Quality of Communication Life in People with Aphasia: Implications for Intervention

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Abstract

Background and Aims: The main goals were to determine the effectiveness of two commonly used communication-related Quality of Life (QoCL) measures, and the impact of aphasia-related factors on quality of life (QoL) and QoCL in persons with aphasia (PWAs). Method: Twenty-one PWAs ranging from 47 to 91 years of age with post-onset periods of 2 months to 14 years were tested using standardized and criterion-measure tools to assess their language and cognitive functions, QoL, and QoCL. Additionally, participants completed a demographics questionnaire, which also included information on their stroke and the kinds of therapies they had received. Assessments were conducted over two sessions with randomized order of test administrations to control fatigue and order effects. Results and Discussions: Correlation-matrix was used to determine the strength of relations between test measures. The impact of QoL related factors (viz., aphasia severity, cognitive functioning, time post-onset, and therapy received) on QoCL was examined using ANOVAs. The ASHA Quality of Communication Life Scale (ASHA-QCL) had more significant correlations with other QoL measures than the ASHA-Functional Assessment of Communication Skills (ASHA-FACS). Aphasia severity, cognitive deficits, and therapy received contributed significantly to QoL and QoCL in PWAs. Conclusions: Evaluating overall QoL may not fully reveal the QoCL in PWAs. Measuring QoCL specifically is crucial in aphasia interventions, and it is equally important to use sensitive tools that can capture the QoCL effectively. ASHA-QCL was more effective than ASHA-FACS in capturing the QoCL. QoCL must be considered even when working with PWAs with severe aphasias and/or mild cognitive deficits.

Keywords: Aphasia, ASHA-FACS, QCL, quality of life, SAQOL-39

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Introduction

Quality of life (QoL) and specifically communication-related quality of life (QoCL) have become increasingly important concepts in aphasia intervention. With this comes the need to use effective measures to assess the QoL and QoCL in persons with aphasia (PWAs). While there are various measures to assess QoL, not all of them effectively capture the QoCL in PWAs. The primary objectives of this study were to determine the effectiveness of two commonly used QoCL measures and the impact of aphasia-related factors on both QoL and QoCL.

Background

Aphasia, a chronic and invisible communication disorder, affects various dimensions of communication and creates significant barriers for PWAs. Communication is fundamental to expressing oneself, creating self-identity, building and maintaining relationships, and managing emotional well-being.[3] Given that an individual’s social involvement relates to internal factors of self-acceptance, personal growth, and development,[3] aphasia can negatively impact the PWA’s communication abilities including their social networks, social activities, relationships with others, and social supports.[3-5] Furthermore, the effects of aphasia are also experienced by relatives and friends of PWAs affecting the relationships that they share.[6] Such changes in relationships and responsibilities impact the PWA’s self-image, social and emotional well-being, and quality of life.[7]
Quality of life (QoL) is defined as “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”. Several factors are known to influence the perceived quality of life. According to Cruice et al., these include the individual’s physical health, social and emotional well-being, psychological functioning, communication, independence and relationships. Compromised independence in performing activities of daily living, changes in relationships, vocational limitations, and lack of accessibility to information and transportation were reported to significantly contribute to lower quality of life. Yet, the intrinsic desire to communicate despite all odds has shown to prevail in PWAs. The need to socialize more with family, friends, and coworkers was shown to be the significantly impacted area as well as the goal for PWAs interviewed by Worrall et al. Lack of communication can lead to social isolation and depression. Therefore, the need to measuring the impact of aphasia and the outcomes of intervention on the QoL in PWAs is paramount.

Theoretical models such as the World Health Organization’s International Classification of Functioning, Disability and Health framework and Living with Aphasia: Framework for Outcome Measurement (A-FROM) have significantly influenced the intervention in PWAs. Both the ICF and A-FROM models focus on the overall health and well-being of the individual taking into consideration the impairments, the effects of impairments on everyday activities and participation in life situations, and the barriers that exist at both the personal and environmental levels. Founded on the principles of WHO-ICF model, the Life Participation Approach to Aphasia (LPAA) is an evidence-based construct that helps PWAs to re-engage in life and supports both the PWAs and others affected by aphasia. Providing such intervention necessitates appropriate tools to evaluate not only the nature and severity of deficits, but also measure the impact of personal and environmental barriers that limit the activities and participation of PWAs in their everyday lives.

Various assessments have been developed to measure the impact of aphasia beyond the linguistic impairments and help determine the QoL domains that are diminished in PWAs. Some of these assessments include the American-Speech-Language-Hearing Association’s Quality of Communication Life Scale (ASHA-QCL), ASHA’s Functional Assessment of Communication Skills (ASHA-FACS), Communication Activities of Daily Living (CADL-2), Communication Confidence Rating Scale for Aphasia (CCRSA), and the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39). Many of these assessments use survey type questions to determine the QoL of the individual and often incorporate participation domains from the WHO-ICF framework. Use of accurate assessments guide the clinician in estimating the outcomes for rehabilitation goals in order to increase functional autonomy within multiple environments and with various communication partners. Yet, oftentimes, the speech-language pathologist (SLP) may be left unsure of how to assess QoL and/or how to choose from among the various measures. Although most SLPs may view assessing QoL as extremely or very important, there is little consensus among the best measures to use and/or the candidacy. For example, people with severe or profound aphasia may be assessed less often than people with moderate levels of aphasia severity, demonstrating the need for comparing QoL assessments to provide a clear understanding of what they assess and for which aphasia profile each assessment is best suited.

Assessing the QoL specifically in PWAs is vital. Using the overall QoL measures may not always fully capture the impact of aphasia on their QoL. Studying the QoL in a large population of 66,193 participants with 60 diseases and 15 conditions from hospital-based long-term care facilities, Lam and Wodchis found that aphasia not only had the largest negative impact on QoL, it was also higher than the impact of cancer and Alzheimer’s disease combined. The authors reasoned that the PWAs felt helpless when trying to request help or express wants to care providers in the hospital. These findings demonstrate a need for increased awareness of sensitive QoL instruments that allow health care professionals to assess the wellbeing of PWAs. Hence the primary objectives of the present study were to: a) compare the outcomes of two commonly used assessment tools that measure the impact of aphasia and QoL in PWAs and establish their effectiveness; and b) determine the effects of aphasia-related factors on the overall QoL and QoL in particular.

Method

Participants

Twenty-one monolingual English PWAs participated in the study. They were recruited from local clinics and other NGO and hospital stroke support groups, after the study protocol had been approved by the Institutional Review Board of the authors’ primary institution. Written informed consent was obtained from all participants. Whenever required, additional details and explanations were provided by the second author to make sure that the participants and their significant others understood the study procedure and protocols including risks, benefits, confidentiality, and their right to withdraw from the study at any time without any penalties. The participants were in the age range of 47 to 91 years (average 67 years) with post-onset periods ranging from two months to 14 years (average 4.4 years). All participants lived in their personal residences, had a variety of aphasia types and severity levels, and were able to complete all assessments. Relevant demographic information was completed by all participants and/or by their family members.

The relevant demographic information along with their aphasia types and severity results are summarized in Table 1.

Materials and Procedure

All participants were tested to determine the extent of damage to their language and cognitive functions, functional communication...
Table 1: Demographic information of participants with aphasia type and severity

| Participant # | Age | Gender | Time Post-Onset | Aphasia Type | Severity |
|---------------|-----|--------|----------------|--------------|----------|
| 1             | 76  | M      | 2-3 years      | Anomic       | Mild     |
| 2             | 62  | M      | 1-2 years      | Broca’s      | Very Severe |
| 3             | 50  | F      | 6+ years       | Conduction   | Mild     |
| 4             | 67  | F      | 6 mos.-1 year  | Anomic       | Mild     |
| 5             | 51  | F      | 3-4 years      | Conduction   | Mild     |
| 6             | 58  | F      | 3-4 years      | Wernicke’s   | Very Severe |
| 7             | 78  | F      | 3-4 years      | Conduction   | Moderate |
| 8             | 69  | M      | 1-2 years      | Anomic       | Mild     |
| 9             | 47  | M      | 4-5 years      | Broca’s      | Moderate |
| 10            | 71  | F      | 1-2 years      | Anomic       | Moderate |
| 11            | 69  | M      | 5-6 years      | Anomic       | Mild     |
| 12            | 58  | M      | 6+ years       | Conduction   | Mild     |
| 13            | 56  | F      | 5-6 years      | Broca’s      | Severe   |
| 14            | 81  | F      | 4-5 years      | Anomic       | Mild     |
| 15            | 75  | F      | 5-6 years      | Anomic       | Mild     |
| 16            | 91  | F      | 2-3 years      | Conduction   | Moderate |
| 17            | 70  | M      | 6+ years       | Anomic       | Mild     |
| 18            | 81  | M      | *              | Anomic       | Mild     |
| 19            | 70  | M      | 6+ years       | Anomic       | Mild     |
| 20            | 60  | M      | 5-6 years      | Global       | Moderate |
| 21            | 65  | F      | <6 months      | Anomic       | Mild     |

* Participant had multiple strokes and was not included in the post-onset period analysis

Accordingly, based on the aphasia severity level as determined by the aphasia quotient on the WAB-R, the participants were grouped into two groups. Due to the small number of participants in the moderate-severe (N = 6) and very severe (N = 2) groups, these groups were combined into one group and compared against the group with mild aphasia (N = 13). Similarly, based on the CLQT scores, two groups were identified. Eleven participants were found to be “within normal limits” and 10 participants were in the “mild” category for cognitive impairments. Furthermore, the participants were again divided into two groups based on the post-onset period. Due to the extreme variations in the post onset period (PoP) ranging from two months to 14 years, an arbitrary period of 4 years was chosen as a cut-off between the 2 groups to enable an equal number of participants in each group for comparisons. This resulted in 10 participants in the group with a PoP of less than 6 months to 4 years; and 10 participants in the group with a PoP of 4 + years. The last type of grouping was based on the amount and type of treatment that was received. Participants reported on three types of treatments, which included one-on-one individual therapy, group therapy, and intensive therapy programs. Based on the amount of treatment hours received, the individual treatment group was divided into 2, with eleven participants reporting less than 100 hours of therapy and 9 participants with 100 + hours. For group therapy, there were some participants that had not received any, so this variable resulted in three groups, viz. zero hours of group therapy (N = 6); less than 100 hours (N = 7); and 100 + hours (N = 7). Finally, the number of participants having attended intensive therapy programs was binary with nine participants having attended some form of...
intensive therapy programs and eleven participants not having attended such programs. Separate ANOVA analyses were conducted for each of the preceding variables to determine the correlations with ASHA-QCL and ASHA-FACS.

Results and Discussion
The results are outlined as follows: a) correlation between ASHA-QCL and ASHA-FACS, and their correlation to other QoL tests; and b) correlations of both ASHA-QCL and ASHA-FACS and the two QoL measures (CCRSA and SAQOL-39) in effectively determining the QoCL and QoL, respectively, among the sub-groups of the 4 aphasia-related variables discussed above.

Correlation between ASHA-QCL and ASHA-FACS, and their correlation to other QoL tests
A correlation matrix was used to determine whether the assessments measured similar aspects of an individual’s QoL and QoCL. The outcomes are as shown in Table 2.

Table 2 includes the correlation coefficients (Pearson’s r) or the strength of association between the measures, and the P values that show statistical significance. The results indicate that although ASHA-QCL correlates significantly with ASHA-FACS, ASHA-QCL had stronger correlations with the QoL measures such as the CCRSA and the SAQOL-39, than ASHA-FACS. In fact, the ASHA-FACS had no significant correlation with the mean score of SAQOL-39. The ASHA-QCL had the most significant correlations with CCRSA, the SAQOL-39 communication subdomain, and the SAQOL-39 mean score, which are consistent with the findings of Bose et al.[9] Bose et al. found positive relationships between the SAQOL-39 communication subdomain and ASHA-QCL socialization/activities subdomain. Also, unlike CCRSA, ASHA-QCL had weak correlations with SAQOL-39 psychosocial or physical subdomains but was highly correlated with all other measures related to communication underscoring its sensitivity to reflect QoCL more effectively than the overall QoL. These results indicate that ASHA-QCL is a more sensitive and socially valid measure than ASHA-FACS to capture the QoCL in PWAs. Furthermore, anecdotally, participants were observed to complete the ASHA-QCL more easily than ASHA-FACS. The ASHA-QCL is designed for PWAs to self-report how difficult a variety of situations are for them. Therefore, it should require minimal to no support from the clinician or caregiver (Eade et al., 2006). In contrast, the PWAs were observed to have challenges in completing the ASHA-FACS, often requiring assistance with reading each item and needing a straight edge to line up the question with the rating scale.

Effectiveness of test measures across the four independent variables, viz., post-onset period, aphasia severity, cognitive dysfunctions, and amount and type of treatments received
Post-onset period and effects of QoL and QoCL: An ANOVA compared the QoL and QoCL outcomes of the two groups – one group with below four years PoP and the other with 4+ years of PoP. While no significant differences were found between the two groups (p < 0.05 or P < 0.10) on any of the QoL or QoCL measures, effect size calculations showed a medium effect size (d = 0.58) on the SAQOL-Psychosocial subdomain for participants in the more recent PoP group (M = 2.91, SD = 0.51) than those with older strokes (M = 3.36, SD = 0.98). These findings are consistent with the results of Spaccavento et al.[21] and a reminder that considering QoCL along with QoL in the early post-onset periods can be crucial in the overall intervention of PWAs.

Aphasia Severity and effects on QoL and QoCL: An ANOVA was used to determine QoL and QoCL differences between the two groups of mild aphasia and those with moderate-severe aphasia. The ASHA-FACS did not detect any significant differences (although there was a small effect size, d = 0.32) between the two groups. However, there was a significant effect of aphasia severity on SAQOL-39 mean score results at the P < 0.05 level for the conditions [F (1, 19) = 6.99, P = 0.016]. The mild group had a significantly higher mean score (M = 3.82, SD = 0.44) when compared to the moderate-severe group (M = 3.2, SD = 0.63). Significant differences were also noted between the two groups on SAQOL-39 communication sub-domain and ASHA-QCL [see Table 3]. Thus, both SAQOL-39 and ASHA-QCL measures were sensitive to detecting differences in QoL and QoCL respectively between the groups of PWAs with differing severities, which implies that aphasia severity can impact QoL and QoCL negatively. These results are also consistent with those of Bose et al.,[3] Hilari et al.,[5] and Spaccavento et al.[21]

Yet, SLPs tend to assess the QoL and QoCL less often in PWAs with severe aphasia,[20] although experts believe that it is critical that their QoL be monitored, as they may have more difficulty expressing their needs and/or emotions.[22]

Cognitive dysfunction and effects on QoL and QoCL: The PWAs were assessed with the 5 non-verbal subtests of the CLQT to determine their cognitive functioning abilities. The two groups, those with mild deficits and those with normal functions, were included in an ANOVA to determine if they had any significant differences on the QoL and QoCL measures. The results showed a statistically significant difference between groups on ASHA-QCL outcomes at the level of P < 0.10 [F (1, 19) = 3.604, P = 0.073]. The participants that had cognitive abilities “within normal limits” had a higher overall mean score (M = 71.64, SD = 10.07) when compared to the scores of the individuals with a “mild impairment” (M = 62.55, SD = 11.86) on the ASHA-QCL. The ANOVA also revealed significant effects of cognitive abilities at the level of P < .10 on the CCRSA outcomes [F (1, 19) = 3.046, P = .097]. The CCRSA outcomes were consistent with ASHA-QCL outcomes with those participants that scored “within normal limits” having a higher mean score (M = 31.55, SD = 5.41), when compared to the “mild impairment” group (M = 27.1, SD = 6.26). These results confirm previous research, indicating that even mild cognitive impairments may impact
Table 2: Correlation Matrix showing the relationships between the four QoL and QoCL measures

|                        | ASHA‑FACS | ASHA‑QCL | CCRSA  | SAQOL‑39 Mean | SAQOL‑39 Phys. | SAQOL‑39 Com. | SAQOL‑39 Psych. |
|------------------------|-----------|----------|--------|--------------|---------------|---------------|---------------|
| ASHA‑FACS              | 1         | 0.549    | 0.644  | 0.316        | 0.432         | 0.239         | -0.002        |
| ASHA‑QCL               | 0.549     | 1        | 0.773  | 0.594        | 0.304         | 0.794         | 0.425         |
| CCRSA                  | 0.644     | 0.773    | 1      | 0.694        | 0.444*        | 0.533*        | 0.578         |
| SAQOL‑39 Mean          | 0.316     | 0.594    | 0.694  | 1            | 0.760*        | 0.608*        | 0.792*        |
| SAQOL‑39 Phys.         | 0.432     | 0.304    | 0.444* | 0.760*       | 1             | 0.188         | 0.289         |
| SAQOL‑39 Com.          | 0.239     | 0.794    | 0.533* | 0.608*       | 0.188         | 1             | 0.452*        |
| SAQOL‑39 Psych.        | -0.002    | 0.425    | 0.578  | 0.792*       | 0.289         | 0.452*        | 1             |

* Significant at the 0.01 level (2 tailed); † Significant at the 0.05 level (2-tailed)

Table 3: Results of ANOVA - comparing groups of PWAs across significant variables

| Aphasia Severity (Mild vs. Mod-Severe) | ASHA‑FACS | ASHA‑QCL | CCRSA  | SAQOL‑39 Mean | SAQOL‑39 Physical | SAQOL‑39 Comm. | SAQOL‑39 Psych. |
|----------------------------------------|-----------|----------|--------|--------------|-------------------|---------------|---------------|
|                        | 0.470     | 0.086    | 0.101  | 0.016        | 0.113             | 0.020         | 0.111         |
| Cog. Deficits (WNL vs. Mild)           | 0.352     | 0.073    | 0.097† | 0.275        | 0.360             | 0.188         | 0.511         |
| Therapy Individ. (<100 hrs. vs. >100 hrs.) | 0.126     | 0.102    | 0.019† | 0.118        | 0.157             | 0.007*        | 0.840         |
| Intensive (no therapy vs. therapy)     | 0.240     | 0.923    | 0.683  | 0.271        | 0.097‡            | 0.563         | 0.968         |

* Significant at the 0.01 level; † Significant at the 0.05 level; ‡ Significant at the 0.10 level

There were no significant findings on the QoL specific measures (SAQOL-39 mean and subdomains). This demonstrates that when comparing the QoCL measures the ASHA-QCL is more sensitive than ASHA-FACS in identifying differences in groups of PWAs based on cognitive functions.

Amount and Type of treatments received and effects on QoL and QoCL: The two groups compared for individual therapy were participants who received less than 100 hours of therapy and those that received 100 or more hours of therapy. There were significant findings for the effects of individual therapy on CCRSA results at the P < 0.05 level [F (1, 18) = 6.680, P = 0.019]. The group that received less than 100 hours of therapy had a significantly higher mean score (M = 32.55, SD = 4.57), when compared to participants that received 100 or more hours of individual therapy (M = 26.33, SD = 6.18) on the CCRSA. This indicates that those participants who received over 100 hours of therapy had significantly lower levels of confidence. There were also significant findings for the effects of individual therapy on SAQOL-39 communication outcomes at the P < 0.05 level [F (1, 18) = 9.304, P = .007]. The group that received less than 100 hours of therapy had a significantly higher mean score (M = 3.8, SD = 0.427) when compared to the group that received 100 or more hours of therapy (M = 2.82, SD = 0.958). These findings show a trend that participants who received less individual therapy had higher scores on the QoCL and QoL outcome measures. However, these individuals were already very high functioning and had a stroke with less severe language deficits, as measured by their WAB-R aphasia quotient. Therefore, it is possible that the higher functioning individuals needed less therapy overall when compared to other groups.

Interestingly, there were no significant findings on the ANOVA when comparing the amount of group therapy (no group therapy; less than 100 hours and 100 + hours) that participants received and the outcomes on QoL and QoCL measures. Yet, the effect size calculations showed that participants who received no group therapy had higher outcomes on the ASHA-QCL and CCRSA measures when compared to the participants who received some group therapy. However, these PWAs had higher QoCL already possibly indicating that they did not need the group therapy.

Finally, there were statistically significant findings for the effects of intensive therapy on SAQOL-39 physical outcomes [F (1, 18) = 3.073, P = 0.097]. The group of participants who did not receive intensive therapy had a higher mean score on the SAQOL-39 physical subdomain (M = 4.28, SD = 0.59) when compared to the group that received intensive therapy (M = 3.7, SD = 0.89). This is possibly because those people who received intensive therapy may have had more severe symptoms overall, including other comorbidities such as hemiplegia.

Conclusions

The primary aims of this study were to determine the effectiveness of two commonly used communication related quality of life (QoCL) measures in PWAs and how they correlated with other quality of life (QoL) measures. Four factors that contributed to QoL and QoCL (viz., aphasia severity, cognitive deficits, post-onset period, and amount and type of therapy received) were examined.

Results indicated that the ASHA-FACS and ASHA-QCL had large positive correlations with each other indicating that they have a linear relationship. However, the ASHA-QCL was found to be more significantly correlated with
aphasia severity levels, cognitive functions, and type and amount of therapy received in PWAs, than ASHA-FACS. Furthermore, the ASHA-QCL had a relationship with all measures of communication but not measures of other areas of QoL (i.e. SAQOL-39 physical and psychosocial subdomains) corroborating the fact that ASHA-QCL was indeed measuring the quality of life pertaining to communication (QoCL) rather than the overall QoL. Anecdotally, participants were observed to complete the ASHA-QCL more easily than ASHA-FACS. Therefore, ASHA-QCL appears to be an effective measure to capture QoCL in PWAs. The present study also provides additional support to the fact that the ASHA-QCL can be used to detect differences among PWAs QoCL based on their cognitive functions and type and amount of therapy received. PWAs, even with mild cognitive deficits, had significantly lower QoCL. The type and duration of therapy received influenced outcomes on various QoL and QoCL measures. However, the different lengths of post-onset time did not have a significant impact on QoL or QoCL outcome measures in this study, which is most likely due to the small sample size.

Thus, in any aphasia intervention, it is highly important to consider how aphasia impacts their QoCL in addition to QoL. The results underscore the importance of using QoCL measures in addition to QoL surveys, especially in stroke survivors with severe aphasia and/or cognitive deficits. The ASHA-QCL is an effective measure that is sensitive for detecting QoCL in stroke survivors with various profiles of aphasia. It is also quick and easy to administer, making it an efficient tool to use with a variety of PWAs in any clinical setting.

While the study results are promising, the generalizability is limited given the relatively small sample size of participants, limited access to participants from different residential environments, and the overlap of therapies along with lack of details of the nature of treatments received. Also, the inability to record the interviews or assessment administration limited the efforts to establish intra- and inter-rater reliability, which will need to be considered in future studies. Future studies can also examine other factors that affect QoL and study their correlations to QoCL in PWAs.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form, the patient (s) has/have given his/her/their consent for clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Nil.

Conflicts of interest

There are no conflicts of interest.

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