singh, S., Jena, R., Naqvi, S. A., Leibowitz, J., & Pilling, S. (2024). Differences in psychological treatment outcomes by ethnicity and gender: an analysis of individual patient data. *Social Psychiatry and Psychiatric Epidemiology*. https://doi.org/10.1007/s00127-024-02610-8
- Bhavsar, V., Jannesari, S., McGuire, P., MacCabe, J. H., Das-Munshi, J., Bhugra, D., Dorrington, S., Brown, J. S. L., Hotopf, M. H., & Hatch, S. L. (2021). The association of migration and ethnicity with use of the Improving Access to Psychological Treatment (IAPT) programme: a general population cohort study. *Social Psychiatry and Psychiatric Epidemiology*, *56*(11), 1943–1956. https://doi.org/10.1007/s00127-021-02035-7
- Hackett, R. A., Ronaldson, A., Bhui, K., Steptoe, A., & Jackson, S. E. (2020). Racial discrimination and health: a prospective study of ethnic minorities in the United Kingdom. *BMC Public Health*, *20*(1). https://doi.org/10.1186/s12889-020-09792-1
- Harwood, H., Rhead, R., Chui, Z., Bakolis, I., Connor, L., Gazard, B., Hall, J., Maccrimmon, S., Rimes, K. A., Woodhead, C., & Hatch, S. L. (2023). Variations by ethnicity in referral and treatment pathways for IAPT service users in South London. *Psychological Medicine*, *53*(3), 1084–1095. https://doi.org/10.1017/S0033291721002518
- Hayanga, B., Stafford, M., & Bécares, L. (2023). Ethnic inequalities in multiple long-term health conditions in the United Kingdom: a systematic review and narrative synthesis. *BMC Public Health*, 23(1). https://doi.org/10.1186/s12889-022-14940-w

- Imai, M., Kanero, J., & Masuda, T. (2016). The relation between language, culture, and thought. In *Current Opinion in Psychology* (Vol. 8, pp. 70–77). Elsevier. https://doi.org/10.1016/j.copsyc.2015.10.011
- IOM (Institute of Medicine). (2011). Cognitive rehabilitation therapy for traumatic brain injury: Evaluating the evidence. *Cognitive Rehabilitation Therapy for Traumatic Brain Injury: Evaluating the Evidence.*, xxii, 333–xxii, 333.
- Lee, S. S., Powell, N. J., & Esdaile, S. (2001). A Functional Model of Cognitive Rehabilitation in occupational therapy. In *OCCUPATIONAL THERAPY* (Vol. 68, Issue 1).
- McGoldrick, M., Giordano, J., & Garcia-Preto, N. (Eds.). (2005). *Ethnicity and family therapy (3rd ed.)*. Guildford Press.
- Nejati, V. (2023). Principles of Cognitive Rehabilitation. In *Principles of Cognitive Rehabilitation*. Elsevier. https://doi.org/10.1016/C2021-0-03320-4
- O'Donoghue, M., Boland, P., Leahy, S., Galvin, R., McManus, J., Lisiecka, D., & Hayes, S. (2022). Exploring the perspectives of key stakeholders on the design and delivery of a cognitive rehabilitation intervention for people post-stroke. *PLoS ONE*, *17*(6 June). https://doi.org/10.1371/journal.pone.0269961
- Office for National Statistics. (2001). Population Census 2001 Ethnicity data (detail) for England and Wales.

 https://www.ons.gov.uk/file?uri=/aboutus/transparencyandgovernance/freedomofinformatio nfoi/populationcensus2001ethnicitydatadetailforenglandandwales/censusethnicgroupm221a.x ls
- Office for National Statistics. (2011). Ethnicity and National Identity in England and Wales: 2011. https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/ethnicityandnationalidentityinenglandandwales/2012-12-11
- Office for National Statistics. (2018). *Mental Health Act Statistics, Annual Figures England, 2017/18*. www.statisticsauthority.gov.uk/assessment/code-of-practice
- Office for National Statistics. (2021). Ethnic group, England and Wales: Census 2021. https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/bulletins/ethnicgroupenglandandwales/census2021
- Tang, E. Y. H., Price, C., Stephan, B. C. M., Robinson, L., & Exley, C. (2019). Post-stroke memory deficits and barriers to seeking help: Views of patients and carers. *Family Practice*, *36*(4), 506–510. https://doi.org/10.1093/fampra/cmy109
- Teager, A., Dunning, G., Mirza, N., Methley, A., & Twigg, J. (2023). A retrospective analysis of the ethnicity of individuals referred to a tertiary neuropsychology service in the United Kingdom. *The Clinical Neuropsychologist*, 1–17. https://doi.org/10.1080/13854046.2023.2215491