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7 Managing Post-stroke Aphasia in Underserved or Unserved Multiethnic–Multilingual Populations

José G. Centeno and Bronwyn Davidson

Key information for local and international policymakers

The goal of this chapter is to inform policymakers, professional organizations, and healthcare institutions about the systemic healthcare needs, including gaps in research and administrative policies, which must be addressed to enhance clinical management and life reintegration in individuals with aphasia in underserved and unserved multiethnic–multilingual populations. Aphasia is a language and communication impairment, most frequently caused by damage to left-sided areas of the brain, affecting a person's communicative and social functioning and quality of life and the quality of life of his/her close social network (Hallowell, 2017; Papathanasiou, Coppens, & Davidson, 2022).

The incidence and prevalence of aphasia

The incidence and prevalence of post-stroke aphasia across the world is estimated to increase, as the world steadily ages and the risk of age-related cardiovascular complications, including stroke, markedly grows (Johnson, Onuma, Owolabi, & Sachdev, 2016; United Nations, Department of Economic and Social Affairs, Population Division, 2017). Aphasia, a frequent post-stroke disability, occurs in 21% to 38% of stroke survivors (Engelter et al., 2006). Yet, as the numbers of older adults with age-related disabilities, including post-stroke aphasia, expand, extensive cohorts of these individuals will be from unserved and underserved multiethnic–multilingual communities. Disability disproportionally affects older people, people living in poverty, indigenous individuals, refugees, and migrants (Centeno & Harris, 2021; WHO, 2015). Older adults from minority ethnoracial populations are more likely to experience age-related neuropathologies, including stroke, from the interaction of multiple health determinants, such as vulnerable life histories, limited access to health services, treatment inequities, and culturally inadequate clinical procedures (Australian Institute of Health and Welfare, 2016; Centeno, Kiran, & Armstrong,

2020a,b; Uomoto & Loughlin, 2016). In fact, caseloads in stroke care are projected to be increasingly ethnically and linguistically heterogenous as multiethnic environments in many countries, including indigenous groups co-existing with other minority populations, keep growing from steady world migration. The number of international migrants has increased progressively worldwide (Centeno & Harris, 2021; International Organization for Migration, 2017).

The impact of aphasia

For individuals with aphasia, all aspects of their life involving language and communication may be affected with social and emotional consequences. For example, individuals may have problems 'finding' the word they want to say (though they know what they want to say), leading to problems communicating their intended message. Their audience, in turn, may have difficulty fully understanding the language produced by the person with aphasia. Individuals with aphasia frequently feel socially inadequate from these experiences and become isolated from social participation (IALP, 2020; WHO, 2001). Aphasia may have a profound impact on individuals from under-resourced multiethnic–multilingual groups and their family and caregivers from the lack of culturally attuned and linguistically appropriate resources and services (Armstrong, McKay, & Hersh, 2017; Centeno, Chazi-Saidi, & Ansaldo, 2022).

Key information for caregivers and healthcare practitioners

The goal of this section is to provide information to both family members and healthcare professionals of people with aphasia, to strengthen the care and social reintegration of individuals with post-stroke aphasia from underserved or unserved multiethnic–multilingual populations.

How to identify the presence of aphasia

Speech-language pathologists (SLPs) work with communities and with individuals and families to identify, treat and support people with aphasia. SLPs assess the type and severity of the aphasia experienced by an individual. The SLP will examine the various aspects of language use (conversational comprehension, reading, spoken language, and writing) and determine the extent individual language and communication problems experienced by each person with aphasia will have on her/his interactions and activities as well as social participation and life quality. It is important that SLPs assess individuals' cognitive skills, such as memory and attention, as these abilities may be disrupted by the brain trauma that caused aphasia (Murray & Mayer, 2022). When the person with aphasia has a history of bilingualism or multilingualism before the cerebral damage, the SLP, where possible, will examine the languages known by the person with aphasia before the stroke by involving an interpreter and/or family members and friends (ASHA, 2020; IALP, 2020).

The impact of aphasia

Aphasia has a substantial impact on the individual and her/his family. Individuals may feel socially disconnected and emotionally uncomfortable due to their communication difficulties. Individuals with aphasia are sometimes devastated as they struggle to communicate with family, healthcare professionals, and the community. Many people with aphasia may experience negative attitudes from communication partners who are unaware of the impact of this disorder. Cultural attitudes to stroke or disabilities may additionally impose social and emotional challenges on the stroke survivor and her/his social network (Centeno et al., 2022). Family members of people with aphasia tend to cope with new responsibilities by taking on new roles in addition to their usual responsibilities, such as serving as a translator for the individual with aphasia (Sather & Howe, 2021). Family members may, however, be unprepared to deal with the daily communication and emotional changes caused by the aphasia. Furthermore, many people with aphasia and their families, especially individuals from minority groups, may find it difficult to access information about stroke and aphasia (Hersh, Armstrong, Panak, & Coombes, 2015; IALP, 2020; Siyambalapitiya & Davidson, 2015).

The importance of identification of this disorder

Since aphasia can affect a person's ability to speak, understand, read and write, prompt identification is critical to enrol the person with aphasia in therapy, thus minimizing social disconnection and associated emotional ramifications from the aphasia. Assessment is an essential factor to determine retained language abilities. It is easy to under- or overestimate the amount a person with aphasia can understand, which can lead to frustration on the part of the individual with aphasia and their family members. Consequently, assessment is essential to assist with decisions relating to mental capacity. In addition, the inability to return to work may place a burden on families.

What to do after identification of this disorder

Speech and language therapy helps the recovery of people with aphasia (Brady et al., 2016). After language assessment, the SLP will understand the nature of the language and communication difficulties the person is experiencing and the extent of her/his/their communication needs. This information helps to plan the approach to language and communication stimulation for therapy. If the person with aphasia used several languages before the stroke, efforts should be made to use one or several of those languages for therapy by involving an interpreter and/or family members and friends (ASHA, 2020; IALP, 2020). In addition, it is also essential to monitor which therapy approach is more effective.

How to support individuals with aphasia

Therapists must consider both the person with aphasia and their communication partners in aphasia rehabilitation. The treatment programme, involving the family and an interpreter when appropriate and necessary, should involve training and advice for

communication partners to enable improved communication. Screening and referral for problems with mood and support for general wellbeing may also be provided. Seeking information about clinical management of multiethnic–multilingual aphasia caseloads is crucial. Gaps in professional training, racism, bias, and unsuitable clinical resources, combined with the stroke survivor's and her/his family's limited access to pertinent literature and medical insurance, among other factors, result in service and outcome disparities (Brewer & Andrews, 2016; Centeno, 2015; Centeno et al., 2020a,b; Uomoto & Loughlin, 2016). Public awareness and community interventions, grounded in principles of human rights and the need to address health and social inequities in marginalized groups, including both individuals with disabilities and minority persons, are crucial (Papathanasiou et al., 2022).

Key Dos and Don'ts

The type or complexity of the language, and the level of social or communication support in the environment, can make a difference in how much someone with aphasia can take part in communication activities and feel socially connected. When speaking with people with aphasia, try to incorporate strategies to support their communication (e.g., increasing gesture, writing key words, picture cards, and slowing down speaking rate). In addition, strategies should be implemented to promote public awareness of aphasia ensuring that health information and services are accessible to people with aphasia, including the use of interpreters when necessary, and facilitate supportive relationships by altering the communication environment to facilitate everyday interaction. Working in partnership with communities to develop culturally responsive interventions, especially in the case of underserved and unserved multiethnic–multilingual populations, is essential (Papathanasiou et al., 2022).

Group therapy, where persons with aphasia and their families meet together, is an effective approach to support communication and conversation. Families and friends should be encouraged to regularly interact with the person with aphasia, and they themselves may also benefit from the support from families and friends of others with aphasia. Resources that serve the needs of practitioners working with this population can be found at the end of this chapter.

Information for professionals serving stroke survivors with aphasia in underserved or unserved multiethnic–multilingual communities

The goal of this section is to update knowledge and research and provide resources pertinent to services for underserved or unserved populations with aphasia. Contemporary approaches to examine the extent of aphasia and its symptoms in individuals with post-stroke aphasia from underserved or unserved multiethnic–multilingual populations synergize neuroscientific, sociocultural, educational, and ethnopsychological factors that can enhance both diagnostic accuracy and scientifically grounded and culturally-attuned intervention (Armstrong et al., 2017; Centeno et al., 2022; Centeno et al., 2020a,b; Penn, 2012).

Evidence-based interventions and additional resources

There are key treatment indicators linked to best recovery, such as early intervention, regular social support, communication stimulation, and verbal interaction. When serving individuals with aphasia from underserved or unserved multiethnic–multilingual environments, intervention requires an integrated approach that combines neurocognitive principles with individual linguistic, communicative, sociocultural, ethnopsychological, and educational histories of each person with aphasia (Centeno et al., 2022; Centeno et al., 2020b; Siyambalapitiya & Davidson, 2015). While this is challenging, it is not impossible! Supporting resources, such as culturally and linguistically appropriate counselling and intervention materials, are critical to enhance the benefits of therapeutic interventions (Brewer, McCann, & Harwood, 2020; Jodache, Howe, & Siyambalapitiya, 2019; Penn et al., 2017). Working in partnership with communities to develop culturally responsive interventions, especially for underserved or unserved multiethnic–multilingual populations, is essential (Papathanasiou et al., 2022). Notably, the creation of communication accessible environments is critical when addressing the needs of people with aphasia to improve social inclusion, communication access in service encounters, and accessible health information (Booth, Armstrong, Taylor, & Hersch, 2019; Rose, Worrall, Hickson, & Hoffman, 2011). There is an added benefit in that accessible environments support not only people with aphasia but also those with aphasia who speak a language other than the main language of that community. In the context of public health, the COVID-19 global pandemic has heightened awareness of the importance of accessible health information for people with aphasia and improved health care for underserved or unserved populations (Devakumar et al., 2020; Papathanasiou et al., 2022).

The principal factors in intervention

Greater recovery takes place when intervention occurs within one month following brain damage, especially for individuals 55 years and younger (RELEASE Collaborators, 2020, 2021). It is important that intervention be adapted to the individual's monolingual, bilingual, or multicultural language (Centeno et al., 2022). The key factors to enhance cross-language generalization include language similarities, cognitive control (being able to activate or inhibit a language), and language proficiency before and after the brain lesion. In addition, culturally and linguistically appropriate counselling and intervention materials are critical to enhance the benefits of therapeutic interventions (Brewer et al., 2020; Jodache et al., 2019; Penn et al., 2017; Siyambalapitiya & Davidson, 2015). Collaborating with the community in which an individual with aphasia lives in order to develop culturally responsive interventions is essential (Papathanasiou et al., 2022) to address the needs of people with aphasia for social inclusion, communication access in service encounters, and for accessible health information (Booth et al., 2019; Rose et al., 2011).

Other factors can be considered to be included in treatment programmes. Electronic technology (iPads, apps, tablet-based programs, and telepractice service delivery) can provide opportunities to augment services for people with aphasia. Collaboration

with the person with aphasia and their family is important in the selection of the appropriate digital services and technological devices, since there may be expenses and convenience connected with use of technologies. In addition, it is essential to select programs that are suitable for the person's communication needs (Papathanasiou et al., 2022). When working with underserved communities, services must be culturally relevant, holistic, accessible, sustainable, and responsive (Centeno et al., 2020b; Wylie, McAllister, Davidson, & Marshall, 2013).

Resources for professionals working with individuals with aphasia

Resources can be found at the following websites:

American Speech-Language-Hearing Association (USA) https://www.asha.org/practice-portal/clinical-topics/aphasia/

Aphasia Access (USA)

Aphasia Alliance (UK) https://www.aphasiaaccess.org/ http://www.aphasiaalliance.org/

Aphasia Hope Foundation (USA) http://www.aphasiahope.org/faq/

Aphasia Institute (Canada) https://www.aphasia.ca/home-page/about-aphasia/

Australian Aphasia Association (Australia) https://aphasia.org.au/

The National Aphasia Association (USA) http://www.aphasia.org/Aphasia%20Facts/aphasia_faq.html

Collaboration of Aphasia Trialists https://www.aphasiatrials.org/

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8 Supporting the Communication of Underserved Children in Viet Nam

Ben Phạm, Sharynne McLeod, Sarah Verdon, Kate Margetson and Van H. Tran

Key information for local and national policy and lawmakers

The purpose of this chapter is to provide a case study of work undertaken in Viet Nam to support underserved children with communication disabilities. This chapter focuses on collaborations between Viet Nam, Australia, and other countries to support children with communication disorders and to nurture the developing speech and language therapy profession in Viet Nam. The chapter also profiles research and initiatives that have focused on understanding children's speech and language acquisition to develop culturally and linguistically appropriate assessments and resources to support intervention.

Childhood communication disorders include difficulties with speech, language, hearing, communication and/or literacy. The following terms are frequently used to describe this population in English-speaking contexts.

- ▪ Communication disability, communication disorders
- ▪ Speech, language and communication needs (SLCN)

In Viet Nam, Rối loạn giao tiếp is the term used for a communication disorder, shown in Table 8.1.

Table 8.1 Common sub-groups of Childhood Communication Disorders.

> - Developmental language disorder (DLD) = Rối loạn ngôn ngữ phát triển
> - Language disability = Khuyết tật ngôn ngữ
> - Language delay = Chậm ngôn ngữ
> - Late talker = Chậm nói
> - Speech sound disorder (SSD) = Rối loạn âm lời nói
> - Childhood apraxia of speech (CAS) = Mất điều khiển lời nói chủ ý ở trẻ em
> - Dysarthria = Rối loạn vận ngôn
> - Stuttering = Lắp
> - Voice disorder = Rối loạn giọng