

Expert Group Meeting on Aphasia: A Report

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Abstract

A multidisciplinary team of experts took stock of the current state of affairs about many aspects of aphasia in India, including community burden, diagnostic assessment, therapy, rehabilitation, research, education, and advocacy. The broad spectrum of aphasiology was matched by the types of participants ranging from neurologists, speech-language pathologists, clinical psychologists, linguists, to experts in neuroimaging and computer sciences. Threadbare discussion in 16 sessions over 3 days leads to the identification of pressing problems and possible solutions. Many action plans have been envisaged and recommendations made. A few examples with high priority are community-based and hospital-based study incidence and prevalence of aphasia, development of test batteries for the assessment of many components of speech and communication in Indian languages which are validated on rigorous psychometric, and linguistic criteria, national registry for aphasia, educational modules about aphasia for different target groups, resources for advocacy and its training, a bank of research questions and outlines of research protocols for young professionals to pursue. The expert group will continue to oversee execution of some of the actionable plans in short and long term.

Keywords: Action plans, aphasia in India, recommendations

INTRODUCTION

An Expert Group Meeting on Aphasia (EGA) was held under the aegis of Indian Academy of Neurology (IAN) at Bengaluru with participants 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 current status on major issues relating to aphasia in the Indian context, identify salient issues, discuss possible solutions, chalk out action plans, and make recommendations [Table 1].

SESSION 1: EPIDEMIOLOGY

Aphasia persists as a disability in 21%–38% of stroke survivors. Community incidence is 43/100,000/year, and prevalence is 3000 per million.^[1] The number of persons with aphasia (PWA) in the country is likely to be around two million. There is need for two types of studies: (i) a community-based epidemiological study for prevalence and incidence. A basic outline of door-to-door survey methodology will be prepared and shared with members of IAN as well as the Indian Speech and Hearing Association (ISHA); (ii) a hospital-based databank on the prevalence of aphasia from stroke registries across the country.

SESSION 2: CLINICAL ASSESSMENT

Appropriate clinical assessment of aphasia is crucial for the diagnosis, prognosis, therapy planning, and research. The syndromic classification of aphasia is undergoing major revision, and its utility is being frequently questioned. New approaches to clinical profiling of speech and language functions are being developed.^[2]

There is a lack of standardized and validated test batteries in Indian languages paying attention to psychometric principles and normative data. Criterion-referenced tests may be preferred to norm-referenced tests.

EGA members differed about the need for indigenous test batteries versus adaptations of well-established western

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DOI: 10.4103/aian.AIAN_330_18

Table 1: Recommendations and action plans**Epidemiology and surveys**

- Multicenter retrospective and prospective hospital-based study of the prevalence of aphasia in stroke
- Community-based study of prevalence and incidence of aphasia and other disorders of speech and communication
- Establishment of national aphasia registry along with facility for archiving our clinical and imaging data (with or without affiliation to International Aphasia Bank)
- To collect and compile population-based data about multilingualism in different states and regions of India from authentic sources and make them accessible for clinicians
- To plan comprehensive national survey about types of SLT, its duration, and intensity, its theoretical basis and updatedness across the professional landscape of SLPs in India
- Collection of normative data of language use with respect to many linguistic parameters

Documents, teaching modules, test batteries

- To prepare a monograph on principles and practice of developing a valid test battery for assessment of aphasia in Indian languages
- To compile a comprehensive inventory of tests developed and used by clinicians in India (some validated and published, while others not) and make them available for download on the website of our group and as hard copy for wide distribution (some gratis, some for sale)
- To develop and validate test batteries for the assessment of various aspects of aphasia assessment, in the Indian context (including multilingual, reading, writing, caregiver burden)
- A teaching module (in print and digital format) on “Aphasia for Linguists”
- A monograph on “Linguistics for Clinicians” for SLPs, neurologists, and clinical neuro-psychologists
- To develop evidence-based guidelines for choice of therapy language in Indian multilingual
- To prepare teaching modules and test batteries about
 - Cognitive, behavioral, and psychiatric assessment in PWA for clinicians (SLP)
 - Speech, language, and communication functions in persons with dementia
- To encourage standard brain imaging protocols (structural and functional) and reporting format for PWA, while increasing awareness about aphasia among the radiology community
- To compile a comprehensive bank of research questions and outlines of research protocols for students, clinicians, and research scholars to pursue them
- To create teaching modules for diverse target groups: MBBS, MD and DM residents, clinical psychologists, linguists, paramedical workers, occupation therapists, computer professions, PWA, caregivers, volunteers, and AYUSH practitioners covering aspects of assessment, therapy, and rehabilitation, along with a collection of educational videos
- To create guidelines on the use of pharmacotherapy, noninvasive brain stimulation, stem cells, biological, etc., for members of IAN, NSI, API, IAP

Workshops

- To plan workshops on research methodology and paper-writing skills for students and clinicians in aphasiology
- To organize training workshops for SLPs, neurologists, clinical psychologists, and clinical linguists
- To organize quizzes on aphasia for MD and DM residents and SLP students with attractive prizes
- To plan regional educational sessions for PWA, their communication partners, and volunteers
- To conduct an annual training program on advocacy skills for members of ISHA

Rehabilitation and therapy

- To explore the role of Sheltered Workshops and Vocational Guidance Centers
- To encourage and guide setting up facilities for tele-rehabilitation and training the personnel at multiple locations
- To encourage and train for the use of AAC devices by PWA, SOs, and clinicians

Computer

- Digitization of assessment batteries and therapy practice in Indian languages
- To encourage the use of smartphone, tablets, and laptops as poststroke lifestyle monitors and devices for augmentative and alternative communication
- Tele-therapy through existing platforms such as Skype, Facetime, and WhatsApp video calls
- To plan development of software and applications for virtual therapy

Advocacy

- To prepare a White Paper (Vision Document) on aphasia in long and short form, in English and Indian languages, and in printed text and digital formats and to get it distributed as a handy-talking tool for advocacy and awareness
- To ensure that the stroke guidelines and clinical audit of quality measures for physicians issued by their professional bodies prominently highlight the imperative of early and repeated referral of PWA to SLPs
- To lobby for approval for SLT from RCI, FDA, and similar authorities for coverage of expenses for extended periods, from medical insurance companies
- To draft a note and popularize it, on “good practices for potential employers”
- To launch a high visibility, long duration public education program in Indian languages using good-quality content in multiple formats
- To identify and approach public celebrities at national and local levels to act as brand ambassador for aphasia
- To create and support a network of PSGs in many cities across India along with a manual for good operation of PSGs
- To draft a “Bill of Rights” for PWA and get it prominently displayed and distributed

SLP=Speech and language pathology, PWA=Persons with aphasia, SLP=Speech and language pathology, PWA=Persons with aphasia, IAN=Indian Academy of Neurology, ISHA=Indian Speech and Hearing Association, AAC=Augmentative and Assistive Communication, SOs=Significant others, RCI=Rehabilitation Council of India, SLT=Speech-language therapy, FDA=Food and Drug Administration, PSGs=Patient-support groups, NSI=Neurology Society of India, API=Association of Physicians of India, IAP=Indian Academy of Pediatrics

tests. Some felt that there is no need to re-invent the wheel while other emphasized the importance of regional, cultural, and linguistic variations.^[3] Best batteries are needed for screening,^[4,5] brief as well as detailed assessment, exhaustive testing for specific functions, progress evaluation, and research.

Indian versions of the Western Aphasia Battery^[6] and the Boston Diagnostic Aphasia Examination are available.^[7] A brief screening test for aphasia has been standardized by an ICMR Task Force as a component of the vascular cognitive test battery for Indian use.^[8] Tools are needed for the assessment of functional communication, caregiver burden,^[9] aphasia-related quality of life (QOL),^[10] discourse analysis,^[11] and pragmatics. We plan to assemble, support, and encourage small groups for these tasks.

SESSION 3: LINGUISTICS

Linguistic considerations play crucial roles in clinical assessment, therapy, and research. Clinicians need to acquaint themselves with major linguistic levels where the language breaks down in aphasia.^[12]

Several linguistic parameters must be considered for the selection of stimuli for test batteries and experimental tasks in research. The stimuli may be phonemes, morphemes, letters, graphemes, syllables, words, nonwords, pictures, phrases, sentences, paragraphs, and discourse.

Some of the important linguistic parameters are (1) word frequency, (2) imageability, (3) concreteness, (4) grammatical class, (5) nameability, (6) phonological features, (7) morphological features, (8) types of sentences, (9) minimally differing word pairs for auditory and visual discrimination, (10) syllabic patterns, (11) number of Akshara, (12) phonologically balanced and pronounceable nonwords, (13) accent, and (14) sonority.

The nature of aphasia may be different in agglutinative versus nonagglutinative languages.^[13,14] The clinicians trying to develop indigenous test batteries or making adaptations from other languages are stuck while selecting the stimuli. The latter cannot be arbitrarily chosen or translated verbatim. This requires help from linguists, which currently remains an arduous task. There is a lack of normative population-based data with regard to age, gender, and educational levels in our country. Most of the linguistic departments in India do not offer courses in neuro-linguistics, in general, and aphasiology, in particular.

SESSION 4: MULTILINGUALISM

We in India have an exceptional opportunity to explore the effect of the same lesions on persons who speak structurally distinct languages.

Aphasia in multilingual speakers poses special challenges. It becomes imperative to assess all the languages used by PWA. The clinical profile of aphasia may differ to a variable extent,

in the two or more languages used by PWA. Cross-language code-shifting and code-switching (shifting between vocabulary and grammar of different languages) are very common in Indian bi- and multi-linguals with aphasia, making it difficult to compare the performance across languages.

A standardized assessment, and in all the languages used by the PWA, is an important requirement in its own right and is also crucial for theoretical aspects and therapeutic planning.^[15] Bilingual aphasia test is available in nine Indian languages but is lengthy.^[16]

The knowledge of multiple languages can serve as both a facilitator and barrier of communication. The language of intervention is done in consultation with the patient and family and is based on their requirements in daily use and for work purposes.^[17] Speech-language therapy (SLT) practices in one language may have beneficial crossover effects to other languages in multi-/bi-lingual PWA. It is interesting to note that multilingualism may be good for cognitive functions.^[18]

SESSION 5: READING AND WRITING

Acquired alexia with or without agraphia is often a part of aphasia. These can also occur without aphasia. The clinical assessment and therapeutic remediation of alexia and agraphia are even more neglected than aphasia. Naturally, verbal communication skills get primacy over written mode. With the increasing proportion of white-collar jobs, more PWA are dependent to a greater degree on written language for their daily needs, vocational rehabilitation, and leisure activities.

There is a paucity of test batteries for reading and writing in most languages. We do not have an equivalent of the National Adult Reading Test, but we can refer to the Coltheart and Karanth reading list in Kannada.^[19,20] Assessment of biscriptal patients offers a unique opportunity.^[21] The remediation of reading and writing deficits may also have beneficial effects on verbal communication.^[22] The insights obtained and resources developed while working for one population may be of relevance to the other.^[23] “Dyslexia Assessment for Languages of India” in seven languages (English, Hindi, Kannada, Marathi, Tamil, Telugu, and Bengali) has been published by the National Brain Research Centre, Manesar. It can be used for adults and the norms are available in Hindi and English.^[24]

SESSIONS 6 AND 7: COGNITIVE FUNCTIONS IN APHASIA AND LANGUAGE IN DEMENTIA

It is well documented that aphasia, a pure disorder of language, is accompanied by other neurological, cognitive, behavioral, and psychiatric dysfunctions. It is imperative to assess many domains of cognition such as arousal, attention, vigilance, intelligence quotient, various types of memory, praxis, executive functions, disinhibition, mood and affect, and motivation.^[25] Cognitive assessment requires a team of neurologists, neuro-psychologists, and SLPs. There are no

validated indigenous tests for cognitive assessment. Most of the tests are adapted from the West. While this may be fair for therapy purposes, standardization is imperative for research. The National Institute of Health cognitive toolbox can be easily adapted to Indian languages and administered with portable devices such as iPads.^[26]

Impairment of language functions is ubiquitous in dementias. The clinical profiles of language impairment in dementia are very different from the ones in poststroke and posttraumatic brain injury.^[27] Despite low prevalence and occurrence in postretirement age, aphasia in dementia is important. The incidence is increasing with the rising longevity. Awareness and the needs for remediation are also enhanced with more active life till late age. Academic research into cognitive-neuro-linguistic and psycho-linguistic aspects of language in dementias is exciting and leading to a better understanding of cognitive functions.^[28] The cross-cultural differences are important while assessing language in dementia.^[29]

SESSION 8: NEUROIMAGING

There is a need for more precise and detailed reporting of anatomical structures and arterial territories mapped on to distinct cortical and subcortical areas on computed tomography scan and magnetic resonance imaging (MRI) templates (line drawings) as listed in standard imaging atlases.^[30] The correlation between structural MRI changes and conventional taxonomic classification of aphasia is not very strong, particularly in the first 3 months after stroke. It would be more meaningful to study correlations between imaging findings and various subcomponents of language profile in subtypes of aphasia.^[31] Subcortical aphasias suggest the existence of cortical–subcortical circuits in language, as observed in other forms of cognition.^[32]

We should have MR physicists and computer scientists in the team to develop protocols and analyze the complex MRI data in more robust and scientific ways. The skills and facilities for more advanced structural brain imaging, for example, voxel-based volumetry, diffusion tensor imaging (DTI), or tractography, for research purposes, are not widely available.^[33]

Radiologists should ensure systematic collection of data preferably running a 3D MPRAGE/3D T1 TFE/3D SPGR sequence along with a good-quality, multishell DTI sequence. Both will take approximately 13–14 min which is worth its time.

Functional neuroimaging (functional MRI, positron emission tomography, and single-photon emission computed tomography) techniques provide evidence for neural modules or networks (not areas or centers) concerned with cognitive and linguistic functions.^[34] Neuroimaging is poised to play an important role in research on the effects of therapeutic interventions. A multidisciplinary project such as the Alzheimer's disease neuroimaging 3 can be undertaken in India.^[35] Preservation of data in the electronic/optical formats,

preferably in the PACS or CDs, should be encouraged for later academic and research purposes.

SESSION 9: RESEARCH

The EGA was of a strong opinion that research in aphasiology is a high priority. Digitization of patient-related data will be crucial. We must not neglect the state-of-the-art frontier areas such as (1) event-related potentials, (2) eye tracking, (3) spectral electroencephalography, (4) Neurotransmitters, (5) stem cells, (6) pharmacotherapy, (7) digital signal processing, (8) brain–computer interface, (9) artificial intelligence, (10) music therapy, and (11) noninvasive brain stimulation. Research is also needed in health systems and health policy concerning the delivery of optimum services for PWA.

There are a very small number of basic neuroscientists and cognitive neurologists in India. It is important to build interdisciplinary teams with them not only for research purposes but for the reason that joint activities may yield practical insights and applications.

SESSION 10: EDUCATION

Education about aphasia for clinicians and a few more special groups would yield far-more results in reducing treatment gap per unit investment of time and money. Education for aphasia will have to be targeted for many groups with differences in scope and emphasis.

Physicians

Clinical and theory education about aphasia during MBBS is rudimentary and depends on interest of teachers. The EGA will reach out to medical teachers (UG level) in internal medicine. Residents (MD medicine) are expected to manage and counsel PWA and caregivers and must refer to SLPs at the earliest. Trainees in neurology must get extensive clinical exposure to a large variety of aphasia during the outpatient consultations, ward rounds, and case presentations.^[36]

Speech-language pathologists

At present, the numbers of chronic patients treated by SLPs are much more than the acute ones, and this needs to be addressed. The academic training programs in SLP are being monitored by the Rehabilitation Council of India (RCI). The updated and revised syllabus and regulations have tried to balance the equilibrium of clinical and academic skills. Further, with effect from the academic year 2018–2019, the RCI has withdrawn the dual degree at the master's level of audiology and SLP and has introduced the specialized program of SLP and audiology. This is expected to strengthen the professional and clinical skills of the SLPs. A large collection of aphasia-related videos in major Indian languages will be used to train professionals.

Linguists

Collaboration with the centers offering training in “Applied Linguistics” will be another action plan. Attempts will be made to reach out to departments of linguistics all over the country

and distribute teaching material about aphasia, appropriate to their faculty and students. Faculty and PhD scholars may be encouraged to take research projects in aphasia.

Paramedical professionals

The EGA felt the need to conduct orientation programs for clinical psychologists, nurses, physiotherapists, occupational therapists, and social workers. Clinical psychologists play an essential role in the assessment of cognitive functions and alleviating psychological distress. Physiotherapists play a vital role in improving the physical mobility of PWA. Occupational therapist tries to promote purposeful activities for restoration of function and to maximize participation in meaningful activities at home, work, and leisure. Recovery of motor and speech-language functions runs somewhat in parallel course, and there is possibly some crossover effects between the two.^[37] The EGA members opined that communication channels should also be kept open with professionals practicing alternative systems of medicine such as Ayurvedic, Homeopathic, and Yoga, to reinforce the care for PWA.

Volunteers

A need for training volunteers was felt because the large gap in diagnosis and therapy is not likely to be reduced significantly in the near future. The EGA will develop a teaching module for this purpose.

SESSION 11: SPEECH-LANGUAGE THERAPY

As per the recent Cochrane review and RCTs, there is strong evidence to show that SLT is beneficial to PWA.^[38,39] The intensity, dose, and duration of therapy are critical factors. Impairment-based therapy and overall communication methods are mutually reinforcing as the ultimate goals are the same.

The short- and long-term goals should be meaningful, relevant, specific, and challenging but achievable with a focus on activity and participation. These goals should be recorded, reviewed, and updated regularly.^[40] There may be cultural and economic factors influencing the goals.^[41]

There is utter lack of awareness about need, efficacy, and availability of therapy and rehabilitation among PWA and caregivers. Hence, the needs of PWA are generally addressed at an elementary level, leading to low expectations and poor QOL. There is no desire or urge to become self-dependent again.^[42] A change in social attitudes must come by imparting an awareness that individual goals for PWA are worth the time and resources.

Inadequate referral and late referrals are the greatest impediments to service delivery to PWA. It is imperative to increase awareness among the public and professionals about the efficacy of speech and language therapy. The benefits of early referral and intervention should be highlighted. Discontinuation of therapy is very common due to several factors such as cost of rehabilitation, access to therapy, commutation problems, availability of qualified therapists, and loss of wages to the caregiver.

Newer methods in SLT such as “constraint-induced therapy” and intensive language action therapy involving intense and prolonged therapy sessions of 3–4 h every day for a short duration of around 15 days as well as constraining the patient to use only speech for a few hours every day (gestures and sign language not allowed) are known to produce measurable gains.^[43]

Pragmatic therapy methods for severe aphasia are less prescriptive than cognitive and psycholinguistic approaches. They encourage compensatory and productive strategies and discourage maladaptive strategies.^[44]

Group therapy sessions can be useful if (i) patients with the nearly similar profile are offered specific practice sessions, (ii) heterogeneous groups are provided general-purpose learning and practice opportunities (pragmatics based) to improve the overall communication skills, and (iii) to provide a platform for social interactions.^[45]

Speech-language therapy with limited resources

We need to explore and set up alternate modes of service delivery with a broader reach, such as teletherapy.^[46] A Manual for Adult Aphasia Therapy has already been developed in six languages and is available at AIISH.^[47] Computer and group therapy have been found to be approximately 30% cheaper compared to the standard service.^[48]

Music therapy

There are a few studies for Western classical and contemporary music being used in therapy on aphasia.^[49] Indian Classical (Hindustani and Carnatic) and other genres are unique and rich in their respect. We must explore opportunities for working with Indian musicians.^[50]

Malpractice in speech-language therapy

In many instances, the SLT may be a sham when offered by unscrupulous quacks or ill-trained practitioners. Such a person treats PWA as deaf-mute or mentally retarded. What is provided in the name of SLT is only flash cards, memory games, repetition of automatized sequences, oro-motor stimulation, etc., The ISHA may conduct surveys to monitor the services being provided to PWA.

SESSION 12: REHABILITATION

The group agreed that uniform protocols should be set up for stroke aphasia rehabilitation.

Augmentative and alternative communication is an umbrella term that encompasses the communication methods used to supplement or replace speech or writing for those with impairments in the production or comprehension of spoken or written language (e.g., communication boards, digital assistants, and gestural systems). Sadly, these devices are not popular, not well propagated, and not improvised and individualized in Indian cultural contexts.^[51]

Quality of life in aphasia

It is essential to measure “QOL” in PWA to identify patient’s problems, determine treatment priorities, manage interventions,

and monitor disease periods. Indian questionnaires have been developed and validated for this purpose and should be part of the assessment protocol in aphasia.^[10]

Role of caregivers

Caregivers burden in supporting PWA may sometimes appear trivial and mutually satisfying, particularly in cultures (like Indian) where family values are held high. However, in the long term, it may be unbearable. Aphasia QOL studies should include “caregiver burden,” as well as “supportive communication strategies” used by significant others and report them separately.^[52,53]

The role of the caregiver as a provider of home-based therapy and as a facilitator during therapy in the clinic is important.^[54,55] Clinical tales or patient stories written by patients, caregivers, and clinicians may be compiled and published.^[56]

Legal aspects of aphasia as a disability

The EGA felt the need to define and quantify various aphasic and communication disabilities, handicaps, and impairments more objectively and explicitly so that legal and administrative help is available to patients and families.^[57] It is essential to educate and train medical fraternity regarding diagnosis and severity of aphasia for purposes of certification.

Reaching out to employers

Clinicians should communicate with employers regarding the capacities and limitations of the PWA. Suitable modifications to the job environment and nature and type of job can be suggested. Early return to work, maybe in sheltered workshops, improves the psychological well-being of an individual and aids recovery.

SESSION 13: BIOLOGICAL THERAPIES

Advances in our understanding of the basic mechanisms of neural regeneration and repair along with animal models of stroke recovery are creating a firm foundation for clinical trials of biological intervention. Stem cells and biologicals have been studied in animals or phase 1 and phase 2 clinical trials.

Pharmacotherapy

The results with drugs have not been very impressive till now, but prospects are improving.^[58] Pharmacological augmentation of the speech therapy may be more robust and reliable with stimulants, cholinesterase inhibitors, dopamine agonists, and other medications. While drugs alone may not result in significant improvement, agents such as memantine have been shown to enhance outcomes of SLT in combination.^[59]

Noninvasive brain stimulation

NIBS through repetitive transcranial magnetic stimulation (rTMS) and transcranial direct current stimulation (tDCS) have been employed in chronic aphasia either to suppress the maladaptive and inhibitory right hemisphere activity or to stimulate compensatory left hemispheric perilesion areas.^[60] A recent meta-analysis reviewed the effect of low-frequency rTMS and cathodal tDCS over the nonlesioned right

hemisphere (with sham controls) and found a significant mean effect size for the accuracy of naming.^[61]

SESSION 14: COMPUTERS, INFORMATION TECHNOLOGY, TELECOMMUNICATION

The EGA members were keen to reach out to computer professionals to arouse interest in their minds. The need for interaction and building of local teams is very strong and urgent. We are in dire need of digital applications, software, and hardware for use in Indian languages. The diagnosis and treatment gap could be partially ameliorated by teletherapy while reducing costs and time incurred in traveling to the therapy center.^[62]

Computers, information technology, telecommunication (C-IT-TC) will be useful in assessment, diagnosis, follow-up, measurement of changes over time, delivery of therapy practices, and augmentative modes of communication for rehabilitation and research. C-IT-TC has many merits. It is portable, editable, interactive, participatory, and expandable. It facilitates scoring and analysis. It is conducive to teletherapy and group therapy. The contents become easily transferable. Individualized and user-friendly designing is possible which can be multilingual and multiscriptal. It has the advantage of being available anytime, anywhere in a cost-effective manner.^[63] Multimodal visual images, scripts, sounds, and videos can easily be incorporated. Computer therapy is effective compared to no therapy. It may be as effective as clinician-delivered therapy. However, the quality of evidence is low due to the small number of studies.^[64]

Many general purpose pre-existing technologies (e.g. voice recognition, text to speech conversion, trans-literation from one script to another, translation and storage of big data, can be potentially used for various needs in aphasiology. Language technology tools can also help to understand the language patterns in different Indian languages and thereby assist in developing test batteries.

Potential for smartphones in India

Several apps that are already available were discussed such as Constant Therapy, Text to Speech, Meri Vani, and Awaz. Android-based Apps for phonological component and semantic feature analyses training have been developed at Manipal and are currently being field tested.^[65,66]

A Bengaluru based start-up working with NIMHANS (psyneuronics) is developing indigenous assessment tasks in digital format. A group at TCS Mumbai is working for machine analysis of dysarthric speech and helping the subjects to communicate better/improve communication. An Indian language version of Constant Therapy is likely to become available soon.

Experts in text analytics, who have studied language, and its syntax structure, will be able to help with understanding the disintegration of linguistic abilities and looking for variations

in the speech following a deficit. Using text analysis of automatically recognized speech, it would be possible to decode what the patient is trying to convey and hence will help caregivers to assist better.

SESSION 15: ADVOCACY

All stakeholders need to chalk out smart action plans. The targets of advocacy include all stakeholders plus ministers and officers in government, media persons, judiciary, NGOs, and legislators.

The EGA plans to prepare a White Paper or Vision Document, which will introduce the subject, describe its community burden and gaps in diagnosis, treatment, and rehabilitation. It will also enlist many demands on behalf of PWA, their caregivers, and clinicians serving PWA.^[67] The White Paper will be converted into various formats such as presentations, handouts, and brochures in Indian languages. We envision that many advocates for aphasia shall use the Vision Document as an ever-handly reference and talking tool while engaging with various targets of advocacy. There is evidence that advocacy works.^[68] We agreed for an annual training program on advocacy for the members of ISHA.

Awareness is the key

A study found a direct correlation between the number of articles in lay press and funding for a medical condition.^[69] Another survey from Kerala documented very poor awareness about aphasia.^[70] The EGA recommends high visibility, long-term, saturation-level public education, and patient education program in Indian languages.^[71]

Advocates for aphasia need to lobby for:

1. Capacity building in the existing and new institutions so that the number of SLPs being trained per year is increased rapidly, more so in the states, which are lagging
2. Aphasia rehabilitation services to be setup up to the level of each district hospital in the public sector, including the appointment of a speech-language pathologist
3. Model Aphasia Clinic and Research Centre affiliated to the Neurology Departments in each government and private medical colleges and large hospitals.

It is a matter of concern that the posts for SLPs are with Departments of Oto-Laryngol-Rhinology and those of clinical psychologists with psychiatry and none or rarely with neurology. This needs rectification.; Our group will try to initiate and support a network of patient-support groups (PSGs) related to aphasia and communication disorders at the city, region, state, and national level. Patient registries for PWA will be created. Our group will draft a manual for successful operation of aphasia PSGs.^[72]

SESSION 16: WEBSITE

The EGA wants to establish its online presence in the form of a long-term website which will serve as a dynamic, updated repository for the following:

1. Actions taken and tasks accomplished with various plans and recommendations
2. A collection of aphasia test batteries developed in India
3. Protocols for research projects and a bank of research questions and ideas to encourage young professionals and departments to choose one or more from it
4. An annotated bibliography of research publications and unpublished dissertations on aphasiology in India
5. An online repository of ongoing and completed projects (including the dissertations at UG/PG level)
6. A listing of ongoing projects in research, teaching, and advocacy
7. Teaching resources for aphasiology targeted to a wide spectrum of audiences
8. Advocacy resources for aphasia (Vision Document or White Paper)
9. A collection of SLT modules and protocols in Indian languages. An editorial committee will select these resources based on standardization, validity, practical use, research use, issues of patent, copyright, and permission
10. A national directory of SLT services in the public and private sector
11. Guidelines for aphasia assessment and therapy.

The EGA discussed the logistics of the website. Additional pages may be created on one or more of the preexisting websites. For example, <http://www.aphasiastrokeindia.com>

We may opt for a new website and can additionally have accounts in the leading social media. Efforts will also be needed for enhanced visibility and popularity of our website.

CONCLUDING REMARKS

It is evident that our recommendations and action plans are over-ambitious. Yet, we hope that they will encourage us to strive for more. Our group will continue to work cohesively for a period of a few more years. There will be additions and attritions. We hope to see achievements and actions on some fronts. The vision for which we stand for is to improve clinical services, rehabilitation, and QOL of persons with aphasia and to improve education and research in aphasiology. Our mission is challenging. We know our limitations. We intend to chalk out a few Specific, Measurable, Attainable, Relevant, Time based (SMART) and doable action plans, find people willing to execute those plans, and to monitor and help the execution itself. We hope that our efforts will lead to tangible, direct or indirect benefits to PWA. It is satisfying to note that our action plans appear in good concurrence with recently published top ten practice recommendations for aphasia^[73] [Table 2].

Acknowledgment

Following experts could not attend the meeting but contributed before and after the event by providing suggestions and comments and helped in editing:

- Dr. Subhash Bhatnagar, Department of Speech Pathology and Audiology, Marquette University, Milwaukee, WI, USA

- Dr. Swathi Kiran, Professor, Doctoral Program Director, Speech Language and Hearing Sciences, Boston University, USA
- Dr. E. Ratnavalli, Consultant Neurologist Bengaluru
- Dr. D. Vasantha, Department of Linguistics, Osmania University, Hyderabad
- Dr. Dipti Mishra, Professor, Linguistics, International Institute of Information Technology, Hyderabad
- Dr. Amitabha Ghosh, Neurologist, Apollo Gleneagles Hospital Limited, Kolkata

- Dr. Padma Vasanta, Professor, Department of Neurology, AIIMS, New Delhi.

Financial support and sponsorship

The Indian Academy of Neurology supported the activity.

Conflicts of interest

There are no conflicts of interest.

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Table 2: Top ten best practice recommendations for aphasia*

<i>n</i>	
1	All patients with brain damage or brain disease should be screened for communication deficits
2	People with suspected communication deficits should be assessed by a qualified professional (determined by country); assessment should extend beyond the use of screening measures to determine the nature, severity, and personal consequences of the suspected communication deficit
3	People with aphasia should receive information regarding aphasia, etiologies of aphasia (e.g., stroke) and options for treatment. This applies throughout all stages of healthcare from acute to chronic stages
4	No one with aphasia should be discharged from services without some means of communicating his or her needs and wishes (e.g., using AAC, supports, trained partners) or a documented plan of how and when this will be achieved
5	People with aphasia should be offered intensive and individualized aphasia therapy designed to have a meaningful impact on communication and life. This intervention should be designed and delivered under the supervision of a qualified professional Intervention might consist of impairment-oriented therapy, compensatory training, conversation therapy, functional/participation-oriented therapy, environmental intervention, and/or training in communication supports or AAC Modes of delivery might include individual therapy, group therapy, tele-rehabilitation and/or computer-assisted treatment Individuals due to stable (e.g., stroke) as well as progressive forms of brain damage should be offered intervention Individuals due to stroke and other static forms of brain damage can benefit from intervention in both acute and chronic recovery phases
6	Communication partner training should be provided to improve communication of people with aphasia
7	Families or caregivers of people with aphasia should be included in the rehabilitation process Family and carers should receive education and support regarding the causes and consequences of aphasia Families and carers should learn to communicate with the person with aphasia
8	Services for people with aphasia should be culturally appropriate and personally relevant
9	All health and social care providers working with people with aphasia across the continuum of care (i.e., acute care to end of life) should be educated about aphasia and trained to support communication in aphasia
10	Information intended for use by people with aphasia should be available in aphasia-friendly/communicatively accessible formats

*All best practice recommendations are underpinned by different levels of evidence. The levels of evidence are not stated in the above table as they use a different system of defining evidence level. AAC=Augmentative and alternative communication

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