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# DEVELOPMENT OF THE INDIAN SCALE OF COMMUNICATIVE EFFECTIVENESS (ISCE) FOR PERSONS WITH APHASIA

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Registration no.- P01II21S0021

A Dissertation Submitted in Part Fulfillment of

the Degree of Master of Science

(Speech-Language Pathology)

**University of Mysore** 



### ALL INDIA INSTITUTE OF SPEECH AND HEARING

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**SEPTEMBER 2023** 

#### **CERTIFICATE**

This is to certify that this dissertation entitled "Development of the Indian Scale of Communicative Effectiveness for Persons with Aphasia" is a Bonafide work submitted in part fulfillment for the degree of Master of Science (Speech-Language Pathology) of the student Registration number P01II21S0021. This has been carried out under the guidance of a faculty of this institute and has not been submitted earlier to any other University for the award of any other Diploma or Degree.

Mysuru

September 2023

Dr. M. Pushpavathi

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**DECLARATION** 

This is to certify that this dissertation entitled "Development of Indian Scale

of Communicative Effectiveness for Persons with Aphasia" is the result of

my own study under the guidance of Dr. Abhishek B. P, Assistant Professor,

Department of Speech-Language Pathology/ Center of Speech Language Science, All

India Institute of Speech and Hearing, Mysuru, and has not been submitted

earlier to any other University for the award of any other Diploma or Degree.

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#### Chapter I

#### Introduction

According to the National Aphasia Association (2009), a person is said to have aphasia when he/she has an impairment in language accompanied by difficulty in expressing or understanding speech with or without reading and writing deficits. Aphasia is generally caused due to brain injury. It is present in 21–38% of acute stroke patients (Berthier, 2005). Aphasia is a multimodal disorder affecting auditory comprehension, reading, oral-expressive language, and writing (McNeil & Pratt, 2001).

The neo-associationist classification (Geschwind, 1967) states that a lesion in a particular brain area is the cause of well-defined aphasia syndrome. Broca's aphasia consists of effortful speech, where the person with aphasia uses simple phrases. The comprehension domain is relatively spared. The other domains affected are word or sentence repetition, naming, and literacy skills. In Wernicke's aphasia, the ability to comprehend language is impaired, while expression remains unaffected (Basso, 2003). The comprehension problems may vary among patients (Basso, 2003). In conduction aphasia, repetition is compromised, and errors majorly consist of word-finding difficulties and phonemic paraphasias. The ability to understand complex structures is hampered (Basso, 2003). Global aphasia consists of severe deficits in all domains of language. Non-fluent stereotypic utterances are seen. A severe deficit in understanding, naming, reading, and writing is observed (Alexander, 2000). Anomic aphasia is characterized by an impaired ability to recollect the name of a person or object. Speech is fluent, but few word-finding difficulties and circumlocutions are observed. A minimal deficit in repetition, comprehension, and reading aloud is noted.

Transcortical motor aphasia demonstrates preserved repetition and comprehension with a minimal deficit in naming. In transcortical sensory aphasia, fluent speech with few neologisms is observed. Comprehension of oral reading and writing is impaired. Repetition is preserved. In mixed transcortical aphasia, speech is non-fluent, and severe impairment in understanding, reading, and writing is noted. Aphasia impacts the ability of a person to execute his/her daily routine and participation in social activities (Ferro & Madureira, 1999). It can impact a person's daily communication needs.

Different assessment protocols are employed to diagnose types of aphasia and their impact on persons with aphasia. The results and observations from the formal assessment assist in planning therapy goals and individualized intervention. (Goodglass et al., 1976). Formal tests frequently used in clinical set-ups are the Mississippi Aphasia Screening Test (MAST)- Nakase-Thompson, (2004); Aphasia Language Performance Scale (ALPS)-Keenan & Brassell, 1975; The Boston Diagnostic Aphasia Examination (BDAE)- Goodglass, & Barresi, (2000); Frenchay Aphasia Screening Test (FAST)- (Enderby et al., 1986); Western Aphasia Battery (WAB)- Shewan & Kertesz (1980) and diagnostics tests such as Minnesota Test for Differential Diagnosis of Aphasia (MTDDA)-Schuell (1973)

Along with diagnostic formulation, it is essential to determine the quality-of-life outcomes in persons with aphasia (PWA). Significant participation restrictions brought on by aphasia can have a negative impact on social interactions and relationships. Due to physical limits and restricted communication abilities, one of the main restrictions on social life is the inability to participate in leisure activities like seeing friends and family, going to events, and going on picnics with family, etc. The social life of people with aphasia is severely constrained, resulting in fewer diverse

social networks. The social life of people with aphasia is closely connected with the severity of aphasia, communication abilities, emotional health, and age, among other factors.

Available functional communication measures are examples- Communicative Abilities in Daily Living- CADL (Holland, 1980), Functional Communication Profile-FCP (Sarno, 1969), American Speech and Hearing Association Functional Assessment of Communication Skills for Adults – ASHA FACS (Frattali et al., 1995) can be included during the intervention. The Stroke Aphasia Quality of Life (SAQOL) Hilari (2003) measures the quality of life in persons with stroke aphasia. Paul (2004) designed a tool for aphasia called the ASHA Quality of Communication Life Scale (ASHA QCL) for assessing perceptions of individuals with aphasia. ASHA QOL assesses domains that might be affected in persons with aphasia. Swati and Goswami (2008) designed a questionnaire to measure the burden on caregivers of persons with aphasia in the Indian context. Quality of life measures are helpful in the assessment of aphasia on the individual's daily needs and functioning. Communicative effectiveness is one of the crucial aspects of quality of life, which is not measured by these questionnaires.

Communicative confidence is defined as "a feeling about one's power to participate in a communication situation, one's sense about one's own skills and ability to express oneself and to understand the communications of others" (Babbitt et al., 2011). A tool for measuring communicative confidence was designed by Babbitt and Cherney (2010). It is one of the measures that assess the beliefs of the person about his/her abilities to understand and express in different communicative situations. The Communicative Confidence Rating Scale for Aphasia (CCSRA) is a visual-analog scale where the participant's responses are assessed from 0-100. After a

comparative study between ASHA QCL and CCRSA, the result showed a considerable improvement from pre-treatment to post-treatment on the CCRSA, in contrast, it did not significantly change on the ASHA QCL. Including quality of life measures in the aphasia intervention will help to assess the client's perspective about aphasia, the therapeutic intervention, and the impact of his/her problems on daily communication needs. (Worrall & Holland, 2003). As communicative confidence and communicative effectiveness are used interchangeably, we would prefer to use the term communicative effectiveness in this study.

#### 1.1 Need of the Study

Communication abilities and the effectiveness of using those abilities impact the functional outcomes of individuals with aphasia prone to social isolation due to language impairment (Dorze & Brassard, 1995). A strong relationship exists between communicative effectiveness and self-efficacy, personal autonomy, and a person's decision-making ability. Due to communication disorder, PWA might face issues in their ability to express themselves, which will impact his/her communicative effectiveness.

The quality-of-life questionnaires do not measure communicative effectiveness. Hence, there is a dearth in the literature assessing the communicative effectiveness in persons with aphasia in the Indian context. As this tool is a helpful way to measure therapy outcomes, there is a need to develop it in the Indian context.

### 1.2 Aim of the Study

To develop and validate the scale of communicative effectiveness for persons with aphasia.

### 1.3 Objectives of the study

- To develop a scale of communicative effectiveness for persons with aphasia.
- To content validate the tool by three Speech-Language Pathologists practicing with persons with aphasia.
- To validate the tool on 20 Hindi-English bilingual persons with aphasia, their caregivers, and their clinician.

#### **Chapter II**

#### **Review of Literature**

#### 2.1 Quality of Life

Disability, well-being in both mind and body, autonomy degree and relationships with others, environmental conditions, and beliefs are thought to impact life satisfaction negatively (De Haan et al., 1993). It is described as one's perspectives of their daily experiences in relation to the customs and beliefs of the community as well as in relation to aims, rules, and aspirations. (The WHOQOL Group, 1996, p. 354)

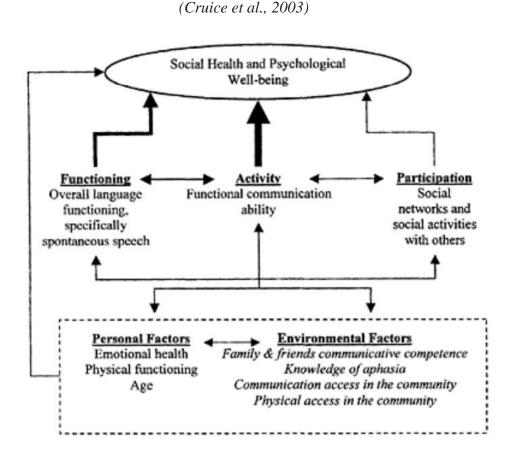
The measure of communication-related quality of life can be described as the extent to which a person can meaningfully participate in circumstances where their communication is confined by the bounds set by their personal and contextual elements and mediated by their perspective (Eadie et al., 2006)

Many authors have explained the quality-of-life aspect using various models. An updated version of the 'operational model,' a 'communication-related quality-of-life model' for aphasia, was created. Psychosocial variables are linked to communication, proving that individuals with communication disabilities should be concerned about this aspect of health. Hence, a better way to conceptualize QOL is as psycho-social well-being. According to the ICIDH-2 paradigm, the 'communication-related quality of life' model categorizes communication into functioning, activity, and participation, as represented in Figure 2.1. The results of the study imply that individual contextual factors, such as emotional well-being, physical and/or physiological functioning, and age, affected the communication and quality of life of aphasia participants.

Other recent studies in aphasia reveal that factors beyond the persons with aphasia's control, such as family and friend interpersonal skills, knowledge about aphasia, and discourse and the community's physical accessibility, have an effect on their communication experience and quality of life (Byng et al., 2000; Kagan et al., 2001; Code et al., 2001). The model incorporates these shortcomings as italicized environment elements. People's QOL is mostly predicted by their emotional well-being, language proficiency, and functional communication skills.

Figure 2.1

'Communication-related quality of life (CRQOL)' model for people with aphasia.

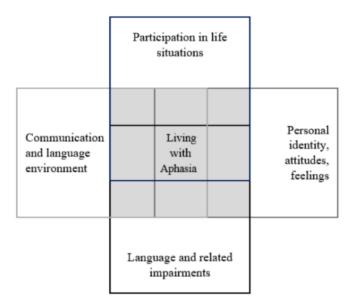


A-FROM, or Living with Aphasia: Framework for Outcome Measurement, was recently described by Kagan (2011) that emphasizes a comprehensive strategy, considering the well-being physically and psychological well-being of persons with

aphasia (PWA). This model has included that living with aphasia is primarily influenced by four domains. The four areas in this approach are participation in daily activities, interpersonal interaction, and linguistic issues relating to the community, language, and others, and one's individual identity, attitudes, and feelings. This model highlights how all four domains influence each other while living with aphasia.

Figure 2.2

Living with aphasia model (Kagen et al., 2011)



#### 2.2 Impact of aphasia on QoL in persons with aphasia

Physiological modes of communication, such as speaking, listening, reading, and writing, might present communication issues (Chapey, 2008) and emotional and interpersonal issues such as avoidance, self-assurance, redefining one's identity, altering relationships, isolating oneself, losing one's job, and withdrawing from leisure activities (Bronken et al., 2012) that may affect the quality of life associated with interpersonal relationships. The sudden onset of aphasia can have an effect on the person because so many facets of their personality and way of life have changed. For

someone with aphasia, certain situations, like placing an order at a drive-through restaurant, may present additional difficulties. The diminished communication skills include those required for day-to-day interactions, including comprehending intent, finding humor in jokes, and expressing one's emotions (Brumfitt, 1993). Persons with aphasia must prioritize their psychological perspectives, emotions, identity, sense of self, independence, and choice, as well as interpersonal interaction, social activities, and participation in society. (Le et al., 1995; Hoen et al., 1997; Zemva, 1999).

#### 2.3 Activity & Participation

Black-Schaåer and Osberg (1990) observed a considerable negative association between aphasia and the capacity to resume work. Aphasia-related communication issues can have an adverse effect on a person's overall involvement in life (Chapey et al., 2000), community participation (Cruice et al., 2006), interaction with others, self-esteem (Shadden & Agan, 2004; Shadden & Koski, 2007), resuming work (Dalemans et al., 2010) community and personal networks (Vickers, 2010), and awareness of oneself and individuality (Strong & Shadden, 2020). Depression and decreased levels of meaningful engagement are linked (Cruice et al., 2003; White et al., 2014) and associated with societal exclusion, isolation, and other social and psychological repercussions (Cruice et al., 2003). Communication within the family and the individual with aphasia's support network are both impacted by aphasia (Howe et al., 2012). The domains that might affect QoL are the severity of aphasia, the level of communication impairment, level of independence, economic status, and educational level (Lee et al., 2015).

The PWA's inadequate language abilities may substantially impact their everyday lives, involving their network of friends, social engagements, interactions

with others, and societal assistance (Hilari & Byng, 2009; Bose et al., 2009; Hilari et al., 2012). A person's level of social engagement is related to internal variables such as a positive attitude towards oneself, growth, and improvement. (Cruice et al., 2003). As a result, one's ability to express themselves may be significantly impacted by aphasia, which may also have significant effects on other aspects of their life. PWA's means of living, level of interaction, and nature concerning their interactions.

Cruise et al. 2010 investigated the implications of multiple variables from both a current and prospective perspective of individuals with aphasia outlook on life. Thirty older aphasia participants with mild to moderate aphasia were asked six short, unprompted open-ended questions regarding their quality of life during a structured interview that took place in their own homes. The findings reported in the study were that the main determinants of QoL for these participants were activities, verbal communication, people, and bodily functioning, and they discussed how these determinants both enhanced and diminished quality of life. Other influencing factors were stroke, independence/dependence, accessibility, an optimistic perspective, personal, and well-being.

The effects of post-stroke aphasia were examined by Matos, Jesus, and Cruice (2014) in 14 Portuguese individuals diagnosed with aphasia, their families, and ten speech-language pathologists. The study used the 'International Classification of Functioning, Activity, and Participation' (ICF) system. The results of the research showed considerable limits in bodily functions and structures, particularly those involved with communication and movement. A substantial effect on activity and participation in community, social relationships were noted. Similar findings about the limitations and impairments experienced by people with aphasia in daily life were reported by individuals, family members, and professionals in the analysis.

#### 2.4 Cognitive functioning

A deficit in cognitive functioning would make communication more tough. A research study by Cruice et al. (2010) investigated 30 PWAs and found that limitation in cognitive performance as a cause of lesser quality of life. This implies that persons with aphasia in the current investigation were conscious of the limitations of their analytical abilities, which complicated simple activities.

Nicholoas et al. 2017 explored the relationship between non-verbal cognitive and linguistic abilities in 28 individuals with aphasia. A battery of tests was administered which included a language test, a non-verbal cognition test, aphasia friendly measure of QoL. The results suggests that nonverbal cognitive deficits may severely lower quality of life (QOL) in aphasic individuals. The researchers also discovered a correlation between lower QoL scores and lower performance on cognitive subtests, including mazes, symbol trails, and design memory. Reduced cognitive and linguistic capacity is closely related to quality-of-life outcomes (Nicholas et al., 2017; Chiou & Yu, 2018).

#### 2.5 Severity of Aphasia

In literature, the impact of severity of aphasia has been researched extensively. Bose et al. (2009) has concluded that the evaluation of one's quality of life is impacted by the level of severity of the aphasia, and individuals with more severe aphasia have lower QoL ratings than those with milder forms of the condition. Spaccavento et al. (2013) administered 'quality of life questionnaire for aphasics (QLQA)' on 147 persons with aphasia and 37 control individuals. According to the research, ratings on questionnaire were lower for persons with severe and acute aphasia than for persons with mild and chronic aphasia.

Bahia and Chun (2014) performed SSQOL on 11 persons with aphasia (5 non-fluent variants and 6 fluent variants of aphasia). They found that the effect of aphasia on the populations tested shows that the non-fluent variant of aphasia, which has more communication challenges, had worse quality of life (QOL) compared to the fluent type. Nicholas, Hunsaker and Guarino (2017) studied effect of post-onset periods on quality of life of persons with aphasia. Due to their acceptance of their post-stroke lifestyle, many participants who were several years post-onset may have given themselves higher QoL ratings than acute people. The quality of life (QoL) of PWAs and their families may change significantly over time as a result of their adaptation to and coping with the consequences of aphasia. In a recent study, Bullier et al. 2020 supported the literature findings, stating that the severity of aphasia and fatigue has an influence on QoL of persons with aphasia.

#### 2.6 Therapeutic Intervention

The authors also reported that the extent and nature of the treatment received by the persons with aphasia play an active role in their quality of life. Lima et al. (2018) aimed to examine how group treatment affects the quality of life of people who have aphasia. The researcher administered 'SAQOL- 39' (Hilari et al., 2003) preand post-group therapy sessions. The results revealed that higher scores were obtained on communication and physical domain of SAQOL-39 post-group therapy sessions.

#### 2.7 Quality of life in Indian scenario

Due to variances in socio-cultural elements like living style, financial situation, support from relatives and close companions, access to care, and willingness to accept the disease and its consequences, the quality of life for individuals diagnosed with aphasia may vary in the Indian setting. Pallavi, Perumal and Krupa

(2018) compared the scores of Broca's aphasia and normal individuals found lower scores in socialization (examples- social outings, telephonic conversations, etc) and activities domains. These lower scores denote that PWA's are not fully engaging in whatever they would like to do. Another significant element affecting the quality of life for PWA is the acceptance level and lack of knowledge among the lower socioeconomic group, which makes up most of the population who are illiterate, regarding the significance of prompt treatment and rehabilitation of aphasia. Due to inadequate communication skills and mobility issues, the realms of familial relationships, language, psychological state, and social responsibilities were the most strongly impacted (Ravi et al., 2018)

#### 2.8 QoL assessment tools

To quantify the effects of aphasia beyond verbal limitations and identify the QoL categories that are compromised in PWAs, several measures have been developed. 11 aphasia who were at recovering stage and 11 stable persons with aphasia were included in the study and Communicative Effectiveness Index (CETI) was administered. Results indicated that the CETI had acceptable inter-rater and test-retest accuracy as well as internal consistency. According to the pattern of correlations with other measures, it was valid as a measure of functional communication (Lomas et al., 1989)

A comprehensive measure known as the "World Health Organization's Quality of Life Instrument" (WHOQOL-100) was created to serve as a reliable, valid, and applicable assessment of quality of life that could be applied across cultural boundaries. WHOQOL-100 (The WHOQOL Group, 1998) measures six domains-

physical, psychological, independence, social, environment, and spiritual. A condensed version is available which includes 25items.

Hobart, et al. (2002) employed the 36-item 'Short-Form Health Survey' (SF-36), researchers looked into the quality of life following a stroke in 177 patients. The findings demonstrated that a stroke significantly affected a person's capacity for psychological, physical, and interpersonal functioning.

One of the well-researched quality of life tool for aphasia is 'Stroke and Aphasia Quality of Life Scale' (Hilari et al., 2003). The researcher assessed the tool on 95 individuals with persistent aphasia for assessing the quality of life. Findings suggests a decrease throughout the scale's key areas, including the physical, psychosocial, communication and energy.

The American-Speech-Language-Hearing Association's Quality Communication Life Scale (ASHA-QCL), a 17-item instrument, was created primarily to assess how communication impairment affects interpersonal relationships, independence, social interactions, wellbeing, and participation in leisure, employment, and educational endeavours. ASHA-QCL (Paul et al., 2004) gauges how communication impairment affects three aspects of quality of life: socialization/activities, self-assurance/self-concept, and roles and responsibilities. The impact of language loss on social interaction and activities is measured by seven elements (e.g., Job-related interpersonal interaction requirements, interpersonal communication). Respondents' perceptions of confidence and self-concept are gauged by six items (e.g., confidence in one's ability to communicate and convey one's views). The four items provide emphasis on each person's responsibility and role (e.g., family responsibilities and activities).

In order to check which dimensions on the scales were most affected by aphasia in addition to how the two tests were linked to one another, a 2009 study compared the ASHA-QCL with the SAQOL-39. (Bose et al., 2009). The ASHAQCL and SAQOL-39 were used to evaluate 19 PWAs with ages ranging from 27 to 79 (mean= 65.3 years). 19 age and gender matched controls were also included in the study. A link was observed between the ASHA-QCL's socialization/activities subdomain and the SAQOL-39's communication subdomain. The results suggests that a high correlation was observed according to two studies, issues with communication can make it difficult to socialize and participate in activities. The researcher observed that the SAQOL tool was concerned with the overall quality of life while ASHA-QCL was better able to assess how the individual's quality of life was impacted by the difficulty in communicating (Bose et al., 2009).

67 patients with an acute aphasic stroke were receiving a multidisciplinary rehabilitation plan, which included traditional speech and language therapy (SLT). The 'Communicative Effectiveness Index (CETI)' was used to assess communicative functional constraints brought on by aphasia, while the 'Western Aphasia Battery (WAB)' was used to evaluate a person's linguistic limitations. The results showed a significant statistical association between the Communicative Effectiveness Index and the WAB score. Hence, impairment and functional level were correlated. (Bakheit, et al., 2005)

Code et al. (2010) assessed the outcome of 1month intensive intervention using 'English version of Aachen Aphasia Test' (EAAT) and 'Communicative Effectiveness Index' (CETI) in chronic aphasia. Overall significant improvement was observed post intervention. In EAAT, naming, comprehension, reading, and writing

were the domains where improvement observed. Additionally, the CETI showed improvement.

Spaccavento et al. (2013) aimed to study if the quality-of-life questionnaire for aphasics (QLQA) is sensitive to severity of aphasia and the post stroke onset period. 146 persons with aphasia and 37 control subjects were involved in the study and QLQA was administered. QLQA consisted of three domains- psychological, communication, autonomy. According to the severity of the aphasia, patients were separated into acute (within 3 months of the stroke) and chronic (beyond 3 months) groups. The results revealed that QLQA had a reliable test-retest and internal consistency. The QLQA total, communication, and autonomy subscales varied between mild and severe PWA as well as between acute and chronic cases.

Chiou and Yu (2018) the study aimed to investigate the modifications in life involvement in person with aphasia (PWA) before and after a stroke from their point of view. Aspects of confidence in language, cognition, and communication that may influence the outcomes of PWA's life involvement were investigated. 'Western Aphasia Battery- Revised' (WAB-R; Kertesz, 2006), 'Cognitive Linguistic Quick Test'; (Helm-Estabrooks, 2001) 'Communicative Confidence Rating Scale' (CCRS; Babbitt et al., 2011) and 'Assessment for Living with Aphasia- Revised' (ALA-R; Kagan et al.,2014) were administered on 33 PWA's for assessing the language, cognition, communicative confidence abilities and life participation aspects respectively. The findings suggested that living with aphasia has an effect on engagement with components of life that affect the quality of life, such as communication difficulties, reduced involvement at home and in the community, increased environmental barriers, and a negative impact on the personal attitude.

47 aphasia individuals from various programmes were given the 10-item CCRSA, included a comprehensive clinical treatment programme, a software-based rehabilitation program, a community-centered aphasia group programme, and six other participants (20 participants). Communicative Confidence Rating Scale (CCRS) was administered to the participants periodically. According to the results, the CCRSA is a reliable psychometric measure for gauging participants' self-reported communication confidence. Gavel Clubs (GCs) for PWA provide unique teambuilding exercises that encourage leadership and public speaking (Toastmasters International, 2016) The present GC was established in September 2012, when the study began, with the help of an SLT initiator and a few foundation members. 8 participants (age- 44-71 years) were enrolled in gavel club. The 'Western Aphasia Battery-Revised' (WAB-R; Kertesz, 2006) was used to evaluate each participant at the study's beginning and conclusion in 2016. The study was initiated between 2012-2016. 'American speech and hearing association Quality of Communication Life' (ASHA QCL; Paul et al., 2009), communicative confidence rating scale (CCRS; Babbitt et al., 2010) These tools were measured periodically during the study phases. The study suggests a connection between participating in Gavel club (GC) activities on a weekly basis, improving communication skills as measured by the CCRSA and the ASHA QCL, and participating in better communication skills. Overall positive impact is observed on the quality-of-life measures. Opportunities for public speaking, positive communicative experiences, improved social skills through daily group meeting in gavel club. Significant improvement was observed in the ability to communicate confidently. A confidence-boosting interactive communication approach may increase autonomy, self-reliance, and life engagement and may even be a sign in and of itself of growing confidence (Babbitt & Cherney, 2010). According to the

current study, communication confidence, QCL, decision-making, engagement in roles and responsibilities, and involvement in GC activities all improve for PWA. There was no connection between the QCL or communication confidence constructs and the degree of aphasia. These figures restrict our ability to draw firm inferences from our findings because two out of eight people had either moderate or severe aphasia, and six out of eight persons had mild aphasia. The caregivers agreed to the communicative problems stated by persons with aphasia.

Jacob et al. (2022) examined the data from 12 PWA in order to assess the relationship between aphasia impairment and communication confidence in people with mild aphasia, information about impairment and communication confidence was gathered during participation in a tele practice rehabilitation programme. Western Aphasia Battery-Revised and Communicative Confidence Rating Scale were assessed. In persons with moderate aphasia, communication of confidence was only marginally associated with aphasia impairment, but strongly and positively correlated with age and educational level. In milder forms of aphasia, communicative confidence varies individually, and the demands can be more than the communicative impairment involved.

#### 2.9 Assessment of QoL in the Indian Scenario

Based on variables such as family type, age, location of residence (rural or urban), and other characteristics, individuals diagnosed with aphasia experience different social lives in the Indian environment. Kiran and Krishnan (2013) translated and adapted the SAQOL ('Stroke and aphasia quality of life') in Kannada considering the societal and cultural differences. The SAQOL-39 was translated from English into Kannada using a forward-backward translation strategy. The authors concluded that

SAQOL-39 in Kannada is a valid and reliable tool. This tool also enables straight translation into additional Indian languages as tool measures are accepted in the Indian population based on cultural grounds.

Ahmadi et al. 2017 carried out a systematic review was carried out which reviewed 20 articles consisting the various adaptions of 'Stroke specific Quality of Life' (SAQOL) in various languages. The 20 publications showed that SAQOL-39 is adapted and validated in 17 different languages. Excellent internal consistency, and high test- retest reliability was obtained for the different versions of SAQOL-39. To retain the societal and cultural appropriateness of the scale, several original items were replaced in the Kannada, Malayalam, and Japanese versions of SAQOL-39. The articles have been mainly preserved in their original form in Spanish and the two Indian translations (Hindi Malayalam). Therefore, the reliability of the original SAQOL-39 could still be relevant to these variations. (Ahmadi et al., 2017). 84 aphasic individuals from various central and northern Indian regions participated in the SAQOL-39 Hindi version of the tool. Like its original English version and its translations into several other languages, the SAQOL-39 in Hindi is an accurate, reliable, and robust scale. It may be used effectively to measure QOL in Hindispeaking aphasic individuals. Additionally, it enables straightforward comparison with cross-cultural and cross-linguistic QOL data from stroke survivors with aphasia (Mitra & Krishnan, 2015)

Ravi et al. (2018) assessed the factors influencing after-stroke quality of life for those with aphasia were investigated. The research involved 35 people (21 males and 14 women) from the Indian state of Andhra Pradesh who had aphasia after a stroke and were 6 months post-stroke. The 'Stroke Specific Quality of Life Scale (SS-QOL)' was used to assess energy, family roles, language, mobility, mood, personality,

self-care, social roles, thinking, upper extremities functionality, vision, and work/productivity. Through an informal interview, twelve individuals who have aphasia and 23 carers were given the scale. Domain scores and an overall score were produced after responses were evaluated on a five-point rating scale, with five representing no assistance needed and one representing all aid required. Due to poor communication and movement skills, the findings of this survey showed that the family, language, mood, and social role domains were substantially compromised, receiving fewer than 50% of the possible points. Due to things like their limited involvement in social events with their family, people with aphasia have a poor quality of life. (e.g., unable to participate in family gatherings), language difficulties (e.g., word-finding difficulties, lack of verbal communication) mobility issues (e.g., walking difficulty, motor difficulties caused by hemiplegia), mood disturbances (e.g., being distinct from friends and family and lacking confidence), less societal involvement (e.g., less social events, fewer interactions with friends and other people, and a lack of hobbies), personal care (e.g., the most self-help techniques demand help or assistance) and inability to get a job or return to employment (Ravi et al., 2018)

Pallavi et al. (2018) studied twelve adults with Broca's aphasia made up the clinical group in this study, while twelve healthy adults made up the non-clinical group across the age range of 28-57 years. The 'Quality of Communication Life Scale (QCL) of the American Speech Language Hearing Association' was translated into Tamil to evaluate 'Quality of Communication Life' (QoCL). In phase 1, original ASHA QCL was translated and validated. Phase 2 consisted of administration on persons with aphasia and non-clinical group. The results suggested that persons with Broca's aphasia received lesser general findings and domain-specific scores than did the non-clinical group. Additionally, compared to other categories, the

socialization/activities domain had the lowest score for people with aphasia. Low confidence/self-concept scores may be caused by persons with aphasia's trouble communicating, which subtly lowers their confidence levels. It is ideal to present this information about the magnitude of the influence of communication problems on the QoCL in a language that is familiar and native to the speaker. Thus, language-specific self-reported scales are needed in a multilingual and multicultural nation like India in order to provide client-specific intervention approaches (Pallavi et al., 2018)

'Stroke specific Quality of life' (SSQOL; William et al., 1999) was translated and adapted into Marathi (Ganvir et al., 2018). The study was conducted into two phases. Phase 1 consisted of translation and adaption of SSQOL in Marathi language and phase 2 was consisted of the administration of the tool on 130 participants (among which 39 participants returned the retest). The results revealed that SSQOL-M (Stroke specific Quality of life questionnaire in Marathi) is a valid and reliable tool in the Indian context. The SF-36's (Short form- 36) FIM (functional independence measure) motor scale and physical function scale have a strong correlation with the SSQOL-M scale.

In the Indian context, the interpersonal interactions of individuals with aphasia differ based on several factors, including nuclear/joint family, age, and where they live (rural or urban), etc. As having a bigger network of relatives and friends can considerably boost social contact in comparison to nuclear families or living in cities, the quality of the person with aphasia's social life and involvement may be stronger if they come from a joint family or reside in a rural area. Due to several cultural variations, it is necessary to further investigate how these elements affect social involvement and living in India. The social lives of stroke survivors or those with

aphasia may also be greatly influenced by cultural influences, which can enhance the overall quality of life and life satisfaction.

#### **Chapter III**

#### **METHOD**

The study was conducted in the following phases

- Phase 1- Development of the Indian Scale of Communicative Effectiveness
- Phase 2- Content validation of the tool
- Phase 3- Validation of the tool on persons with aphasia

#### 3.1 Procedure

#### 3.1.1 Phase 1- Development of the tool of Communicative Effectiveness

During the initial phase of development of the tool, the researcher reviewed different quality-of-life questionnaire tools. The communicative confidence rating scale (Cherney et al., 2011), the American Speech and Hearing Association Functional Assessment of Communicative Skills for Adults (Figueiredo, 1995; ASHA FACS), the ASHA Quality of Communication Life Scale (Paul et al., 2004), Stroke specific quality of life questionnaire (Williams et al., 1999) and Stroke and Aphasia Quality of life questionnaire (Hilari et al., 2003) are the tool studied. The communicative situations were selected based on the reviews of other quality-of-life questionnaires.

The tool was developed in Hindi and English language. The tool was designed in two forms, one for Persons with Aphasia and another for their caregivers and respective clinicians. The questionnaire was designed with simplified vocabulary for persons with aphasia and their caregivers. The questionnaire consisted of 18 questions, including the common situations that persons with aphasia have to face in their day-to-day environment.

The questionnaire was divided into three categories- Comprehension, Expression, and Other. The comprehension domain would include the ability to comprehend the conversation/ communicative context. Questions include were- How effective are persons with aphasia in following day-to-day conversations? (Similarly, for Hindi tool, question was दिन-प्रतिदिन की बातचीत समझने में वाचाधात से प्रस्त व्यक्ति / पर्सन विथ अफेसिया कितने समर्थ हैं?) The ability to express oneself would be included in the expression domain. Questions included were 'How effective are persons with aphasia in initiating a conversation?' (Similarly, in Hindi- बातचीत शुरू करने में वाचाधात से प्रस्त व्यक्ति / पर्सन विथ अफेसिया कितने समर्थ हैं?) The other domain would include the person's ability to execute his daily living activities in a communicative context. Example- How effective are persons with aphasia in returning to their daily conversational tasks? (Similarly in Hindi- पर्सन विथ अफेसिया/ वाचाधात से प्रस्त व्यक्ति अपने दिन प्रतिदिन का काम बातचीत द्वारा करने में कितने समर्थ हैं?) Appropriate examples were provided during administration.

The questionnaire was also given to persons with aphasia, where the questions were modified accordingly. For example, in the comprehension domain question included, was 'How effective are you in following day-to-day conversations?' (Similarly for Hindi, आप दिन-प्रतिदिन की बातचीत समझने में कितने समर्थ हैं?) In the expression domain, how effective are you in speaking in new situations? Similarly for Hindi, आप नई परिस्थितियों में बोलने में कितने समर्थ हैं?)

The response choices would be based on a three-point categorical rating scale where persons with aphasia and their caregiver would mark - 0- Not effective, 1-Somewhat Effective, and 2- Very Effective. Few questions would be specific to individuals' needs and might differ for others; for those questions, the participants

would be instructed to mark not applicable in the questionnaire designed, and no scoring would be provided for the question. The total scores should be obtained.

#### 3.1.2 Phase 2- Content Validation of the tool

The tool was validated by three Speech-Language pathologists practicing with persons with aphasia. Speech-Language Pathologists would be practicing in rehabilitation centers, institutional setups, and hospital setups and working with persons with aphasia daily. They must have professional working proficiency in Hindi and/or English. Based on proficiency, the relevant language-specific tool will be given for validation. Relevancy, simplicity, and ambiguity would be the criteria for validation. The relevancy parameter would be assessed to check the applicability of questions to persons with aphasia. The simplicity parameter estimates how easily persons with aphasia can understand the questions portrayed. The ambiguity aspect would be judged to rule out the possibility of any other interpretation of the questions included for persons with aphasia.

The validator had to mark on a four-point rating scale where 1- Not relevant, 2- Somewhat relevant, 3- Quite relevant, and 4- Highly relevant. Similarly, for simplicity (1- Not Simple, 2- item needs revision, 3- simple but minor revision, 4- Very Simple) and ambiguity (1- Doubtful, 2- Item need some revision, 3- no doubt but need minor revision, 4- meaning is clear) were obtained. The speech-language pathologist was asked to provide remarks for the questions wherever it was required. The Content Validity Index (CVI) was calculated considering the relevance parameter for each individual question.

#### 3.1.3 Phase 3- Validating the tool on persons with aphasia

The questionnaire was administered online and offline, depending on the participants' availability. It was administered to persons with aphasia, their caregivers, and the respective clinicians.

### 3.2 Participants

20 (11 Females and 9 Males) Hindi- English bilingual persons with aphasia were included in the study (mean age of 43.55) Among them, 12 were the non-fluent type of aphasia, and 8 were the fluent type of aphasia as represented in Table 3.1. Prior consent was taken from the participants to enroll themselves in the study. The participants included had minimum post-stroke onset of three to six months and were attending therapy for a minimum of three months. The population having a history of neurological illness, psychiatric disorders, cognitive decline, and sensory deficits were excluded from the study. The comprehension scores on Western Aphasia Battery-Revised (Kertesz, 2006) were equal to or greater than five. The participants were multilingual, with Hindi and English as one of the languages known. The tool was also performed on the caregiver and clinician of the respective PWA. Wherever required, the questions were explained to persons with aphasia. The aphasia quotient of individual cases will be obtained and compared with the persons with aphasia scores on the tool. Appropriate examples will be provided while administering the questionnaire.

Table 3.1

Demographic data of participants included in the study, considering variables- poststroke, age, therapy attended.

Type of Aphasia	Age				stroke set	Therapy (mor	Total	
	20- 40 years	41- 60years	>60years	<1 (year)	>1 (year)	<6 (months)	>6 (months)	(Total number of participants)
Non- Fluent	9	2	1	7	5	10	2	12
Fluent	2	4	2	4	4	5	3	8

Figure 3.1

Illustration of the method of the study



 Table 3.2

 Demographic details of participants included in the present study

Sr no.	Patient Name	Age/ Gender	Post-stroke onset (Months)	Therapy attended (months)	Type of Aphasia (Present Diagnosis)
1	SK	27/M	31	4	Broca's Aphasia
2	VK	29/M	36	36	Broca's Aphasia
3	BS	60/F	17	5	Broca's Aphasia
4	NI	40/F	7	4	Broca's Aphasia
5	BD	38/F	30	6	Broca's Aphasia
6	SP	28/F	9	3	Transcortical
7	R	40/M	12	3	Motor Aphasia Broca's Aphasia
8	TJ	36/F	10	4	Transcortical
9	A	30/M	25	12	Motor Aphasia Broca's Aphasia
10	D	76/M	6	4	Broca's Aphasia
11	SR	50/M	6	3	Broca's Aphasia
12	CP	28/M	26	4	Broca's Aphasia
13	AA	43/M	9	6	Anomic Aphasia
14	SK	25/F	26	7	Anomic Aphasia
15	NH	51/M	32	9	Conduction
16	SA	41/F	19	3	Aphasia Anomic Aphasia
17	AV	76/M	6	4	Anomic Aphasia
18	C	40/M	120	12	Anomic Aphasia
19	P	50/M	16	4	Conduction
20	AR	63/F	7	4	Aphasia Anomic Aphasia

Statistical Analysis- The data obtained were statistically analyzed using SPSS software Version 26. Descriptive analysis was implemented where frequency of the scores of individual questions was obtained. To assess the internal consistency, Cronbach's alpha was obtained. The data was analyzed for the test of normality using Shapiro Wilk's test. A comparison was achieved between fluent and non-fluent types of aphasia scores of the tool using an independent sample t-test. The variants of aphasia (fluent and non-fluent) were descriptively analyzed. A correlation was obtained between the aphasia quotient (AQ) and the scores of the tool Indian Scale of Communicative Effectiveness using Pearson's correlation coefficient.

#### **Chapter IV**

#### **Results & Discussion**

The present study aimed at developing a scale of communicative effectiveness for persons with aphasia. Further the content validity of the tool was determined. The tool was field tested on 20 persons with aphasia, their caregivers, and clinicians to analyze the scores obtained by the participants descriptively. In addition to the pre-set objective, comparison between the scores of different variants of aphasia (fluent vs. non-fluent) and the correlation between the scores of the tool and aphasia severity was carried out.

The Indian Scale of Communicative Effectiveness was developed in Hindi and English. The tool consisted of three domains- Comprehension, Expression, and Other with a total of 18 questions. The three domains each had 6, 10, and 2 questions, respectively. The impact of aphasia on individual domains was assessed using the developed tool. The responses were obtained on a three-point rating scale (0- Not effective, 1- Somewhat Effective, 2- Very Effective). The tool was validated by three Speech-Language Pathologists practicing in the clinic, hospital set-ups, and rehabilitating persons with aphasia in their set-up. The following results were obtained after assessing the content validity.

#### **4.1 Content Validation Index (CVI) of the tool** (Yusoff, 2019)

The content validation index was calculated based on the relevance parameter. Three speech-language pathologists validated the relevance parameter based on a 4-point rating scale (1- Not Relevant, 2- Somewhat Relevant, 3- Quite Relevant, 4- Highly Relevant). When the validator provided a score of 3 and 4, the relevance rating was considered as 1 (Yusoff, 2019), as shown in the score section of Table 4.1. The three

experts/ validators agreed for all 18 questions and gave 3 or 4 ratings; hence score was given as 1 for all the questions (I-CVI = agreed item/ number of experts; Example- 3 experts agreed for 1<sup>st</sup> question- 3/3) I-CVI for all 18 questions was obtained as represented in Table 4.1. As the average I-CVI score was 1, it was considered acceptable with an excellent content validity index (Polit et al., 2007).

 Table 4.1

 Content validation index scores of individual validators for the relevance parameter

Q no.	C1	Score	C2	Score	C3	Score	Experts Agree	I-CVI
1	4	1	4	1	4	1	3	1
2	4	1	4	1	4	1	3	1
3	4	1	4	1	4	1	3	1
4	4	1	4	1	4	1	3	1
5	4	1	4	1	3	1	3	1
6	4	1	3	1	4	1	3	1
7	4	1	4	1	4	1	3	1
8	4	1	4	1	4	1	3	1
9	4	1	4	1	4	1	3	1
10	4	1	4	1	4	1	3	1
11	4	1	4	1	4	1	3	1
12	4	1	4	1	4	1	3	1
13	4	1	4	1	4	1	3	1
14	4	1	3	1	4	1	3	1
15	4	1	4	1	4	1	3	1
16	4	1	4	1	4	1	3	1
17	4	1	4	1	4	1	3	1
18	4	1	4	1	4	1	3	1

C1- Validator 1; C2- Validator 2; C3- Validator 3

Along with relevancy, the validators had to rate on ambiguity (1- Doubtful, 2- Item needs some revision, 3- no doubt but needs minor revision, 4- Meaning is clear) and simplicity (1-not simple, 2- Needs Revision, 3- Simple but need minor revision, 4- Very Simple) parameters. The validators had to rate the English version, as shown in Table 4.2, for the Hindi version, as represented in Table 4.3.

Table 4.2

Content validators' rating on ambiguity & simplicity parameters for the English version tool

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
	C1	4	4	4	4	4	4	3	4	4	4	4	4	4	4	4	4	4	4
Ambiguity	C2	4	3	3	3	3	2	2	3	3	3	3	3	3	3	3	3	3	3
	C3	4	4	4	4	4	3	4	4	4	4	4	4	4	3	4	4	4	4
	C1	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4
Simplicity	C2	4	3	3	3	3	2	2	3	3	3	3	3	3	3	3	3	3	3
	C3	4	4	4	4	4	3	4	4	4	4	4	4	4	3	4	4	4	4

C1- Validator 1; C2- Validator 2; C3- Validator 3

**Table 4.3** 

Content validators' rating on ambiguity and simplicity parameters for the Hindi version of the tool

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
	C1	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4
Ambiguity	C2	4	4	3	4	4	2	2	3	2	4	4	4	4	4	4	3	4	4
	C3	4	4	4	4	4	3	4	4	4	4	4	4	4	4	4	4	4	4
	C1	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4
Simplicity	C2	4	4	2	4	3	2	1	3	1	4	4	4	4	4	4	3	4	4
	C3	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4

C1- Validator 1; C2- Validator 2; C3- Validator 3

The questions were modified according to the validator's responses. The following changes were adapted in the tool

- Relevant examples for the questions were added in English and Hindi versions wherever required.
- 2. Few questions from the Hindi version of the tool were further simplified for better understanding.

### 4.2 Measuring the Internal Consistency

The internal consistency/ reliability of the items in the questionnaire was assessed using Cronbach's alpha test. The alpha value obtained was 0.89 for questions, which indicated good and acceptable internal consistency. Hence, the results specify that there is significant high test-retest reliability.

Table 4.4

Item-wise analysis of questions using Cronbach's alpha

Questions	Mean	SD
1	1.50	0.624
2	1.60	0.494
3	1.08	0.743
4	1.78	0.415
5	1.27	0.710
6	1.68	0.537
7	1.07	0.482
8	1.38	0.739
9	0.70	0.720
10	1.10	0.752
11	1.45	0.534
12	0.92	0.696
13	1.17	0.557
14	0.90	0.681
15	0.90	0.656
16	0.73	0.660
17	1.58	0.561
18	0.83	0.693

## 4.3 Descriptive analysis of scores obtained on the scale of communicative effectiveness by non-fluent variants

Descriptive analysis was carried out to assess the relationship between persons with aphasia, caregiver, and clinician on 20 participants in each group. The responses were recorded on a three-point categorical rating scale (0-Not effective; 1- somewhat effective & 2- Very effective). The tool was divided into three domains-Comprehension, Expression and Other. Frequency of the occurrence of individual responses obtained were calculated in percentage for the groups (persons with aphasia, caregiver, and clinician) in domains denoted in Table 4.5

The scores obtained for non-fluent aphasia in the comprehension domain are presented in Table 4.5. Certain comprehension-related deficits do persist in non-fluent variants of aphasia, as depicted by the scores for Q1 to Q6. For Q1, the major frequency of occurrence of the scores was established as somewhat effective (41.7%, 50%, & 58.3% for persons with aphasia, caregivers and clinician respectively); few rated as very effective (50% for persons with aphasia, 33.3% caregiver & clinician). Among the participants, only a handful rated as not effective (8.3% for persons with aphasia & clinician, 16.7% for caregivers) which had a severe form of aphasia. For Q2, similar scores were obtained for persons with aphasia, caregiver, and clinician. An equal rating was established for effective (50%) and very effective scores (50%). As reading writing deficits (Q3) can be present in non-fluent variants of aphasia, a majorly rating was given for somewhat effective (50%, 58.3% & 66.7% for persons with aphasia, caregiver & clinician, respectively). According to the perspective of persons with aphasia, a low score was given for Q3 as not effective (25%), effective (50%) & very effective (25%). Majorly scores were obtained as very effective (75%) for persons with aphasia & caregiver & 58.3% for clinician); few as effective (25%)

for persons with aphasia & caregiver; 41.7% for the clinician) on Q4. In Q4, similar finding was obtained for persons with aphasia and caregiver. As the Q4 deals with comprehension of television content major trend was observed towards very effective in understanding the content. On Q5, majorly scores were obtained for somewhat effective (58.3%, 50%, 66.7% for persons with aphasia, caregiver & clinician respectively) as the task involves understating multi-speaker situations. Few rated not effective (25% for persons with aphasia & caregiver, 16.7% for clinician) as these situations could be difficult for the participants. Differentiating tone of voice (Q6) was found to be very effective (75%, 50%, 66.7% for persons with aphasia, caregiver & clinician, respectively) and for few (25% for persons with aphasia & clinician, 41.7% for caregiver). Few rated as not effective (8.3% caregiver & clinician) for Q6, as mentioned in Table 4.5. In most of the cases, comprehension of different emotions was found to be easy, as seen in the frequency of occurrence of scores for Q6.

**Table 4.5**Percentage of the frequency the scores occurred within groups- persons with aphasia, caregiver, clinician in comprehension domain (N=12)

Questions	Scores	PWA (%)	Caregiver (%)	Clinician (%)
Q1	0.0	8.3*	16.7	8.3*
How effective are persons	1.0	41.7	50	58.3
with aphasia in following day- to-day conversations?	2.0	50	33.3*	33.3*
Q2*	0.0	0	0	0
How effective are persons with aphasia in following	1.0	50	50	50
instructions and commands?	2.0	50	50	50
Q3	0.0	25*	16.7	25*
How effective are persons	1.0	50	58.3	66.7
with aphasia in understanding the content of the reading material?	2.0	25*	25*	8.3
Q4	0.0	0	0	0
How effective are persons	1.0	25*	25*	41.7
with aphasia in following content on television?	2.0	75*	75*	58.3
Q5	0.0	25*	25*	16.7
How effective are persons with aphasia in following a	1.0	58.3	50	66.7
multi-speaker/ group conversation?	2.0	16.7*	25	16.7*
Q6	0.0	0	8.3*	8.3*
How effective are persons with aphasia in following the	1.0	25*	41.7	25*
tone of voice?	2.0	75	50	66.7

<sup>\*</sup>Denotes similarity between scores obtained.

As persons with a non-fluent variant of aphasia experience difficulty in expressing themselves in L1 and L2, the scores obtained are poor, as presented in Q7. The question scores are generally graded towards somewhat effective (66.7% for persons with aphasia and caregiver, 75% for clinician) and few for not effective (16.7% for persons with aphasia, caregiver & 8.3% for clinician) and very effective (16.7% for

persons with aphasia, caregiver & clinician). Less percentage of scores were obtained for very effective, which states that the confidence in communicating in their L1 and L2 could be challenging for few participants. Q8, which deals with the use of gestures/ AAC board, most of the scores were obtained for effective (50% for persons with aphasia & clinician, 41.7% by caregiver) and very effective (50% for persons with aphasia & clinician, 41.7% by caregiver). Most of the participants included in the present study were very confident to use gestures/AAC board (as per therapeutic intervention) as seen in Table 4.6. Few rated as not effective (8.3% for persons with aphasia, caregiver & clinician) which denotes poor usage of gestures to communicate their needs. Equal scores were observed between persons with aphasia and clinician for Q8.

Ruben (2000) stated that for individuals with aphasia, integrating into working life is an important challenge. Same has been depicted by the scores obtained in the present study. Communicating in job environment could be challenging for persons with aphasia (non-fluent variant) and similar is portrayed by scores as not effective (50% for persons with aphasia; 41.7% for caregiver, 33.3% for clinician) on Q9. 25% of scores tended towards very effective in communicating their needs within all groups. Few as effective (25% for persons with aphasia; 33.3% for caregiver, 41.7% for clinicians). The perspectives of the three groups varied for this domain.

For situations pertaining to initiating conversation, half of them rated as effective (50% for all three groups), few as not effective (33.3% for persons with aphasia & caregiver & 41.7% for clinician), very few as very effective (16.7% persons with aphasia & caregiver & 8.3% for clinician). Effective scores were given for 75% of persons with aphasia, 83.3% of caregivers & 91.7% of clinician scores were present for questions dealing with conversation with family members. Overall,

most of them found it confident to communicate with their family members. 25% of persons with aphasia, 16.7% caregivers, and 8.3% of clinician scores were found to be rated as very effective.

Speaking with strangers (Q12) is one of the challenging tasks for persons with aphasia, as shown by the scores obtained from the tool (not effective- 50% for persons with aphasia and caregiver; 58.3% for clinician; effective- 41.7% for persons with aphasia & 33.3% for caregiver & clinician) as represented in Table 4.6. Similar frequency of occurrence of scores were present for Q13 (speaking over telephone) and most of them rated as effective (75% for all domains), few not effective (16.7% for all domains), and handful of them as very effective (8.3% for all domains). Overall, the communication on telephone was found be confident task among majority of participants as seen in Table 4.6. For the tasks facing new situations (Q14) most of them were not confident (not effective- 58.3% for persons with aphasia & caregiver, 41.7% for clinician) and few of them found it comparatively easy (very effective-8.3% for all three domains, effective- 33.3% for persons with aphasia & caregiver and 50% for clinician). Situations dealing with generalization of skills (Q15) acquired was found to be taxing for participants as shown in the scores (not effective- 33% for persons with aphasia & 41.7% for caregiver & clinician; effective- 58.3% for persons with aphasia, 50% for caregiver & clinician).

According to Brookshire et al. 2014 persons with aphasia are projected to have reading difficulties after stroke, and this finding is similar to the score findings obtained in the present study. Expressing through writing (Q16) was tough for participants, and similar has been shown by the scores (most of them rated as not effective- 75% for persons with aphasia, 58.3% for caregivers, 41.7% for clinicians; effective- 16.7% for persons with aphasia; 33.3% for the caregiver and 41.7% for the

clinician; very effective- 8.3%, 8.3% & 16.7% by persons with aphasia, caregiver, and clinician respectively) as shown in Table 4.6.

**Table 4.6**Percentage of the frequency the scores occurred within groups- persons with aphasia, caregiver, the clinician in expression domain (N=12)

Questions	Scores	PWA	Caregiver	Clinician
		(%)	(%)	(%)
Q7	0.0	16.7*	16.7*	8.3
How effective are persons with aphasia	1.0	66.7*	66.7*	75
in expressing themselves in Hindi, English	2.0	16.7*	16.7*	16.7*
Q8	0.0	8.3*	8.3*	8.3*
How effective are persons with aphasia at using gestures/AAC board for	1.0	50*	41.7	50*
expressing themselves?	2.0	41.7*	50	41.7*
Q9	0.0	50	41.7	33.3
How effective are persons with aphasia	1.0	25	33.3	41.7
in communicating their needs at a job/school?	2.0	25*	25*	25*
Q10	0.0	33.3*	33.3*	41.7
How effective are persons with aphasia	1.0	50*	50*	50*
in initiating a conversation?	2.0	16.7*	16.7*	8.3
Q11	0.0	0	0	0
How effective are persons with aphasia	1.0	75	83.3	91.7
while speaking with family members?	2.0	25	16.7	8.3
Q12	0.0	5	58.3	58.3
How effective are persons with aphasia	1.0	41.7	33.3	33.3
while speaking to strangers?	2.0	8.3	8.3	8.3
Q13*	0.0	16.7	16.7	16.7
How effective are persons with aphasia	1.0	75	75	75
in speaking over the telephone?	2.0	8.3	8.3	8.3
Q14	0.0	58.3	58.3	41.7
How effective are persons with aphasia	1.0	33.3	33.3	50
in speaking in new situations?	2.0	8.3	8.3	8.3
Q15	0.0	33.3	41.7	41.7
How effective are persons with aphasia in speaking in the following situations-	1.0	58.3	50	50
Mall/Shop, Bank, Supermarket & Restaurant	2.0	8.3	8.3	8.3
Q16	0.0	75	58.3	41.7
How effective are persons with aphasia	1.0	16.7	33.3	41.7
in expressing themselves through writing?	2.0	8.3	8.3	16.7

<sup>\*</sup>Denotes similarity between scores obtained

As an advantage of using gestures and verbal mode was given for Question 17 (Gaining attention), the scores were rated as effective (50% for persons with aphasia, 41.7% for caregiver, 58.3% for clinician) and very effective (41.7% for persons with aphasia & clinician; 58.3% for caregiver); few scored not effective (8.3% for persons with aphasia). There were similar scores for caregiver and clinician, persons with aphasia and clinician, as presented in Table 4.7.

In the non-fluent group, for Q18 majority of the participants rated as not effective (PWA-58.3%, Caregiver- 58,3%, Clinician- 50%); effective (25% for persons with aphasia; 33.3% for caregiver; 41.7% for clinician) and very effective for few (16.7% for persons with aphasia; 8.3% for caregiver & clinician) due to difficulties in their language impairment. Due to difficulty in communicating their daily requirements, most of the scores fall for not effective for the question pertaining to conversing for daily needs. Overall, the perceptions among persons with aphasia, caregiver, and clinician groups varied for the other domain.

**Table 4.7**Percentage of frequency the scores occurred within groups- persons with aphasia, caregivers, clinicians in other domain (N=12)

Questions	Scores	PWA	Caregiver	Clinician
		(%)	(%)	(%)
Q17	0.0	8.3	0.0*	0.0*
How effective are persons with aphasia in getting a	1.0	50	41.7	58.3
person's attention during conversations?	2.0	41.7	58.3	41.7*
Q18	0.0	58.3	58.3*	50.0
How effective are persons	1.0	25	33.3	41.7
with aphasia in returning to their daily tasks?	2.0	16.7	8.3*	8.3*

<sup>\*</sup>Denotes similarity between scores obtained

# 4.4 Descriptive analysis of scores obtained on the scale of communicative effectiveness by individuals with fluent aphasia

The tool was administered to 8 fluent variants of aphasia on person with aphasia, caregiver, and clinician. The percentage of scores was obtained for three domains of the tool. The scores obtained question-wise are represented in Table 4.8. The Q1, Q2, Q4, and Q5 scores were similar across the three groups, as depicted in Table 4.8. Due to milder forms of aphasia included in this sub-group, participants rated understanding day-to-day conversations as very effective (100% by all three groups), and most of them rated following commands as very effective (87.5% by all three groups). Few scored as effective (12.5% for all three domains). The participants were comparatively very confident in understanding instructions & commands (Q2) and following them, as shown in Table 4.8. Reading difficulties specific to understanding the content of the material persist in persons with aphasia, which is represented in Table 4.8. Due to a milder form of variants included in the sub-group, comparatively equal weightage was given for effective and very effective. In Q3, most of the participants rated as very effective and somewhat effective (50% for persons with aphasia & caregiver, 37.5% for clinicians), respectively. An equal frequency of scores was obtained for all three groups as 12.5% for not effective. A high score for very effective (100%) was obtained in Q4 (Understanding content on television). Understanding the multi-speaker situations (Q5) was found to be challenging for a few participants (25% for all three domains) and very effective (75% for all three domains) for others. For Q6, nearly all scores fall in very effective (100% for persons with aphasia, 87.5% for caregiver & clinician) and few effective (12.5% for caregiver & clinician).

**Table 4.8**Percentage of the frequency the scores occurred within groups- persons with aphasia, caregiver, clinician in comprehension domain (N=8)

Questions	Scores	PWA (%)	Caregiver (%)	Clinician (%)
Q1*	0.0	0	0	0
How effective are persons with	1.0	0	0	0
aphasia in following day-to-day conversations?	2.0	100	100	100
Q2*	0.0	0	0	0
How effective are persons with aphasia in following instructions and	1.0	12.5	12.5	12.5
commands?	2.0	87.5	87.5	87.5
Q3	0.0	12.5	12.5	12.5
How effective are persons with aphasia in understanding the content	1.0	50	50	37.5
of the reading material?	2.0	37.5	37.5	50
Q4*	0.0	0	0	0
How effective are persons with	1.0	0	0	0
aphasia in following content on television?	2.0	100	100	100
Q5*	0.0	0	0	0
How effective are persons with	1.0	25	25	25
aphasia in following a multi-speaker/	2.0	75	75	75
group conversation?				
Q6	0.0	0	0	0
How effective are persons with	1.0	0	12.5	12.5
aphasia in following the tone of voice?	2.0	100	87.5	87.5

<sup>\*</sup>Denotes similarity between scores obtained

In Q7, most of the participants rated as effective (87% for persons with aphasia and caregiver; 75% for the clinician), and a limited number of participants as very effective (12.5 % by persons with aphasia and caregiver; 25% by the clinician). The perception of the three groups across Q7, Q8, Q9, and Q10 varied to a certain extent. There was consensus present between the two groups for the few questions. As the group was fluent aphasia, participants rated the use of gestural mode (Q8) as very

effective (PWA & caregiver-75%; Clinician- 87.5%); fewer participants rated as not effective (PWA & caregiver-25%; Clinician- 12.5%). In situations related to communication in the job environment (Q9), ratings tended to be not effective (50% for all three groups) and somewhat effective (50% for persons with aphasia & caregiver & 37.5% for clinicians). Communicating and returning to their job environment is difficult for this group, hence very few are rated as very effective (12.5% by clinician), as seen in Table 4.9. An unequal weightage of scores was present for initiating the conversation (Q10) for somewhat effective (62.5% for person with aphasia; 37.5% for caregiver & clinician) and very effective (62.5% for caregiver & clinician; 37.5% for persons with aphasia). With more scores, as very effective. In the present study, initiating conversation tasks was found to be very confident in most of the individuals.

Similar findings were obtained for Q11, Q12, Q13, Q14, Q15 and Q16 within three groups. For Q11, which pertains to having conversations with family members, many of the responses were rated as very effective (87.5% for all three groups). This concludes that the situation was very confident for participants. Very few participants (12.5% for all three groups) rated it as effective. On Q12, concerning communication with strangers, half of the scores (50% for all three groups) were rated as effective, and another half as very effective for the fluent aphasia group. Responses obtained on another situation-specific Q13 (Conversations on Telephone) were equally obtained as effective (50% for all three groups) and very effective (50% for all three groups) outcomes. Q14 dealt with communication in new situations, and as the task is difficult most scores obtained were effective (75% for all three groups). Very few were rated as very effective (25% for all three groups). As the task involved generalization across various situations (Situations like bank, mall, etc.) scores obtained on Q15, most of

the scores were rated as effective (62.5% for all three groups) and few as very effective (37.5% for all three groups). Along with language impairments, reading-writing difficulties can also be observed in persons with aphasia. Hence several ratings on Q16 were effective (87.5% for all three groups) and few (12.5% for all three groups), as depicted in Table 4.9.

**Table 4.9**Percentage of the frequency the scores occurred within groups- persons with aphasia, caregiver, clinician in expression domain (N=8)

Questions	Scores	PWA	Caregiver	Clinician
		(%)	(%)	(%)
Q7	0.0	0	0	0
How effective are persons with aphasia in	1.0	87.5	87.5	75
expressing themselves in Hindi or English	2.0	12.5	12.5	25
Q8	0.0	25	25	12.5
How effective are persons with aphasia at	1.0	0	0	0
using gestures/AAC board for expressing?	2.0	75	75	87.5
Q9	0.0	50	50	50
How effective are persons with aphasia in	1.0	50	50	37.5
communicating their needs at a job/ school?	2.0	0	0	12.5
Q10	0.0	0*	0*	0*
How effective are persons with aphasia in	1.0	62.5	37.5	37.5
initiating a conversation?	2.0	37.5	62.5	62.5
Q11*	0.0	0	0	0
How effective are persons with aphasia	1.0	12.5	12.5	12.5
while speaking with family members?	2.0	87.5	87.5	87.5
Q12*	0.0	0	0	0
How effective are persons with aphasia	1.0	50	50	50
while speaking to strangers?	2.0	50	50	50
Q13*	0.0	0	0	0
How effective are persons with aphasia in	1.0	50	50	50
speaking over the telephone?	2.0	50	50	50
Q14*	0.0	0	0	0
How effective are persons with aphasia in	1.0	75	75	75
speaking in new situations?	2.0	25	25	25
Q15*	0.0	0	0	0
How effective are persons with aphasia in	1.0	62.5	62.5	62.5
speaking in the following situations- Mall/Shop, Bank, Supermarket, Restaurant	2.0	37.5	37.5	37.5
Q16*	0.0	0	0	0
How effective are persons with aphasia in	1.0	87.5	87.5	87.5
expressing themselves through writing?	2.0	12.5	12.5	12.5

The percentages obtained on the other domain are convergent across the groups (persons with aphasia, caregiver and clinician). All the participants rated very effective (100% on all three groups) on Q17 (capturing others' attention during conversations) of the tool, as mentioned in Table 4.10, which concludes that most of the participants are confident in gaining others' attention using any mode of communication. On Question 18, many of the participants rated effective (75% for all three groups) in returning to their daily conversational needs, as depicted in Table 4.10. 25% of the individuals in all three groups rated them very effective. There is consensus achieved between the three groups on the other domain of the tool.

**Table 4.10**Percentage of the frequency the scores occurred within groups- persons with aphasia, caregivers, clinicians other domain (N=8)

Questions	Scores	PWA	Caregiver	Clinician
		(%)	(%)	(%)
Q17* How effective are persons	0.0	0	0.0	0
with aphasia in getting a	1.0	0	0.0	0
person's attention during conversations?	2.0	100	100	100
Q18* How effective are persons	0.0	0	0.0	0
with aphasia in returning to	1.0	75	75	75
their daily conversational tasks?	2.0	25	25	25

<sup>\*</sup>Denotes similarity between scores obtained

# 4.5 Comparison between scores obtained by fluent versus non-fluent aphasia types on the Communicative Effectiveness Scale

The data was analyzed for normality testing using the Shapiro-Wilks test. The results of the test are elaborated in Table 4.11.

Table 4.11

Test of Normality- Shapiro Wilks test for the groups

Scores	Group	Statistics	Sig.
AQ Score	Non-fluent aphasia	0.961	0.795
	Fluent Aphasia	0.763	0.011
Communicative effectiveness score	Non-fluent aphasia	0.864	0.055
	Fluent Aphasia	0.915	0.387

As most of the values obtained by the Shapiro-Wilk test was greater than 0.05, the data is normally distributed. Hence, the parametric test was used for comparison between scores of different types of aphasia. The comparison was obtained between the scores of fluent and non-fluent aphasia types using the independent sample t-test of aphasia quotient scores and the Indian scale of communicative effectiveness scores. The scores are depicted in Table 4.12. The mean and standard deviation of fluent and non-fluent were obtained. There is a difference obtained for the means in both groups. The mean scores of the fluent variants are more compared to the mean scores of the non-fluent variant of aphasia, as shown in Table 4.12. This implies that the impact of aphasia on quality of life is less in fluent aphasia (Better scores indicated lesser impact).

Table 4.12

Independent sample t-test- Values of two independent mean (Non-fluent- NFA; FA-Fluent aphasia) on communicative effectiveness tool and aphasia quotient scores

Score	Group	N	Mean	Std. Deviation
Aphasia Score	NFA	12	30.750	5.6749
	FA	8	54.563	9.0768
Communicative Effectiveness Scores	NFA	12	19.25	7.021
	FA	8	26.13	3.907

 Table 4.13

 Independent sample t-test values for persons with aphasia scores

Scores	t	df	Sig (2-tailed)
AQ Score	-7.254	18	.000
PWA Score	-2.508	18	.022

As the scores are less than 0.05, there was a statistically significant difference between the fluent and non-fluent variants of aphasia for the scores obtained on the communicative effectiveness tool, as shown in Table 4.13.

## 4.6 Correlation between the Aphasia Quotient Scores and Indian Scale of Communicative Effectiveness Tool score

A correlation was obtained between the scores of aphasia quotient and communicative effectiveness tool scores to assess the impact of severity on the quality of life of persons with aphasia. Pearson's correlation coefficient was obtained by correlating the scores of the aphasia quotient and the Indian scale of communicative effectiveness, as depicted in Table 4.14.

Table 4.14

Correlation between aphasia quotient scores and Indian Scale of Communicative Effectiveness scores using Pearson's correlation coefficient.

		AQ score	PWA Score
AQ score (N=20)	Pearsons' correlation	1	*0.673
	Sig (2- tailed)	-	0.001
Persons with Aphasia Score (N=20)	Pearson coefficient	*0.673	1
	Sig (2-tailed)	0.01	-

A strong positive correlation (at 0.01 level- 2-tailed) was observed between the aphasia quotient scores and scores obtained on the communicative effectiveness scale. This indicates that the lower the scores of aphasia quotient, the lesser the scores on the communicative effectiveness scale obtained. The more severe the aphasia (aphasia severity), the lesser the scores of aphasia quotient, and the greater will be the impact on quality of life with aphasia. This impact can be observed using the scale of communicative effectiveness developed in the present study.

To summarize the results of the present study-

- The average content validation index (I-CVI) score obtained was 1, which indicated acceptable and excellent CVI.
- The Indian Scale of Communicative Effectiveness had a good internal consistency on Cronbach's alpha coefficient.
- Descriptive analysis of three groups was obtained, and individual percentage according to the questions was achieved. Depending on the situation, the scores varied across the groups. Generalization to other communicative situations was the most difficult for persons with aphasia, as found in the scores of participants.

- There was a significant difference between scores obtained for fluent and nonfluent variants of aphasia on the independent sample t-test. This indicates that compared to non-fluent aphasia, fluent aphasia has a lesser impact on quality of life.
- The correlation obtained between the scores of Aphasia Quotient and Indian Scale of Communicative Effectiveness tool scores revealed that there is a positive correlation on Pearson's correlation coefficient. This indicates that as the aphasia scores improve, there was a subsequent increase on the communicative effectiveness tool, suggesting that the severity of aphasia has an impact on the quality-of-life measure.

#### Chapter V

#### **General Discussion**

The present study aimed to develop a quality-of-life tool titled the Indian Scale of Communicative Effectiveness. The study was carried out in three phases. The tool was intended to develop in two languages. It was divided into three domains: Comprehension, Expression & Other domain. The second purpose was to validate the content of the tool. The results of this objective reveal that the questions of the tool have excellent content validity, as found from I-CVI. Further appropriate modifications were made to the tool based on the validator's feedback. The results of the internal reliability of the tool revealed a good internal consistency among the scores obtained across the questions. The third objective was to validate the tool on persons with aphasia, caregivers, and clinicians. Situations were identified to assess the impact on quality of life.

### 5.1 Impact of Aphasia on Communicative Effectiveness

Black-Schaåer and Osberg (1990) observed a considerable negative association between aphasia and the capacity to resume work. Communication difficulties caused by aphasia can negatively affect a person's ability to return to employment (Dalemans et al., 2010). Howe et al. (2012) assessed the effect of aphasia on interactions between familial relationships and among the person with aphasia's carers. Matos, Jesus and Cruice (2014) found the effects of poststroke onset on persons with aphasia, family members, and 10 Speech Language pathologists. The results revealed that stroke had an effect on activity & participation in the community and social relationships in daily life. Due to challenges with communication, comprehension, and literacy, aphasia can have a significant influence on an individual's daily activities, engagement, and role in

society (Papathanasiou et al., 2016). Pallavi, Perumal, and Krupa (2018) aimed to compare the scores of Broca's aphasia and normal individuals. They found lower scores in socialization (examples- social outings, telephonic conversations, etc.) and activities domains. These lower scores denote that PWAs are not fully engaging in whatever they would like to do. Ravi et al. (2018) stated that individuals with aphasia have a low quality of life because of factors like their limited participation in gatherings with their families. (For example, being unwilling to attend family events) decreased engagement in society (e.g., lesser social gatherings, fewer communications with friends and acquaintances), being unable to find work or resume work.

Similar findings have been obtained in the current study among the participants. Table 5.1 shows a distinct categorization of the variants of aphasia and the scoring. Situations from the questions are categorized according to the responses obtained into very effective, effective, and not effective. For the non-fluent variant of aphasia, the questions pertaining to speaking with strangers and speaking in new situations were found to be not effective. Speaking over the telephone, and initiating conversations, speaking in varied situations were found to be effective, as represented in Table 5.1. Expressing through writing was found to be challenging and rated as not effective. In comparison, for the fluent variants of aphasia, initiating conversations was very effective, and returning to their daily conversational tasks and speaking in various situations was found to be effective. An equal weightage was given for situations like speaking on the telephone and speaking with strangers. Expressing through writing was rated as effective by this group of participants.

Overall, for these situations, certain difficulties persisted; hence a high score was not attained. Both variants of aphasia have difficulty in resuming work post-stroke onset, as seen in the results of the present study. The results revealed that

questions pertaining to the generalization of skills acquired during therapy were taxing for the participants.

**Table 5.1** 

Situations are categorized based on maximum scores obtained with respect to ratings in two variants of aphasia.

#### Non-Fluent Variant Fluent Variant Very Effective Very Effective • Understanding day-to-day Understanding day-to-day conversations conversations • Understanding the content of Following instructions & command Television Understanding the content of Television • Following the tone of voice Understanding multi-speaker situations Following the tone of voice Using gestures to express themselves Initiating conversations Equal rating **Equal Rating** (50% - Effective; 50% very effective) (50% - Effective; 50% very effective) • Following instructions & command Speaking with strangers Speaking over the telephone Using gestures to express themselves Effective Effective Understanding the reading content Understanding the reading content Understanding multi-speaker situations Expressing themselves in Hindi or English Expressing themselves in Hindi or English Speaking in various communication situations Initiating conversations Expressing through writing Speaking with family members Returning to their daily Speaking over the telephone conversational tasks Speaking in various communication situations • Gaining attention Not Effective Not Effective Communicating in the job environment Communicating in the job environment Speaking with strangers

Speaking in new situations Expressing through writing

tasks

Returning to their daily conversational

#### 5.2 Communicative Effectiveness in Non-fluent vs Fluent Aphasia

In comparison to participants with other aphasia variants, the study's findings revealed that individuals with mixed non-fluent aphasia and Broca's aphasia have a lower quality of life (Engell et al., 2003). People with fluent aphasia have a much better quality of life than people with non-fluent aphasia, according to Posteraro et al. (2006), Researchers found that the discrepancy is substantial in all areas, except for the energy domain of the SAQOL-39's general quality of life. Bahia and Chun (2014) performed SSQOL on 11 persons with aphasia (5 non-fluent variants and 6 fluent variants of aphasia). They found that the effect of aphasia on the populations tested shows that the non-fluent variant of aphasia, which has more communication challenges, had worse QOL compared to the fluent type.

The results of the present study showed a significant difference between the fluent and the non-fluent variants of persons with aphasia scores on the Indian scale of communicative effectiveness. The mean scores obtained were more for the fluent variant of aphasia compared to the non-fluent variant of aphasia. This is in consensus with previous literature, which states that the impact on QoL is more in the non-fluent variant than the fluent variant of aphasia. Situation-specific differences were obtained in the findings of the present study, as shown in Table 5.1. Most of the ratings were inclined to very effective and effective scoring in the tool for the fluent variant of aphasia compared to the non-fluent variant of aphasia. The ratings obtained were majorly tending toward the effective and not effective scores in the non-fluent variant of aphasia. Thus, suggesting that the type of aphasia has an influence on the quality of life.

#### **5.3** Severity and Communicative Effectiveness

Bose et al. (2009) assessed the impact of quality of life on the severity of aphasia. The individuals with severe aphasia have lower QoL ratings than the milder forms. Bakheit et al. (2005) performed Western Aphasia Battery (WAB) and Communicative Effectiveness Index (CETI) on 67 participants with acute stroke. The results showed a significant statistical association between the Communicative Effectiveness Index and the WAB score. Hence, impairment and functional level were correlated. Spaccavento et al. (2013) administered a quality-of-life questionnaire for aphasics (QLQA) to 147 persons with aphasia and 37 control individuals. The findings obtained are severe and acute aphasia had lower Qol ratings than those with mild and chronic aphasia. In a recent study, Bullier et al. 2020 administered Sickness Impact Profile (SIP-65) and Boston Diagnostic Aphasia Examination (BDAE) on 32 individuals with aphasia. This study supported the literature findings, stating that the severity of aphasia and fatigue have an influence on the QoL of persons with aphasia.

The results of the present study obtained a correlation between the communicative effectiveness scores and aphasia quotient scores which revealed a good positive correlation between the two variables. That is, as the aphasia quotient increases (Less severe), the scores on the communicative effectiveness tool as well increase. It implies that the less severe the aphasia, the better the communicative effectiveness in various situations. This finding is consistent with the outcomes obtained from previous studies (Bose et al., 2009; Bakheit et al., 2005; Spaccavento et al., 2013; Bullier et al., 2020).

Thus, the tool titled 'Indian Scale of Communicative Effectiveness' was developed and validated on persons with aphasia, caregivers, and clinicians. The tool

had good internal reliability and acceptable content validation index scores. The non-fluent type of aphasia had a greater impact on Quality of Life when compared to the fluent type of aphasia. The aphasia severity had an impact on the quality of life. The more severe the aphasia, scores reduced on the Communicative Effectiveness tool.

#### **Chapter VI**

### **Summary & Conclusions**

The present study aimed to develop a quality-of-life measure to assess the communicative effectiveness in persons with aphasia. The study comprised of three phases. In phase 1, the questionnaire was developed, and it consisted of 18 questions, divided into three domains- comprehension, expression, and other. The questionnaire was developed in English and Hindi. The tool comprised different communicative situations where persons with aphasia would face difficulties in their day-to-day needs. In phase 2, the tool was validated (content validation) by three speech-language pathologists practicing in various set-ups and rehabilitating persons with aphasia daily. The Content Validation Index (CVI) score was 1, which suggests a good and acceptable score. It indicated an excellent agreement between the validators. The tool was further simplified as per the suggestion from the validators.

In Phase 3, the modified questionnaire was administered to 20 persons with aphasia, their caregivers, and their clinicians. As the tool was administered to caregivers and clinicians, the questions were formatted to form another version (Appendix). The responses were obtained on a three-point rating scale (0-Not effective; 1- Effective and 2- Very effective). Few questions were specific to individuals' needs (For example- Communicating in a job environment) and might differ for others; for those questions, the participants were instructed to mark not applicable, and no scoring was provided for the question. The tool was administered in both online and offline mode. Using SPSS software version 26, the responses were analyzed and compared.

The developed tool had good internal reliability as analyzed by Cronbach's alpha. Thus, from the results, it can be concluded that the situations pertaining to

social involvement, speaking on the telephone, and communicating in various situations had an impact post-stroke. The individuals with aphasia face challenges in communicating in the job environment. Overall, aphasia has an influence on the ability of a person to communicate effectively. The impact of aphasia on the person with aphasia, caregiver, and clinician can be different as concluded from the scores obtained. Thus, consideration of social situations must be taken into account during management.

Persons with a fluent variant of aphasia have a lesser impact than the non-fluent type of aphasia on the ability to communicate effectively. Both types of aphasia faced challenges in communicating in a job environment. Thus, suggesting that the skills acquired during therapy have not been generalized in social contexts. The more severe the aphasia, the lesser scores obtained on the communicative effectiveness tool. It concludes that the severity has an impact on the quality of life.

To conclude, the present study highlighted the impact of aphasia on communicative effectiveness, factors contributing to the quality of life, and the differences among the different types of aphasia. Communicative effectiveness was influenced by the type and severity of aphasia. To conclude further, the Indian Scale of Communicative Effectiveness (ISCE) can be used as a reliable tool to assess the quality-of-life measure in persons with aphasia, caregiver, and clinician.

#### **Implications of the study**

- The present study provides more insights into the person's ability to communicate effectively in various social situations post-stroke onset in the Indian context.
- The tool can be used as an effective measure in assessing the therapy outcomes in persons with aphasia.

- The tool developed can be helpful in assessing the generalization of skills (in various day-to-day communicative situations) acquired during therapy.
- The impact of stroke on the person with aphasia and caregiver with respect to communication can be obtained using the tool.
- The questionnaire can be an effective measure to assess the performance of a
  person with aphasia in various social contexts. Identification of situations that
  the person is facing difficulty can be found and can be incorporated during
  management.
- Limited research is available in the Indian context pertaining to communicative effectiveness measures. This tool can be a valid assessment of quality-of-life for Indian socioeconomic and cultural backgrounds.

### **Limitations of the study**

- Limited sample size can have an influence during the generalization of results.
- Association among persons with aphasia, caregiver, and clinician using an appropriate statistical analysis could not be obtained due to the limited sample size.

#### **Future directions**

- Various other factors (age, education, type of therapy attended, duration of therapy attended, post-stroke onset duration) that might impact the communicative effectiveness of an individual can be assessed.
- A comparison among the recovered and recovering aphasia on communicative effectiveness can be obtained.
- A statistical comparison can be obtained to assess the association among the persons with aphasia, caregiver, and clinician by increasing the sample size.

- The tool can be expanded for other groups of communication disorders.
- The impact of group versus individual therapy can be obtained using this questionnaire.
- The tool is a self-report questionnaire and hence can be expanded into other Indian languages.

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#### Appendix A

# English Version of the 'Indian Scale of Communicative Effectiveness (ISCE)' for Caregiver & Clinician (Version 1)

#### **Instructions-**

Please tick the appropriate score among 0, 1, and 2, which you feel is most appropriate.

(0-Not Effective; 1-Somewhat Effective; 2- Very Effective)

Score '0' indicates the person with aphasia can understand/express 0% of the time.

Score '1' indicates the person with aphasia can understand/express 50% of the time.

Score '2' indicates the person with aphasia can understand/express 100% of the time.

If the particular question is not applicable, please mark Not Applicable (NA).

Name-

Age/Sex-

Relation with person with aphasia-

Sr. no	Questions	0	1	2	NA
1	How effective are persons with aphasia in				
	following day-to-day conversations?				
2	How effective are persons with aphasia in				
	following instructions and commands?				
	<b>Example-</b> Follow instructions of taking timely medicines.				
3	How effective are persons with aphasia in				
	understanding the content of the reading material?				
	<b>Examples-</b> Newspapers, typed messages, books, etc				
4	How effective are persons with aphasia in				
	following content on television?				
	Example- He/she reacts by laughing while				
	watching TV/ video, etc				

_	TT CC (' '.1 1 '.'			
5	How effective are persons with aphasia in			
	following a multi-speaker/ group conversation?			
	<b>Examples-</b> Public gatherings, social events			
6	How effective are persons with aphasia in			
	following the tone of voice?			
	Evample Basespize when you are engry/sed ate			
7	Example- Recognize when you are angry/sad, etc  How effective are persons with aphasia in			
<b>'</b>	expressing themselves in			
	Hindi or			
	• English			
8	How effective are persons with aphasia at using			
0	gestures/AAC board for expressing themselves?			
	gestures/14/10 board for expressing themserves:			
	<b>Examples-</b> Expressing his/her needs (Hunger,			
	thirst, etc) using correct gestures.			
9	How effective are persons with aphasia in			
	communicating their needs at a job/ school?			
	, , , , , , , , , , , , , , , , , , ,			
10	How effective are persons with aphasia in initiating			
	a conversation?			
	<b>Examples-</b> Starts a conversation himself/herself,			
	asks for his/her desired needs.			
11	How effective are persons with aphasia while			
	speaking with family members?			
12	How effective are persons with aphasia while			
	speaking to strangers?			
	<b>Examples-</b> Speaking with a delivery boy, talking			
12	to a cab/ auto driver.			
13	How effective are persons with aphasia in speaking			
	over the telephone?			
	<b>Examples</b> - talking on phone with familiar and			
	unfamiliar persons			
14	How effective are persons with aphasia in speaking			
17	in new situations?			
	m non situations.			
	<b>Examples-</b> A new therapist, a new place, etc			
<u> </u>	r	l		

15	How effective are persons with aphasia in speaking		
	in the following situations-		
	Mall/Shop		
	Bank		
	Supermarket		
	Restaurant		
16	How effective are persons with aphasia in		
	expressing themselves through writing?		
	<b>Examples-</b> Expressing through messages by		
	typing, writing his/her needs for bank/mails/		
	letters, etc		
17	How effective are persons with aphasia in getting a		
	person's attention during conversations?		
	<b>Example-</b> He/she indicated gesturally/ verbally to		
	call for the person.		
18	How effective are persons with aphasia in returning		
	to their daily conversational tasks?		

#### For Persons with Aphasia (Version 2)

### **Instructions-**

Please tick the appropriate score among 0, 1, and 2, which you feel is most appropriate

(0-Not Effective; 1-Somewhat Effective; 2- Very Effective)

Score '0' indicates you can effectively understand/express 0% of the time.

Score '1' indicates you can effectively understand/express 50% of the time.

Score '2' indicates you can effectively understand/express 100% of the time.

If the particular question is not applicable, please mark Not Applicable (NA). Name-

#### Age/Sex-

Sr no.	Questions	0	1	2	NA
1	How effective are you in following day-to-day conversations?				
2	How effective are you in understanding instructions and commands?				
	<b>Example-</b> Follow instructions of taking timely medicines.				
3	How effective are you in understanding the content of the reading material?				
	<b>Examples-</b> Newspapers, typed messages, books, etc				
4	How effective are you in following content on television?				
	<b>Example-</b> He/she reacts by laughing while watching TV/ video, etc				
5	How effective are you in following a multi-speaker/ group conversation?				
	Examples- Public gatherings, social events				

6	How effective are you in following the tone of		
	voice?		
	<b>Example-</b> Recognize when you are angry/sad, etc		
7	How effective are you in expressing yourself in		
	Hindi		
	• English		
8	How effective are you at using gestures/AAC board		
	for expressing yourself?		
	<b>Examples-</b> Expressing his/her needs (Hunger, thirst,		
	etc) using correct gestures.		
9	How effective are you in communicating your needs		
	for a job/ school?		
10	How effective are you in initiating a conversation?		
	<i>g</i>		
	Examples- Starts a conversation himself/herself,		
	asks for his/her desired needs.		
11	How effective are you while speaking with family		
	members?		
12	How effective are you while speaking to strangers?		
12	How effective are you willie speaking to strangers:		
	<b>Examples-</b> Speaking with a delivery boy, talking to		
	a cab/ auto driver.		
13	How effective are you in speaking over the		
	telephone?		
	<b>Examples</b> - talking on phone with familiar and		
	unfamiliar persons		
14	How effective are you in speaking in new situations?		
	<b>Examples-</b> A new therapist, a new place, etc		
15	How effective are you in speaking in the following		
	situations-		
	Mall/Shop		
	• Bank		
	<ul> <li>Supermarket</li> </ul>		
	Restaurant		

16	How effective are you in expressing yourself through		
	writing?		
	<b>Examples-</b> Expressing through messages by typing,		
	writing his/her needs for bank/mails/ letters, etc		
17	How effective are you in getting a person's attention		
	during conversations?		
	<b>Example-</b> He/she indicated gesturally/ verbally to		
	call for the person.		
18	How effective are you in returning to your daily		
	tasks?		

## Appendix B

## Hindi Version of the 'Indian Scale of Communicative Effectiveness (ISCE)'

## Caregiver/Clinician (Version 1)

## Scoring

- 0- समर्थ नहीं हैं
- 1- समर्थ हैं
- 2- पूरी तरह से समर्थ हैं

नाम-

उम्र/लिंग-

क्रमांक	प्रशन	0	8	7	लागू नहीं
1	दिन-प्रतिदिन की बातचीत समझने में वाचाघात से ग्रस्त व्यक्ति / पर्सन विथ अफेसिया कितने समर्थ हैं?				
2	वाचाघात से ग्रस्त व्यक्ति / पर्सन विथ अफेसिया सूचनाओं को समझने में कितने समर्थ हैं?				
	उदाहरण- समय पर दवाएँ लेने के निर्देशों का पालन करना				
3	वाचाघात से ग्रस्त व्यक्ति /पर्सन विथ अफेसिया लिखी हुई बात का मतलब समझने में कितने समर्थ हैं?				
	उदाहरण- मोबाइल पर आयी हुई सूचना,अखबार पढ़ना, किताबे पढ़ना				
4	वाचाघात से ग्रस्त व्यक्ति /पर्सन विश्व अफेसिया टीवी पर आये हुए कार्यक्रम को समझने में कितने समर्थ हैं?				
	उदाहरण- वीडियो देखके समझकर मुस्कुराना				
5	वाचाघात से ग्रस्त व्यक्ति / पर्सन विथ अफेसिया सामूहिक बातचीत को समझने में कितने समर्थ हैं?				
	<b>उदाहरण-</b> सार्वजनिक कार्यक्रम				
6	वाचाघात से ग्रस्त व्यक्ति /पर्सन विथ अफेसिया आवाज़ में फरक समझने में कितने समर्थ हैं ?				
	<b>उदाहरण-</b> बातचीत करते वक्त गुस्सा और उदासी में फरक पहचानना				
7	वाचाघात से ग्रस्त व्यक्ति /पर्सन विथ अफेसिया स्वयं को व्यक्त करने में कितने समर्थ हैं?				
	● हिंदी ● अंग्रेज़ी				
8	खुदको व्यक्त करने के लिए इशारों/ए ए सी बोर्ड का उपयोग करने में वाचाघात से ग्रस्त व्यक्ति / पर्सन विथ अफेसिया कितने समर्थ हैं?				
	<b>उदाहरण-</b> खुदकी जरूरते (भूक, प्यास) पूरी करने के लिए  इशारा करना				

			1	
9	नौकरी/शाला में अपनी जरूरतों को व्यक्त करने में वाचाघात से ग्रस्त व्यक्ति			
	/ पर्सन विथ अफेसिया कितने समर्थ हैं?			
10	बातचीत शुरू करने में वाचाघात से ग्रस्त व्यक्ति / पर्सन विथ अफेसिया			
	कितने समर्थ हैं?			
	उदाहरण- खुदकी जरूरते बताना, खुद से बात शुरू करना			
11	वाचाघात से ग्रस्त व्यक्ति/ पर्सन विथ अफेसिया परिवार के सदस्यों के साथ			
	बात करते समय कितने समर्थ हैं?			
12	अजनबियों से बात करते समय वाचाघात से ग्रस्त व्यक्ति / पर्सन विथ			
	अफेसिया कितने समर्थ हैं?			
	उदाहरण- टैक्सी ड्राइवर से बात करना, डिलीवरी बॉय से बात करना			
13	वाचाघात से ग्रस्त व्यक्ति / पर्सन विथ अफेसिया टेलीफोन पर बात करने में			
	कितने समर्थ हैं?			
	उदाहरण- पहचानवाले और अनजान व्यक्ति से फ़ोन पर बात करना			
14	वाचाघात से ग्रस्त व्यक्ति/ पर्सन विथ अफेसिया नई परिस्थितियों में बोलने			
1.	में कितने समर्थ हैं?			
	भावता रागव है:			
	<del></del>			
	उदाहरण- नए डॉक्टर्स, नई जगा			
15	वाचाघात से ग्रस्त व्यक्ति / पर्सन विथ अफेसिया नीचे दिए गयी स्थितियों में			
	बोलने के लिए कितने समर्थ हैं?			
	• <b>т</b> іल			
	• बैंक			
	•सुपरमार्केट/ किराना दुकान			
	•रेस्टोरेंट			
16	वाचाघात से ग्रस्त व्यक्ति/ पर्सन विथ अफेसिया लेखन के माध्यम से खुदको			
	को व्यक्त करने में कितने समर्थ हैं?			
	<b>उदाहरण-</b> मोबाइल पे सन्देश लिखना, ईमेल करना, पत्र लिखना			
	च्यादराना नामार्या । सामसा सावना, रंगसा मध्या, मधारावना			
17	बातचीत के दौरान किसी व्यक्ति का ध्यान आकर्षित करने में वाचाघात से			
1 /	ग्रस्त व्यक्ति / पर्सन विथ अफेसिया कितने समर्थ हैं?			
	प्रस्ता प्याकः / पसन् ।वय अफासया ।कतन् समय हः			
	<b>उदाहरण-</b> संकेत या पुकारके ध्यान आकर्षित करना			
10	वाचाघात से ग्रस्त व्यक्ति /पर्सन विथ अफेसिया अपने दिन प्रतिदिन का			
18				
	काम बातचीत द्वारा करने में कितने समर्थ हैं?			

## For Persons with Aphasia (Version 2)

### Scoring

- 0- समर्थ नहीं हैं
- 1- समर्थ हैं
- 2- पूरी तरह से समर्थ हैं

नाम-

उम्र/लिंग-

क्रमांक	प्रशन	0	8	3	लागू <del>उन्ह</del> ीं
1	आप दिन-प्रतिदिन की बातचीत समझने में कितने समर्थ हैं?				नहीं
1	आप दिन-प्रातादन का बातचात समझन म कितन समय ह <i>!</i> 				
2	आप सूचनाओं को समझने में कितने समर्थ हैं?				
	उदाहरण- समय पर दवाएँ लेने के निर्देशों का पालन करना				
3	आप लिखी हुई बात का मतलब समझने में कितने समर्थ हैं?				
	उदाहरण- मोबाइल पर आयी हुई सूचना, अखबार पढ़ना, किताबे पढ़ना				
4	आप टीवी पर आये हुए कार्यक्रम को समझने में कितने समर्थ हैं?				
	उदाहरण- वीडियो देखके समझकर मुस्कुराना				
5	आप सामूहिक बातचीत को समझने में कितने समर्थ हैं?				
3	जाव सानूरिक बारावारा का सनझन न किरान सनव है!				
	<b>उदाहरण-</b> सार्वजनिक कार्यक्रम				
6	आप आवाज़ में फरक समझने में कितने समर्थ हैं ?				
	0 1 2 07				
	उदाहरण- बातचीत करते वक्त गुस्सा और उदासी में फरक पहचानना				
7	आप स्वयं को व्यक्त करने में कितने समर्थ हैं?				
7	_				
	<ul> <li>िहिंदी</li> </ul>				
	• अंग्रेज़ी				
8	खुदको को व्यक्त करने के लिए इशारों/ए ए सी बोर्ड का उपयोग करने में आप				
	कितने समर्थ हैं?				
	उदाहरण- खुदकी जरूरते (भूक, प्यास) पूरी करने के लिए इशारा करना				
9	नौकरी/शाला में अपनी जरूरतों को व्यक्त करने में आप कितने समर्थ हैं?				
10	बातचीत शुरू करने में आप कितने समर्थ हैं?				
	उदाहरण- खुदकी जरूरते बताना, खुद से बात शुरू करना				

11	आप परिवार के सदस्यों के साथ बात करते समय कितने समर्थ हैं?		
12	अजनबियों से बात करते समय आप कितने समर्थ हैं?		
	उदाहरण- टैक्सी ड्राइवर से बात करना, डिलीवरी बॉय से बात करना		
13	आप टेलीफोन पर बात करने में कितने समर्थ हैं?		
	<b>उदाहरण-</b> पहचानवाले और अनजान व्यक्ति से फ़ोन पर बात करना		
14	आप नई परिस्थितियों में बोलने में कितने समर्थ हैं?		
	<b>उदाहरण-</b> नए डॉक्टर्स, नई जगा		
15	आप नीचे दिए गयी स्थितियों में बोलने के लिए कितने समर्थ हैं-		
	• मॉल • बैंक		
	•सुपरमार्केट/ किराना दुकान		
	•रेस्टोरेंट		
16	आप लेखन के माध्यम से खुदको को व्यक्त करने में कितने समर्थ हैं?		
	<b>उदाहरण-</b> मोबाइल पे सन्देश लिखना, ईमेल करना, पत्र लिखना		
17	बातचीत के दौरान किसी व्यक्ति का ध्यान आकर्षित करने में आप कितने समर्थ हैं?		
	6:		
	<b>उदाहरण-</b> संकेत या पुकारके ध्यान आकर्षित करना		
18	आप अपने दिन प्रतिदिन का काम बातचीत द्वारा करने में कितने समर्थ हैं?		



## **Appendix C**

# All India Institute of Speech and Hearing, Naimisham Campus, Manasagangothri, Mysore-570006

Consent Form
I, Mahajani Urvi Shantanu student at All India Institute of Speech and Hearing, am conducting a study on communicative effectiveness in persons with aphasia, under the guidance of Dr. Abhishek B P.
18 Questions-based tool has two versions, one for caregivers and another for persons with aphasia, developed in Hindi and English Language.
I,, am willing to participate in the study and provide the information required. I am aware that the information provided would be used only for research purposes. The identity of the individual will be kept confidential, and your cooperation will be duly acknowledged.

Sign of the Caregiver

Sign of the Patient

Sign of the clinician