Quality Improvement

Self-Reported Quality of Life Outcomes in Aphasia Using Life Participation Approach Values: 1-Year Outcomes

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\textbf{Abstract}  
Objective: To evaluate the effectiveness of a newly initiated aphasia center program using Life Participation Approach to Aphasia (LPAA) values.  
Design: Evidence-based practice quality improvement project.  
Setting: Ambulatory care aphasia center part of a larger health care system.  
Participants: Participants included 41 clients with aphasia and 40 primary caregivers of clients with aphasia. Participants included all clients and caregivers that were enrolled in the aphasia center within the first year of opening. All participants were enrolled in 1-4 eleven-week sessions of the aphasia center program. Participants with aphasia included 19 women and 22 men with a mean age of 65.2 years (range, 33-84 years).  
Interventions: Group therapy was provided using the LPAA statement of values with each client receiving 3 hours of treatment once per week for 11 weeks. Clients were provided with the opportunity to complete multiple 11-week enrollment sessions if they chose to do so.  

\textbf{Keywords}  
Aphasia; Quality of life; Rehabilitation; Stroke

\textit{List of abbreviations:} A-FROM, Living with Aphasia: Framework for Outcome Measurement; LPAA, Life Participation Approach to Aphasia; MCSI, Modified Caregiver Strain Index; SAQOL-39, Stroke and Aphasia Quality of Life Scale.

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Main Outcome Measures: Client-reported outcomes included the Stroke and Aphasia Quality of Life Scale, and caregiver-reported outcomes included the Modified Caregiver Strain Index. Both measures are self-reported and scale based. Client satisfaction data were also collected via a self-reported program evaluation upon completion of each 11-week session.

Results: Results indicated statistically significant improvements in quality of life scores for clients with aphasia following initial participation of an 11-week aphasia center program (P ≤ .0001) and following 1-year participation (P ≤ .0001). Additionally, caregiver's level of burden decreased significantly following initial participation of the family member (P = .003) and following completion of three 11-week sessions (P ≤ .0001). Self-reported client satisfaction program evaluation results also demonstrated improved quality of life (100%) and improved language skills (average = 89.75%).

Conclusions: The project provided further evidence supporting the use of LPAA values with clients experiencing chronic aphasia.

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Aphasia is the medical term for loss of language following a stroke or brain injury, most commonly affecting the left hemisphere of the brain. Aphasia can be a chronic condition affecting persons for the duration of their lives. Living with chronic aphasia can be an isolating experience and can affect social relationships.

According to Code and Herrmann, aphasia can have a marked negative effect on recovery, response to rehabilitation, and psychosocial adjustment. Additionally, these psychosocial effects have a direct effect on quality of life in people with aphasia. Given that quality of life is multifactorial, unique service delivery approaches such as the Life Participation Approach to Aphasia (LPAA) have been developed to address all aspects of a person’s life, including psychosocial effects.

LPAA is a consumer-driven service delivery approach that allows for the individual with aphasia to be at the center of all decision making with opportunities to meet their short- and long-term life goals. It is a statement of values that focuses on reengagement in life activities and allows opportunities for continued communication support until the person with aphasia chooses to no longer participate. The LPAA statement of values was developed to address all aspects of a person’s life, including psychosocial effects.

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Traditionally in rehabilitation, the World Health Organization’s International Classification of Functioning, Disability, and Health (fig 1) model is used to incorporate a well-rounded evaluation of a person’s impairment, quality of life, and effect of disability on their life participation. This model was adapted specifically for aphasia and developed into the Living with Aphasia: Framework for Outcome Measurement (A-FROM) (fig 2). A-FROM was developed to consider the complexities of living with aphasia and provide clinicians with a tool that allows them to assess quality of life in individuals with aphasia. The development of A-FROM was built upon the values of LPAA and is often used in aphasia centers to allow for adequate outcome measurement.

Given the literature supporting use of LPAA values in treatment of chronic aphasia, the investigators in conjunction with the sponsoring hospital and health system created an aphasia center that uses these principles. The aphasia center was developed as an ambulatory care program to facilitate continued support for rehabilitation services and improve the quality of care provided to individuals with aphasia in this location.

Methods

Program development

The aphasia center discussed in this project uses an interdisciplinary approach that includes the following professionals: speech-language pathologists, certified personal trainers, recreational therapists, and music therapists. Each professional involved in the program was a licensed therapist specializing in neurologic disorders. The aphasia center operates on 11-week enrollment sessions. As with most programs using LPAA values, sessions are group based.
to facilitate opportunities for social communication in a supportive environment. Each client attends 3 hours of group treatment per day, once per week. Clients who attend the morning sessions also receive a 1-hour lunch break where a speech-language pathologist facilitates a conversation group over a shared meal. Seven various activities are targeted across the duration of the 11 weeks. These 7 activities include book club, music club, technology club, game club, math club, cooking club, and fitness club. The activities are facilitated in 1-hour sessions in small groups (5-6 clients per group). Each client participates in all activities through a rotating activity schedule across the 11-week session (see appendix 1 for sample schedule). The activities and therapists are the same for each group but are modified for each client to appropriately address their communication needs. Individualized goals are created for each client following an initial interview with client and family where personal and family goals are shared. These goals are then targeted throughout the 11 weeks with final reports being prepared for each client after the conclusion of the session. Every client has the option to reenroll in the program as many times as they choose. Initially, the program was opened part time with a capacity for 20 clients. Given the demand over the first year of programming, given the rolling enrollment during the first year, 77% of participants reenrolled from their initial session to a subsequent session, 55% from a second to a third session, and 44% from the third to a fourth session. All clients were English speaking. Caregivers were considered primary caregivers either through legal status or via client report. Caregiver’s data were only included if they had direct access and responsibilities related to the client. Clients and caregivers participated in the baseline assessment prior to beginning the program and following the completion of each 11-week session.

Outcome measures

The 2 self-reported outcome measures for this quality improvement project were the Stroke and Aphasia Quality of Life Scale (SAQOL-39) for clients with aphasia and the Modified Caregiver Strain Index (MCSI) to measure caregiver’s burden. Each outcome measure was administered pre-and post enrollment into the 11-week program. These outcome measures were selected for this project as they were previously published, validated surveys. Specifically, the SAQOL-39 was chosen because it contained questions consistent with the A-FROM model and related domains including impairment, participation, environment, and personal feelings.

The SAQOL-39 was developed by Hilari et al and was reported in the literature as a valid and reliable scale to capture health-related quality of life in poststroke aphasia. The SAQOL-39 measures 4 domains (ie, physical, communication, psychosocial, and energy), and these 4 domains including impairment, participation, environment, and personal feelings.
domains have been reported as being psychometrically robust to measure quality of life for individuals living with aphasia. Each domain is rated on a 5-point Likert scale, with a higher number reflecting a higher quality of life level. In addition to the 4 domain scores, the SAQOL-39 also provides an overall mean score. All questions on the SAQOL-39 are self-reported by the person with aphasia.

The MCSI was developed by Thornton and Travis and is a 13-item tool designed to quickly screen for caregiver strain with long-term family caregivers. The MCSI is administered to caregivers to assess the level of strain, defined as a combination of stress and burden that has consequences on caregivers’ overall health. Each question has 3 potential responses and correlates to a numerical score (ie, no = 0; sometimes = 1; always = 3). The clinician then adds up the score obtained for each question, with a scoring range from 0 (no strain) to 26 (extreme strain). There were no reported clinically meaningful difference scores reported for the MCSI.

Self-reported client satisfaction information was also collected at the end of each 11-week session and consisted of yes or no questions to obtain the client’s perspective on the program. Two questions in the program evaluation were, “Do you feel your happiness or satisfaction with life has improved?” and “Do you feel your language skills have improved?” Results were collected via an anonymous electronic survey, and caregivers were asked to assist clients in completing the survey if/when required.

Data analysis

The SAQOL-39 uses a Likert response scale to collect ordinal data; therefore, the nonparamedic Wilcoxon signed-rank test was used to evaluate differences between the initial pre- and postprogram evaluations. To compare repeated outcomes for each participant following completion of multiple 11-week program sessions, the Friedman analysis of variance was used with the Bonferroni correction being applied. The MCSI raw scores are considered continuous data, and parametric tests were used. For the initial pre- and postprogram evaluation using the MCSI, paired t tests were used. To compare repeated outcomes for each caregiver following the completion of multiple 11-week program sessions, a repeated analysis of variance was used with the Bonferroni correction being applied. To address missing data, multiple computations were completed for each outcome by time point using a listwise deletion method. The listwise deletion would drop any observation with the missing data for the specific timeframe being evaluated.

Results

Forty-one clients with aphasia and 40 caregivers participated with the respective outcome measure pre- and post enrollment. Data are available for 41 clients who completed one 11-week program session, 27 who completed two 11-week sessions, 12 who completed three 11-week sessions, and 8 who completed four 11-week sessions. For the caregivers, data are available for 40 caregivers’ pre- and postprogram enrollment for one 11-week session, 17 for two 11-week sessions, 9 for three 11-week sessions, and 3 for four 11-week sessions.

Clients with aphasia included 19 women and 22 men with a mean age of 65.2 ± 10.5 years and an age range of 33-84 years. Time post onset ranged from approximately 3 months to 37 years, with 41% of clients being <1 year, 47% from 1-4 years, and 12% >5 years. Inclusion in the aphasia center program was consistent with LPAA core values that state all individuals with aphasia are included despite their stage of recovery. Clients presented with both fluent and nonfluent aphasia. Severity level for individuals with nonfluent aphasia included the following: 4 mild, 5 mild-moderate, 8 moderate, 5 moderate-severe, and 8 severe. Severity level for individuals with fluent aphasia included the following: 4 mild, 1 mild-moderate, 1 moderate-severe, and 5 severe.

SAQOL-39 outcomes

Overall, 90% of the clients who participated in the initial 11-week program demonstrated improvements with their reported quality of life as measured by the SAQOL-39. Table 1 summarizes the SAQOL-39 results for the initial 11-week program based upon the overall mean and the specific domains of the SAQOL-39. Higher scores reflect a higher level of quality of life. Statistically significant improvements were observed based on the overall mean score as well as for each specific domain of the SAQOL-39.

Tables 2-4 summarize the durability of the outcomes during multiple 11-week sessions. Results revealed the gains observed after each 11-week session were sustained, which in some cases continued to improve, with the overall mean rank score and score in each domain as measured by the SAQOL-39. This finding suggests the ongoing value of continued participation for clients with aphasia to participate in a program using LPAA values.

Finally, client satisfaction data were collected via self-reported yes or no questions as part of a program evaluation after each 11-week session to gain perspective of client’s improvements with quality of life and/or language. Across the 4 program evaluations completed within the first year, 100% of clients consistently reported improved happiness or satisfaction with life. Results varied across 11-week sessions for subjective reports of improved language skills, with 100% of clients reporting improved language following the first session, 74% reporting improved language following the second session, 100% reporting improved language following the third session, and 100% reporting improved language following the fourth session.

Table 1: SAQOL-39 program outcomes: presession to post 1st session

| Domain       | Pre session Mean Score | Post 1st session Mean Score | Sample Size | Significance |
|--------------|------------------------|----------------------------|-------------|--------------|
| Overall      | 3.365                  | 3.776                      | 41          | P < .0001    |
| Physical     | 3.672                  | 3.968                      | 41          | P < .0001    |
| Communication| 2.619                  | 3.142                      | 41          | P < .0001    |
| Psychosocial | 3.351                  | 3.880                      | 41          | P < .0001    |
| Energy       | 3.402                  | 3.780                      | 41          | P < .0001    |
improved language following the third session, and 85% reporting improved language following the fourth session. This averages out to 89.75% of clients reporting improved language skills within the first year. These responses were collected electronically and were anonymous.

**Modified Caregiver Strain Index**

Overall, 73% of the caregivers reported a reduction in caregiver burden as measured by the MCSI. The mean MCSI preenrollment score was 10.025±5.04, and postenrollment score following the initial 11-week program was 8.325±5.784. A lower score reflects a lower reported level of caregiver burden. This difference was statistically significant (P<.003) and represents a mean reduction in caregiver burden of 16.96%.

Table 5 summarizes the durability of the outcomes during multiple 11-week training sessions for caregiver burden. Results were only available for up to three 11-week sessions because limited data were available following the fourth 11-week session. Results revealed that the reduction of caregiver burden observed after each 11-week session were sustained as measured by the MCSI. This finding suggests the indirect benefit of the ongoing value of continued participation of a client with aphasia for their caregiver related to the caregiver’s perceived burden of care.

**Discussion**

The results of this evidence-based quality improvement project are consistent with previous reports in the literature regarding improvements with quality of life following participation in an aphasia center group program. Aphasia group treatment has been studied for many years with literature supporting its effectiveness and efficiency. Additionally, the aphasia center community-based concept has been supported to provide ongoing disability services to individuals living with aphasia despite challenges related to health care reimbursement.

Hoen et al investigated the psychosocial well-being changes in individuals with aphasia following participation in a community-based aphasia center program using the Ryff’s Psychological Well-being Scale. This study evaluated 35 clients at a 6-month interval, and the results revealed a positive change in 5 of the 6 dimensions of psychological well-being. The individuals evaluated in that study were also at all stages of recovery post onset. These results are consistent with the findings of this current quality improvement project demonstrating individuals with aphasia in various stages of recovery can make improvements in quality of life.

Similarly, Van der Gaag et al investigated quality of life and communication improvements in individuals with aphasia both quantitatively and qualitatively following participation in a community-based aphasia center. Results of their study indicated improvements on all outcomes at a 6-month postparticipation evaluation because statistically significant improvements were observed in quality of life outcome measures via EuroQol. Van der Gaag et al also used the SAQOL-39 with positive direction of change in scores, but it was not statistically significant. Qualitative measures were also obtained in this study via interviews with individuals with aphasia and their families. Their study indicated the individuals with aphasia and their relatives or caregivers reported changes in communication, increased confidence in their communication, and more success in communication following participation in their aphasia center program. These results are consistent with the findings of this current quality improvement project with statistically significant improvements in quality of life. Furthermore, their qualitative findings were consistent with this project’s self-reported program evaluation results.

| Domain         | Pre-sess. Mean Score | Post 1st Session Mean Score | Post 2nd Session Mean Score | Sample Size | Significance |
|----------------|----------------------|----------------------------|----------------------------|-------------|--------------|
| Overall average| 3.419                | 3.798                      | 3.932                      | 27          | P<.0001      |
| Physical       | 3.6381               | 3.9544                     | 4.0574                     | 27          | P<.0001      |
| Communication  | 2.6589               | 3.1359                     | 3.3915                     | 27          | P<.0001      |
| Psychosocial   | 3.5167               | 3.98                       | 4.0811                     | 27          | P<.0001      |
| Energy         | 3.5463               | 3.7870                     | 3.9537                     | 27          | P<.0001      |
Study limitations

Because of limited time and staffing resources, only quality of life measures were completed as part of this quality improvement project. Considerations for future research are to measure the effectiveness of the program via quantitative measures related to improvements in impairment level of aphasia and compare it with quality of life data to determine if there was a correlation or effect. Furthermore, while both the SAQOL-39 and the MCSI are psychometrically sound measures appropriate to evaluate quality of life measures for patients and caregivers, there was no reported clinically meaningful difference in scores reported for either measure with the various scales developed.9,11 Further research is needed to evaluate the appropriateness of these instruments as an outcome measure following intervention. Another consideration for continued development of this aphasia center relates to the caregiver component. Although caregiver level of burden showed statistically significant reductions, there was no caregiver support or training regularly provided in a standardized fashion. It is hypothesized that caregivers demonstrated less caregiver burden given the 3-4-hour reprieve from caregiving they received because of the family member’s weekly participation in the aphasia center. Additionally, it could be hypothesized reduced caregiver burden was observed because of the family member’s increased quality of life or improved psychosocial well-being; however, a limitation of this study is the unknown source of these documented improvements.

Conclusions

Clients with aphasia who participated in this 11-week aphasia center program demonstrated improvements with quality of life measures from pre- to post enrollment. In addition, the primary caregivers also reported a reduction in overall caregiver strain from pre- to post enrollment. Further, most of the participants decided to reenroll for a subsequent 11-week session, demonstrating motivation and continued interest in group participation. Durability of outcomes was measured following completion of multiple sessions with data indicating maintained and improved quality of life following each session. These results provide additional evidence regarding the potential to continue to make progress in participation and quality of life, even in chronic cases. Individuals with aphasia should be afforded ongoing opportunities through innovative programming options throughout their lifespan.

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| Table 4   | SAQOL-39 program outcomes: presession to post 4th session |
|-----------|----------------------------------------------------------|
| Domain    | Mean Score   | Post 1st Session Mean Score | Post 2nd Session Mean Score | Post 3rd Session Mean Score | Post 4th Session Mean Score | Sample Size | Significance   |
|-----------|--------------|-----------------------------|----------------------------|-----------------------------|----------------------------|-------------|----------------|
| Overall   | 3.225        | 3.7138                      | 3.9050                     | 3.9087                      | 3.9750                     | 8           | P≤.0001        |
| Physical  | 3.48         | 3.8525                      | 4.08                       | 4.0963                      | 4.1475                     | 8           | P≤.0001        |
| Communication | 2.31       | 2.9588                      | 3.2663                     | 3.3213                      | 3.5175                     | 8           | P≤.0001        |
| Psychosocial | 3.387      | 3.9788                      | 4.0825                     | 4.0338                      | 4.0113                     | 8           | P≤.0001        |
| Energy    | 3.4063       | 3.6875                      | 4.00                       | 3.7813                      | 3.9375                     | 8           | P≤.0001        |

Abbreviation: NA, not applicable.

| Table 5   | Modified Caregiver Strain Index initial and durability of outcomes |
|-----------|---------------------------------------------------------------|
| Time Frame | N  | Overall Raw Score   |
| Presession | 40 | 10.025             |
| Post 1st   | 40 | 8.325              |
| Post 2nd   | 17 | 8.235              |
| Post 3rd   | 9  | 8.111              |
| Post 4th   | 3  | NA                 |
| Significance | P≤.0001             |

Appendix 1 Sample Schedule

| Time   | N     | Overall Raw Score |
|--------|-------|-------------------|
| Pre    | 40    | 10.025            |
| Post 1 | 40    | 8.325             |
| Post 2 | 17    | 8.235             |
| Post 3 | 9     | 8.111             |
| Post 4 | 3     | NA                |

Abbreviation: NA, not applicable.
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