

**LIFE SATISFACTION AND QUALITY OF LIFE IN PERSONS WITH  
APHASIA BEYOND COMMUNICATION**

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# **CHAPTER I**

## **INTRODUCTION**

Life satisfaction is a cognitive evaluation of where one is in life now compared to one's aspirations. Positive affect is the experience of positive feelings and is more dependent on external stimulation than internal control. Additionally, negative affect is the experience of negative emotions such as anxiety or sadness, and the reverse is true, that is, it is more dependent on internal control. Decreased life satisfaction can be attributed to physical (volatility, irritability, tiredness), material (loss of one's car, loss of income, loss of work, drop in standards), and social (fear of another stroke, restriction of social life) factors. Increased life participation in persons' with aphasia life includes family and social life (family seems closer, partner closer, partnership closer, relationship improved, people more friendly, helping people), freedom from previous restrictions (more relaxed, more time, life slower, more laid back, free from work, reduced consumption of alcohol), and enhanced sense of the value of life (Jordan & Kaiser, 1996).

The diagnosis of aphasia differs based on the site of lesion, severity, the impact of the injury, and many more factors including demographic details. The experience of aphasia following stroke may affect each and their families in different ways. Also, timely treatment is crucial in individuals who have had a stroke, and the perception of stroke has been seen as treatable in the recent past due to the introduction of the drug 'tissue plasminogen activator' known as tPA (National Institute of Neurological Disorders and Stroke rt-PA Stroke Study Group, 1995). Therefore, the severity of aphasia will vary

among individuals and the intervention will have to be tailor-made to cater to every individual and their family involved in recovery.

In the recent past, therapy approaches are tending towards more participation based and social approaches. The World Health Organization has been focusing on different strategies that aim at reducing the consequences of the injury or the condition that contribute to long-term effects both financially and emotionally. Quality of life (QOL) is a vague concept which has been used across many subjects and theoretically includes all aspects of the life of a person (Bowling, 1995). The World Health Organization (WHO) defines QOL as follows:

*“An individual perception of position in life in the context of the culture and value systems in which they live and about their goals, expectations, standards, and concerns. It is a broad-ranging concept affected in complex ways by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment”.*(WHOQOL Group, 1995, p.1405)

In PWAs, to investigate this aspect a variety of questionnaires ranging from an overall QoL (Ross & Wertz, 2003), subjective and psychological well-being (Cruice, Worrall, Hickson, & Murison, 2003; Hilari, Byng, & Pring, 2001) and health-related quality of life measures (HRQOL: Cruice, Wiggins, Roy, Byng & Smith 2003) have been used. Researchers have been exploring various domains like physical health, communication, family support, psychosocial issues, societal involvement, mental health, emotional health, energy, body image, financial situation and life satisfaction (Cruice et al., 2005).

There has been a considerable amount of research documented in the western and European countries, which have explicitly stated that QOL of persons with aphasia is different from that of persons with and without stroke on social, independence, relationship and access to aspects of the environment (Ross & Wertz, 2003). Loss of autonomy has been reported by the persons with aphasia, their spouses and the speech pathologists intervening in the cases (Herrmann & Wallesch, 1989). In cases of chronic aphasia, reports have been obtained which revealed social isolation and identity crisis (Artes & Hoops, 1976; Kinsella & Duffy, 1978; Sarno, 1993). Functional communication ability and linguistic ability varies depending on the severity and type of aphasia (Cruice et al., 2003; Hilari, Wiggins, Roy, Byng, & Smith, 2003).

Earlier studies conducted by Dorze & Brassard, 1995; Zemva, 1999, reported similar findings. The results were obtained from conducting interviews and focus groups which revealed communication difficulties, changes in interpersonal relationships and social activities, being labeled or stigmatization, physical dependency as well as having negative feelings like irritation, annoyance, frustration, and stress. According to a study conducted by Bendz (2000) where 10 participants were interviewed three months post-stroke, the condition affected their bodily functioning, instilled fear of an ensuing stroke, feeling a loss of identity, loss of energy in carrying out daily living activities along with memory and concentration problems.

Caregivers of persons with aphasia rate significantly lower on quality of life than the person with aphasia himself or herself (Cruice, Worrall, Hickson & Murison, 2005). For the quality of life following are some of the critical factors which play an essential role these include activities, people, stroke, body functioning, personal outlook, mobility,



verbal communication, independence, home, and health. The other factors such as discussion with family members, emotional consequences, ability to socialize, psychological impact, financial issues are also essential in improving the quality of life of persons with aphasia (Cruice, Hill, Worrall, & Hickson, 2010). These factors may be experienced differently by the PWA and the caregivers as there may be a financial burden, emotional stress and other negative feelings that the caregivers undergo. It is necessary to acknowledge the opinions of both the PWAs and their caregivers to bring more clarity into communication and the subtle feelings experienced by each party.

According to some studies reported in India, the incidence and 30-day case fatality rates of stroke are significantly higher than those in developed countries (Das, Banerjee, Biswas, Roy, Raut, Mukherjee, Chaudhuri, Hazra, Roy, 2007; Dalal, Bhattacharjee, Vairala, Bhat, 2007). In developed countries, there have been ample studies done studying the QOL post stroke. Whereas, looking into the literature from India and other developing countries the amount of research conducted is sparse.

In India, a large portion of the population belongs to a joint family and therefore, if PWA belongs to such a family will be surrounded by family members and relatives during the recovery process. It may be understood that these factors may influence the quality of life and life satisfaction in such individuals and this may not be the case in all persons with aphasia. However, the psychosocial problems in PWAs in India could differ from those experienced by patients in other developed countries.

Raju, Sarma, and Pandian (2010) reported that PWAs with a post-stroke of at least more than a month had an impaired quality of life which was associated with the presence of depression, anxiety, and functional dependence. Therefore, there is a great need to

explore these aspects and to help individuals more holistically than intervening using the traditional approaches. A social approach will help the PWAs to get integrated back into society and regain a social identity and serve as a valued member of the community. The current study was proposed with the following objectives:

1. To translate, adapt and validate the Life Satisfaction Questionnaire (Lisat-9) in Kannada.
2. To administer and correlate the results obtained from the Stroke and Aphasia Quality of Life Scale (SAQOL-39) in Kannada and the translated Life Satisfaction questionnaire (Lisat-9).
3. To examine and understand life satisfaction and quality of life in persons with aphasia.

## **CHAPTER II**

### **REVIEW OF LITERATURE**

Understanding life satisfaction and quality of life among persons with aphasia (PWA) are of considerable interest because of the immense impact of communication-related difficulty which affects life satisfaction (Spaccavento, Craca, Del Prete, Falcone, Colucci, Di Palma and Loverre, 2014). The occurrence of aphasia following a stroke will have an adverse effect on the quality of life in individuals, which may be attributed to the limited physical abilities, communication skills, reduced social participation, and emotional stress. It was revealed that persons with aphasia had an affected quality of life followed by persons affected by cancer and Alzheimer's disease (Lam & Wodchis, 2010). Researchers in the past carried out several studies to study the communication difficulties and psychosocial issues from, persons with aphasia, their caregivers, and speech-language pathologists' perspectives (Herrmann & Wallesch, 1989; Shewan & Cameron, 1984; Rolnick & Hoops, 1969).

Shewan and Cameron (1984) reported that persons with aphasia and their caregivers perceived pronounced communication difficulties. However, the degree to which both groups rated the severity varied. Therefore, it is understood that each person experiences the challenges differently and it may not pertain to the severity of the disability. In the past few years, professionals have directed increasingly greater attention towards the study of life satisfaction and quality of life in persons with aphasia. Reviews of life satisfaction and quality of life among persons with aphasia are limited both locally and globally. There is a need to learn much about the range of factors associated with life

satisfaction and quality of life in persons with aphasia. Understanding these issues is essential to facilitate optimal outcomes for the benefit of the person with aphasia (Ellis & Peach, 2017).

Ross and Wertz (2003) compared the quality of life in PWA and non-aphasic individuals. The authors administered two questionnaires, the WHO- Quality of Life Instrument, Short Form- WHOQOL-BREF (The WHOQOL Group, 1998a,p. 1569), and the Psychosocial Wellbeing Index-PWI (Lyon, Cariski, Keisler, Rosenbek, Levine, Kumpula, & Blanc, 1997). The results revealed that persons with chronic aphasia experienced a low quality of life. There were significant differences between the PWA and the non-aphasics in the different facets consisting of positive feelings, mobility, personal relationships, and leisure life.

Bakas, Kroenke, Plue, Perkins, and Williams (2006) reported that the caregivers of those individuals with aphasia had negative feelings and perceived difficulty handling tasks than those stroke survivors who did not have aphasia. The authors recruited 159 family caregivers and administered questionnaires about survivor impairments, difficulty in task handling, depression, and other related caregiver outcomes. The surveys used in the study were Stroke Specific Quality of Life Scale Proxy version (SSQOL Proxy: Williams, Redmon, Martinez & Weinberger, 2000); Oberst Caregiving Burden Scale (Bakas, Austin, Jessup, Williams & Oberst, 2004) and Patient Health Questionnaire Depression Scale (Kroenke, Spitzer, & Williams, 2001). The results revealed that survivors rated severely and also expressed depressive symptoms. The most challenging situation was reported to be communication and dealing with problem behaviors. It was also found that in the case of female caregivers, it was their responsibility to handle finances and coordinating with a

team of healthcare professionals. The authors also revealed that the caregivers of the persons with aphasia reported social exclusion and lack of time with their family and friends, one portion of the participants showed that their physical health had deteriorated as a result of constant caregiving.

Le Dorze, Croteau and Baril (2007) described the consequences of aphasia on the PWA, their family members, and friends. The authors carried out semi-structured interviews including personal accounts to understand the issues the individuals face, and the qualitative analysis was employed to reach conclusive results. The findings revealed that the PWA had severe language-related difficulties which were also reported by the family and friends. The family and friends also reported inability to control coprolalia and emotional outbursts. The authors also stated that the spouses tend to be more affected than the other family members as primary caregivers which affect their psychosocial well-being.

Lam and Wodchis (2010) found that persons with aphasia had a significantly worse quality of life than a patient without aphasia since aphasia influenced social relationships, access to their environment, and independence. Based on the analysis of personal accounts of individuals with aphasia, their friends and relatives, Le Dorze and Brassard (1995) grouped the consequences of aphasia into three categories. The first group included language related difficulties (due to aphasia); situational change, affected interpersonal relationships, activity restriction and loss of autonomy were integrated into the second group as a consequence of the handicap. The third category included coping mechanisms adopted as strategies by the PWA and their family to acclimatize with the undesired effects of stroke they experienced.

Nagayoshi, Iwata, and Hachisuka (2008) studied life satisfaction in stroke outpatients (people with moderate to severe aphasia included) and community-dwelling adults or older. The author found that severity of aphasia had a significant impact on perceptions of life satisfaction.

Spaccavento et al., 2014 aimed at measuring QOL in persons with aphasia using Quality of Life Questionnaire for Aphasics (QLQA) based on the conceptual models of the ICF. The questionnaire was developed including different aspects: linguistic, verbal psychosocial problems, residual problems post stroke. Based on the psychometric examination, the QLQA was found to be a reliable tool to measure QOL in persons with aphasia. The authors additionally reported that the linguistic, psychosocial and emotional aspects were distinctly found.

Corsten, Konradi, Schimpf, Harding, and Keilmann(2014) examined life satisfaction among persons with aphasia, using the Satisfaction with Life Scale (SWLS), following interventions to improve the overall quality of life. Post-intervention life satisfaction was measured among 27 persons with aphasia. Although persons with aphasia observed growth in communication and self-confidence, improvements were not reported between pre-intervention and post-intervention life satisfaction scores.

From the research conducted, it can be inferred that the effect of aphasia is not only challenging for the affected person, but the negative experience also has an impact on the primary caregivers. The PWA and the spouses report the reduced quality of life and low life satisfaction to varying degrees. It is necessary to take account of these feelings and experiences of both parties to bring a positive impact on therapeutic intervention. Speech-

language pathologists should incorporate more social, and life participation related approaches to therapy need to be considered during the intervention.

## **2.1 Methodology used to examine Quality of Life in Persons with Aphasia**

Researchers around the globe use different methods while conducting studies which include administration of questionnaires, using a predetermined set of questions conducting interviews that are unstructured and applied data analysis. This method is disparate from the framework method analysis and in-depth interviewing (Parr, Byng & Gilpin, 1997) that is traditionally used in aphasia research. The strengths of the interviewing approach include being able to gather the perspectives of large numbers of participants in a time-efficient manner, meaning the technique is attractive for inclusion in an otherwise large assessment battery (Cruice et al., 2003). The strengths of the approach to analysis include a bottom-up or data-driven approach to identifying findings, with clearly defined concepts meaning that data can be traced and coded by persons unfamiliar with the original review. However, there are also weaknesses arising from the lack of probing or prompting of participant responses, meaning it is inappropriate to infer relationships or causation in the data. This also means that participants' responses may not reflect their full appreciation of QOL.

Ellis and Peach (2017) carried out a review of literature relating to research studying life satisfaction and reported that most of the research investigation QOL in PWA is limited and inconclusive. They opined the following: quantitative scales may not give adequate information about the influence of aphasia on the life satisfaction in PWA;

psychometric measures examining improved life satisfaction as a consequence of a particular therapy goal may be flawed. Further, a combination of both quantitative and qualitative approach can provide a holistic view and provide information about specific complex constructs like life satisfaction.

Therefore, multiple methods have been employed to assess the quality of life and satisfaction with life in persons with aphasia, their caregivers including spouse and immediate family members. Carrying out both quantitative and qualitative analysis will provide sufficient data to arrive at conclusive and accurate results regarding the QOL in persons with aphasia. It is also suggested that researchers should be skeptical of the proxy responses as they may not reveal the definitive results and the true feelings of the PWA.

## **2.2 Stroke and Aphasia Quality of Life: Related studies**

Hilari, Wiggins, Roy, Byngand Smith (2003) developed the Stroke and Aphasia Quality of Life (SAQOL) as a 39 item self-report scale that can be administered during an interview having two response formats. The five-point scale ranges from couldn't do at all = 5 to no trouble at all = 1, and definitely yes = 1 to definitely no = 5. The authors reported the following findings: 87% of the participants were able to report accurately, and the responses were documented based on an interview, and there were significant differences between the reactions of the proxy (family members) and the self-reports of the PWA about the QOL post stroke. The findings also suggest that SAQOL -39 showed good acceptability, internal consistency, construct validity and test-retest reliability. Therefore, it was concluded that the questionnaire is a highly relevant and robust tool to measure the



quality of life in individuals post stroke that is not time-consuming and does not pose a burden on the participants.

The SAQOL-39 has been adapted into many languages including Spanish (Lata-Caneda, Piñero-Temprano, García-Fraga, García-Armesto, Barrueco-Egido & Meijide-Failde, 2009), Greek (Kartsona & Hilari, 2007), Dutch (Manders, Dammekens, Leemans, & Michiels, 2010), Italian (Posteraro, Formis, Bidini & Grassi 2004), Portuguese (Rodrigues & Leal, 2013), Slovene (Žemva, 2006), Turkish (Calis, Celik, Demir, Aykanat & On, 2016), Chilean (Diaz, Gonzalez, Salgado & Perez, 2013), Danish (Isaksen & Andersen, 2016), Chinese (Lin, Chen, Feng, Cai & Deng, 2013) Korean (Kim, Shin, Kim & Kim, 2012) and Japanese (Kamiya, Kamiya, Tatsumi, Suzuki & Horiguchi, 2015). In the Indian context, it has been adapted into Hindi (Mitra & Krishnan, 2015), Kannada (Kiran & Krishnan, 2013) and Malayalam (Raju & Krishnan, 2015). The findings of some of the adaptations in European and Asian languages are discussed below.

Posteraro et al. (2004) aimed at adapting and validating the Italian version of the SAQOL- 39 by translation and correlating the finding. The authors found that after rendition there was a low percentage of few variations semantically. Cronbach's alpha and inter-class correlation coefficient (ICC) was performed, and a global score for ICC was 0.898 and Cronbach's alpha ranged from 0.767-0.976 suggesting that this measure was a reliable and acceptable tool. The adapted Greek version was developed by Kartsona and Hilari (2007) by translating and linguistically validating the instrument. The findings revealed good accessibility, acceptability and content validity. The authors opined and concluded that the adapted version was a close match to the original version. Lata-Caneda et al. (2009) carried out the Spanish adaptation using the translation and back-translation

method. The ceiling and floor effects were examined to evaluate the acceptability, and it was found to have good acceptability. Using Cronbach's alpha, the internal consistency was found to be 0.950, and the test-retest reliability of overall scores was 0.949 (0.854-0.944) revealing good consistency and reliability. Manders et al. (2010) aimed at adapting the SAQOL to the Dutch language and the tool was administered to 43 persons with aphasia and re-administered eight months post the first testing. The results showed that low scores on the communication and psychosocial domains contributed to the overall reduced quality of life. The retesting, however, showed slightly improved scores on both the domains which the authors opined to be the result of therapeutic intervention.

Among the Asian languages, Kim et al. (2012) adapted the tool and aimed at validating the Korean version of the questionnaire through translation and assessed the validity and reliability of the instrument. The findings of the study revealed that the internal consistency was high and the test had good test-retest reliability. Concurrent validity was also obtained, and it was found to have high correlation concluding that this version was an appropriate measure and can be administered on Korean PWA. Lin et al. (2013) administered the Chinese version of the SAQOL on 121 patients (post stroke), and the internal consistency for the total scale was found to be 0.94 (Cronbach's  $\alpha$ ), and the test-retest reliability was 0.97. The authors concluded that the adapted scale had good psychometric quality and can be used as an appropriate measure in the Chinese population. The Japanese version was developed, and its psychometric properties were evaluated using the method of official translation and back translation. The authors revealed that the SAQOL-39-J had high internal consistency (Cronbach's  $\alpha$ : 0.90) and test-retest reliability

(ICC: 0.97), it was showed good acceptability concluding that the adapted version can be used to assess the quality of life in persons with aphasia (Kimayaet al., 2015).

In summary, the SAQOL had been adapted to various languages across the world using the forward-back translation, and most studies reported the different versions to have good acceptability, high internal consistency, and good reliability and validity.

### **2.3 Life Satisfaction Questionnaire: Persons' with Aphasia and Caregivers perspectives**

Viitanen, Fugl-Meyer, Bernspang and Fugl-Meyer (1988) aimed at investigating the quality of life and satisfaction in post-stroke survivors and administered the LISAT-9 in persons post-stroke (four to six years post onset). There was evidence that 61% of the participants reported at least one aspect of QOL as reduced. Further, the most widely reported reduction in life satisfaction was related to the entirety of living, sexual life and leisure activity being more affected than the other areas. Fugl-Meyer, Branholm, and Fugl-Meyer (1991) aimed at investigating domain specific satisfaction of life and to understand happiness. The questions were formed based on eight areas and one main question (life as a whole) which had to be rated on a six-point scale. Self-reports on life satisfaction were analyzed, and the results revealed that there were no age-dependent differences for the domains of the vocational and financial situation. However, few gender differences were observed.

In 2011, Verhoeven, Post, Schiemanck, van Zandvoort, Vrancken and van Heugten studied the relationship between the domains of quality of life and cognitive functioning in one-year post-stroke duration. A neuropsychological test battery was

utilized to measure the cognitive functions and various tests including LISAT -9 was administered to assess the quality of life and life satisfaction in these individuals. Based on the analysis, it was found that reduced cognitive functioning was directly correlated with reduced functional independence, participation in social activities, depression and most importantly life satisfaction. The authors additionally reported that motor impairment was an essential determinant for the quality of life in the future.

Smeets, van Heugten, Geboers, Visser-Meily and Schepers (2012) investigated the satisfaction of the caregivers of patients with acquired brain injury and their well-being. LISAT 9 to examine life satisfaction and Hospital Anxiety and Depression Scale to assess emotional functioning and a caregiver burden scale were administered on the caregivers. The results obtained revealed that 61% of the caregivers reported reduced life satisfaction and 69% of the caregivers mentioned increased subjective burden. The authors concluded that it is crucial to address the feelings of the caregivers along with the patients.

Achten, Visser-Meily, Post, and Schepers (2012) aimed at comparing the life satisfaction of individuals post-stroke and their spouses; and to understand the factors that determine the life satisfaction in the individuals. The LISAT- 9 was administered in three years post-stroke. The results revealed that 50% of the spouses were dissatisfied whereas only 28% of the individuals post-stroke reported dissatisfaction. The spouses reported being dissatisfied in all the domains of life as mentioned in the tool. It was associated with poor social participation and the post-stroke condition of the individuals. The authors concluded that more spouses have a dissatisfied life, however, in the chronic phase both the individuals affected by stroke and their spouses experience reduced life satisfaction.

A study was conducted in 2014 by Brands, Köhler, Stapert, Wade, and van Heugten, to examine the link between self-efficacy and coping mechanism concerning QOL and participation in social activities. The authors also aimed at identifying the strategies for dealing with long-term social participation and quality of life. The participants with acquired brain injury recruited were in the chronic state, and the tests were administered during baseline assessment and one-year post onset. Multiple tools were used to assess these variables including LISAT-9 for QOL, Frenchay Activities Index (Post & De Witte, 2003) for social participation, Coping Inventory for Stressful Situations (Endler & Parker, 1990) for assessing coping strategies and TBI Self efficacy Questionnaire (Cicerone & Azulay, 2007) to examine the self- efficacy. Based on the analysis, avoidance coping was exhibited, and the feelings-oriented coping mechanism was moderated by self-efficacy. There was an increase in the self-efficacy index over time, and better scores were observed at follow-up after a year for LISAT-9. The authors opined that long-term quality of life could be predicted based on coping and self-efficacy. They concluded that the negative feelings related to coping might be curbed with high self-efficacy.

It can be understood that on the administration of the LISAT - 9 questionnaire, PWA and caregivers reported dissatisfaction. The spouse of the stroke affected person is prone to have negative feelings and experience emotional and financial burden. Therefore, communication between the PWA and caregivers is vital to express these feelings as gain closure in understanding the experience from the perspective of the individual and their spouses.

## 2.4 National Status

Raju, Sarma, and Pandian (2010) studied psychosocial problems, functional independence, and quality of life among Indian stroke survivors. The authors found that the presence of functional dependence, anxiety, and depression was associated with poor quality of life. Older age and stroke severity resulted in increased functional dependence. There was a low prevalence of anxiety and depression. Whereas, Gupta, Deepika, Taly, Srivastava, Surender, and Thyloth (2008) reported that patients with neurological disorders requiring inpatient treatment have a poor quality of life that affects all spheres of life. There is a high prevalence of psychological problems, including anxiety and depression. The social domain of quality of life adversely affected functional abilities, but the correlation between psychological issues and practical skills was insignificant.

In the Indian context, the SAQOL has been adopted in three languages. Kiran and Krishnan (2013) conducted a study that aimed at developing and validating the Kannada version of the instrument and measured the test-retest reliability and internal consistency. The adapted version was performed using the forward-backward translation method. The scale was administered on 32 PWA, and Cronbach's alpha was used for statistical analysis. The results revealed that the adapted version good acceptability and there was minimum missing data, the test-retest reliability was found to be high (ICC= 0.8). High internal consistency was found for the tool using Cronbach's alpha (0.9). The authors concluded that the instrument allows direct translation and permits the adaptation to many languages.

Mitra and Krishnan (2015) have adapted and validated of SAQOL-39 to Hindi. The test was administered on 84 persons with aphasia to determine the acceptability,

internal consistency, and test-retest reliability. The SAQOL-39 in Hindi showed high test-retest reliability and acceptability with minimal missing data. This scale presented high internal consistency as well as both item to total and interdomain correlations. The tool has also been adapted and validated in Malayalam by Raju and Krishnan (2015) on 48 Malayalam speaking persons with aphasia, and the result showed high test-retest reliability as well as high internal consistency.

It has been well documented and researched, that most of the time professionals emphasize improving the overt deficits in persons with aphasia such as communication, cognitive and physical. The relationship among normal life satisfaction, quality of life and disruption caused by aphasia is not very clear and worthy of research. Additionally, there is not much research done correlating two questionnaires aimed at examining the same aspect of quality of life in persons with aphasia and comparing the perspectives of the caregivers. The results of the present study will be helpful to design management strategies for improvement of persons with aphasia in a more holistic approach. It will also give an insight into the differences in perception of the communication and physical abilities, and psychosocial issues of the PWA and what the caregivers perceive the severity of the problem as. The following section will emphasize the methodology used, and participants recruited to study the quality of life and life participation in persons with aphasia and the caregivers' perception of the same.

## **CHAPTER III**

### **METHODOLOGY**

The main aim of the study was to examine and understand the essential essence of living which is the life satisfaction and quality of life in persons with aphasia (PWA) and their caregivers' perspective. The objectives included translating, adapting and validating the Life Satisfaction Questionnaire (LISAT-9); administering and correlating the results obtained from the Stroke and Aphasia Quality of Life Scale (SAQOL-39) in Kannada and the translated LISAT-9. A total of 160 adult Kannada speaking participants were recruited for the present study. These participants were grouped into two categories. Group-I consisted of normal healthy participants who were their immediate caregivers and other family members. These included 37 dependants (parent/spouse), 37 immediate family members (siblings/offspring) and 35 friends/ relatives of persons with aphasia. Group-II consisted of 40 persons with aphasia.

Persons with aphasia were recruited in and around Mysore with an only inclusion criterion that they have been treated or undergoing therapy for communication difficulties and had no dementia at the time of interview. All the relevant information related to PWA were documented such as the details of stroke, personal details and any other information reported or recorded by PWA or their family members. The factors such as the type of aphasia, site of lesion, type of treatment (physical, occupational, speech-language, psychotherapy, and any other treatment) educations, geographical distribution socioeconomic status, knowledge of languages, handedness, vocation, family status, and



any additional information were documented and these were considered while analyzing the data.

Before initiation, the authors of the Life Satisfaction Questionnaire (Lisat-9) were notified, and formal permission for translation and adaption in Kannada was sought. Authors of the Stroke and Aphasia Quality of Life -39 (Kannada version) were provided access to the tool, and the authors of both tools were appropriately acknowledged.

### **3.1. Life Satisfaction questionnaire- 9 (LISAT - 9)**

Lisat-9 (Fugl-Meyer, A. R., Bränholm, I. B., & Fugl-Meyer, K. S., 1991) consists of 9-item. It is a self-administered questionnaire including one question about general life satisfaction and eight questions about life satisfaction for the specific domains of ‘self-care ability’, ‘leisure situation’, ‘vocational situation’ (including home-making), ‘financial situation’, ‘sexual life’, ‘relationship with partner/spouse’, ‘family life’ and ‘contacts with friends and acquaintances’. All nine questions have to be answered on six-point (1=very dissatisfied, 6=very satisfied).

### **3.2. Stroke and Aphasia Quality of Life (SAQOL - 39)**

The SAQOL (Kannada version) translated and validated by Kiran, S., & Krishnan, G. (2013), contains 39 items, each of which is scored on a five-point scale. It uses two formats for responses, where 1: could not do it at all, 5: no trouble at all; 1: definitely yes, 5: definitely no. It provides an overall and four domain scores (score ranges from 1 to 5). High scores indicate the better health-related quality of life. This scale has good reliability and validity and differentiates persons by stroke severity. The questions are framed

concerning the person's experiences in the previous week. It taps into the person's subjective evaluation of functioning in four domains such as Physical (e.g., How much trouble did you have walking?), Psychosocial (e.g., Did you feel that you were burden to your family?) Communication (e.g., How much did you have finding the word you wanted to say?) and Energy (e.g., Did you feel too tired to do what you wanted to do?).

### **3.3. Phase-I: Translation, Adaptation of the Life Satisfaction Questionnaire (Lisat-9)**

The first phase involved the translation of the test items of the Life Satisfaction Questionnaire, nine-item questionnaire. A review of the available literature on the development and validation of these the tool in different languages was carried out. The translated and adapted material was given to seven native Kannada speaking speech-language pathologists (SLPs) for rating the content of each scale. Based on the ratings provided by the SLPs, one modification made in the Kannada translated version was in the placement of the seventh and eighth item.

### **3.4 Phase-II: Administering the test on persons with aphasia**

For validation of the test, the test material was administered on 40 persons with aphasia who were Kannada speaking participants. The caregivers, immediate family members, and friends/relatives were asked to fill out the questionnaire from the perspective of the person with aphasia. The questions were read out to those participants who were uneducated, and their responses were documented. The demographic details of the participants of each group are provided in tables 1, 2, 3, and 4 respectively.

Table 1: Demographic profile of persons with aphasia (Group 1)

<b>S.No</b>	<b>Participant code</b>	<b>Age/ Gender</b>	<b>Provisional Diagnosis</b>	<b>Etiology</b>	<b>Socio- economic status</b>	<b>Marital Status</b>	<b>Occupation</b>	<b>Language status</b>
1.	P1	38y8m/ M	Resolving Wernicke's aphasia	CVA**	Middle	Married	Petrol Bunk	Bilingual
2.	P2	64y/F	Conduction aphasia	CVA	Upper Middle	Married	Not working	Bilingual
3.	P3	52y/M	Broca's aphasia	CVA	Middle	Married	Electrical Supervisor	Bilingual
4.	P4	49y/M	Global aphasia	CVA	Lower Middle	Married	Business	Monolingual
5.	P6	48y/M	Conduction aphasia	CVA	Middle	Married	Unemployed	Bilingual
6.	P7	65y/M	Wernicke's aphasia	CVA	Upper	Married	Politician	Bilingual
7.	P8	43y/F	Anomic Aphasia	CVA	Upper	Married	Unemployed	Multilingual
8.	P9	42y/M	Isolation aphasia	CVA	Lower	Separated post stroke	Unemployed	Monolingual
9.	P10	64y/M	Wernicke's aphasia	CVA	Upper Middle	Married	Pharmacist	Multilingual
10.	P11	50y/M	Broca's Aphasia	CVA	Upper	Separated pre- stroke	Watch Merchant/Owner	Bilingual
11.	P12	26y/M	Anomic aphasia	CVA	Lower Middle	Unmarried	Revenue Department officer	Bilingual
12.	P13	33y/M	Broca's aphasia	CVA	Lower Middle	Unmarried	Supervisor: Construction company	Multilingual
13.	P14	38y/F	Conduction aphasia	CVA	Middle	Married	Unemployed	Bilingual

14.	P15	23y/M	Anomic Aphasia with Dysarthria	Infection	Middle	Unmarried	Unemployed	Multilingual
15.	P17	44y/F	Anomic aphasia	Aneurysm	Upper Middle	Married	Teacher	Bilingual
16.	P18	41y/M	Broca's aphasia	CVA	Upper Middle	Married	Real estate agent	Bilingual
17.	P19	61y/M	Transcortical sensory aphasia	CVA	Lower	Married	Restaurant business	Multilingual
18.	P20	42y/M	Broca's aphasia	CVA	Middle	Married	Real estate agent/Politics	Multilingual
19.	P21	27y/F	Anomic aphasia	TBI*	Middle	Separated after stroke	Private employee	Bilingual
20.	P22	26Y/F	Anomic aphasia	CVA	Middle	Married	Housewife	Bilingual
21.	P23	62Y/M	Global aphasia	CVA	Lower	Married	Vendor	Multilingual
22.	P25	52y9m/M	Broca's Aphasia	CVA	Middle	Married	DTP center business	Multilingual
23.	P26	23/M	Global aphasia	TBI	Lower	Unmarried	Diploma	Monolingual
24.	P27	51/F	Conduction aphasia	CVA	Middle	Married	Housewife	Monolingual
25.	P28	57y/F	Anomic aphasia	TBI	Upper	Married	Chemical & Metereological officer	Multilingual
26.	P29	59/M	Broca's aphasia	TBI	Middle	Married	Vendor	Multilingual
27.	P30	32y/F	Anomic aphasia	Tumor	Lower Middle	Unmarried	Unemployed	Bilingual
28.	P31	46y/M	Broca's Aphasia	CVA	Lower	Married	Driver	Monolingual
29.	P32	28y/M	Conduction aphasia	CVA	Middle	Unmarried	Business	Multilingual

30.	P33	31y/M	Broca's aphasia	TBI-CVA	Lower	Unmarried	Tractor Driver	Monolingual
31.	P34	67y/F	Global aphasia	CVA	Middle	Widow	Unemployed	Monolingual
32.	P37	69y/M	Broca's Aphasia	CVA	Lower	Married	Daily wager	Monolingual
33.	P38	39y5m/ M	Broca's Aphasia	CVA	Middle	Married	Weaver	Bilingual
34.	P39	44y/M	Broca's Aphasia	CVA	Middle	Married	Army officer	Multilingual
35.	P40	52/M	Conduction aphasia	CVA	Middle	Married	Private employee	Multilingual
36.	P41	54y/M	Global Aphasia	CVA	Middle	Married	Business	Monolingual
37.	P42	28y/F	Global resolving to Broca's aphasia	TBI	Middle	Married	Housewife	Bilingual
38.	P43	40/M	Global Aphasia	CVA	Middle	Married	Business	Multilingual
39.	P45	39/M	Conduction aphasia	Tumor	Middle	Married	Private employee	Bilingual
40.	P46	66y/F	Transcortical sensory aphasia	CVA	Upper Middle	Widow	Unemployed	Bilingual

Table 2: Demographic profile of the dependents (group 2) of PWA (group 1)

<b>S.No</b>	<b>Participant code</b>	<b>Age/ Gender</b>	<b>Relation with PWA</b>	<b>Education</b>	<b>Occupation</b>
1.	P1D	33y/F	Spouse	X Grade	Homemaker
2.	P2D	74y/M	Spouse	Graduate	Retired sales manager
3.	P3D	47y/F	Spouse	X Grade	Homemaker
4.	P4D	44y/F	Spouse	Illiterate	Homemaker
5.	P6D	50y/F	Spouse	X Grade	Homemaker
6.	P7D	56y/F	Spouse	Graduate	Homemaker
7.	P8D	53y/M	Spouse	Graduate	Politician
8.	P9D	76y/F	Parent	Illiterate	Unemployed
9.	P10D	58y/F	Spouse	XII Grade	Homemaker
10.	P12D	56y/F	Parent	X Grade	Homemaker
11.	P13D	55y/F	Parent	Illiterate	Homemaker
12.	P14D	48y/M	Spouse	Graduate	Private employee
13.	P15D	57y/M	Parent	Graduate	Bank employee
14.	P17D	52y/M	Spouse	Graduate	Bank employee
15.	P18D	44y/F	Spouse	XII Grade	Homemaker
16.	P19D	52y/F	Spouse	Illiterate	Homemaker
17.	P20D	47y/F	Spouse	X Grade	Homemaker
18.	P21D	61y/M	Parent	Graduate	Retired manager
19.	P22D	31y/M	Spouse	Graduate	Private employee
20.	P23D	50y/F	Spouse	Illiterate	Homemaker

21.	P25D	45y/F	Spouse	Graduate	Administration officer
22.	P26D	58y/F	Parent	Illiterate	Homemaker
23.	P27D	55y/M	Spouse	Diploma	Private employee
24.	P28D	61y/M	Spouse	Graduate	Retired Air force Officer
25.	P29D	53y/F	Spouse	Illiterate	Homemaker
26.	P30D	60/F	Parent	Illiterate	Homemaker
27.	P31D	36y/F	Spouse	X Grade	Tailor
28.	P32D	55y/M	Parent	Graduate	Private employee
29.	P33D	72y/F	Parent	Illiterate	Homemaker
30.	P37D	55y/F	Spouse	Illiterate	Homemaker
31.	P38D	30y/F	Spouse	Graduate	Accountant
32.	P39D	39y/F	Spouse	X Grade	Homemaker
33.	P40D	38y/M	Spouse	Graduate	Private employee
34.	P41D	47y/F	Spouse	X Grade	Homemaker
35.	P42D	55y/F	Spouse	Illiterate	Homemaker
36.	P43D	36y/F	Spouse	X Grade	Homemaker
37.	P45D	38y/F	Spouse	Graduate	Teacher

Table 3: Demographic profile of the immediate family members (group 3) of persons with aphasia (group 1)

<b>S.No</b>	<b>Participant code</b>	<b>Age/ Gender</b>	<b>Relation with PWA</b>	<b>Education</b>	<b>Occupation</b>
1.	P1IM	42y/M	Brother	Graduate	Private employee
2.	P2IM	36y/F	Daughter	X Grade	Unemployed
3.	P3IM	22y/F	Daughter	Graduate Student	-
4.	P4IM	40y/M	Brother	Illiterate	Vendor
5.	P6IM	25y/M	Son	B-Tech	Engineer
6.	P7IM	34y/F	Daughter	Graduate	IT Professional
7.	P8IM	48y/F	Sister	Graduate	Homemaker
8.	P9IM	49y/M	Brother	Illiterate	Daily wager
9.	P10IM	26y/F	Daughter	Graduate	Bank employee
10.	P12IM	22y/F	Sister	Graduate	Unemployed
11.	P13IM	28y/M	Brother	XII Grade	Factory employee
12.	P14IM	40y/F	Sister	XII Grade	Homemaker
13.	P15IM	21y/M	Brother	Graduate Student	-
14.	P17IM	45y/M	Brother	Graduate	Bank employee
15.	P18IM	40y/M	Brother	Graduate	Private employee
16.	P19IM	44y/F	Sister	IV Grade	Homemaker
17.	P20IM	45y/F	Sister	XII Grade	Homemaker
18.	P22IM	39y/F	Sister	X Grade	Homemaker
19.	P23IM	57y/M	Brother	V Grade	Business
20.	P25IM	57y/M	Brother	Graduate	Business



21.	P26IM	17y/F	Sister	Student	-
22.	P27IM	21y/M	Son	Student	-
23.	P28IM	27y/M	Son	B-Tech	Engineer
24.	P29IM	24y/M	Son	ITI	Private employee
25.	P30IM	30y/M	Brother	X Grade	Unemployed
26.	P31IM	46y/M	Brother	VIII Grade	Agriculture
27.	P32IM	23y/M	Brother	Student	-
28.	P33IM	29y/F	Sister	VIII Grade	Homemaker
29.	P34IM	64y/F	Sister	Illiterate	Homemaker
30.	P37IM	55y/F	Sister	Illiterate	Homemaker
31.	P38IM	35y/F	Sister	XII Grade	Homemaker
32.	P40IM	54y/F	Sister	X Grade	Homemaker
33.	P41IM	30y/M	Son	Graduate	Private employee
34.	P42IM	36y/F	Sister	XII Grade	Homemaker
35.	P43IM	35y/F	Sister	VIII Grade	Homemaker
36.	P45IM	42/M	Brother	XII Grade	Agriculture
37.	P46IM	27y/M	Son	B-Tech	Engineer

Table 4: Demographic profile of friends and relatives (group 4) of persons with aphasia (group 1)

<b>S.No</b>	<b>Participant code</b>	<b>Age/ Gender</b>	<b>Relation with PWA</b>	<b>Education</b>	<b>Occupation</b>
1.	P1FR	42Y/M	Friend	Graduate	Government employee
2.	P2FR	24y/M	Friend	Graduate	Private employee
3.	P3FR	54y/F	Relative	XII Grade	Homemaker
4.	P4FR	52y/M	Relative	VIII Grade	Business
5.	P6FR	53y/M	Relative	XII Grade	Factory Supervisor
6.	P7FR	65y/M	Friend	Graduate	Real estate
7.	P8FR	43y/F	Friend	Graduate	Homemaker
8.	P9FR	50y/M	Friend	VIII Grade	Self-employed
9.	P10FR	64y/M	Friend	Graduate	Retired Manager
10.	P12FR	28y/M	Friend	Graduate	Private employee
11.	P13FR	34y/M	Friend	XII Grade	Factory employee
12.	P14FR	35y/F	Friend	Graduate	Supervisor: Construction company
13.	P15FR	35y/M	Relative	Graduate	Electrical Supervisor
14.	P17FR	23y/M	Friend	Infection	Unemployed
15.	P18FR	44y/M	Friend	Graduate	Real estate
16.	P19FR	60y/M	Friend	XII Grade	Business
17.	P21FR	31y/M	Friend	Graduate	Private employee
18.	P22FR	40y/F	Friend	XII Grade	Homemaker
19.	P23FR	56y/M	Friend	Illiterate	Unemployed

20.	P25FR	47y/F	Relative	XII Grade	Homemaker
21.	P26FR	26y/M	Friend	VIII Grade	Vendor
22.	P27FR	52y/F	Friend	XII Grade	Homemaker
23.	P28FR	55y/F	Relative	Graduate	Teacher
24.	P29FR	51y/M	Friend	V Grade	Self-employed
25.	P30FR	30y/F	Friend	Graduate	Teacher
26.	P32FR	24y/M	Friend	Diploma	Marketing
27.	P33FR	31y/F	Friend	VI Grade	Driver
28.	P34FR	66y/F	Friend	X Grade	Homemaker
29.	P37FR	38y/M	Friend	Illiterate	Factory employee
30.	P38FR	38y/M	Relative	Graduate	IT Professional
31.	P40FR	57y/M	Friend	XII Grade	Government employee
32.	P41FR	62y/M	Friend	XII Grade	Retired private employee
33.	P42FR	39y/F	Friend	XII Grade	Cashier
34.	P45FR	44y/M	Friend	Graduate	Marketing
35.	P46FR	43y/F	Relative	Graduate	Homemaker

### **3.5 Phase-III: Checking the reliability and validity of the test**

The inter-judge reliability and test re-test reliability was carried out, where ten percent of the data was retested by a competent Kannada Speaking Speech-Language Pathologist.

### **3.6 Procedure for data collection**

The aim of the study, procedure, and duration of testing was explained to the participants and their caregiver. In the situation where the participant had comprehension deficits, the caregivers were informed and the purpose of the study. Prior written consent was obtained from the participant and their caregiver for participation in the study. All the participants were tested in a noise-free, quiet environment at home, or clinical setting. Attempts were made for the audio-video recordings of the session while administering the test based on the consent of the participants. However, most participants refrained from consenting to the audio-video recording while filling out the questionnaire. Literate persons with aphasia were given the Life Satisfaction Questionnaire (Lisat-9) and the stroke and Aphasia Quality of life scale (SAQOL-39) and were asked to rate the questionnaire appropriately as per the instructions provided in the two questionnaires. In the case of the participants or caregivers being uneducated, the question items/stimuli were presented verbally, and their responses were recorded appropriately for these two questionnaire. Separate scoring criteria were followed for the two tools as stated in the original questionnaire. Obtained scores were tabulated, and appropriate statistical analyses were carried out which is dealt with in the upcoming section.

## **CHAPTER IV**

### **RESULTS**

The study was aimed at understanding the quality of life and life satisfaction in persons with aphasia and to look at the caregivers' perception regarding this aspect. The objectives included in the study were translating, adapting and validating the Life Satisfaction Questionnaire (LISAT-9); administering and correlating the results obtained from the Stroke and Aphasia Quality of Life Scale (SAQOL-39) in Kannada and the translated LISAT-9. The Stroke and Aphasia Quality of Life (SAQOL-39) and the Life Satisfaction Questionnaire (LISAT-9) were administered on 40 persons with aphasia, 37 dependents (spouse or parents), 37 immediate family (sibling or offspring), and 35 friends or relatives (N=149). The different domains in SAQOL-39 including physical, communication, psychosocial and energy scores, along with the overall ratings of SAQOL-39 and LISAT-9 were considered for analysis. Mean (M), standard deviation (S.D.) and median were obtained for the domains mentioned above.

Initially, the LISAT-9 was distributed to five practicing speech-language pathologists (SLPs) for content validation (Appendix I). A feedback questionnaire was given to each of them and the translated Kannada version of the Life Satisfaction Questionnaire- 9. The SLPs were asked to rate different parameters: simplicity, presentation, relevance, complexity, accessible, flexibility, trainability, stimulability, generalization, the scope of practice and scoring pattern. The gradation of rating was from very poor to excellent (5-point rating).

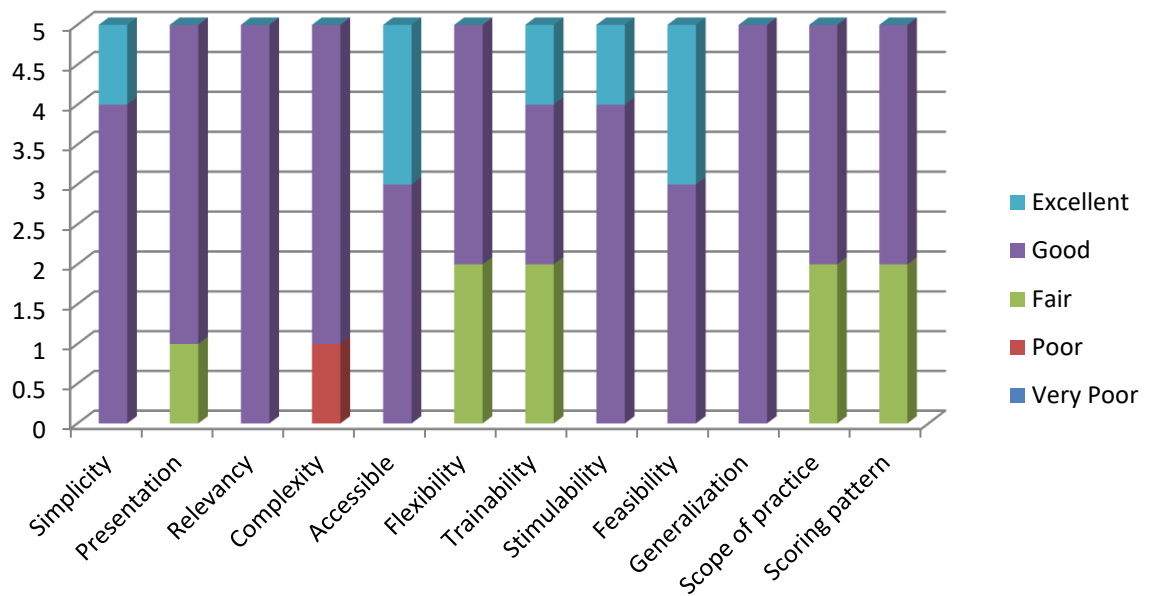


Figure 1: Validation provide by five speech-language pathologists

Based on figure 1, four out of five SLPs rated ‘good’ and one SLP rated ‘excellent’ for simplicity. For presentation, four SLPs rated ‘good’ and one SLP rated ‘fair’. All five SLPs rated ‘good’ for relevancy and generalization; for complexity, one SLP rated ‘fair’ and four of them rated ‘good’. Three SLPs rated ‘good’ for accessible and two of them rated ‘excellent’. Flexibility was rated ‘fair’ by two SLPs and ‘good’ by three SLPs, whereas trainability was rated ‘fair’ and ‘good’ by two SLPs respectively and one SLP rated ‘excellent. Stimulability was rated good by four SLPs and one SLP rated ‘excellent. Three SLPs rated ‘good’ and two rated ‘excellent’ for feasibility. For both scoring pattern and scope of practice, two SLPs rated ‘fair’ and three SLPs rated ‘good’. Hence, based on the results of validation the modification made in the questionnaire was the placement change of item 6 and item 7 in the questionnaire, where the questionnaires were interchanged in position. Additionally, a clause was added where the participants could choose to not answer

the question regarding 'sexual life' satisfaction by indicating with an 'X' mark beside the question if they did not wish to respond.

The statistical analysis was carried out for two main reasons: to examine the effect of groups (comparison of groups) in any of the average scores and total scores of each domain in SAQOL-39, and to compare the mean SAQOL-39 score, mean LISAT-9 score and their overall total scores. Attempts were made to correlate the scores of SAQOL-39 and LISAT-9. Additionally, the reliability and validity of the translated version of LISAT-9 were also conducted. The data were subjected to five different types of analyses:

i) Shapiro Wilk test was carried out to check if the data was normally distributed across groups.

ii) Kruskal-Wallis test, a non-parametric test that is rank-based, was employed to understand if there was any statistically significant difference across groups for each of the domains of SAQOL-39 and the overall score of LISAT-9.

iii) Mann-Whitney U test, another non-parametric test was carried out to know the pair-wise group difference for the parameters or domains that showed a significant difference in the rank-based non-parametric test.

iv) Spearman's rank correlation coefficient was performed to look for the link strength and significant correlation between SAQOL-39 and LISAT-9.

v) Cronbach's alpha was carried out to assess the test-retest reliability of the Kannada translated version of LISAT-9

#### 4.1 Descriptive statistics

The data set was analyzed in terms of group 1 (PWA), group 2 (dependents), group 3 (immediate family members) and group 4 (friends or relatives). The mean, standard deviation, and median were obtained across groups for the average scores of all the domains of SAQOL (physical, communication, psychosocial and energy) along with the overall mean. Similarly, descriptive statistics was employed across groups for the total scores of each of the domains and overall scores of SAQOL-39, and LISAT-9.

Table 5  
Mean, Standard Deviation and Median for the average scores of all domains of SAQOL and mean scores of SAQOL-39 and LISAT-9

Groups	PS_AVG	CS_AVG	PSS_AVG	ES_AVG	SAQOL_MEAN	LISAT_MEAN	
1	Mean	3.375	2.300	2.575	3.2125	3.0245	2.7903
	S.D.	1.3144	.8829	1.1297	1.15823	.58911	.87917
	Median	3.000	2.000	2.000	4.0000	2.9050	2.4400
2	Mean	3.757	2.297	2.486	3.3919	3.0194	2.9459
	S.D.	1.1403	1.0766	1.0960	1.23116	.72846	.76651
	Median	4.000	2.000	2.000	4.0000	2.9487	2.8889
3	Mean	3.892	2.757	3.189	3.8784	3.3749	2.9730
	S.D.	.9656	1.1157	.9079	.81142	.49133	.66739
	Median	4.000	3.000	3.000	4.0000	3.3333	2.7778
4	Mean	3.714	2.343	2.686	3.5143	3.1634	2.8667
	S.D.	1.1775	1.0274	.8321	1.12122	.61426	.75542
	Median	4.000	2.000	3.000	4.0000	3.1538	2.6667

PS\_AVG: physical score average CS\_AVG: communication score average PSS\_AVG: psychosocial score average ES\_AVG: energy score average

As seen in table 5, the mean of the physical score was observed to be highest (3.89) in group 3 (immediate family members), and the lowest was 3.37 in group 1 (PWA). The mean communication score was observed to be highest (2.75) in group 3, and it was found to



be lowest (2.30) in group 1 (PWA). In the psychosocial domain, the highest mean (3.18) was observed in group 3, whereas the lowest mean (2.48) was found in group 2. Looking into the energy domain, the highest mean (3.87) was observed in group 3 and group 1 obtained the lowest mean (3.21). When SAQOL average mean score were compared across groups, group 2 obtained the lowest mean (3.01) and the highest mean was obtained by group 3 (3.37). On a comparison of the average LISAT scores, group 1 obtained the lowest mean (2.79) and the highest mean was obtained by group 3 (2.97).

Table 6  
Mean Standard Deviation and Median for the total scores of all domains of SAQOL

Groups		PS_TOTAL	CS_TOTAL	PSS_TOTAL	ES_TOTAL
	Mean	61.200	16.575	27.775	12.575
1	S.D.	15.0046	5.2325	7.1521	3.1123
	Median	59.000	15.000	26.500	13.500
	Mean	61.243	17.162	26.946	12.405
2	S.D.	16.6240	5.3099	8.1443	4.1329
	Median	62.000	17.000	25.000	14.000
	Mean	64.973	18.973	33.486	14.108
3	S.D.	12.2893	4.1129	6.6442	2.8556
	Median	61.000	20.000	34.000	15.000
	Mean	63.971	17.343	29.171	12.886
4	S.D.	16.2471	5.5727	5.6542	3.3499
	Median	65.000	17.000	29.000	14.000

PS\_AVG: physical score average CS\_AVG: communication score average  
PSS\_AVG: psychosocial score average ES\_AVG: energy score average

The above-shown table 6 provides the mean, standard deviation, and median for the total scores of each domain of the SAQOL-39. It can be understood that the highest mean for a total physical score was obtained by group 3 (64.97), and the lowest mean was obtained by

group 1 (61.20). While comparing the scores in the communication domain, the highest mean was obtained by group 3 (18.97), and the lowest mean was found in group 1 (16.57). The results of the psychosocial domain revealed the highest mean in group 3 (33.48) and lowest mean in group 2 (26.94). Finally, on comparing the total energy scores, it was found that the highest mean was obtained by group 3 (14.10) and the lowest mean found in group 2 (12.40). To sum up, it was found that the highest mean value was predominantly obtained by group 3 (siblings or offspring) and the lowest mean was mostly obtained by group 1 (PWA) in most domains and two parameters; it was found to be group 2 (dependents).

Table 7  
Mean, Standard Deviation and Median for the total scores of SAQOL and LISAT

Groups		SAQOL_TOTAL	LISAT_TOTAL
1	Mean	118.125	25.150
	S.D.	22.9785	7.9148
	Median	113.500	22.000
2	Mean	117.757	26.514
	S.D.	28.4101	6.8986
	Median	115.000	26.000
3	Mean	131.541	26.757
	S.D.	19.2391	6.0065
	Median	130.000	25.000
4	Mean	123.371	25.800
	S.D.	23.9559	6.7988
	Median	123.000	24.000

On comparing the total scores of SAQOL-39 across groups, the lowest mean was obtained by group 2 (117.75) and group 3 showed the highest mean value (131.54). Whereas on the comparison of the LISAT total scores, the lowest mean value was obtained by group 4

(25.00) and the highest mean was found by group 3 (26.75). Therefore, it can be understood that the group 3 (siblings/ offspring) displayed the highest mean value and lowest mean value varies slightly across different parameters and groups.

#### 4.2 Test for normality and across group comparisons

The former part of the first objective of the study was to administer the two questionnaires. Shapiro Wilk test was carried out to examine if the data followed a normal distribution, the results of the test revealed that that data was not normally distributed concerning groups. Therefore, a non-parametric Kruskal-Wallis test was carried out to check the significant difference across groups. If the data showed a significant difference, it was further subjected to the Mann-Whitney U test to see the pair-wise group difference for those parameters.

Domains	Chi-Square	Asymp. Sig.
PS_AVG	3.195	.363
CS_AVG	5.226	.156
PSS_AVG	12.124	.007*
ES_AVG	6.198	.102
SAQOL_MEAN	8.388	.039*
LISAT_MEAN	4.571	.206
PS_TOTAL	1.916	.590
CS_TOTAL	6.014	.111
PSS_TOTAL	18.389	.000*
ES_TOTAL	6.021	.111
LISAT_TOTAL	3.206	.361
SAQOL_TOTAL	7.858	.049*

PS\_AVG: physical score average CS\_AVG: communication score average PSS\_AVG: psychosocial score average ES\_AVG: energy score average; \*p<0.05

The table above indicates that a significant influence of groups was seen for the psychosocial domain, mean of the psychosocial domain  $\chi^2(3)= 12.124$  ( $p<0.05^*$ ) and total score  $\chi^2(3)=18.389$ ,  $p<0.05^*$ . Similarly, a significant difference was observed across groups for a mean of SAQOL [ $\chi^2(3) =8.388$ ,  $p<0.05^*$ ] and a total score of SAQOL [ $\chi^2(3) =7.858$ ,  $p<0.05^*$ ]. However, significant differences were not observed for the other domains of the SAQOL (physical, communication, and energy), and LISAT mean and total score. Further, the parameters that showed significantly were subjected to the Mann-Whitney U test to understand the pair-wise group difference.

Test Statistics	Group 1 versus Group 2			Group 1 versus Group 4		
	Mann-Whitney U	Z	Asymp.sig (2 tailed)	Mann-Whitney U	Z	Asymp.sig (2 tailed)
Domains						
PSS_AVG	709.50	-0.33	0.74	620.50	-0.89	0.36
PSS_TOTAL	719.00	-0.21	0.83	566.00	-1.42	0.15
SAQOL_MEAN	733.00	-0.07	0.94	600.00	-1.06	0.28
SAQOL_TOTAL	738.50	-0.01	0.98	608.50	-0.97	0.33

PSS\_AVG: psychosocial score average, PSS\_total: psychosocial total

As seen in table 9, on pairwise comparison of group 1 (PWA) and group 2 (dependents) Mann-Whitney U was 709.50,  $|Z|=0.33$  ( $p>0.05$ ) and 719.00,  $|Z|=0.21$  ( $p<0.05$ ) for scores of psychosocial average and total respectively. Similarly, for SAQOL mean and SAQOL total, Mann-Whitney U was 733.00,  $|Z|=0.07$  ( $p>0.05$ ) and 738.50;  $|Z|=0.01$  ( $p>0.05$ ) respectively. When group 1 and group 4 were considered for the pairwise difference, Mann-Whitney U was found to be 620.50, 566.00, 600.00 and 608.50 for

psychosocial average, psychosocial total, SAQOL mean and SAQOL total respectively. For psychosocial average  $|Z|= 0.89$  ( $p>0.05$ ); and  $|Z|=1.42$  ( $p>0.05$ ) for psychosocial total; and for SAQOL mean and total were  $|Z|=1.06$  and  $0.97$  ( $p>0.05$ ) respectively. Hence, for both pairs, i.e., group 1 and group 2, and group 1 and group 4 pair-wise significant differences were not seen on employing the Mann-Whitney U test ( $p>0.05$ ).

Table 10: Pair-wise difference for Group 1 and Group 3

Test Statistics Domains	Mann-Whitney U	Z	Asymp. Sig. (2-tailed)
PSS_AVG	477.00	-2.80	0.005*
PSS_TOTAL	387.00	-3.60	0.000*
SAQOL_MEAN	465.00	-2.80	0.005*
SAQOL_TOTAL	478.00	-2.67	0.008*

PSS\_AVG: psychosocial score average, PSS\_total: psychosocial total; \* ( $p<0.05$ )

Table 10 as shown above revealed that Mann-Whitney U was 477.00 for psychosocial average, with  $|Z|= 2.80$  ( $p<0.05$ ); and for psychosocial total, Mann-Whitney U was found to be 387.00 with  $|Z|=3.60$  ( $p<0.05$ ). Additionally, for SAQOL mean and total, Mann-Whitney U obtained were 465.00 and 478.00 respectively and  $|Z|=2.80$  ( $p<0.05$ ) for SAQOL mean and  $|Z|=2.67$  ( $p<0.05$ ) for SAQOL total. All four parameters were found to be statistically significant.

Table 11

Pair-wise group difference for Group 2 and Group 3, and Group 2 and Group 4

Test Statistics	Group 2 versus Group 3			Group 2 versus Group 4		
	Mann-Whitney U	Z	Asymp.sig (2 tailed)	Mann-Whitney U	Z	Asymp.sig (2 tailed)
Domains						
PSS_AVG	424.00	-2.93	0.03	553.00	-1.13	0.25
PSS_TOTAL	364.00	-3.47	0.001	521.50	-1.42	0.15
SAQOL_MEAN	484.50	-2.16	0.031	575.00	-0.81	0.41
SAQOL_TOTAL	486.00	-2.14	0.032	575.00	-0.81	0.41

PSS\_AVG: psychosocial score average, PSS\_total: psychosocial total; \* (p<0.05)

As per the findings from the above table, for psychosocial average, Mann-Whitney was found to be 424.00 for group 2 (dependents) with group 3 (immediate family members), and 553.00 for group 2 with group 4 (friends or relatives), with  $|Z|=2.93$  ( $p<0.05$ ) for group 2 and group 3 and  $|Z|=1.13$  ( $p>0.05$ ) for group 2 and group 4. Hence, it was found that there was a statistically significant difference for group 2 and group 3 pair, whereas group 2 and group 4 results for the psychosocial score were not statistically significant. For the psychosocial total, Mann Whitney U was 364.00 for group 2 and group 3; and 521.00 for group 2 and group 4. For group 2 and group 3,  $|Z|=3.47$  ( $p<0.05$ ) and for group 2 and group 4  $|Z|=1.42$  ( $p>0.05$ ). Therefore, significant differences were observed for group 2 and group 3, whereas group 2 and group 3 findings were not statistically significant.

Similar findings were obtained for SAQOL mean, and total, wherein group 2 and group 3 pair, Mann-Whitney U was found to be 484.50 and 486.00 for SAQOL mean and SAQOL total respectively. For SAQOL mean  $|Z|= 2.16$  ( $p<0.05$ ) and  $|Z|=2.14$  ( $p<0.05$ ) for SAQOL total. Overall, all the parameters were found to be statistically significant ( $p<0.05$ )

for group 2- group 3 pair. However, for group 2 and group 4, both SAQOL mean, and the total had identical results where Mann Whitney U was 575.00 and  $|Z|=0.81$  ( $p>0.05$ ) for both parameters. Hence, the findings suggest that the pairwise group2 and group 4 findings were statistically insignificant.

Table 12: Pair-wise group difference for Group 3 and Group 4

	PSS_AVG	SAQOL_MEAN	PSS_TOTAL	SAQOL_TOTAL
Mann-Whitney U	451.000	513.500	402.000	515.500
Z	-2.366	-1.510	-2.773	-1.488
Asymp. Sig. (2-tailed)	.018	.131	.006	.137

PSS\_AVG: psychosocial score average, PSS\_total: psychosocial total; \* ( $p<0.05$ )

On considering group 3 (immediate family members) and group 4 (friends or relatives) pair, the Mann-Whitney U obtained for psychosocial average was 451.00 with  $|Z|=2.36$  ( $p<0.05$ ); and for psychosocial total, Mann-Whitney U was 402.00 with  $|Z|=2.73$  ( $p<0.05$ ). Hence, statistically significant differences were found for these two parameters. On the other hand, Mann-Whitney U obtained were 513.00, and 515.00 for SAQOL mean, and total, respectively. For SAQOL mean,  $|Z|=1.51$  ( $p>0.05$ ), and  $|Z|=1.48$  ( $p>0.05$ ) for SAQOL total. Statistically significant findings were not seen in both these parameters in group 2- group 4 pair.

Overall, statistically significant differences for all parameters (psychosocial average, SAQOL mean, psychosocial total and SAQOL total scores) were found in group 1 (PWA) – group 3 (immediate family members), and group 2 (dependents) – group 3;

whereas in group 3-group 4 (friends or relatives) pair, statistically significant differences were found in psychosocial average, and total domains. When group 1 – group 2 pair, and group 2- group 4 pair were considered no statistically significant differences were found.

### 4.3 Correlation of Stroke and Aphasia Quality of Life, and Life Satisfaction Questionnaire

To test one of the objectives, the data was subjected to Spearman’s rank correlation to examine the significant correlation between the two questionnaires (SAQOL-39, and LISAT-9). Figure 2 depicts the correlation coefficient for the comparison of LISAT mean, and SAQOL mean, and LISAT total score, and SAQOL total for each of the groups.

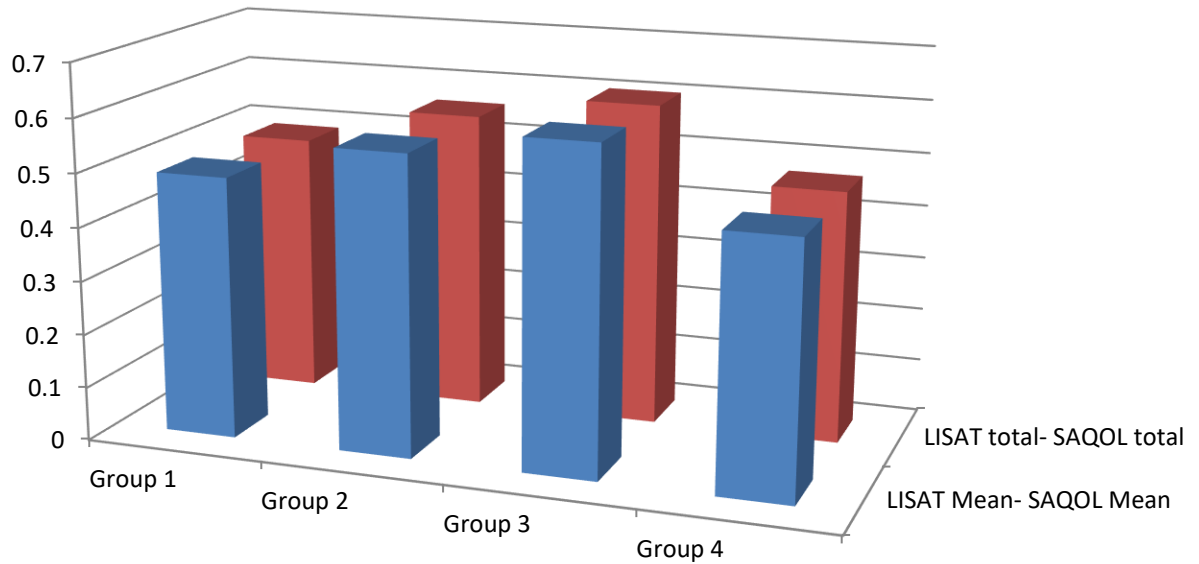


Figure 2: Correlation coefficient across groups



From the figure above, it can be observed that the correlation coefficient was identical for both LISAT mean-SAQOL mean and LISAT total- SAQOL total for each of the groups. The correlation coefficient was found to be 0.489 for group 1 (LISAT mean-SAQOL mean; LISAT total-SAQOL total) and  $r=0.559$  for group 2 (both parameters). Similarly,  $r=0.603$  for group 3 and 0.47 for group 4 for both LISAT mean-SAQOL mean, and LISAT total-SAQOL total. The results suggested an overall positive significant correlation across groups.

#### **4.4 Reliability measure**

The reliability test was conducted by randomly selecting four participants from PWA group and selected their dependents, immediate family members, and friends or relatives. The Life Satisfaction Questionnaire was reassessed by another rater two weeks after the first assessment. The Cronbach's alpha test is usually employed to serve this purpose and  $\alpha$  should be at least 0.7 for satisfactory reliability. The  $\alpha$  obtained when LISAT-9 was re-administered by another rater was found to be 0.9 indicating high reliability which indicated high inter-rater agreement. The inter-item correlation was found to be 0.9 indicating good internal consistency of the items assessed by the other rater. Therefore, the finding suggests very high test-retest reliability and is acceptable and good internal consistency.

#### **4.5 Qualitative Analysis**

To begin with qualitative analysis; in group 1, '40' persons with aphasia were recruited; where two participants were widows, and therefore there were no dependents for both of them, and questions regarding 'married life' satisfaction, and 'sexual life' satisfaction

were left unanswered (scored '0'). One participant (P11, 50y/Male) reported to be living in a nursing home pre-morbidly, and he reported that he had bare minimum contact with his family. He was also quite emotional regarding the topic, and his life satisfaction scores depicted the same (LISAT mean: 2.77).

Another participant (P21, 27y/F) separated from her husband post-stroke and preferred to live alone, away from her family, she too had similar LISAT mean score (2.66). P9 (42y/Male) reported that his wife abandoned him post-stroke and his mother was his primary caregiver post-stroke, his scores depicted affected QOL and reduced life satisfaction (SAQOL mean: 2.43; LISAT mean: 2.22).

Seven participants (P12, P13, P15, P26, P30, P32, and P33) were unmarried and hence the questions pertaining to 'married life' satisfaction, and 'sexual life' satisfaction were not applicable, and their family members and/or friends also did not rate those two questions (score = 0). P28 (57y/F) and P45 (39y/M) rated highly for the life satisfaction and more importantly gave a maximum rating (6= very satisfied) for questions regarding married life, sexual life, and family life. It can be understood that the two participants responded with respect to premorbid condition and experience and they were probably unable to understand the effect of a stroke at present. Seven other participants (P4, P9, P10, P19, P23, P29 and P37) did not wish to rate the question regarding 'sexual life' satisfaction.

In group 2 (dependents), eight participants refrained from responding to the question regarding 'sexual life' satisfaction, indicating that they were uncomfortable answering the question. Seven out of the eight participants were the spouse of the PWA, and one participant was the mother of the PWA. As two participants were widows, no

dependents were available to rate the QOL and life satisfaction from the PWA' perspective. Also, P11 had no family members with whom he was in constant contact and hence, no dependents were available to be included in the study; therefore, 'N' was reduced to 37 participants in group 2.

Similarly, in group 3 (immediate family members) 'N' was reduced to 37 participants, P11 and P21 did not consent to contact their siblings to participate in the study stating that they were not in contact and that there was limited communication post-morbidly. P39 mentioned that his sibling did not provide any support post-stroke and that family issues strained their relationship; hence, they were not contacted. Twenty-two participants in group 3 did not feel comfortable in rating the question regarding their perception of the PWA's 'sexual life satisfaction. Eight participants were the children, and fourteen participants were the siblings of the PWAs'.

In group 4 (friends or relatives), as P11 lived in a nursing home, his friend's circle was limited, and he remained aloof with reduced communication opportunities, no friends or relatives were available for participation in the study. The spouse and sibling of P20 (PWA, 42y/M) reported that he was ousted from his position in society and did not receive any support from other family members and friends. Hence, they did not provide any details of his friends or relatives for being recruited in the study.

The spouses of P31, P39, P43 reported that there was limited contact by friends or relative of the PWAs' due to various reasons and therefore no friends or relatives were contacted for the study, thus reducing 'N' to 35 in this group. Twelve participants in group 4 did not consent to rate the question regarding their perception of satisfaction in 'sexual life'

for the PWA. Eight participants were relatives, and four participants were friends of the persons with aphasia.

In summary, the group 1 participants had more compliance in answering all the questions related to their quality of life and life satisfaction and the participants felt more comfortable in responding in written format than expressing verbally. Only a few participants of group 2 (dependents including spouse or parents) did not respond to all questions, others complied and responded accurately to all the questions of both questionnaires followed by group 4 (friends or relatives); where except for 12 participants, others responded accurately regarding their perceptions of the QOL and life satisfaction of the persons with aphasia . The least compliance to answer to all questions was observed in group 3 (siblings or offspring), and the participants reported that they were not aware of the feelings of the persons with aphasia to rate accurately and additionally mentioned that they were not comfortable in responding to very personal questions regarding the private life of the PWA.

## **CHAPTER V**

### **DISCUSSION**

The present study aimed to understand the life satisfaction and quality of life in persons with aphasia (PWA) and their caregivers' perspective. Quantitative analysis was carried out to assess the overall scores of life satisfaction and quality of life in PWA and the perceptions of these two aspects of the dependents, immediate family members, and friends or relatives. Qualitative analysis was done to obtain information regarding the nature of responses and compliance in responding to all items in both the questionnaires. The following section will discuss the findings of descriptive statistics across the group for both the tools.

#### **5.1 Descriptive statistics across groups for mean and total scores of SAQOL-39 and LISAT-9**

The mean values obtained for the average scores of all the domains of SAQOL as depicted in Table 5 showed that group 3 (immediate family) had the highest mean in all the domains of SAQOL (physical, communication, psychosocial, and energy), and LISAT mean scores. The lowest mean was obtained by group 1 (PWA) for physical, communication, and energy domains, and LISAT mean scores, and group 2 (dependants) had the lowest mean for the psychosocial domain, and SAQOL mean score. The findings revealed that the participants of group 3 (immediate family including siblings or children) are less aware of the physical and communication skills, psychosocial aspects and general physical energy in PWAs and their life satisfaction. Group 2 (dependants) obtained the least in the psychosocial domain and the mean score of SAQOL, although the difference between the mean values of

group 1, and 2 are minimal. It can be understood that the dependents are well aware of the psychosocial issues faced by their spouses or children (28 participants were spouses, and nine participants were parents of the persons with aphasia). The participants of group 2 were the primary caregivers and spent most of their time with the PWA. Therefore, they were aware of the challenges faced by them.

When total scores were considered similar results were obtained, where group 3 (siblings or children) scored the highest mean in all the domains of SAQOL, and total scores of SAQOL, and LISAT (see Table 6 and 7). Group 1 (PWA) showed the lowest mean in the total scores of physical and communication domain, and group 2 showed the lowest mean in psychosocial, energy and SAQOL total scores. The differences between the mean values of group 1 and group 2 are minimal. The marginally lower rating by group 2 participants can be attributed to anticipating the difficulties faced by the PWA and not having open communication channels regarding the subtlety in these aspects. Shewan and Cameron (1984) reported similar findings where they reported that the degree of severity of the difficulties varied between PWA and their caregivers; nonetheless, persons with aphasia had affected physical, and communication skills and the caregivers' perceptions matched them as well.

Group 4 (25 participants were friends of the persons with PWA, and 10 participants were relatives) had marginally higher mean values than group 1 for LISAT total scores which may be negligible. The findings reveal that the friends and relatives who visit frequently or are in contact with the persons with aphasia are aware of the physical, communication and other skills and also the emotional and mental struggles faced by the PWA.

Therefore, the results indicated that group 3 participants (siblings or children) were oblivious of the physical, communication, psychosocial and energy skills of the persons with aphasia. Thus, they were less familiar with the effect of stroke and aphasia on the quality of life, and life satisfaction in PWA.

## **5.2 Pair-wise group differences**

To examine the group effects of various domains of the SAQOL-39 questionnaire, and the LISAT-9, initially a non-parametric test (Kruskal-Wallis) was carried out. Table 8 shows that significant differences were found in psychosocial average, and total scores and SAQOL mean values, and total scores. Therefore, the Mann-Whitney U test was carried out and pair-wise group differences were investigated. Group 1 – group 2; group 1– group 4 (refer Table 9), and group 2 – group 4 (refer Table 11) did not show statistically significant differences ( $p > 0.05$ ) in any of the domains of SAQOL or LISAT. The findings suggest that the differences in the scores obtained for the domains of SAQOL, and LISAT did not have many variations across the three groups.

Corsten et al. (2004) aimed at investigating life satisfaction following the intervention. The authors revealed that there was an increase in communication skills and overall self-confidence. However, life satisfaction scores did not improve, suggesting that life satisfaction does not necessarily correlate with communication skills, it is a holistic effect of an amalgamation of multiple factors that works together to improve life satisfaction and quality of life. In this study, a trend was observed based on the results obtained from the different groups for both questionnaires; ratings given by group 2 participants (dependents)

complemented the scores of PWA (group 1). This was followed by the ratings provided by group 4 participants (friends/relatives), and lastly group 3 (immediate family members).

As mentioned afore, the PWA responded to all the items pertaining to the psychosocial domain and other items as well of SAQOL; and LISAT appropriately and accurately and the spouses or parents (group 2: dependents) were the primary caregivers who spent the most of their time with the PWA. The participants of group 4 (friends or relatives) who were recruited for the study were those friends and relatives who frequented the person with aphasia and provide emotional and mental support to face the challenging life experience. Le Corze, Croteau and Baril (2007) quoted that PWA had severe language deficits, emotional outbursts and spouses were reported affected psychosocial well-being.

On examining the pair-wise differences for group 1 – group 3 (Table 10), and group 2 – group 3 (Table 11), significant differences ( $p < 0.05$ ) were seen for psychosocial average and total scores of SAQOL, and mean and total scores of SAQOL. The findings revealed that the PWA rated the psychosocial domain poor and the perceptions of the siblings or offspring did not match. Correspondingly, group 2 – group 3 results also suggest the same ratiocination. The scores of group 1 and group 2 are parallel, whereas the scores of group 3 did not match either group (1 and 2). This can be attributed to less knowledge of the stroke and aphasia experiences faced by the PWA and his/her primary caregivers.

On pair-wise comparison of group 3 and group 4 (Table 12), significant differences were noticed for psychosocial average and total psychosocial scores. This can be ascribed to the fact that there are fewer conversations within the family (with children) about the psychosocial difficulties faced by the persons with aphasia. Parents generally tend to be the



providers and problem solvers. In the Indian scenario, the children raise issues that need to be resolved with their parents. Therefore, it is only natural that parents do not have open conversations with their children regarding their feelings especially after the experience of stroke. It tends to be a matter of maintaining the image of being active and capable parents. Also, in the present day living situations, the prevalence of the nuclear family is more; therefore, the siblings or children may not be living near the PWA.

### **5.3 Participant group dynamics**

Group 1 consisted of persons with aphasia ( $n=40$ ); whereas, group 2 (their dependents) included 28 spouses and nine parents ( $n=37$ ). Parents were recruited in the study due to two reasons; the persons with aphasia were either unmarried or, separated from their partner (pre or post-stroke). Two persons with aphasia (P9 and P21) reported to be separated from their spouse post-stroke, and one PWA (P11) reported to have been separated from his spouse pre-stroke. P11 informed that he lived in a residential facility and was separated from his family for almost a decade and before the experience of stroke. Remaining participants were those dependents who accompanied the PWA for therapy.

The ratings provided by the participants of group 2 were relatively similar to the ratings of the PWA. This can be attributed to the presence of the spouses or the parents through the experience of stroke and later during rehabilitation. The female spouses reported that they spent more than 12 hours a day by caring for and tending to the needs of the PWA. Most of the male spouses mentioned that despite their working schedule, they prioritized the health and psychological well-being of their partner. Many participants also mentioned the consideration taken to accompany the PWA and participate in their therapy sessions.

Therefore, these participants who spent most of their time with the PWA were more aware of the struggles faced by these people physically, emotionally. The one observation made by the researcher was that there were cases where the spouses underestimated the capabilities of their partner and scored a low rating for certain items. However, on taking an average of the ratings provided by the participants of group 2, a close similarity was observed between the scores of both group 1 and 2.

The persons with aphasia were asked to nominate a participant for group 3, which included immediate family members. This group ultimately consisted of ten children and 27 siblings ( $n=37$ ); each of them was selected based on the convenience and contact details provided by the PWA. The responses were recorded directly from those children or siblings who accompanied the PWA to the therapy intervention clinic. In cases where the PWA reported that their immediate family members lived away or in different cities, telephonic interview was carried out and the researcher recorded the responses appropriately. The participants who responded directly consisted of only 37% of the group size, the rest of the participants was contacted over distance mode.

It was observed that the participants of this group were less aware of the quality of life and life satisfaction experienced by their parents or siblings. Physical and communication skills were gauged by most of the participants. However, subtle aspects related to psychosocial well-being and energy was not rated accurately. Some of the participants also refrained from responding to specific items in the psychosocial section. The items that were left unanswered were questions pertaining to the married life and sexual life of the person with aphasia. During distance mode interview, the researcher asked if the

responder felt comfortable answering some personal questions about the PWA and only with consent the questions were presented.

The persons with aphasia also recommended the participants of group 4 by either nominating their relative or a close friend to participate in the study. Out of the 40, 12 participants did not provide consent and opted out of the study. Few of the reasons stated by these individuals were that they were not aware of the situation after stroke; some of them mentioned that there was no close affinity towards the PWA post-stroke. There were also individuals who mentioned that some of the questions were intimate and that they did not want to reveal personal details about their friend. Initially, the close relatives were contacted and when these individuals did not consent to share the after stroke experience.

Further, the group 1 participant nominated friends who were acquainted with them and stayed in contact with them post-stroke. Finally, this group comprised of 27 friends and eight relatives ( $n=35$ ). In most situations, these participants lived in close proximity or frequently visited the PWA and therefore were able to respond to the items of both the questionnaires accurately.

It was well observed that the majority of this group's participants were friends who provided with a great deal of psychological support and were involved in assisting the PWA in whichever way possible. Some of the friends also accompanied the PWA to therapy and were involved in the therapy sessions promoting and supporting the intervention. For this particular reason, the friends of these individuals post-stroke were able to rate the items in the questionnaire with much more accuracy than the group 3 participants (immediate family members). It was also observed that the friends were aware of certain details about the

personal lives of the PWA and felt comfortable sharing information regarding married and sexual life satisfaction, with the researcher.

The main observation made from analyzing the group dynamics is that communication difficulties are overt, which means that even if family members were not connected with the PWA after stroke, these difficulties were evident consequences and perceivable to anyone who attempted communication with the PWA. Similarly, physical abilities are viewed to be crucial, and after a stroke, physical disabilities lead to a burden on the spouse or their dependents. These individuals also spend most of their time tending to the needs of their partner. Therefore, communication and physical skills were rated more accurately by the participants of groups 2, 3, and 4 (dependants, immediate family members, and friends or relatives respectively). These ratings matched the scores obtained from group 1 participants (PWA). On the other hand, psychosocial effects are covert, and only those individuals who were in direct contact with the group 1 participants responded accurately to items relating to certain personal details. The scores and ratings of the questionnaires obtained from the participants of group 2 and 4 closely matched with the scores of group 1 participants.

#### **5.4 Qualitative Analysis**

From the exploration of participant group dynamics, it was evident that psychosocial aspects are overlooked when compared to other domains like physical and communication skills. Maslow (1943,1954) proposed a hierarchy of needs within a pyramid which included five needs of motivation. The five hierarchical levels which can be considered to be basic needs are; physiological, safety and belongingness, social, self-esteem

and finally self-actualization. The physiological needs come at the bottom of the pyramid and self-actualization is at the peak. According to this model, the lower or the most basic needs must be satisfied to allow an individual to progress and meet higher needs. The persons with aphasia and their QOL can be applied to the different levels of hierarchy. The physical, communication and energy domains can be equated to the physiological needs, and psychosocial aspects can be represented in belongingness and love needs and self-esteem. Self-actualization comprises the overall quality of life and life satisfaction, which comes at the top of the hierarchy.

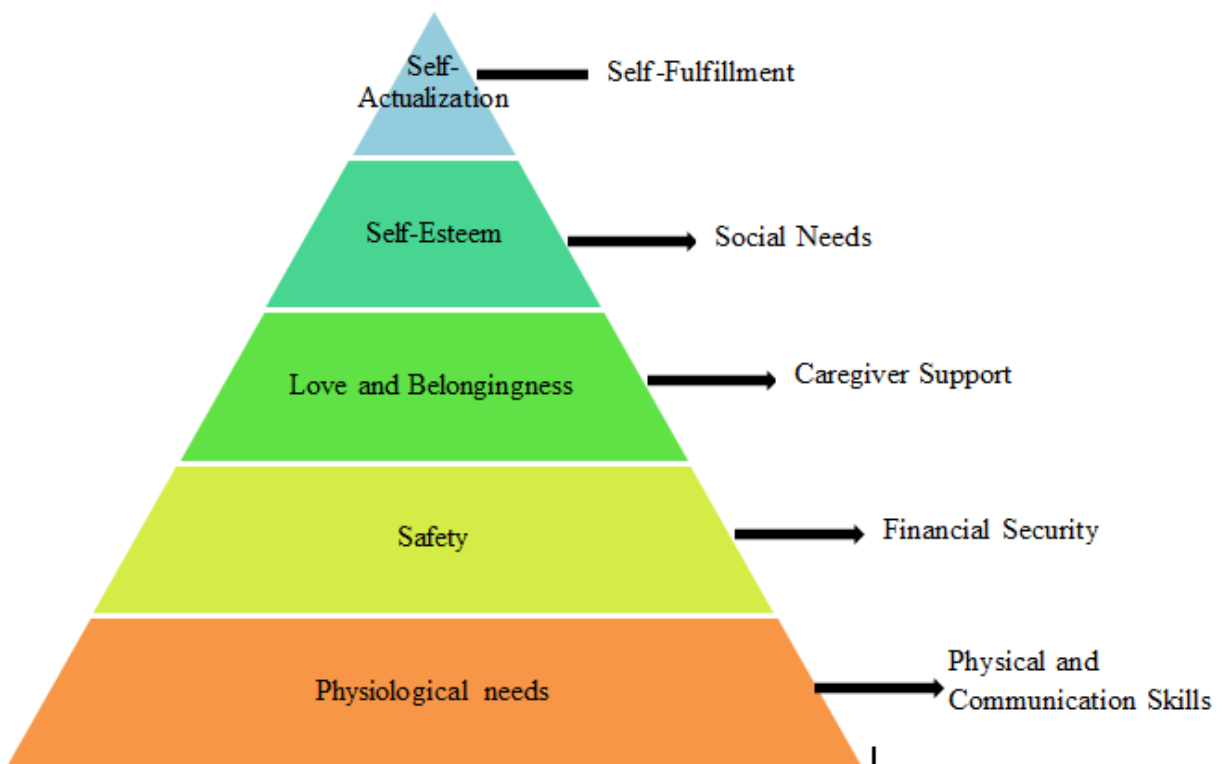


Figure 3: Hierarchy of needs in PWA, adapted from the Maslow’s hierarchy of needs, McLeod, S. A. (2018, May 21) Retrieved from <https://www.simplypsychology.org/maslow.html>

To elaborate (fig 3), physical independence and energy along with good communication needs are pivotal for any individual. Taking the perspective of a person with

aphasia, these skills will be fundamental. If these skills are unaffected, one feels secure, and there is a sense of both freedom of mobility and speech. Hence, if these needs are satisfied, the next level will also be fulfilled which is safety. Being able to communicate and express one's thoughts and feelings bring a secure feeling and confidence to share opinions and resolve conflicts verbally. Relationships with family and loved ones will help overcome and cope up with challenging situations. It is possible that relationship changes over time or some circumstances may lead to reduced affinity. These effects are reflected in the fulfillment of love and belongingness, and self-esteem levels. Self-actualization is a level where an individual accomplishes being self-fulfilled and contented; it refers to a state of enlightenment (Maslow, 1962; Hoffman, 1988). The mean total scores of all domains of the SAQOL-39 are tabulated below (Table 13) to link the model with the results of this study.

<i>Table 13: Group wise average and total scores of all domains of the Stroke and Aphasia Quality of life – 39</i>				
Participant Groups	Physical score average	Communication score average	Psychosocial score average	Energy score average
PWA	3.37	2.30	2.57	3.21
Dependants	3.75	2.29	2.48	3.39
Immediate family members	3.89	2.75	3.18	3.87
Friends or Relatives	3.71	2.34	2.68	3.51
Participant groups	Physical domain total (Out of 85)	Communication domain total (Out of 35)	Psychosocial domain total (Out of 55)	Energy domain total (out of 20)
PWA	61.20	16.57	27.77	12.57
Dependants	61.24	17.16	26.94	12.40
Immediate family members	64.97	18.97	33.48	14.10
Friends or Relatives	33.97	17.34	29.17	12.88

Based on the results obtained in the study, it is obvious that there was a congruency in the scores of the physical, communication and energy scores (refer to Table 13). On considering the average and total scores of all the four domains of the SAQOL, similar average scores were obtained by all the four groups. Nonetheless, there is an evident difference in the scores obtained by the participants of group 3 (siblings or children), where higher scores can be observed in both the average scores and total scores of the SAQOL-39. These findings can be applied to the model, and it can be understood that the spouses and friends or relatives are sensitive to the physiological needs of the PWA. The immediate family members including the siblings and/or children of the PWA are not well aware of the consequences of stroke and the impact on the lives of persons with aphasia.

Though the ratings are given by the participants of group 2 (dependants) and 4 (friends or relatives) closely matched the scores of group 1 (persons with aphasia), the PWA rated themselves the lowest in the communication followed by the psychosocial domain. This can be attributed to the fact that the questionnaires were administered by a speech-language pathologist and the PWA while attending language intervention might have had communication as a challenge and primary concern. These participants also rated themselves poorly on the items pertaining to psychosocial skills. This suggests that the PWA have not been able to progress to the love and belongingness needs level. They might be able to achieve some level of satisfaction regarding physical mobility and communication. The next level which is safety is determined by the feelings of being financially secure. In situations where a person post-stroke can get back into routine occupation soon and can handle financial burdens faced during the experience, the impact of stroke may be viewed to be relatively less. Nevertheless, the efficiency at work may be compromised, or the individual

may not be offered the same position and responsibilities. Several factors may affect the psychosocial regard which will further hinder the progression to higher levels in the hierarchy.

The findings propose that persons with aphasia place themselves in physiological and safety needs. After a stroke experience, the only priority is survival; followed by regaining mobility and communication. Further, the concerns that arise are related to financial and economic security. At higher levels of hierarchy comes caregiver support followed by the social needs which include acceptance from family and society. The overall quality of life and life satisfaction can be considered as self-fulfillment which falls into self-actualization. For persons with aphasia, they are caught in the level of physiological needs as they may be physically dependent on their family and experience difficulty to communicate. This can be understood to be the reason why they find it a challenge to progress further to safety needs level and so on. In most scenarios, the financial burden is on the immediate family members because the PWA would have had a sudden loss of job which would have affected the household income. Therefore, the PWA will be stagnated at the first two levels of the hierarchy and unable to progress higher due to many constraints.

The ratings given by the participants of group 2 (dependants) and group 4 (friends or relatives) were similar to the scores obtained by the group 1 participants (PWA). The communication domain was scored the least followed by psychosocial skills by the participants of both groups 2 and 4. This suggests that these participants perceive the challenges faced by the individuals post-stroke. The closeness of the relationship shared with the PWA also leads to being attentive to the needs and observant of the feelings and emotions faced by the PWA. Based on subjective interpretation, it can be assumed that the



participants of both the groups (2 and 4) place the person with aphasia in the love and belongingness level. The reason is that the spouse or parents may have been looking after the person post-stroke and have been attentive to the necessities of the individual. During the interview, it was stated explicitly by many participants about the support and encouragement provided by them to motivate the PWA and assist them throughout the rehabilitation process. For the dependants, relatives, and friends, the primary concern was that timely intervention was provided and that measures had been taken for better and fast recovery. Therefore, these participants would not place the persons with aphasia at the basic levels of the hierarchy. They would rather be under the impression that the PWA would have surpassed the bottom levels and have progressed higher in the hierarchy.

On analyzing the scores obtained by the group 3 participants who were the immediate family members including siblings or children of the persons with aphasia, the ratings did not match with that of the group 1 participants (PWA). It can be assumed that siblings who lived away have different priorities and so, they are not self-informed about the consequences of stroke in the lives of persons with aphasia. It is also possible that the dependants including spouse or parents have not informed other family members regarding the consequences due to various personal reasons such as the need to maintain the social image, unwillingness to share social securities. Children of the PWA may not have the real picture regarding the impact of stroke. This may be due to reduced awareness or the inability to accept the event of stroke and its effects on their lives. There is an evident lack of communication and openness in sharing the stroke experience and the challenges faced by the PWA after the incident. Additionally, children usually expect their parents to be capable

of handling any situation, and they may not be mindful of the strengths and weaknesses of their parents.

Hence, from the perspective of the group 3 participants, the person with aphasia belong between the love and belongingness (caregiver support) and self-esteem (social needs) level. Based on the high ratings given these individuals for all the domains of SAQOL-39 and LISAT-9, it can be supposed that due to lack of awareness and communication, they do not have a clear understanding of the struggles faced by the PWA. It is however observed that the participants of this group have rated the least for the communication domain which may be attributed to attempts made to communicate with the PWA and the reduced receptive and expressive skills by the latter.

While the group 3 participants place the person with aphasia reasonably high in the needs hierarchy, the PWA himself or herself put themselves in the bottom two levels. This intends for a definite need for communication as it is the responsibility of the immediate family members to provide care and support the PWA. Considering that these members of the family may not live near the PWA, they may be obligated to motivate, emotionally and if feasible financially support their loved one.

To recapitulate, the ratings that were given by the participants of group 2 and 4 (dependants and friends or relatives respectively) closely matched that of group 1 (PWA). Nevertheless, the dependants rated slightly lesser for both communication and psychosocial skills. Although this difference may be negligible, better communication can prevent underestimating these aspects. Continuous support from close friends and relatives will help the PWA get accepted in society and encourage them to overcome challenging situations.

The participants of group 3 (immediate family members) need to make efforts to keep themselves informed about the consequences of stroke and its effects on the lives of PWA and their spouses or parents. It is possible that the PWA may deal with denial and struggle to accept the reality of the situation. It is warranted that better communication channels need to be initiated to communicate about the effects on the emotional and mental struggles that arise as a consequence of stroke.

## **CHAPTER V**

### **SUMMARY AND CONCLUSION**

Life satisfaction refers to the basic well-being of an individual. Long-term disability may be a consequence of stroke. Aphasia causes a profound negative effect by bringing about motivational, behavioral, social, and emotional changes (Hemsley & Code, 1996). Prior to the experience of stroke, the individuals would have been playing different roles of a parent, colleague, or partner and post-stroke it becomes a great challenge to regain their roles and fulfill those (Parr, 2001). The World Health Organization has affirmed that social and occupational reintegration of individuals with a health condition should be the primary goal of professionals working in the rehabilitation process. Participation has been defined as the involvement in one's life situation by the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). The ICF shifts focus to social life, how people live with their health conditions, and how these health conditions can be improved to achieve a productive, fulfilling life in the context in which the people live. Both personal factors (demographic, socio-cultural, education, labor, income, accommodation, address) as well as environmental factors (the physical, social, and attitudinal environment in which people live and conduct their lives) can have an important impact on the participation in life of people with aphasia (Howe, Worrall, & Hickson, 2004).

The literature focus has mainly been on linguistic and related aspects although there has been upcoming research which has shifted to social participation. It is important to get insight into the effect of aphasia on life satisfaction and quality of life. In the Indian scenario, the family provides support throughout the process of recovery. Therefore, there

could be a difference in the perception of psychosocial problems when compared to the results obtained in studies conducted in other developed countries. Thus the need arose to evaluate the QOL and life satisfaction in persons with aphasia and the caregivers' perspective in the same aspect.

The aim of the current study was to examine and understand the most important essence of living which is the life satisfaction and quality of life in persons with aphasia (PWA) and their caregivers' perspective. The objectives that were included were translating, adapting and validating the Life Satisfaction Questionnaire (LISAT-9); administering and correlating the results obtained from the Stroke and Aphasia Quality of Life Scale (SAQOL-39) in Kannada and the translated LISAT-9. A total of 149 adult Kannada speaking participants were recruited for the study. These participants were grouped into two major categories. Group -1 consisted of normal healthy participants who were their immediate caregivers and other family members. These included 37 dependants (parent/spouse), 37 immediate family members (siblings/offspring) and 35 friends/relatives of persons with aphasia. Group-II consisted of 40 persons with aphasia. The Life Satisfaction questionnaire (Lisat-9) and the Stroke and Aphasia Quality of life scale (SAQOL-39) were administered on the participants and were asked to rate appropriately as per the instructions provided in the two tools. In the case of the participants or caregivers being uneducated, the question items were presented verbally and their responses were recorded appropriately for these two questionnaires.

Descriptive statistics was employed initially to obtain mean, standard deviation and median were obtained across groups for both questionnaires. It was found that the highest mean value was predominantly obtained by group 3 (siblings or offspring) and the lowest

mean was mostly obtained by group 1 (PWA) in most domains and in two parameters, it was found to be group 2 (dependents). A non-parametric Kruskal-Wallis test was carried out to check the significant difference across groups and the Mann-Whitney U test was applied to see the pair-wise group differences. Statistically significant differences for all parameters (psychosocial average, SAQOL mean, psychosocial total and SAQOL total scores) were found in group 1 (PWA) – group 3 (immediate family members), and group 2 (dependents) – group 3; whereas in group 3-group 4 (friends or relatives) pair, statistically significant differences were found in psychosocial average, and total domains. When group 1 – group 2 pair, and group 2- group 4 pair were considered no statistically significant differences were found. The data were subjected to Spearman's rank correlation to examine the significant correlation between the two questionnaires (SAQOL-39, and LISAT-9) and the results suggested overall positive significant correlation across groups.

Qualitative analysis was carried out and it was observed that all the participants in group 1 and most participants of group 2 complied and responded to the items of both questionnaires appropriately. Some members of group 4 chose not to respond to certain items on the LISAT- 9 questionnaire. Similarly, many participants of group 3 did not respond and mentioned the discomfort in answering certain items of both questionnaires.

The results suggested that group 3 participants (siblings or children) were unaware of the physical, communication, psychosocial and energy skills of the persons with aphasia. Thus, they were less familiar with the consequences of stroke and aphasia on the quality of life, and life satisfaction in PWA. This can be attributed to the changes in the living situation in our present day. Also, the need to maintain a certain image for the family as the providers and problem solvers prevents open conversations within the family. Applying the

adapted Maslow's model provides an insight into the level of understanding among the different group participants. The findings propose that the persons with aphasia associate themselves in the physiological and safety needs viz. the first two levels in the hierarchy. The participants of group 2 and 4 (dependants and friends or relatives respectively) placed the PWA in love and belongingness level (third level in the hierarchy). This can be attributed to the care and support provided by these individuals in the rehabilitation process. However, the ratings provided by group 3 participants (immediate family members) indicated that they placed the PWA in between love and belongingness (caregiver support) and self-esteem (social needs) level. Less awareness and limited communication may be the reasons for a reduced understanding of the consequences of stroke especially the psychosocial aspects. Therefore, better communication might be the key to tackle less awareness of the magnitude of stroke and aphasia consequences.

## **5.1 Conclusion**

The present study provides great insight into the effects of stroke and aphasia and its impact on the lives of persons with aphasia. The study establishes that not only physical and communication-related aspects are limited, but even psychosocial effects are profound. There is a need for better communication amongst family members and active involvement is required holistically in understanding the effects of stroke and aphasia and the emotional toll it takes on these individuals. It can be understood that the communication aspects were given a higher weightage and all the participants responded accurately for these items. This may be accredited to the fact that the study was carried out by a speech-language pathologist. It can, therefore, be hypothesized that if the study is conducted by other

rehabilitation professionals, the findings may vary. This may be an indication of future prospects of the study.

## **5.2 Implications of the study**

The experience of stroke affects the quality of life and life satisfaction in persons with aphasia. The overt ramifications including physical limitations and communication difficulties are not the only concern for these individuals. It is important to address issues like psychosocial effects during the rehabilitation process and speech and language intervention should be provided from a holistic perspective. Traditional approaches for speech and language intervention cannot guarantee a better quality of life, rather more social approaches can help in better life participation and inclusion into society. The ultimate goal of therapeutic rehabilitation should be a better quality of life and life satisfaction. It is the responsibility of the professionals involved in the rehabilitation process to break barriers and introduce topics related to emotional wellbeing and psychosocial aspects. Communication channels need to be open within the family and active involvement by the family members will help in facilitating better recovery in persons with aphasia.



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## APPENDIX I

### LIFE SATISFACTION QUESTIONNAIRE – 9

ಈ ಕೆಳಕಂಡ ವಿವರಣೆಗಳ ಮೂಲಕ ನಿಮ್ಮ ಜೀವನದ ವಿವಿಧ ಅಂಶಗಳು ಎಷ್ಟು ತೃಪ್ತಿಕರವಾಗಿದೆ ಎಂಬುದನ್ನು ಸೂಚಿಸಿ:-

1 = ಬಹಳ/ಹೆಚ್ಚು ಅತೃಪ್ತಿಕರವಾಗಿದೆ						
2 = ಅತೃಪ್ತಿಕರವಾಗಿದೆ						
3 = ಬಹುಶಃ ಅತೃಪ್ತಿಕರವಾಗಿದೆ						
4 = ಬಹುಶಃ ತೃಪ್ತಿಕರವಾಗಿದೆ						
5 = ತೃಪ್ತಿಕರವಾಗಿದೆ						
6 = ಬಹಳ/ಹೆಚ್ಚು ತೃಪ್ತಿಕರವಾಗಿದೆ						
ಒಟ್ಟಾರೆ ನನ್ನ ಜೀವನ	1	2	3	4	5	6
ನನ್ನನ್ನು ನಾನು ನೋಡಿಕೊಳ್ಳ ಬಲ್ಲೆ (ಬಟ್ಟೆ ಹಾಕಿಕೊಳ್ಳುವುದು, ಸ್ವಚ್ಛತೆ.....)	1	2	3	4	5	6
ನನ್ನ ಬಿಡುವಿನ ಸಮಯ	1	2	3	4	5	6
ನನ್ನ ವೃತ್ತಿಪರ ಪರಿಸ್ಥಿತಿ	1	2	3	4	5	6
ನನ್ನ ಆರ್ಥಿಕ ಪರಿಸ್ಥಿತಿ	1	2	3	4	5	6
ನನ್ನ ವೈವಾಹಿಕ ಜೀವನ	1	2	3	4	5	6
*ನನ್ನ ಲೈಂಗಿಕ ಜೀವನ	1	2	3	4	5	6
ನನ್ನ ಕುಟುಂಬ ಜೀವನ	1	2	3	4	5	6
ಸ್ನೇಹಿತರು ಹಾಗೂ ಪರಿಚಯಸ್ತರೊಂದಿಗೆ ನನ್ನ ಸಂಪರ್ಕಗಳು	1	2	3	4	5	6

\*ಇಲ್ಲಿ 'X' UÀÄgÀÄvÀÄ 9ÁQ

## APPENDIX II

### Feedback questionnaire for the Kannada version of the Life Satisfaction

#### Questionnaire- 9

Name & designation:

Date:

Sl. No	Parameters	Very Poor	Poor	Fair	Good	Excellent
1.	Simplicity					
2.	Presentation					
3.	Relevancy					
4.	Complexity					
5.	Accessibility					
6.	Flexibility					
7.	Trainability					
8.	Stimulability					
9.	Feasibility					
10.	Generalization					
11.	Scope of practice					
12.	Scoring Pattern					
13.	Publications, Outcomes and Developers (professional background) *					

Put a tick (√) in the appropriate box

Any other suggestions:-

## Definitions of Parameters

- i. Simplicity: Are the test stimuli comprehensible?
- ii. Familiarity : Is the test material familiar to the user?
- iii. Presentation: Are the number of stimuli in each section placed appropriately?
- iv. Relevancy: Whether the test material is culturally and ethically acceptable?
- v. Complexity: Is the material arranged in the increasing order of difficulty?
- vi. Accessibility: Is the test material user-friendly?
- vii. Flexibility: Can the stimuli be easily modified?
- viii. Trainability: Can the stimuli be used for intervention purposes in different milieu?
- ix. Stimulability: Does the stimulus material elicit responses from the individuals?
- x. Feasibility: Whether the test material is viable?
- xi. Generalization: Can the test material be generalized to any other adult language disorders and various settings?
- xii. Scope of Practice: Is the test material within the profession's scope of practice or within the personal scope of practice?
- xiii. Scoring Pattern: Whether the scoring pattern followed in the resource material applicable?
- xiv. Publications, outcomes and developers (Professional Background): Is there any other resource material similar to this test material which you are aware of?

