Chapter 12
Discourse Elicitation in Aphasia: An Indian Framework

S. P. Goswami
All India Institute of Speech and Hearing, India

Brajesh Priyadarshi
All India Institute of Speech and Hearing, India

Sharon Mathews
All India Institute of Speech and Hearing, India

ABSTRACT

Persons with aphasia (PWA) face varying difficulties of communication breakdown through different stages of recovery. With speech-language therapy, significant recovery may be seen at unitary levels, but the ultimate success of therapy is evident when the PWA uses all of the units as a whole and is able to communicate optimally to sustain social identities. An individualized intervention program as the focus, a protocol is proposed with seven semi-structured interviews aimed at eliciting discourse incorporating the philosophies of the social model, LPAA, SCA, AphasiaBank Protocol, and Protocol to Measure Participation of Persons with Aphasia. The interviews with the PWA and their communication partners in individual and joint sessions can help the clinician answer questions regarding the PWA's physical abilities, dietary issues, functional independence, personal traits, relationships at home, different social roles played, and subsequently plan a treatment program, and track the holistic recovery of the PWA.

DISCOURSE IN COMMUNICATION

Successful social bonds form the foundations of human communication. Social networking is cemented with concrete conversational episodes whose primary purpose is information exchange. Each individual's innate desire to communicate brings about the multitude of language forms witnessed in the environment. Language is molded, modified, scaffolded and presented as discourse for sharing of ideas, thoughts and feelings. This transmission of information between individual units is indispensable for the existence of the unit as a whole. Language disorders hinder the smooth flow of information causing an imbalance in

DOI: 10.4018/978-1-5225-4955-0.ch012

Copyright © 2018, IGI Global. Copying or distributing in print or electronic forms without written permission of IGI Global is prohibited.

the social unit. The presence of discourse elicitation works as an appendage buttressing the connections in this network.

Discourse is defined as the basic unit of human communication. Pragmatics-component of language-defines the contextual use of language. The mutual relationship of language and context determine "why a speaker says something, when the speaker says it; to whom the speaker says it and how it is said". Yet, words and sentences alone cannot completely describe how discourse is produced, given the variations in the linguistic structures based on the context. The cognitive and social aspects of language play exhibit a symbiotic reaction in discourse. Cognition and language are two interrelated domains working on the various aspects of information processing in the brain. The role of cognition in language dissemination is visible in the pragmatic ability of an individual. Discourse being the denouement of the interaction of cognition, language and context, deserves a multifaceted investigation (Cherney, Shadden, and Coelho, 1998). The pragmatic appropriateness of discourse revolves around three context: extra-linguistic, paralinguistic and linguistic contexts (Davis, 1986). The extra-linguistic context is inclusive of external-physical surroundings, time of the day and the number and location of the participants- and internal factors of participants. The paralinguistic context refers to the prosodic and suprasegmental component of an utterance. The linguistic context refers to the verbal output. Discourse is a series of connected sentences that convey a message. Although typically discourse is longer than a word, it has been argued that when a word alone expresses a message, it may be considered discourse. This is particularly relevant for persons with aphasia (PWA) in which the unit of analysis may be as short as a word.

Types of discourse entail descriptive, narrative, procedural, persuasive, expository and conversational. Discourse is classified based on the functions it serves. Analysis of discourse involves multilevel examination that (a) assesses PWAs' performance across discourse tasks that require different cognitive and discourse skills and (b) assesses different aspects of discourse performance within the same task. Microstructural analyses focus at the local level of the word. They are concerned with the small elements in a text and the relations between these small elements. Macrostructural analyses focus at the level of the entire text. Superstructural analysis overlies the text and includes the analysis of story grammar. PWA may show differential impairments at each level. Therefore, it is important to use a variety of discourse elicitation and analysis procedure to identify the specific discourse impairments of the PWA.

ASSESSMENT OF DISCOURSE

The proliferation of research on discourse analysis has occurred concomitantly with changes in health care that emphasizes the need for determining functional goals for communicatively impaired PWA and measuring functional outcomes in clinical practice. The environment determines the nature of communication; if the environment changes, the communication changes accordingly. Functional communication goals for a specific person can be determined only with respect to that persons' own social and physical setting and therefore can be defined only with respect to the individual (Hartley, 1995). Discourse analysis procedures provide the clinician with a set of evaluation tools that (a) describe the impairment in objective and measurable terms, (b) help identify the underlying cognitive or linguistic processes that contribute to the discourse impairment, (c) assist in treatment planning, and (d) are sensitive to changes over time. It is important to consider the discourse of PWA. However, the systematic application of discourse analysis procedures may not be warranted for all individuals, particularly, if the communication

problem is severe and the output is limited. Therefore, for each PWA, clinicians must make decisions about when and what kind of discourse is to be sampled and how the discourse is to be analyzed.

For a keen assessment, the selection of tasks for eliciting a substantive sample for discourse should encompass a broad range of behaviors especially focusing on the individual strengths and deficits of a person. As the etiology and the ramifications of stroke vary with each individual, the method of assessment of discourse also follows a distinctive pattern. These specific decisions need to be made considering the variety of task-related variables. As for the stimulus used, the different modes of presentation can be simple to complex, auditory and/ or visual with a shared and/or absent reference between the PWA and clinician. The memory and sequential organization at the level of PWA can set the macro-structural level of discourse. Disruptions, like repetitions, revisions, excessive pausing in the task can be anticipated by the clinician, but not often, while setting the complexity of the stimulus. The testing instructions are solely at the disposal of the clinician and how s/he conveys them effectively. For example, instructions for a picture description task can vary from direct to elaborate as in, 'Describe this picture' to 'Connect the events in the picture to form a story' will influence the quality of the verbal performance. Similarly, a request to tell a story in their own words or follow the clinician would affect the elicited response. Personal relevance comes into play when the clinician intends to tap into the individual's emotional plane. Overall functioning can be assessed using a general topic of conversation, but with a topic of personal relevance, the PWA may not just give the details about the topic, but also state personal experiences that add to the content of discourse, and higher quality of performance. For instance, upon asking an older gentleman about smart phones, the quality of the description and information content would clearly be different from when the same topic is given to a teenager. The factor of personal style in discourse is also associated closely with the aspect of personal relevance, again left to the judgment of the clinician. Open-ended tasks generally allow the individual to exercise their personal style. Accounts of past events and general conversation gives a good opportunity for the person to exhibit their stylistic variations in discourse, than do constrained tasks such as story retelling or picture descriptions. Discourse analysis procedures, although vast, provide the clinician with an extensive understanding of the strengths and weaknesses of an individual. An attempt to include all the variability in a discourse elicitation task is analogous to pattern in chaos. A clinician's discretion even though aims at individualized analysis, may more often seem subjective, with the clinician choosing only tasks that are adept at assessing the overt needs of the PWA. Having a specified framework for discourse assessment, builds on the confidence of the clinician as s/he would not miss the minute details, simultaneously working on the initiation of rehabilitative services.

DISCOURSE ELICITATION IN PERSONS WITH APHASIA

The essence of discourse elicitation lies in the purpose of reintegration of the PWA in society. The scope of recovery is measured by the number of social roles the individual can carry off after the advent of stroke followed by aphasia. The current treatment models focusing on the narrow linguistic parameters assessed by standardized test batteries allow only as much improvement as can be achieved within the clinical setting and the recovery tends to remain incomplete. Termination of traditional language intervention programs reflects the sheer ignorance of the social aspect of recovery. Issues on lack or change in social identities of PWA remain disregarded when clearly the "ceiling effect" in their recovery is an effect of their social isolation. An understanding of this idea leads us to the social model applied to

aphasia (Simmons-Mackie, 1998a; Gee, 1999). The social model looks at aphasic impairments from two different perspectives that are essentially two sides of the same coin! Societal and communicative perspective constitute the 'social model' with the former addressing issues of social barriers to communication and life participation and the latter focusing on the individualistic interactions of the PWA with his/her environment. This model projects the outlook that the treatment approach should follow a social holistic pattern wherein along with addressing the language impairment the PWA and his family comes forth as a thriving social unit.

Supported Conversation Analysis (SCA; Simmons-Mackie, 1998b; Kagan, 1999) as a technique embodies that a supportive environment assuages the conversational episodes of PWA; thereby improving one's opportunity for restoring social identities. SCA (Parr and Byng, 1998) helps in revealing the inner strength of person in conversational interactions which play a central role in life participation. This is achieved by training the caregiver to view PWA as a competent conversational partner by providing a communicative ramp. The philosophy of SCA is derived from the Life Participation Approach to aphasia (LPAA; Chapey et al., 2001). The LPAA is based on the premise that whatever be the strengths or weaknesses of the PWA, a supportive environment dampens the effect of disability on the individual's life. This approach advocates the need for intervention at three levels, classifying the different activities of a PWA, i.e., at the body level, individual level and the society level. Anomia or hemiparesis reflects problems at body level, and is differentiated from problems at the individual level that involve difficulties in taking bath or reading a book. The society level comprises of activities like practicing one's profession, being a part of a social gathering, or going to a movie. Targeting treatment at all three levels ensures quality services for the PWA and professional support for the PWA and family throughout the course of recovery. Keeping in mind the importance of life enhancement changes with its dependence on social model, clinician may also look into the environment in which activity or discourse is carried out. The conversation partner in the adjoining environment is the key to understanding how the situated meaning, grammar and social identities in conversation vary within discourse. Thus, the recovery of PWA involves a reorientation of the conversation partner to the communicative needs of the reformed person. The social integration of PWA falls within the purview of the International Classification of Functioning, Disability and Health (ICF) schematic (World Health Organization, 2001) which centralizes on the activity and is co-dependent on the health condition, body functions, contextual factors and participation levels of the PWA. The social perspective of treatment for PWAs focuses not only on the medical aspects of improving the body functions and structures, but also enhancing the participation levels by improving the life activities, wherein the environmental factors and personal factors act as either a barrier or a facilitator.

THE PROPOSED PROTOCOL FOR DISCOURSE ELICITATION IN PERSONS WITH APHASIA

The road to social recovery of a PWA begins with identification and assessment of the person and the family as a holistic unit (Joanette and Brownell, 1993). Assessment of aphasia entails precise and extensive tools each having their own advantages. The decision lies in the hands of the clinician on how to use these tools in a time effective manner. A discourse analysis incorporated in the assessment of aphasia helps to strike a balance between an extensive and precise assessment procedure, in order to accomplish an efficient assessment. It is a tedious job to approximate an appropriate discourse elici-

tation procedure without any specific guidelines. This study introduces a manual consisting of seven semi-structured interviews enabling to gather copious amounts of information right from the first session. These interviews, accommodating a range of tasks were designed keeping in view the problems in PWA, and to obtain information about the subtle changes in their discourse production. Whilst giving structure to what kind of data needs to be collected, it provides freedom to clinicians for organizing interviews in discrete sessions. This ensures that the assessment duration does not outgrow the duration of rehabilitative services provided.

The proposed protocol prepared for discourse elicitation is a result of the incorporation of philosophies of the social model, LPAA, SCA, AphasiaBank Protocol, Protocol to Measure Participation of Persons with Aphasia and an opinion of how a uniform protocol aimed at holistic recovery enables a person with aphasia. Priority should be given to the person as a whole and not the disability as discussed in these aforementioned concepts. The PWA's social identities and his life as an individual are valued and it is believed that every individual contributes to the society in the minutest and the biggest possible ways.

The present protocol is a booklet of questions that set the stage for elaborate discourse elicitation via semi-structured interviews with PWA and others who are a part of his social unit. A social unit in this study comprised of the PWA, the conversation partner, an employer or colleague. A conversation partner can be the spouse, parents or friends who is vital to the PWA's current communication episodes. In the proposed manual, specific demeanor of clinician in each interview and their attitude through which they can create maximum opportunities for detailed responses is outlined. The proposed interviews are divided into definite topics with a single open-ended question and a set of prompt questions for each topic. Each session is expected to be conducted in 45-60 minutes, wherein a single interview may extend for more than one session based on the discourse abilities of the PWA and the quality of discourses itself. Prior to beginning the interviews, informing the PWA and caregiver about the format of the interviews and the confidentiality of the information provided by them helps the clinician build a better rapport. It is also easier when the PWA is informed that he/she may take a break at any point during the interview, or even choose not to answer certain questions.

Interview 1

The first semi-structured interview is a joint interview involving the PWA and caregiver(s) and begins with questions that help build a rapport with the clinician. The first interview format is illustrated in Appendix 1. Beginning with a brief introduction and a casual exchange of information, this interview session kicks off the assessment by obtaining information about the PWA and caregivers, covering all facets of demographic detail, specifics of stroke and neurological, psychological, behavioral, motor, linguistic aftermath. Further, the details of any alternate therapies, allied and medical assessments and treatments to improve the overall quality of life are also inquired by the clinician. Having gathered these basic demographics of the individual, the clinician can now move to communication with the PWA at a discourse level. Discourse topics listed in the protocol such as relationships at home, dietary issues, physical abilities, social life, functional independence and personal traits include questions that will help direct the PWA-clinician conversation. This provides an opportunity for the clinician to understand the communicative level of the PWA in the presence of the caregivers and the extent and type of support received from the caregiver when there is a communication breakdown. The clinician can directly observe the communicative roles of the PWA and caregiver as being active or passive partners during this interview.

In addition to gathering information, the first joint interview session sets the way to establishing a professional trust between the social unit and the clinician. As the clinician and the social unit move further, the format of the interviews enable the clinician to build an understanding within this unit, and intervention goals can be focused on the unit as a whole and not PWA alone.

Interview 2

The AphasiaBank Protocol (http://aphasia.talkbank.org/protocol/) forms the second interview session with the PWA. The AphasiaBank Protocol which is freely available online was used with linguistic and ethno-cultural adaptations for Indian languages. The AphasiaBank protocol is a detailed procedure assessing all aspects of linguistic competence and has two major sections and various sub-sections. The first section is broken down into four subsections: conversation, picture description, story re-telling and procedural discourse. Each of these subsections has set of tasks and questions that elicit verbal discourse. The first subsection (illustrated in Appendix 2) involves the clinician inquiring about the stroke story, coping with the condition and an important event that molded the PWA's life. The second subsection is a picture description task that includes three stimuli: broken window, refused umbrella and cat rescue. The first two stimuli consisted of a four-panel and six-panel sequence. The clinician may simply present these stimuli and instruct the PWA to look at the pictures carefully and describe what they see. The PWA's may require prompts to help them connect the story sequence at the beginning of this subsection and the clinician is free to decide the type of prompts to be used with each of these picture description tasks.

Keeping in mind the cultural variations of the target population, certain adaptations and modifications are made to the subsections in the AphasiaBank Protocol as in the third subsection. Story re-telling requires the PWA to tell the 'Hare and Tortoise' story commonly known to the target population. This section can employ a different story based on the target population. When assessing PWA from varied ethno-cultural background, childhood fables specific to them should be assessed. For Indian population, the 'Hare and Tortoise' story is an appropriate option. The fourth subsection which elicits procedural discourse skills entails the step-by-step delineation of making tea. Making a peanut butter-jelly sandwich is a concept alien to the Indian population. However, tea is a common drink throughout the country and the procedure would be known to all individuals albeit with certain variations. This change in the procedural task is only made to make the evaluation relevant to the target population. The second section of the AphasiaBank Protocol involves administration of Western Aphasia Battery-Revised (Kertesz, 1982), Aphasia Bank Repetition Test and Verb Naming Test. The word and sentence repetition test and verb naming test are translated into Indian languages or appropriately adapted such that the stimuli has an ascending level of difficulty and are culturally appropriate. Observations and results from these tests will help the clinician specifically target the linguistic challenges faced by the PWA during language therapy. Administration and scoring of each test is explained systematically in the manual as is in the online AphasiaBank protocol.

The incorporation of internationally developed and recognized AphasiaBank protocol assists the clinician to establish a clear understanding of the PWA's linguistic abilities and deficits. Comprehensive knowledge of the PWA's shortcomings becomes the basis of the succeeding interviews with the clinician being the sole communication partner, finds it easier to carry out supported conversations.

Interview 3

The third interview (see Appendix 3) is an individual interview session with the PWA, investigating the personal feats, relations, work expertise, public relations, current responsibilities, financial status, quality of service delivery and further expectations. This session brings the focus on the PWA; the clinician is free to enquire about the individual's feelings and thus, gather an understanding of his/her fears, anxieties, and sorrows and how they are coping with these feelings over the continuum of recovery. The interview format for this session lists questions that are directed toward the individual and his experiences, helping the clinician drive the conversation into understanding the PWAs personality. The clinician can trace out the various changes in the individual's personality with respect to each of their social identities. Most individuals may put on a strong face in front of their dear ones and hide the deepest fears about their condition. In many situations, PWAs are dependent on their caregivers for activities of daily living, and the extent of help required depends on their communicative and motor difficulties. They often consider themselves as a burden on the family and thus, hide their worries and fears hoping not to cause any further problems to their caregivers. Difficulty accepting change in their social role could be another reason for not sharing their feelings with the caregiver, which could be sometimes expressed in terms of anger or frustration. For most PWAs, a space to talk about themselves in the absence of the caregiver gives them an opportunity to vent out suppressed feelings over the whole situation, something that they keep thinking about every minute of their life post-stroke. This gives them a chance to talk about their anxieties, fears, depression and hope for recovery from their own perspective. Clinicians may bear in mind that, although an individual interview is intended to gather subtle information about the PWA, it is the choice of the PWA to disclose any of the information. By establishing oneself as an ardent listener who is neither biased nor detached, the clinician is able to gain the trust of the PWA. This further emphasizes the role of the speech-language pathologist as a professional with a better understanding of the PWA's current situation.

With this interview session, the clinician discusses matters that are of the highest priority to the PWA, matters concerning the past, present and future. This way, the clinician can track the change within and across interviews, from feelings solely of anger and depression to more positive attitudes toward life changes.

Interview 4

The fourth interview session (see Appendix 4) is an individual session with the conversation partner or caregiver to explore the changes in the dynamics of their relationship after the onset of stroke and aphasia, extent of setback faced by this event and strength of the support system coming into play for coping up. It goes on to understand the scope of hope and good-will, factors responsible for improvement, people who have come forward to be a part of the PWA's recovery and the need for training of conversation partner. It also maps out the conversation partner's personal life and career plans and where PWA's recovery falls on this timeline. A strong support system is imperative for inclusion of PWA in his social circles post aphasia.

Interview 5

The fifth session lays out the administration of Protocol to Measure Participation of Persons with Aphasia for appraising the ability of PWA to participate in desired life situations, and was developed by Mathur and Goswami in 2010. This tool measures the effect of aphasia on a person's life in the horizon with the goals of ICF schematic (World Health Organization, 2001). It is a picture based rating measure wherein the PWA rates on a 5 point rating scale for an extensive set of questions broadly categorized under (a) understanding and expression, (b) general tasks and demands, (c) interpersonal interactions and relationships (d) facilitators and barriers. The clinician begins the session by explaining PWA about the questionnaire and how to rate each question using an illustration of the scale provided. The clinician continues by asking the questions and prompting the PWA to choose a number on the scale based on their experiences in the present and based on their perception of how easy or difficult an activity is. The questionnaire also includes certain questions wherein the PWA has to compare the pre-morbid abilities and skills to the present condition. This self-rating scale gives a vivid picture on how the PWA perceives his/her life with aphasia. Having meticulously observed PWA's discourse skills over the days, the clinician must now be able to decide if these ratings are in line with the actual difficulties faced by the individual. Moreover, PWA's self-perception is also an indication of their confidence in carrying out various communicative and daily life activities. The Protocol to Measure Participation of Persons with Aphasia tremendously helps in the early phase of assessment as the included illustrations supplement the verbal instructions and traditional quality of life measures.

Interview 6

The sixth session (see Appendix 5) draws attention to the work arena. Taking into consideration the ICF model and social model, the identities and activities of the PWA are not only restricted to family and home, but to the society and the workplace too. The session would be applicable if the PWAs were pre-morbidly employed or held an identity that was away from home and family members. The clinician interviews an employer or colleague for the new found expectations and consignment of duties to the individual who now has aphasia. This interview attempts to consider the demands of PWA's job and tries to make it clear to the employer/colleague that PWA still has the abilities to contribute though in an altered way. The session observes if the co-worker/ employer is willing to keep the PWA employed despite their communicative and/or physical difficulties. It gives an opportunity for the clinician, PWA and the co-worker/employer to discuss the modifications, accommodations and adjustments that can be made at workplace. As professionals, it gives a chance to counsel the employer that taking a PWA back at workplace will be a determiner of good prognosis.

Interview 7

The seventh session (see Appendix 6) is communicative counseling session that consolidates a profile description of PWA to the social unit. The employer, conversation partner/caregiver and PWAs are all privy to the results of the seven semi-structured interview sessions. These sessions will help in knowing the strengths, weaknesses, opportunities, threats, barriers and facilitators with respect to home, com-

munity and workplace, understanding and interpreting the findings to unearth to improve and maintain the role of PWA in house, work and community; thereby, improving the mental, physical, social well being of the PWA, conversation partner and the employer. Each session provides an opportunity to PWAs to clarify doubts, queries, suggestions, views they have regarding the assessment and treatment plan. This manual provides a conglomerate of multichannel communicative access between the PWA family, employer and clinician serving as confidence building measure for better recovery.

CONCLUSION

The present protocol for discourse elicitation in PWA is fundamentally a semi-structured questionnaire that enables the clinician to be feasible with the questions as per PWA's emotional state. It helps in building a strong foundation for intervention. Voicing out personal stories of PWA and caregiver establishes a bond between them and the clinician. By empathizing with the PWA whilst keeping a professional outlook, the clinician is able to build the rapport for future sessions. It enumerates life participation goals for PWA. In order for clinician to attend to life enhancement skills of PWA, it is important to establish the different activities of PWA pre and post-stroke. This manual with its vast range of discourse elicitation task gives a better picture of PWA's life at personal, individual and societal levels. It is instrumental in charting changes/ improvements in PWA. It evaluates the motivational level of PWA in terms of volubility and overall demeanor while coming for rehabilitative services. A set of seven sessions is important for PWA and clinician to accept and adjust to the new situation, forge new bonds, come to terms with new way of life. A week of discourse between the clinician, PWA and his social unit builds confidence, connects them on a personal level, co-ordinates the flow of service delivery, and improves communication amplifying the caliber of all involved.

Starting from first interview session, the current discourse manual becomes a rich source of information for carrying out clinical services and detailed research programs outlining the road to recovery. The number of sessions is flexible and can be selected based on what the situation demands. A clinician can pick and choose the topics to be elicited and manipulate the manual as per the needs of PWA and the environment. The current study describes a manual that paves the way for qualitative research as the quantity and quality of data gathered can be enormous. Further, it entails a discourse analysis incorporating the ideas of LPAA and ICF, providing a true insight about the feelings, coping mechanisms, expectations, failures and course of recovery.

ACKNOWLEDGMENT

This research was funded by the All India Institute of Speech and Hearing, Mysuru [grant number SH/CDN/ARF-19/2016-17].

REFERENCES

Chapey, R., Duchan, J. F., Elman, R. J., Garcia, L. J., Kagan, A., Lyon, J. G., & Simmons-Mackie, N. (2001). Life participation approach to aphasia: A statement of values for the future. In R. Chapey (Ed.), *Language intervention strategies in aphasia and related neurogenic communication disorders* (pp. 235–245). Baltimore, MD: Lippincott, Williams and Wilkins.

Cherney, L. R., Shadden, B. B., & Coelho, C. A. (1998). *Analyzing discourse in communicatively impaired adults*. Gaithersburg, MD: Aspen Publishers, Inc.

Davis, G. A. (1986). Pragmatics and treatment. In R. Chapey (Ed.), *Language intervention strategies in adult aphasia* (pp. 251–265). Baltimore, MD: Williams and Wilkins.

Gee, J. P. (1999). *An introduction to discourse analysis: Theory and practice*. London: Routledge.

Hartley, L. L. (1995). *Cognitive-communicative abilities following brain injury: A functional approach*. San Diego, CA: Singular Publishing Group.

Joanette, Y., & Brownell, H. H. (Eds.). (1993). *Narrative discourse in neurologically impaired and normal aging adults*. San Diego, CA: Singular Publishing Group.

Kagan, A. (1999). *Supported conversation for adults with aphasia: Methods and evaluation* (Published doctoral dissertation). Toronto: University of Toronto.

Kertesz, A. (1982). *Western Aphasia Battery*. New York: Grune and Stratton.

Mathur, R., & Goswami, S. P. (2010). *Protocol to Measure Participation of Persons with Aphasia* (Unpublished dissertation). University of Mysore.

Parr, S., & Byng, S. (1998). Breaking new ground in familiar territory: A response to 'Supported conversation for adults with aphasia' by Aura Kagan. *Aphasiology*, *12*(9), 839–844. doi:10.1080/02687039808249579

Simmons-Mackie, N. (1998a). A solution to the discharge dilemma in aphasia: Social approaches to aphasia management. *Aphasiology*, *12*(3), 231–239. doi:10.1080/02687039808249451

Simmons-Mackie, N. (1998b). In support of supported conversation for adults with aphasia. *Aphasiology*, *12*(9), 831–838. doi:10.1080/02687039808249576

World Health Organisation. (2001). *Classification of Functioning, Disability and Health. Retrieved from* http://www.who.int/classifications/icf/en/

KEY TERMS AND DEFINITIONS

Aphasia: It is the condition resulting from any kind of damage to the brain leading to impaired ability to comprehend speech or formulate language in terms of verbal or even written mode.

Cohesion: It is one of the integral parts of discourse which refers to the continuity in text or speech, within and between sentences giving lexical and semantic links in the discourse. The cohesiveness determines the connectivity and overall understanding of a discourse.

Communication: Communication is the act of exchanging one's ideas, thoughts, and opinions effectively with one or multiple participants. This transferring of information can be made using verbal or nonverbal modes.

Discourse: Discourse refers to the continuity and appropriateness of the use of words during conversation. It reflects the ability of an individual to retain the theme of conversation using varied linguistic components. In persons with aphasia, loss of language should not be viewed only from a linguistic perspective pertaining to phonology, syntax, and semantics but also from a holistic view including discourse in communication. Thus, discourse should be an integral component in the assessment and treatment of persons with aphasia.

Language: It is an arbitrary system of communication consisting of symbols like words, gestures, signs, and written text. It follows a set of rules to convey information and ideas in a group or within a community.

Life Participation Approach: This is a service delivery model in aphasia which is more individual-centered and advocates the activities which are focused to improve the activity and participation of an individual from a holistic perspective.

Recovery: Recovery in aphasia refers to the improvement in the condition post-stroke where the individual regains the lost skills and is able to gain independency thereby improving quality of life. The recovery is, however, dependent on various factors including severity of the stroke and the individual's ability.

Social Identity: The identity of a person in the society is the sense of understanding of the person's beliefs and opinions which builds a perception of their recognition in a particular social group.

APPENDIX 1

The following is an illustration of the first semi-structured interview in the proposed protocol for discourse elicitation in PWA. This interview is a joint session with the patient and family members

- **For the Researcher:** This session will record the relationship between the patient and the spouse/ communication partner. It will try to gauge the comfort levels between them, the level of dependency of the patient on the spouse/ communication partner and each of their contribution in successful communication during the meeting.
- **Note:** The researcher should follow the role of a conversation partner, be assertively involved in the conversation, should speak encouragingly to extend the conversation, speak in smaller sentences that help the patient put up a better discourse. The researcher should use the following questions to shape the interview into a conversation. The researchers should make sure all points are discussed, but feel free to change the ordering of the questions in order to follow conversational topics. The researcher should create opportunities for eliciting stories from the patient by being cooperative and not authoritative during the sessions.
- **For the Participant:** We intend to cement a strong bond amongst all of us for laying out your ideas, feelings and expectations which will help us in better understanding of the issues resulting in improved health, functioning and service delivery.

Introductory Conversation

Hello.

How are you feeling today?

Did you have your breakfast? Tell me about your favorite breakfast and how you prepare it? Do you get it in a restaurant and where is it?

Do you like the weather here? Which is your favorite season and why do you like it so much? What is the one thing that you like to do in that season?

Documenting Details

- **Demographic Details:** Name, Age/Gender, Education, Pre and post-morbid: vocation, socioeconomic status, languages known, handedness, family status, geographical location
- **Details of Stroke:** Site of lesion, Age, Medical Treatment
- **Results of Stroke:** Neurological, Psychological, Behavioral, Motor, Linguistic aftermath of stroke (Based on the available reports from PWA viz. hospital discharge reports, case files or any other sources available.)
- **Type of Services:** Medical, Physical, Occupational, Speech-Language, Psychotherapy and any other treatment (Eg: Ayurveda, Homeopathy etc.) and/or rehabilitation.

Framework

Clinician should use this framework but also use situational prompts and questions to encourage the patient in a discourse.

Family and Home

Tell me about your family.

Prompts from the clinician:

Oh, so all of them are living with you at your home?

How are the household chores divided?

Is this similar to before the accident/stroke?

Do both of you enjoy close-knit family activities?

Nutrition

Tell me about your favorite food and how you cook it?

Prompts

Has your diet changed since some days?

Any change in your feeding schedule?

Who helps you in cooking?

Does your spouse enjoy cooking?

What is your spouse's favorite meal?

Physical Status

Tell me about your health.

Prompts

You fancy a walk in the park?

How do you go to the market?

Does your family accompany you to the market?

Tell me about a day spend in the market/ park with your family members.

Social Life

Tell me about your friends.

Prompts

Where do you use to meet them? And where do you meet them now?

What is your favorite pastime? Tell me about a day you have done that recently.

What are your hobbies and interests?

Who is your best friend?

Tell me when you first met them/ tell me about your fondest memory with them.

Functional Independence

Tell me the directions to your hospital.

Prompts

How often do you meet your doctor?

What is your daily schedule?

Who takes care of you around the house?

Personality

Tell me what do you like best about yourself?

Prompts

Are people impressed with this attribute?

What do you like best about your spouse?

Do you feel there is a change in her/his behavior?

This brings us to the end of this session. If you have any queries now or later, we will oblige with pleasure. Hope you all had a good time. Thank you for your time. I really appreciate it. See you soon. Bye.

APPENDIX 2

Conversation: Stroke Story and Coping

1. "I'm going to be asking you to do some talking. How do you think you speak in English/Hindi, Kannada/Malayalam?" (Choose the dominant language spoken by the PWA pre-morbidly)
    a. If no response in approximately 10 seconds, prompt: "How's your talking/ability to tell a story?"
    b. Listen, encourage full response.
    c. If no response, ask, "Are you having trouble with your talking?"
2. "Do you speak any languages besides your mother tongue?" (ask to specify)
3. "Have you ever had a stroke or serious illness?"
    a. If yes, "Please tell me about it."
    b. If no, "Well how about anyone in your family or anyone you know? Can you tell me about that?"
    c. If no response in approximately 10 seconds prompt: "Try to tell me about the day you/they had your/their stroke/illness."
4. At a natural juncture add: "Tell me about your/their recovery. What kinds of things have you/they done to try to get better since your/their stroke/illness?"
    a. If no response in approximately 10 seconds, prompt: "Tell me about any changes you/they needed to make in your/their daily life."

Important Event

Thinking back, can you tell me a story about something important that happened to you in your life? It could be happy or sad or from any time -- from when you were a kid or more recently.

If no response in approximately 10 seconds, prompt:

For instance, you could tell me about a trip you took or something about your family or your work -- anything.

APPENDIX 3

Session 3: Individual Session With Patient

This session is aimed at understanding how you feel about yourself on a personal level and how you deem your future to be.

Leisure

Tell me the most fun time you have had.

Prompts

Pick on the activity that the patient explains and ask questions about it. In case of not understanding the question or no answer, ask these

Do you like shopping?

Do you like hanging out with friends?

Do you like adventure sports?

What are your hobbies?

What do you like to do for fun at home?

What does your family enjoy on holidays?

After stroke, tell me a time when you have done your favorite activity (whichever is mentioned by the patient) with your friends/family?

Work

Tell me what you were/are doing for a living.

Prompts

What do you hope to achieve in the next one year in office?

Are your colleagues helpful?

Has your work environment changed?

What are your employer/boss's expectations from you before and now?

How are you coping with the work in your present medical condition?

How do you go to your office?

Social Identities

Tell me the things that you have done in your neighborhood.

Prompts

Pick on the role that the patient speaks about and ask,

Why do you like it so much?

Is the recipient of your love and attention equally responsive?

Tell me about your wedding.

Tell me about your fondest memory with your child.

Tell me about a promotion/ successful moment at work?

Tell me about your biggest accomplishment.

Communication

Tell me how best you communicate.

Prompts

Do you write to communicate?

Are you able to understand the body language and express in the same way?

Do you use gestures for common everyday situations?

Have you learnt any sign language?

How do people react when you communicate?

Responsibilities

Tell me about your work and finances.

Prompts

Do you want to go back to work?

Who makes the budget of your house?

How has this budget planning with the medical expenditures?

Service Delivery

Tell me about all treatments you have received so far?

Prompts

Are you satisfied with them?

Do you want some changes in them?

How has your spouse helped you during the treatment?

This is the end of this session. Please ask if you have any queries, doubts or any suggestions for improving these meetings. Thank you for your time and participation. We will see you soon. Bye.

APPENDIX 4

Session 4: Individual Interview With Caregiver/Spouse

This meeting aims to understand the caregiver's idea of his future life in the company of a patient with aphasia and what are his individual hopes and dreams.

Change

Tell me what changes you see in the PWA since the stroke/ accident?

Prompts

In terms of his behavior, mobility, intellect, mood, attitude towards work and life?

Have both of your reactions changed towards each other?

How did you meet your spouse?

Was your wedding love/ arrange?

How has your life in terms of the emotional bond and physical relations with him/her before and post-stroke?

Are your children affected by his condition?

Do they still consider him an authoritative figure in the household?

How has your life changed since the stroke?

Do you feel there are added responsibilities?

Do you get enough rest?

Hope

Where do you see the PWA and yourself in the future?

Prompts

Which area has he improved in?

Are you hopeful of his improvement?

Do you hope for improvement over a period of time?

What do you think whether the PWA is hopeful or not?

Where do you wish to see yourself in the work arena 5 years from now?

How do you see your married life in the future?

Improvement

What is the improvement that you have seen in him post-stroke rehabilitation?

Prompts

What do you think are the main barriers and facilitators in his recovery?

Tell me how his recovery is improving your personal life.

Caregiver Training

Have you undergone any specific training to help his/ her condition and has it helped?

Prompts

Are you satisfied with the training?

Do you feel that PWA is able to perform better with your trained approach?

Are you able to cope with his/her condition?

People

Tell me about your friends and relatives and how they have helped.

Prompts

Are your relatives coming in to help?

Are your friends visiting and encouraging?

Are your work colleagues helping with your work schedule and his colleagues with his?

Do you hope to achieve a stable family life for all of you?

This is the end of this session. We will answer your doubts and queries with pleasure. Please give us any suggestions for improvement. Thank you for your help. We will see you soon. Bye

APPENDIX 5

Session 6: Individual Session With the Employer

This session is to explain his current and future recovery pattern at work.

Q. What are your expectations from PWA?
Q. How do you feel towards the PWA?
Q. Do you think the PWA is an asset/ liability to the workplace?
Q. Compare the pre-and post morbid role of PWA in workplace?
Q. Do you see a recovery pattern since the accident?
Q. How would you rate his current performance and expect the progress to be?
Q. What are the barriers and facilitators in his improvement?
Q. Are you planning to change his work duties?
Q. What changes can be made in the office to accommodate him?
Q. Do you have confidence in his work?
Q. Do you see an improvement in the near future?

This is the end of this session. What do you feel about your office decorum and its flexibility? We will answer your doubts and queries with pleasure. Please give us any suggestions for improvement. We will see you soon. Bye

APPENDIX 6

Session 7: Communicative Counseling Session

This is a concluding session to make the PWA and important people in his life understand about his health, his feelings, their mental state and contribution to his effective social functioning in the future.

- Results of the interview will be explained- weakness and strength, barriers and facilitators with respect to home, community and workplace, understand and interpret the finding to find a decent correlation
- Ways to improve and maintain the role of the PWA in house, work and community.
- Mental, physical, social well being of the PWA, communication partner, and employer

This is the end of this session. We are very thankful for all the help in this study and hope that these meetings have helped you realize the importance of each other and the relevance of personal ideas and identities for the effective functioning of the society and its members. Have a good day. All the best for your future. Bye