

## APHASIA: Not Yet at the High Table [In the Comity of Neurology Sub-Specialities]

The history of research and publication on aphasia and related disorders of speech and communication is rich and of about 200 years duration. Unfortunately, the number of publications from India and those about South Asian languages in peer reviewed, indexed journal is exceedingly small. This is in stark contrast to the fact that India is home to one in every sixth person of the World's population. We have 20 something major languages spoken by millions of people. Multilingualism is common. We have had rich tradition of linguistics, philology, and grammar from the days of Panini and Patanjali.

We know that lot of work has been done in this field over last two decades from various departments of speech and language pathology, neurology, neuropsychology, and linguistics. This output is not reflected in literature search, as it is not published in peer reviewed, indexed journals.

On the other hand, most articles on aphasia in international journals are related to English-speaking patients, with additional bias towards western European languages. Some of the most widely spoken languages in the world, such as Arabic, Hindi, Bengali, Russian, as well as Portuguese, accounted for less than 0.5% of the aphasia literature, rendering it un-representative of the world's languages, in terms of linguistic typology and the number of speakers.<sup>[1]</sup>

Such a bias limits the worldwide applicability of clinical findings (in aphasia therapy) and undermines the universality of theoretical models, which are based on observations from a small number of closely related languages.

This Supplement is probably a small step to reduce that bias tangibly and is also a small contribution towards a more cross-linguistic approach to aphasia which should be one of the priorities in future aphasia research. Aphasiology in India is too important a subject for us, to languish in anonymity at national and international level. The motive behind curating and publishing a full Supplement for an exotic looking subject like aphasia is to sensitise the neurologists and related professionals, arouse their interest, add to their knowledge, and enhance the motivation.

The Supplement's entries are in different formats.: original articles (11), view-points (3), reviews (4), editorial commentaries, (2) and letter to editor (1). Some overlap was inevitable across the formats, as well as across the subjects or themes.

The primary readership for The Annals is neurologists. Aphasia is a straddler between neurology and speech-language pathology along with a significant smattering of neuropsychology and linguistics. The Supplement on aphasia would have been incomplete if we restricted the type of articles to

only neurology. It is a matter of satisfaction that we have manuscripts on a variety of themes [Panel 1]. Many of the manuscripts would never have been accepted for a regular issue of a neurology journal, but we did. The compelling desire behind was that neurologists should be exposed to the rich spectrum of aphasiology. We are sure that SLPs and other related professionals will find The Supplement interesting and useful. We regret not being able to have articles on a few important subjects, like, newer neuro-imaging techniques, epidemiology, and indigenous randomized controlled trials. Knowledge of risk factors and demographic patterns of a health condition help with primary and secondary prevention, as well as planning for services and funding needs.

We expect The Supplement to work as a short-term step for bridging the cross-disciplinary gap. A beginning was made in July 2017, when on the behest of IAN, an Expert Group Meeting on Aphasia was organized by me. The participants were from neurology, speech and language pathology (SLP), clinical psychology, neuroimaging, information technology, and linguistics. The objective of the EGM was to take stock of the status on major issues relating to aphasia in the Indian context, identify salient issues, discuss possible solutions, chalk out action plans, and make recommendations.<sup>[2]</sup> Follow-up meeting and email discussions have been going on. More experts have joined. A Memorandum of Understanding has been approved by Indian Speech and Hearing Association and Indian Academy of Neurology. The Expert Group on Aphasia is acting as a liaison.

The Panel 1 lists many issues which were discussed at EGM. Many of them have been covered in The Supplement [Panel 2]

### Panel 1: Subjects or Themes Discussed at Expert Group Meeting on Aphasia (July 2017)

- Epidemiology
- Clinical Assessment
- Linguistics
- Multi-lingualism
- Reading and Writing
- Cognitive Functions in Aphasia
- Language Functions in Dementia
- Neuro-imaging
- Research
- Education
- Speech Language Therapy
- Rehabilitation
- Biological therapies
- Computers and Information technology
- Advocacy

but some could not be, for example, the points number 1, 4, 5, 6, 8, 12, 14 in Panel 1.

There is one important supplementary resource with this publication, accessible online only; “Annotated Bibliography of Aphasiology Literature in India.”<sup>[3]</sup> This has been a labor of love for me and Dr Gopee Krishnan since 2012, when we started compiling, tagging, classifying, and annotating all good and sundry aphasiology literature in India, from India or pertaining to Indian Languages. The emphasis has been on publications in good journals, but we deliberately kept our bar low, to include as much work as possible. We knew that we would end up having many entries of doubtful quality. We also included many unpublished works in the form of dissertations for MASLP, PhD, MD., and abstracts of presentations at conferences, etc.,. The entries have been grouped into 14 subject wise categories, with some overlaps. [Panel 3] Keywords have also been provided for abstracts. Brief editorial annotations have been appended with many, but not all entries. We hope this compilation would serve as a quick reference to the interested students, clinicians, and researchers. The Bibliography will be updated at regular intervals. Readers are requested to share citations about old and new publications with the editors, so that they may be added into it.

We did a quick search in five neurology journals for number of articles about aphasia and 4 other neurological disorders. We carefully read all the titles. After a while, within one to two pages of results, the titles start losing degree of relevance and relation to the given ailment. Table 1 shows that not only the numbers of results for aphasia were substantially less than those for diseases much less common; the proportion of relevant articles for aphasia was also lower. This was a simple “back of the envelop calculation” with a significant element of subjectivity in adjudicating which article is relevant and which not. But the point cannot be missed that researchers and editors both tend to neglect aphasia. One explanation is valid though. Many good manuscripts, particularly those about SLT are not submitted to general neurology journals. They go to periodicals from the fields of SLP and other related domains. This compartmentalization is not good for aphasia. Attempts should be made to reduce it.

What to say of poor public awareness, many health care professionals and physicians are poorly informed about aphasia. Many PWA often complain that they do not have the same medical access as people without a language disorder. Doctors fail to discuss the medical condition or even may not utter the word aphasia, explaining it to them or their caregivers is more unlikely. The family is rarely told about resources, services, or outcomes.<sup>[4,5]</sup> Many health care professionals are unaware of the long-term impact of aphasia, the potential for long-term improvement and the critical need for support services.

Aphasia is not on the radar of neuro-epidemiologists either. A search in Indian and some leading international journals for key words including “neurology,” “epidemiology,”

## Panel 2: Subjects or Themes covered in The Supplement

Neurobiology of Language function in brain (Review)  
 Research Methodology (Viewpoint, Editorial Commentary, Original Article)  
 Diagnostic Screening Test for Indian PWA (Original Article)  
 Language in Dementia (Review)  
 Clinico-Radiological correlations. (Subcortical Aphasia) (Original Article)  
 Status of Post Stroke Aphasia and role of Big Data (Beyond RCT) (Review and Original Article)  
 One of the many methods of neuro-Linguistic Profiling (Original article)  
 Validation and Standardization of Test Stimuli (Original articles)  
 Review Biological Interventions  
 Non-invasive Brain Stimulation (Original Article)  
 Home Therapy Workbook (Original Article)  
 Differential Diagnosis: Aboulia. (Letter to Editor)  
 Public Awareness about aphasia (Narrative review)  
 Awareness survey about aphasia in Neurologists (Original Article)  
 Medico-Legal Status (Editorial Commentary)  
 Trial of a special method of SLT (Original Article)  
 Overlap: Aphasia & Autism. (Viewpoint)  
 Quality of Life in aphasia (Original Article)

## Panel 3: The Subject categories in the Annotated Bibliography on Aphasia in India (see the link in references)<sup>[3]</sup>

Overview, Review Articles, Status Reports, Theoretical Essays  
 Speech and Language Functions in Neuro-degenerative disorders  
 Auditory Comprehension  
 (Cog) Cognitive Deficits Associated with Aphasia  
 Lexicon, Semantics, Naming  
 Narrative Discourse, Pragmatics  
 Multi-lingualism  
 Morphology, Syntax, Agrammatism  
 Language Acquisition Children, Developmental Disorders  
 Clinical Neurology, Clinico-anatomical Correlations  
 Reading, Writing  
 Assessment Methods, Testing Batteries  
 Phonology, Prosody, Articulation  
 Quality of Life, Therapy, Rehabilitation

“incidence,” “prevalence,” “DALY,” “community burden” did not return any references for aphasia, unless one includes that word in search terms. The authors of landmark and mammoth study in *The Lancet*, on Global Burden of Diseases and its neurology component, in *Lancet Neurology*, while expanding the categories of neurological disorders proudly listed: stroke, Alzheimer’s disease and other dementias, Parkinson’s disease, epilepsy, multiple sclerosis, migraine, tension-type headache, medication overuse headache, meningitis, tetanus, encephalitis, brain and nervous system cancer, motor neuron disease, and a residual category of other neurological disorders such as muscular dystrophy and Huntington’s disease; but not Aphasia.<sup>[6]</sup> The same applies to Indian studies.<sup>[7]</sup>

The irony couldn’t have been starker. Aphasia is one of the most pervasive communication disorders of our times, yet the

**Table 1: Number of publications (and the proportion of relevant articles) pertaining to Aphasia and 4 more neurological disorders as published in 5 Neurology Journals**

	Aphasia		Parkinsonism		Multiple Sclerosis		Myopathy		Alzheimer's	
	Total	Good (%)	Total	Good (%)	Total	Good (%)	Total	Good (%)	Total	Good (%)
Annals of IAN	122	17 (13.93)	162	42 (25.92)	864	35 (4.05)	128	35 (27.34)	165	22 (13.33)
Neurology India	178	6 (3.37)	220	28 (12.72)	2109	40 (1.89)	198	45 (22.72)	200	24 (12)
Brain	2134	205 (9.6)	4193	730 (17.4)	3897	680 (17.05)	959	140 (14.59)	3712	280 (12.18)
JNNP	2309	130 (5.63)	6234	225 (3.6)	5985	850 (14.2)	1638	140 (8.54)	3877	430 (11.09)
Neurology.org	4664	330 (7.07)	6574	500 (7.63)	16429	1600 (9.73)	3271	280 (8.56)	1211	40 (3.3)

silencing ailment itself is muted. Even in North America, where we would imagine the situation to be far better than India, a recent White Paper paints a grim picture.<sup>[8]</sup> The need of the hour is an all-encompassing advocacy.<sup>[9]</sup> This Supplement may itself be considered as a humble attempt at advocacy, apart from its main purpose of scientific communication.

Notwithstanding all the lamentations expressed heretofore, the future for People Living with Aphasia is brighter than their past.

There are reasons for being optimistic. The numbers of trainees at M.B.B.S., M.D. (Internal medicine), D.M. (Neurology), MCh. (Neurosurgery), Bachelor of Audiology, Speech-Language Pathology (BASLSP), M.Sc. Speech Language Pathology are increasing in the country. More hospitals will have departments of neuroscience, SLP and clinical neuropsychology. Public awareness on aphasia, and about a potential for its improvement by SLT will increase, thereby enhancing the felt need and demand. Improvements in public literacy and education will help in acceptance and compliance with therapy and rehabilitative measures. The computer and Information Technology professionals will pitch in with digital applications.

Research has shown that language and communication can continue to improve for many years after the onset of aphasia. These improvements are accompanied by new activity in the brain.<sup>[10]</sup> These changes in the brain relate to the concept of neuroplasticity – the ability of the brain to adapt and change in response to stimulation and experience. We wish all the stakeholder not to carry an iota of nihilistic baggage from the past.

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The Supplement for Aphasia is but one of the many achievement out of joint endeavours.

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