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Importance of health-related quality of life for persons with aphasia, their significant others, and SLPs: Who do we ask?

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Background: Outcomes that support improved health-related quality of life (HRQL) are increasingly identified as desirable products to aphasia intervention. Although domain importance has been examined for survivors of stroke, little research evidence exists indicating what particular HRQL domains are or are not important to persons with aphasia (PwA).

Aims: The study aimed to determine if persons with mild, moderate, and severe aphasia, their respective speech-language pathologists (SLPs) and respective significant others (SOs) attribute similar importance rankings to different domains and overall HRQL.

Method & Procedures: This study was a prospective, observational, non-randomised group design. The *Stroke and Aphasia Quality of Life Scale-39* (SAQOL-39; Hilari, Byng, Lamping, & Smith, 2003a) and the *Quality of Communication Life* scale (Paul et al., 2004) were administered to 24 PwA, their treating SLPs ($n = 7$), and SOs ($n = 24$). Importance ratings on a 5-point Likert scale were obtained for each scale item. Severity of aphasia was determined by expressive ability resulting in by chance assignment of eight participants per severity group.

Outcomes & Results: The SAQOL-39 physical domain was the only HRQL domain to be statistically significant with a significant group main effect, $F(2, 21) = 4.057, p < .05$. The SLP and SO significantly correlated with each other for importance of HRQL, but not with the PwA who had no significant correlations with the importance ratings made by the SO or the SLP on the SAQOL-39 and QCL. A total of 43% of variance in the overall importance ratings by PwA was accounted for by age, $R^2 = .434, F(1, 22) = 16.89, p < .01$.

Conclusions: Seeking importance ratings of HRQL domains from persons with mild, moderate, and severe aphasia may result in development of treatment goals more relevant to the PwA. Assessment of multiple HRQL domains is necessary to understanding priorities PwA place on rehabilitation outcomes across the continuum of care. Consideration for severity assignments beyond impairment-based assessments is discussed.

Keywords: Health-related quality of life; Aphasia; Stroke.

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The term *health-related quality of life* (HRQL) is increasingly used in the medical and health science literature to refer to components of overall quality of life (QOL) that centre on or are directly affected by health, disease, disorder, and/or injury. General consensus was noted in the literature with regard to identifying the components of HRQL (Guyatt, Feeny & Patrick, 1993; Hilari, Wiggins, Roy, Byng & Smith, 2003a; Naughton & Shumaker, 2003). Health-related quality of life is defined as the impact of a health state on a person's ability to lead a fulfilling life (Hilari et al., 2003b) and examines attributes valued by individuals whose lives have been affected by illness or disease.

Many researchers agree that HRQL and associated factors are subjective and dynamic by nature (Orely & Kuyken, 1994). Because persons with aphasia (PwA) have impaired communication abilities, their participation in quality of life research is often limited. Some researchers have examined quality of life for survivors of stroke but excluded PwA from participation (e.g., Smout, Koudstaal, Ribbers, Janssen, & Passchier, 2001). Other researchers have not included speech-language pathologists (SLPs) in surveys of rehabilitation health professionals in an effort to define HRQL for survivors of stroke (e.g., McKevitt, Redfern, La-Placa, & Wolfe, 2003). Failure to include PwA, their significant others (SOs) and SLPs serving this population eliminates a substantial population of individuals impacted by stroke.

Proxy responses have been considered as an alternative to not including individuals with aphasia (Duncan et al., 2002). Duncan and colleagues (2002) determined that the best agreements were for domains that represented observable physical behaviours, and the worst agreements were on more subjective domains (e.g., memory and thinking, communication, emotion, and strength). Sneeuw, Aaronson, DeHaan, and Limburg (1997) suggested that there are significant differences in perceptions of HRQL between survivors of stroke and their proxy respondents. Proxies tended to rate the survivors of stroke as more impaired or with a lesser QOL than the survivors of stroke rated themselves.

Speech-language pathologists (SLPs) generally believe their clients experience an enhanced HRQL as a result of treatment for aphasia (Doyle, 2002, 2005; Doyle, Matthews, Mikolic, Hula, & McNeil, 2006). However, there is limited published research evidence examining the importance of HRQL domains to individuals with communication disorders, their SOs, and/or their treating SLPs. The emotional impact of aphasia (Code, Hemsley, & Herrmann, 1999) and the need to manage the psychosocial adjustment of aphasia (Müller, 1999) are identified as important aspects of aphasia management, but researchers fall short of providing a means for determining what is most important to the PwA. Understanding the importance of HRQL domains to PwA is vital to promoting their involvement in goal development and movement toward outcomes that are personally germane (King, 1996). Impairment-based assessments do not measure communication difficulty or associated psychological distress that frequently accompanies language impairment (Ross & Wertz, 2003), so they are inadequate in identifying what it means to live with aphasia. Without assessment of the individual's perspective of assigned values, interventions may be directed towards the possibility of an event, rather than the day-to-day domains important to the PwA. For example, the clinician may consider it important that the client be able to make phone calls, particularly emergency calls for assistance. Yet, unless there is an event to precipitate the need, the client may not consider this important on a day-to-day basis because the caretaker is able to provide that assistance. Identifying the importance of particular HRQL domains such as social

relationships, language, mood, self-care, and family roles could reveal diagnostically distinct areas that would enable clinicians to target more specific interventions for PwA (Herrmann & Wallesch, 1990) along the continuum of care.

Health-related quality of life assessments need to reflect the importance of specific domains to the individual in relation to a given context or situation. Since aphasia is described as “a disorder of communication leading to a disorder of the person” (Sarno, 1993, p. 323), individuals with aphasia, regardless of severity, should be provided with an opportunity to supplement standardised measurement items with those regarded as personally relevant (Ross & Wertz, 2003). Indicating whether one is satisfied or dissatisfied with some aspect of one’s life does not necessarily correlate to whether those aspects are important or lack importance. Individuals who recently developed paraplegia or quadriplegia following a motor vehicle accident were reported as not significantly different from recent lottery winners when asked to report their level of happiness (Ubel, Loewenstein, & Jepson, 2002). This example seems counterintuitive, but indicates the significance of the insider’s perspective (Hunt, 1997) and supports the value of asking participants to rate the importance of items used to determine HRQL (King, 1996).

The primary research questions were:

1. Are there significant differences between importance ratings of four HRQL domains (physical, psychosocial, communication, and energy) and overall HRQL for participants identified with mild, moderate, and severe aphasia (determined by expressive language impairment)?
2. Are there significant differences between importance ratings of the HRQL domains and overall HRQL for different respondent types (PwA, SO, SLP)?

METHOD

Participants

Person with aphasia. A total of 24 participants with aphasia (PwA), with a mean age of 70 ($SD = 13.17$), took part in the study. They included 10 males and 14 females from rural and urban areas. A diagnosis of aphasia was determined by performance on the *Western Aphasia Battery* (WAB; Kertesz, 1982). Overall mean score for the WAB Aphasia Quotient (AQ) was 67.4 ($SD = 23$). All participants reported a history of English proficiency. Three participants were African-American and the remainder Caucasian. All participants met the following criteria: (1) diagnosis of aphasia; (2) history of one or more strokes, with the most recent stroke occurring at least 1 month prior to study entry; (3) current enrolment in speech-language therapy at least once per week; (4) moderate (or better) aided or unaided hearing acuity as determined by the *Hearing Handicap Inventory for the Elderly – Screening Questionnaire* (HHIE-S; Ventry & Weinstein, 1983); sensitivity when compared to an audiogram-defined hearing impairment is reported as 72–76% (Demers, 2004); (5) brain damage confined to the left hemisphere; (6) no history of other diseases that would affect communicative ability; (7) corrected visual acuity no worse than 20/100 in the better eye as determined by a pocket-size Snellen chart for illiteracy; (8) either upper extremity sufficiently preserved to indicate a clear choice; and (9) living in their own home, in a rehabilitation facility, or in an assisted living facility. Information about the PwA was obtained through medical chart review, interviews with the individual and his or her SO, and formal assessments. Table 1 provides descriptive data for PwA.

TABLE 1
Descriptive data for participants with aphasia (PwA)

<i>PwA</i>	<i>Age</i>	<i>Gender</i>	<i>Ed¹ level</i>	<i>Race</i>	<i>WAB AQ²</i>	<i>MPO³</i>	<i>SQL39⁴</i>	<i>QCL⁵</i>	<i>Amb⁶ status</i>
<i>Mild</i>									
1	67	M ⁷	14	W ⁹	57.8	6	144	60	Ind ¹¹
2	81	F ⁸	16	W	89.8	1	133	42	W/C ¹²
3	86	M	8	W	91	1	133	72	W/C
4	75	F	12	W	88.3	2	154	75	Cane ¹³
5	54	F	12	W	90.8	1	156	63	Walker
6	55	M	4	W	85.4	13	133	72	Walker
7	76	F	12	W	92.2	180	155	58	Cane
8	82	M	12	B ¹⁰	88	2	129	73	W/C
Mean	72		11.3		85.4	25.8	142.1	64.4	
(SD)	(12.2)		(3.7)		(11.4)	(62.5)	(11.5)	(11.1)	
<i>Moderate</i>									
1	75	M	16	W	72.2	52	96	63	W/C
2	79	F	18	W	57.4	53	123	61	Walker
3	90	M	12	W	88	5	82	74	W/C
4	92	F	6	W	86.9	1	126	47	W/C
5	84	F	18	W	65.4	4	180	81	W/C
6	51	F	8	B	63.3	23	104	60	Ind
7	54	M	16	W	37.5	9	78	39	Ind
8	52	F	8	B	83.7	10	107	35	Ind
Mean	63.1		10.9		69.3	19.6	112	57.5	
(SD)	(17.3)		(4.5)		(17.2)	(21.3)	(32.4)	(16.2)	
<i>Severe</i>									
1	77	F	12	W	53.2	1	122	67	Ind
2	71	F	12	W	63.8	3	81	65	Ind
3	61	M	12	W	28	2	116	64	W/C
4	70	F	18	W	73.2	1	140	79	W/C
5	61	F	16	W	39.9	84	134	73	Cane
6	77	M	16	W	33.3	9	69	33	Ind
7	70	F	12	W	14.8	17	105	61	Cane
8	47	M	14	W	72.8	12	125	38	Ind
Mean	66.8		14		51.4	16.1	111.5	60	
(SD)	(10.0)		(2.4)		(21.7)	(28.0)	(25.1)	(16.2)	

¹Education; ²Western Aphasia Battery Aphasia Quotient; ³months post onset of stroke; ⁴Stroke and Aphasia Quality of Life Scales-39 total score; ⁵Quality of Communication Life Scale total score; ⁶ambulatory; ⁷male; ⁸female; ⁹White/Caucasian; ¹⁰Black/African-American; ¹¹independent; ¹²wheelchair bound; ¹³ambulates with cane.

Participants were excluded if: (1) they had been discharged from speech-language pathology services; (2) they lived alone without continuous family support; (3) they had history of cognitive decline or progressive disorders; (4) family or SLPs did not agree to enrol in the study; (5) their scores on *Raven's Coloured Progressive Matrices* (RCPM; Raven, Court, & Raven, 1995) placed them below the 50th percentile for their age group; (6) they scored below 14 of 20 correct (70%) on the yes/no question response section of WAB; or (7) they had a history of substance abuse within the past 12 months.

Severity was determined using a unit of information count similar to a content unit count (Yorkston & Beukelman, 1980) scored from a taped transcript of the WAB picture description task (the Picnic Scene). Units of information were judged

as the amount of information conveyed and defined as a unit of expression by normal speakers (Yorkston & Beukelman, 1980). Severity rankings were conceptualised from those used by Yorkston and Beukelman (1980) for the Cookie Theft picture from the Boston Diagnostic Aphasia Examination (Goodglass & Kaplan, 1983). Participants with aphasia were categorised as presenting with severe aphasia if they produced five or fewer units of information in their description of the WAB picture. Moderate rankings were assigned to individuals producing six to eleven units of information; those producing greater than 11 units of information during WAB picture descriptions were categorised as mild. Eight participants were identified for each severity group by chance. Reliability was assessed by having two SLPs judge a series of six randomly selected speech samples previously scored by the primary investigator (PI). Judges were within ± 1 content unit of the PI score 98% of the time. Intra-rater agreement for scoring six randomly selected samples was 100%. Differences in scoring between the judges did not influence severity group assignments.

Significant other of the participant with aphasia. The mean age for the significant other (SO) of the PwA was 64.8 years ($SD = 14.1$); they included 15 females and 9 males. Although a spouse or partner was preferred, adult children and parents of the PwA were allowed; they included 14 spouses, 8 adult children of the PwA, and 2 parents of the PwA. All SOs reported daily face-to-face contact with the PwA. Significant others met the following criteria: (1) reported normal aided or unaided hearing; (2) evidence of normal cognition (> 28) as measured by the *Mini-Mental State Examination* (MMSE; Folstein, Folstein, & McHugh, 1975) and by observation; (3) no history of current unmanaged psychological disorders by report and observation; (4) reported normal corrected or uncorrected visual acuity; and (5) English as the primary language. Significant others also were the primary caregiver for the PwA.

Speech-language pathologist of the participant with aphasia. The SLPs were licensed and ASHA certified as well as having professional experience with PwA. Multiple PwA were clients of each SLP, resulting in a total of seven SLP participants. Licensure and professional certification were determined at the time of initial contact.

Measures

All participants (i.e., PwA, SOs, and SLPs) were administered two measures: *Stroke and Aphasia Quality of Life Scale -39* (SAQOL-39; Hilari et al., 2003a) and *Quality of Communication Life* (QCL; Paul et al., 2004) scales. The SAQOL-39 is an instrument for assessing HRQL in people who have had a stroke and who present with aphasia. The QCL is a measure of quality of communication life as a distinct, but related, aspect of general quality of life. Both measures were selected for their inclusion of individuals with varying severity levels of aphasia during development, and determination of life quality domains, since PwA have typically been excluded from validation studies for instruments to assess quality of life (Buck et al., 2004; Duncan et al., 1999; Williams, Weinberger, Harris, Clark, & Biller, 1999). A one-to-one interviewer-assisted format was employed using the recommended procedures for each instrument for all respondents. Participants were also asked to rate the importance of each individual test item using a 5-point scale (5 = very important, 4 = important, 3 = neutral/somewhat important, 2 = unimportant, 1 = very unimportant). The evaluator asked, "How important is this to you?" to elicit the responses, and then directed the

participant's attention to the 5-point scale. If necessary, repetition, rephrasing, and item-specific examples were used to enhance the validity of responses and permit each participant to provide his/her own reactions. Rephrasing was necessary only for the neutral, important, and very important ratings. Verbal and nonverbal responses were accepted. The PwA responded from a personal perspective of item importance. The SLP and SO ranked items of importance based on his/her opinions of importance for the PwA.

Additional instruments were used to supplement HRQL measures. All PwA completed the *Brief Carroll Depression Scale* (B-CDS; Carroll, 1998), *Frenchay Activities Index* (FAI; Holbrook & Skilbeck, 1983), and *MOS Social Support Survey* (MOS-SS; Sherbourne & Stewart, 1991). The B-CDS is a 12-item yes/no rapid screening questionnaire with a severity score range from 0 to 12. The depression ratings provided by the B-CDS informed on possible correlations with responses on the HRQL scales, but were not used to eliminate participants from the study. The FAI is a brief measure of lifestyle consisting of 15 four-point measures and examines three major factors: domestic chores, leisure/work, and outdoor activities. The MOS-SS is a self-administered questionnaire measuring strength of perceived social support available on an ordinal 5-point scale. Five dimensions of support are measured: emotional support (four items), informational support (four items), tangible support (four items), positive social interactions (four items), and affection (three items).

Procedure

A Latin square design was used to determine the order of presentation of HRQL assessments for each triad. Although the order of assessments was randomised, the number of assessments completed on a given day varied for the convenience of the PwA, SO, and SLP. Following informed consent, 23 PwA and SO pairs were tested on the same day. The one exception was completed on consecutive days. Responses were obtained individually without the presence of other triad members. Testing took place at the PwA's primary residence. SLPs were tested at their workplace within the same week as the PwA and SO. The average time for completion of the QCL with the PwA was 15 minutes, inclusive of importance ratings; with the SO and SLP it was 12 minutes. The SAQOL-39 averaged 23 minutes for administration, inclusive of importance ratings, for the PwA. Significant others and SLPs completed the SAQOL-39 and importance ratings in an average of 18 minutes.

RESULTS

Reliabilities of the two HRQL scales were calculated for responses and importance ratings for each respondent group using Cronbach alpha. Reliability was acceptable for each respondent type on the SAQOL-39, range: 0.89–0.95, and QCL, range: 0.77–0.90.

Importance of HRQL across different severities of aphasia

Several one-way analyses of variance (ANOVA) with pairwise planned comparisons using Tukey HSD were conducted to explore the impact of severity (three grouped levels: mild, moderate, severe determined by expressive ability) on importance ratings for HRQL domains (physical, communication, psychosocial, energy) and overall HRQL

(SAQOL-39 total score and QCL total score). Analysis of the four HRQL domains revealed a significant group main effect for importance of the physical domain, $F(2, 21) = 4.057, p < .05$. Planned comparisons revealed significant differences between the mild and moderate severity groups and the moderate and severe groups; as severity increased, importance of the physical domain also increased. No other HRQL domains yielded statistically different results. No differences among aphasia severity groups were found for importance ratings of overall HRQL.

Stepwise multiple regression was conducted to determine which independent variables—severity, age, gender, education level, time post onset of stroke, perceived support (MOS-SS), depression (B-CDS), activity level (FAI), cognition (RCPM), and WAB-AQ—were predictors for overall HRQL importance ratings by PwA. Results indicated a significant regression equation for age, $R^2 = .434, F(1, 22) = 16.89, p < .01$. This model accounted for 43% of variance in the overall importance ratings by PwA. A total of 56% of variance was accounted for with a second regression equation with scores from the RCPM and age, R^2 of .564, $F(1, 21) = 6.22, p = .021$. Age and cognition made a greater contribution to HRQL importance perceptions than other independent variables.

Rating importance of HRQL domains among PwA, SOs, and SLPs

To explore the differences in mean importance ratings of the two scales among triad members (PwA, SO, SLP), a multivariate analysis of variance (MANOVA) of respondent type (PwA, SO, SLP) by measure (importance rating for SAQOL-39, importance rating for QCL) by severity (mild, moderate, severe expressive ability) was conducted. No significant differences were found among respondent types for importance ratings of overall HRQL on either measure. Severity assignments for the SO and SLP were based on that of the PwA. Pearson correlation coefficients further examined the association among the total importance ratings of overall HRQL on the SAQOL-39 and QCL and respondent type. As demonstrated in Table 2, ratings by the SLP and SO significantly correlated for importance of HRQL on both scales (SAQOL-39, $r = .43, p < .05$, and QCL, $r = .47, p < .05$), but not with the ratings from the PwA.

MANOVA with multiple comparisons were calculated with severity as the independent variable and respondent type (PwA, SO, SLP) and importance ratings on

TABLE 2
Correlation coefficients

	<i>SLP¹-QCL</i>	<i>SLP-39²</i>	<i>SO³-QCL</i>	<i>SO-39</i>	<i>PwA⁴-QCL</i>	<i>PwA-39</i>
SLP-QCL	1.00	.653**	.470*	.425*	.093	-.263
SLP-39		1.00	.276	.605**	-.057	-.168
SO-QCL			1.00	.540**	.392	.003
SO-39				1.00	.206	.301
PwA-QCL					1.00	.334
PwA-39						1.00

Significant Pearson correlation coefficients examining importance ratings on the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39) and Quality of Communication Life (QCL) for respondent type. ¹Speech-language pathologists; ²SAQOL-39; ³significant other; ⁴participants with aphasia; *significant at $p < .05$; **significant at $p < .01$.

HRQL domains (physical, communication, psychosocial, energy) as dependent variables. Statistically significant differences were found for importance of the physical domain for the three respondent types within severity groups. Significant differences for the PwA were found, $F(2, 21) = 4.057, p < .05$, between the moderate and severe aphasia groups. Participants with moderate aphasia attributed more importance to the physical domain's influence on HRQL than participants with severe aphasia. Significant differences for the SOs were found, $F(2, 21) = 5.56, p < .05$, between the mild and the moderate severity groups. The SOs of the mild group attributed more importance to the physical domain's influence on HRQL than SOs from the moderate group. The SLP importance ratings for physical domain were significantly different, $F(2, 21) = 4.65, p < .05$, between the mild and moderate severity groups and between the moderate and the severe groups. As aphasia severity increased, the SLP attributed more importance to the physical domain's influence on HRQL to the PwA. The physical domain was perceived as significantly more important to HRQL among respondent types compared to the psychosocial, communication, and energy domains.

DISCUSSION

The current study examined HRQL domains (physical, communication, psychosocial, energy), overall HRQL and attribution of their importance with mild, moderate, and severe aphasia groups. SLPs and significant others (SOs) of the PwA were included in the study to compare ratings among the respondent types, thus adding another element to previous proxy research. The PwA were divided into the three severity groups based on verbal expressive ability. No significant differences were found in importance ratings for HRQL domains or overall HRQL between the different respondent groups. The SOs and SLPs rated what they perceived was the HRQL for the PwA. These results were compared to the PwA rating. Importance ratings by the SOs and SLPs were more similar to each other than ratings by the PwA.

HRQL across different severities of aphasia

Clinical judgements based on severity of aphasia alone using verbal expressive ability do not identify the areas of greatest concern for the PwA regarding their HRQL and rehabilitation, supporting, and extending previous research in this area (Ross & Wertz, 2002). In this study, severity of physical functioning was of greater concern than communication functioning for many PwA. Although the findings add to the growing body of literature in this area, it was surprising that the aphasia groups did not significantly differ on more of the HRQL measures. One possible explanation is that importance of HRQL domains is influenced by areas other than the severity of the condition. A total of 40% of PwA were 1 month post onset of stroke. The 30-day post-onset inclusion criterion, when regaining physical independence, may outweigh the importance of communicative independence, and might have been a confounding factor. Previous researchers have found that other factors beyond aphasia severity influence perceptions of HRQL, such as self-esteem (Bakheit, Barrett, & Wood, 2004) and functional communication ability (Cruise, Worrall, Hickson, & Murison, 2003). Psychosocial and emotional adjustment of PwA varies even within different levels of aphasia severity (Hemsley & Code, 1996) resulting in broad patterns of response to stroke and aphasia being described (King, 1996).

Another possibility is that PwA viewed importance of HRQL according to their belief system rather than their communication impairment. The importance of HRQL domains and overall HRQL attributed by persons rated with mild versus severe aphasia did not vary significantly. Five of the participants with mild aphasia had higher importance ratings on the communication domain than six of the individuals in the severe group. The PwA's attribution of importance on a particular area appeared just as high for minor deficits as major ones. For example, a PwA who was able to communicate with only one-word utterances indicated the same importance for talking on the phone as a participant who had only mild word-retrieval deficits during conversation. Their abilities to perform the task differed greatly, but the importance of the activity was judged the same. Further, increased expressive language impairment did not equate to increased personal concern for improvement. Physical function, not communication, was considered more influential to overall HRQL across aphasia groups. The emotional and physical demands associated with fine and gross motor disabilities may be considerable compared to communicative disabilities. Anecdotal comments from participants suggested that the energy needed to adapt to communication limitations was less than that required for physical ability. For example, giving a nod for yes/no responses or using one-word responses to identify preferences with a broad range of communication partners requires less energy than adapting to the point of independent transfer from bed to chair or to regaining the ability to write with severe hemiparesis. This perspective may be particularly true during the initial stages of recovery.

A third possible explanation may be how severity was determined. All PwA presented with sufficient auditory comprehension ability, as this was necessary for following task instructions. However, using a verbal expressive measure of content production resulted in greater variability within the mild severity group, ($SD = 6.18$). The moderate ($SD = 1.66$) and severe aphasia groups ($SD = 2.12$) had finite boundaries for identification. Assignment to the mild severity group required 12 or more content units, a potentially infinite range (i.e., range = 12–33). Greater variability within the mild severity group may have made it difficult to capture differences. Different analyses of information content within verbal expression of PwA, such as Utterance with New Information (Toro, Altmann, Raymer, Leon, Blonder, & Rothi, 2008) and main event analysis (Capilouto, Wright, & Wagovich, 2006), have also been proposed as potential measures for capturing relevant communicative changes through discourse and picture descriptions. Although not used for determination of aphasia severity, results from this study suggest further exploration on the relevance of these types of measures for severity assignment in addition to impairment models to continue to address the bias towards exclusion of individuals with mild, moderate, and severe levels of aphasia in studies of HRQL among survivors of stroke.

HRQL ratings among PwA, SOs, and SLPs

A large amount of variance in scores was found for importance ratings for the PwA and the SO groups across both HRQL measures. Responses between the PwA and SO were not statistically different. The overall importance of HRQL ratings correlated significantly with responses between the SLP and the SO, but not with the PwA. The SLP and the SO ratings on the SAQOL-39 and QCL also significantly correlated; however, neither correlated with ratings provided by the PwA. In previous studies researchers have suggested that proxy respondents rate the survivors of

stroke and aphasia as more impaired or with less QOL than the PwA rates themselves (Duncan et al., 2002; Sneeuw et al., 1997), yet proxies have been suggested as reliable raters of social communication function of PwA (Donovan, Rosenbek, Ketterson, & Velozo, 2006). Another consideration is the assumption underlying HRQL measures that the questions posed are supposed to make sense to the people answering them. It appears possible that variance could have been influenced by individuals within the respondent groups who did not want to speculate on a choice or comparison. For objective criteria, experiences of the PwA must be, in the end, submitted to the judgement of the PwA.

Importance of HRQL domains can differ across the participant groups (i.e., PwA, SO, & SLP). Additional analyses results indicated that age and cognition of the PwA had a greater influence on importance of HRQL on the SAQOL-39 than severity of aphasia. Few would argue that with age, priorities change with or without a chronic illness, such as aphasia. PwA in the study ranged in age from 46 to 92 years; cognition scores on the RCPM were within normal range ($SD = 3.2$). Personal priorities are adjusted as circumstances change under normal conditions. Gradual adjustments are not possible for PwA and their SOs, since stroke is a sudden rather than insidious event. One explanation may be that personal biases on importance attributions of life quality assigned by SOs and SLPs could not be eliminated, despite emphasis placed on taking the perspective of the PwA. Response shifts (Sprangers & Schwartz, 1999) resulting in change of values or redefinition of life quality experienced by PwA require further exploration with regard to how PwA, SOs, and SLPs accommodate the change in health state. Results from this study suggest variability of response shifts exists among triad respondents.

Caution is recommended in interpreting the data and in summing ordinal data for parametric comparisons. Statistical analyses with a larger sample may have indicated significance or non-significance in domains not identified within this study.

Conclusions and future directions

This study offered an initial effort to examine the importance of HRQL domains to persons with mild, moderate, and severe aphasia judged by expressive ability, their SOs, and SLPs. Significant differences among aphasia severity groups were not found and the HRQL ratings for the PwA group did not significantly correlate with those of their SOs and SLPs. However, the HRQL ratings between the SO and SLPs groups did correlate significantly. Although there are limitations to the study, the results do add to the growing body of literature regarding HRQL for PwA. Future studies should include a larger sample of participants, include aphasia groups that consider severity across the language spectrum, and include aphasia groups, respective SOs, and SLPs across the recovery continuum (i.e., during rehab, post rehab). Qualitative examination of the dynamics of the triad relationship, the influence of time known in the triad relationship, and the pre-morbid value systems of the triad members may inform the profession with regard to internal variables influencing outcomes.

Despite these limitations, the results are promising and have implications for assessment and intervention for aphasia, as well as directions for future research. Physical function, not communication, was considered more influential to overall HRQL for the PwA. Assessment of multiple HRQL domains is necessary in order to understand the priorities PwA set for their rehabilitation processes. Content of

HRQL assessment should include more domains than communication-focused items to prevent bias from limiting our (i.e., SLP) perspectives about how best to help the PwA achieve an improved HRQL. Further, importance ratings of HRQL domains should be included as an essential component of overall HRQL assessment for accurate identification of treatment goals relevant to the PwA. Including assessment of the importance of HRQL domains in addition to performance of HRQL domains can provide the SLPs and SOs with a broader and more accurate understanding of the judgements PwA make about themselves and their HRQL along the continuum of care.

Intervention resources may be more appropriately designed and applied when treatment frequency, intensity, and goals are based primarily on assessment of what functional abilities are most significant to the PwA rather than severity of impairment. Asking the PwA what is and is not personally important empowers and encourages active participation in care. Such participation may provide opportunities for expression of hopes and fears not obtained with impairment-based assessments or proxy responses. Factors more important to the PwA than to others should serve as a partial guide to the role the PwA wants to play in the plan of care. Finally, further understanding of how others (i.e., SOs, SLPs, social networks) influence the perspectives of the PwA with regard to recovery would inform the profession and clinical practice.

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REFERENCES

- Bakheit, A., Barrett, L., & Wood, J. (2004). The relationship between severity of post-stroke aphasia and stated self-esteem. *Aphasiology*, *18*, 759–764.
- Buck, D., Jacoby, A., Massey, A., Steen, N., Sharma, A., & Ford, G. (2004). Development and validation of the NEWSQOL, The Newcastle Stroke Specific Quality of Life Scale. *Cerebrovascular Diseases*, *17*, 143–152.
- Capilouto, G., Wright, H. H., & Wagovich, S. (2006). Reliability of main event measurement in the discourse of individuals with aphasia. *Aphasiology*, *20*, 205–216.
- Carroll, B. (1998). *Carroll Depression Scales technical manual*. North Tonawanda, NY: Multi-Health Systems.
- Code, C., Hemsley, G., & Herrmann, M. (1999). The emotional impact of stroke. *Seminars in Speech and Language*, *20*, 19–31.
- Cruice, M., Worrall, L., Hickson, L., & Murison, R. (2003). Finding a focus for quality of life with aphasia: Social and emotional health, and psychological well-being. *Aphasiology*, *17*, 333–353.
- Demers, K. (2004). Try this: Best nursing practices to older adults: Hearing screening (*Dermatology Nursing*, 6 August 2004). Retrieved 13 July 2006 from: <http://www.medscape.com>
- Donovan, N., Rosenbek, J., Ketterson, T., & Velozo, C. (2006). Adding meaning to measurement: Initial Rasch analyses of the ASHA FACS Social Communication Subtest. *Aphasiology*, *20*, 362–373.
- Doyle, P. (2002). Measuring health outcomes in stroke survivors. *Archives of Physical Medicine and Rehabilitation*, *83*, S39–43.
- Doyle, P. (2005). Advancing the development and understanding of patient-based outcomes in persons with aphasia. *Perspectives on Neurophysiology and Neurogenic Speech and Language Disorders, ASHA Division 2*, *15*(4), 7–9.
- Doyle, P., Matthews, C., Mikolic, J., Hula, W., & McNeil, M. (2006). Do measures of language impairment predict patient-reported communication difficulty and distress as measured by the burden of strokescale (BOSS)? *Aphasiology*, *20*, 349–361.
- Duncan, P., Lai, S., Tyler, D., Perera, S., Reker, D., & Studenski, S. (2002). Evaluation of proxy responses to the Stroke Impact Scale. *Stroke*, *33*, 2593–2599.

- Duncan, P., Lai, S., Wallace, D., Embretson, S., Johnson, D., & Studenski, S. (1999). Stroke impact scale version 2.0: Evaluation of reliability, validity, and sensitivity to change. *Stroke*, *30*, 2131–2140.
- Folstein, M. F., Folstein, S., & McHugh, P. (1975). Mini-mental state: A practical method for grading the state of patients for the clinician. *Journal of Psychiatric Research*, *12*, 189–198.
- Goodglass, H., & Kaplan, E. (1983). *Boston Diagnostic Aphasia Evaluation*. Baltimore, MD: Williams & Wilkins.
- Guyatt, G., Feeny, D., & Patrick, D. (1993). Measuring health-related quality of life. *Annals of Internal Medicine*, *118*, 622–629.
- Hemsley, G., & Code, C. (1996). Interactions between recovery in aphasia, emotional and psychosocial factors in subjects with aphasia, their significant others and speech pathologists. *Disability and Rehabilitation*, *18*, 567–584.
- Herrmann, M., & Wallesch, C. (1990). Expectations of psychosocial adjustment in aphasia: A MAUT study with the Code-Muller scale of psychosocial adjustment. *Aphasiology*, *4*, 527–538.
- Hilari, K., Byng, S., Lamping, D., & Smith, S. (2003a). Stroke and Aphasia Quality of Life Scale – 39 (SAQOL-39). Evaluation of acceptability, reliability, and validity. *Stroke*, *34*, 1944–1950.
- Hilari, K., Wiggins, R., Roy, P., Byng, S., & Smith, S. (2003b). Predictors of health-related quality of life (HRQL) in people with chronic aphasia. *Aphasiology*, *17*(4), 365–381.
- Holbrook, M., & Skilbeck, C. (1983). An activities index for use with stroke patients. *Age and Ageing*, *12*, 166–170.
- Hunt, S. M. (1997). The problem of quality of life. *Quality of Life Research*, *6*, 205–212.
- Kertesz, A. (1982). *Western Aphasia Battery*. New York: Grune & Stratton.
- King, R. (1996). Quality of life after stroke. *Stroke*, *27*, 1467–1472.
- McKevitt, C., Redfern, J., La-Placa, V., & Wolfe, C. (2003). Defining and using quality of life: A survey of health care professionals. *Clinical Rehabilitation*, *17*, 865–870.
- Müller, D. (1999). Managing psychosocial adjustment to aphasia. *Seminars in Speech and Language*, *20*, 85–92.
- Naughton, M., & Shumaker, S. (2003). The case for domains of function in quality of life assessment. *Quality of Life Research*, *12*, 73–80.
- Orely, J., & Kuyken, W. (1994). *Quality of life assessment: International perspectives*. Berlin: Springer-Verlag.
- Paul, D., Frattali, C., Holland, A., Thompson, C., Caperton, C., & Slater, S. (2004). *Quality of Communication Life Scale*. Rockville, MD: ASHA.
- Raven, J., Court, J., & Raven, J. (1995). *Coloured Progressive Matrices*. Oxford, UK; Oxford Psychological Press.
- Ross, K., & Wertz, R. (2002). Relationships between language-based disability and quality of life in chronically aphasic adults. *Aphasiology*, *16*, 791–800.
- Ross, K., & Wertz, R. (2003). Quality of life with and without aphasia. *Aphasiology*, *17*, 355–364.
- Sarno, M. (1993). Aphasia rehabilitation: Psychosocial and ethical considerations. *Aphasiology*, *7*, 321–334.
- Sherbourne, C., & Stewart, A. (1991). The MOS social support survey. *Social Science Medicine*, *32*, 705–714.
- Smout, S., Koudstaal, P., Ribbers, G., Janssen, W., & Passchier, J. (2001). Struck by stroke: A pilot study exploring quality of life and coping patterns in younger patients and spouses. *International Journal of Rehabilitation Research*, *24*, 261–268.
- Sneeuw, K., Aaronson, N., DeHaan, R., & Limburg, M. (1997). Assessing quality of life after stroke. *Stroke*, *28*, 1541–1549.
- Sprangers, M., & Schwartz, C. (1999). Integrating response shift into health-related quality of life research: A theoretical model. *Social Science & Medicine*, *48*, 1507–1515.
- Toro, C., Altman, L., Raymer, A., Blonder, L., & Rothi, L. (2008). Changes in aphasia discourse after contrasting treatments for anomia. *Aphasiology*, *22*, 881–892.
- Ubel, P., Loewenstein, G., & Jepson, C. (2002). Whose quality of life? A commentary exploring discrepancies between health state evaluations of patients and the general public. *Quality of Life Research*, *12*, 599–607.
- Ventry, I., & Weinstein, B. (1983). Identification of elderly people with hearing problems. *ASHA*, *25*, 37–42.
- Williams, L., Weinberger, M., Harris, L., Clark, D., & Biller, J. (1999). Development of a stroke-specific quality of life scale. *Stroke*, *30*, 1362–1369.
- Yorkston, K., & Beukelman, D. (1980). An analysis of connected speech samples of aphasic and normal speakers. *Journal of Speech and Hearing Disorders*, *45*, 27–36.