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Keeping people with aphasia worldwide “COVID-informed” amid and after the pandemic

Abstract

Aphasia is an acquired language disorder commonly caused by a stroke or brain injury. A slowly growing number of studies have emerged reporting the psychosocial disruptions experienced by people with aphasia (PWA) in the present COVID-19 pandemic. To extend this topic of better addressing PWA's rehabilitation needs, this paper aims to draw attention to the significance of helping PWA stay “COVID-informed” through the use of resources that are communicatively-accessible. Keeping PWA abreast of the evolution of the pandemic can reasonably ensure they stay connected to their society, even without an actual physical presence in their community. However, aphasia-friendly health information is currently available predominantly in English only. Similar materials are relatively scarce in other languages and not necessarily updated, albeit such a need for these resources is apparent globally. It is essential that healthcare providers ensure that accessible, comprehensible, high-quality and reliable health-related resources are made available for PWA; this will ultimately benefit them to navigate the pandemic and prepare for the post-COVID era.

Keywords: aphasia, COVID-19, aphasia-friendly, accessible information, health literacy

Aphasia is an acquired language disorder commonly caused by a left-hemispheric stroke or an injury to brain regions responsible for language [1]. It can impair one's auditory comprehension, verbal expression, reading, and/or writing across different performance levels such as processing of words, phrases, sentences, and narrative discourse [2]. At present, approximately one in 270 people in the UK (0.37% of the population) [3] and about one in 250 people in the US (0.40% of the population) are living with aphasia [4].

A recent article by Ellis and Jacobs [5] has summarised the reduction in psychological well-

being among people with aphasia (PWA) due to social isolation amid COVID-19, and justified the fundamental needs to promote “physical distancing and social connectedness” aphasia treatment and support groups that can benefit PWA's social and emotional fulfilment. This echoed not only the reported communication challenges and social inactivity experienced by PWA during lockdowns [6], but also the exacerbating side effects such as stress and depression in PWA as the pandemic progressed [7]. To extend this topic of better addressing PWA's rehabilitation needs, this article aims to draw attention to the significance of helping PWA stay informed about the pandemic.

Health literacy refers to the degree to which one can identify, understand, and use information and services to inform health-related decisions and actions [8]. Clinically, it is important that healthcare service receivers, including PWA and their carers, can easily obtain health information related to COVID-19. This is particularly the case given that the evolving situation of this pandemic is multifaceted in nature and, therefore, complicated. According to a recent investigation conducted to compare readability of existing official public health information on COVID-19 written by three international public health agencies and governments of 15 countries [9], these materials available on the internet are far too complex for the general public to understand, with a reading level of approximately three grades higher than the recommended “eighth-grade” level suggested by The American Medical Association, National Institutes of Health, and Centers for Disease Control and Prevention (CDC) [10]. A similar cross-sectional study based on 61 online educational articles about COVID-19 [11] paralleled the above findings. Specifically, these articles contained information that was too difficult for the general population to read as all of them failed to meet the recommended “fifth- to sixth-grade” level (i.e., all exceeded the reading level of an 11-12 year old reader) suggested by United States Department of Health and Human Services. As further stated by The Center for Literacy & Disability Studies at University of North Carolina at Chapel Hill [12], although many written resources

about COVID-19 have been created for the general public, these materials were generally found to be too demanding and complicated for those with an intellectual and/or developmental disability (who typically demonstrate a “third-grade” written or auditory comprehension level, or lower competency). This finding was surprising because it implied that even for the language-unimpaired audience or readers, keeping up with updated and accurate knowledge about the pandemic (such as its origin and cause(s), spreading mechanism and related symptoms, diagnosis, safety measures, and key rehabilitation principles including vaccination options and side effects) can be a daunting and difficult task. In fact, an article published in early 2021 that reviewed and compiled studies on appropriate reading level of COVID-19 online information [13] suggested that this problem still persists and has not improved – the readability level of most, if not all, existing COVID-19 education/information resources is far exceeding that recommended for patient information. More critically, if solely relying on these existing written (educational) materials, the PWA audience will arguably face more challenges in understanding the characteristics of COVID-19 and keeping abreast of the evolution and latest information on the coronavirus because of their underlying difficulties in processing language materials and inherent selective cognitive problems [7,14].

Amid the pandemic, it is crucial that PWA are provided with updated information and/or resources about COVID-19 that are communicatively-accessible, i.e., aphasia-friendly [15]. Specifically, the format and typography of these materials should ensure readability in the PWA population, through (a) careful control of text complexity and writing style (e.g., use of short and simple sentences, use of straightforward language, avoiding technical terminology or complex syntax, etc.) (b) considerations of formatting and design (e.g., increased print size, use of symbols, bullet points, ample spacing, headings and/or signposting, bolding key words, etc.), and (c) inclusion of appropriate images or graphics (e.g., photographs or pictures that directly support the text). Currently, such materials that fulfil the above-mentioned aphasia-friendly criteria are available predominantly in English only (e.g., focusing mainly on explanations of some major and basic COVID facts [16,17]), but the content of these resources may not necessarily be updated. Comparable materials are also arguably scarce in other languages, albeit the need for these related materials is apparent globally. In April 2020, the CDC [18] made some up-to-date COVID-19 materials available in an easy-to-read format. The content, primarily developed for those who read or listen with understanding below a third-grade level, generally follows many aphasia-friendly principles such as having simple sentence structure, additional white space, and a clear and simple font. Multiple topics are addressed as separate pages/links that are available for download and/or printing. Practitioners who

work with PWA may refer to this type of platform, or similar sites in the National Health Service (NHS) (e.g., <https://www.nhs.uk/conditions/coronavirus-covid-19/>) or Public Health England (e.g., <https://www.gov.uk/coronavirus>), to share updated information about the pandemic. In addition, some UK-based nonprofit organisations (e.g., Social Care Institute for Excellence, SCIE; <https://www.scie.org.uk/care-providers/coronavirus-covid-19/>) have also translated more accessible information on COVID-19 that may be appropriate for PWA. Finally, the presentation of the materials on the internet will mean that PWA can have the content read to them by one of several easily accessed screen readers (such as text-to-speech systems) to further facilitate comprehension.

The earlier Delta variant of coronavirus and the most recent Omicron mutations are of global concern. There has been disparity between the availability of accessible information on COVID-19 vaccination and the need to better understand health information among the general population [19]. This is worrying because it puts individuals at risk from COVID-19 and allows more rapid spread of infection in the community. In Autumn 2020, the CDC published guidelines to instruct all state health departments to develop inclusive vaccine communication strategies guided by the Americans with Disabilities Act (ADA) and Plain Language Act [20]. Currently, some additional and updated resources are also available to help PWA navigate the vaccine scheduling process (e.g., <https://www.marchofdimes.ca/en-ca/aboutus/newsroom/cia/Pages/Covid19-aphasia-resources.aspx>). It is believed that good use of the above-mentioned materials by the PWA (and caregivers) as well as timely awareness among service receivers facilitated by clinicians can reasonably minimise the spread of vaccine misinformation within the aphasia community.

To a certain extent, helping PWA stay up-to-date on (or become adequately informed about) the ever-changing pandemic is a way to facilitate their staying connected to their society, even without a physical presence in the community. The need for aphasia-friendly health information is apparent worldwide, but very few studies at present have fully explored the potential disparate effects of the lack of resources in this needed format that can benefit non-English speaking PWA. Note that some general work on language equity for public health communication has already emphasised the disparity in availability of multilingual resources pertaining to medical and COVID-19 public health information [21]. In the UK, for example, although online COVID-19 information in English is readily available to the British public, corresponding translated versions targeting minority ethnicities and graphics-based materials are very limited [22], which could amplify the level of misunderstanding about the COVID-19 pandemic. More importantly, such a lack of these non-anglophone resources would further hinder the development of the more aphasia-friendly versions for communities of PWA

with different language backgrounds.

Based on the perspective of PWA and their family members, Wallace and colleagues [23] examined and identified important aphasia treatment outcomes with reference to the International Classification of Functioning, Disability and Health (ICF) put forth by the World Health Organization. Apart from outcomes related to the ICF components of ‘Activity/Participation’ and ‘Body functions’, PWA also expressed a desire for (a) improved independence with daily routines and activities and (b) better health services and access to related information. In the current COVID context, this latter expectation becomes particularly relevant for PWA worldwide to stay motivated and lead a life successfully with aphasia [24,25], and can be easily achievable by ensuring information about the pandemic is accessible. Furthermore, the significant others of PWA can also be empowered through the use of aphasia-friendly resources to educate, support, and help their loved ones cope during the pandemic. Hence, it is essential that health-care providers ensure that accessible, comprehensible, high-quality, and reliable health-related resources are made available for PWA, as part of an effort to keep them “COVID-informed”. This will ultimately benefit PWA in terms of their better ability to navigate the pandemic and, in the near foreseeable future, prepare for the post-COVID era.

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