

Measuring Changes in Quality of Life in Persons with Aphasia: Is Communication Confidence a Good Measure?

Many aphasiologists have discussed the lack of sensitivity of standardized measures to identify changes reported by individuals with aphasia regarding their quality of life following a treatment protocol. In particular, increased confidence in communication situations has been identified by our research participants as an important factor in their satisfaction with treatment. There are many tests which measure quality of life or communication skills: Burden of Stroke Scale (BOSS) (Doyle et al., 2003), ASHA Quality of Communication Life (ASHA-QCL) (Paul et al., 2004), and the Communicative Effectiveness Index (CETI) (Lomas et al., 1989). However, only one of these touches on the theme of communication confidence, the ASHA-QCL, but this scale directly asks about confidence in only one question and very generally, "I am confident that I can communicate." Other quality of life measures specific to aphasia, the Communication Disability Profile (CDP) (Swinbourne, 2006) and the Stroke and Aphasia Quality of Life Scale (SAQOL-39) (Hilari et al., 2003) also do not address communication confidence. However, a literature review of other communication disorders found one measure which directly assessed confidence in different communication contexts: the Self-Efficacy Scaling for Adult Stutters (SESAS) (Ornstein, et al., 1985).

Another issue with the current rating scales is that there is no standard among the measures. For example, the ASHA-QCL uses a vertical five-point scale with no numbers but graphic representations at the end points. The CETI uses a 100cm line without numbers. The SESAS uses a 90-point scale but requires the respondent to write their response in numbers. The BOSS uses three different rating scales and some of the items are linguistically complex.

The purpose of this presentation is to describe the development of the Communication Confidence Rating Scale (CCRS), a tool used in an ongoing treatment research study and provide preliminary data about its usefulness.

Methods:

The development of the Communication Confidence Rating Scale was based on features of the ASHA-QCL, the CETI and the SESAS, all self-report scales. The ASHA-QCL is comprised of 18 items regarding socialization/activities, confidence/self-concept, and roles/responsibilities. Responses are given based on a vertical five-point visual analog scale with graphics to indicate positive or negative responses. The CCRS borrows eight of the ASHA-QCL questions; these were selected because they seemed to have the most generalizability to most subjects in most situations. However, the questions were reworded so that they were similar to the SESAS and addressed the issue of confidence. See Table 1 for the original ASHA-QCL questions and the modified CCRS questions.

The CCRS also borrows the features of the response scales of the CETI and SESAS. The CETI uses a horizontal scale and respondents rate their communicative abilities as "the same as before their stroke" or "not able to do at all" on a 100cm line. The SESAS asks respondents to think about their abilities for particular situations on a decile scale from 10-100 and write their response as a number. Therefore, a combination of a horizontal scale with number markings from 0 to 100 was developed. For the CCRS, each question is read out loud and the subject is asked to circle their response. An average of the responses is then calculated.

The following is an example from the CCRS:

How confident are you about your ability to talk with people ?

0	10	20	30	40	50	60	70	80	90	100
1	1	1	1	1	1	1	1	1	1	1
Not Confident				Moderately Confident				Very Confident		

Subjects:

Eight subjects (4 males; 4 females) with non-fluent, Broca's aphasia participated. Ages ranged from 32 to 70 (mean=52; SD=15); months post onset ranged from 19 to 92 (Mean=47; SD=26); and WAB AQ scores ranged from 34.1 to 81.3 (Mean = 67.9 ; SD=16).

Procedures:

The CCRS, together with other standardized tests, was administered two different times: 1) prior to starting treatment and 2) at the end of nine weeks of treatment.

Results:

Results are shown in Table 2. Mean change between the pre and post scores on the CCRS was 21%. In contrast, mean change on the ASHA-QCL for the eight matched questions was only 3%, while mean change for the entire ASHA-QCL was only 2%. Standardized test scores also did not show much change. The absolute change in WAB-AQ scores ranged from -0.9 to 4.4 points for seven subjects with one other subject demonstrating improvement greater than five points (subject PER = 22.6). Mean percent change for all the WAB-AQ scores was 7%. The Boston Naming Test showed mean change of only 3%. When comparing to a functional communication measure, the Communication Activities of Daily Living, second edition (CADL-2) (Holland, et.al., 1999), the subjects also did not show changes. The mean change was 2%. However, mean change of scores on the CETI and the BOSS were similar to the CCRS; improvements were 17% and -14% respectively (the negative score indicates the respondent reports less burden from their stroke, therefore, is a positive outcome).

Discussion and Conclusions:

Data has provided preliminary support for the potential usefulness of a rating scale of communication confidence for individuals with aphasia. Our data show that subjects made only limited change on standardized language tests (ie. WAB, BNT), on a functional communication measure (CADL-2), and on a measure of quality of life (ASHA-QCL). However, changes were comparable between the CCRS, the BOSS and the CETI.

Exploration of the concept of communication confidence and aphasia is in the beginning stages. Considerable more work needs to be done to examine the external and internal validity of such a measure, as well as correlating it with other measures of quality of life, and determining inter- and intra-rater reliability. Although preliminary, these results are provocative and raise several theoretical issues that are worthy of discussion. First, what is confidence and how does it relate to a person's quality of life? Second, is communication confidence something that can be affected by therapy? Third, is communication confidence important to assess? Is assessment of communication confidence important only in the context of this one research study or is it an

important outcome for other aphasia research studies? Fourth, if it is important to measure, then the wording and types of questions need to be explored.

Given the myriad of options in the scales already in use, some lessons learned here might be applied in further development of a communication confidence rating scale such as having short, simple items, a broad visual scale, and only one response scale. It was noted that subjects all tended to rate themselves higher on a five-point scale like the ASHA-QCL as compared to their rating on a 100-point scale. Perhaps a five-point scale is not sensitive enough or does not provide enough “room for improvement” in a subject’s self-analysis. Additionally, including the word “confidence” in the question might allow for more self-analysis of communication skills. For example, the question “How confident are you about your ability to speak on the telephone?” asks for more reflection than rating the statement “I use the telephone.”

Perhaps using a measure based on one’s own perception of communication confidence will give an objective measure of information that has previously been elusive to assess with standardized language measures and even some quality of life assessments.

References:

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Table 1 – Questions from ASHA-QCL developed for the CCRS

ASHA QCL	Communication Confidence Rating Scale
1. I like to talk with people.	1. How confident are you about your ability to talk with people?
6. I stay in touch with family and friends.	2. How confident are you about your ability to stay in touch with family and friends?
7. People include me in conversations.	3. How confident are you that people include you in conversations?
8. I follow news, sports, and stories on TV/movies.	4. How confident are you about your ability to follow news, sports, and stories on TV/movies?
9. I use the telephone.	5. How confident are you about your ability to speak on the telephone?
11. People understand me when I talk.	6. How confident are you that people understand you when you talk?
13. I make my own decisions.	7. How confident are you that you can make your own decisions?
17. I speak for myself.	8. How confident are you about your ability to speak for yourself?

Table 2 – Quality of Life and Language measures from pre-treatment to post-treatment

Subject Code	CCRS Pre	CCRS Post	QCL-8 Pre	QCL-8 Post	QCL-17 Pre	QCL-17 Post	CETI Pre	CETI Post	BOSS Pre	BOSS Post	CADL 2 Pre	CADL 2 Post	BNT Pre	BNT Post	WAB AQ Pre	WAB AQ Post
COL	43	66	3.13	3.88	3.31	3.97	58	91	143	95	92	95	42	46	77.5	80.1
DOW	65	91	4.75	4.75	4.69	4.81	85	86	49	53	92	89	35	40	75.3	77.4
LUE	54	63	3.63	3.5	3.5	3.5	45	53	135	85	84	91	41	49	77.0	80.8
MAN	84	83	4.88	4.88	4.94	4.88			28	28	80	78	15	24	58.3	61.8
PEA	64	76	4.75	4.13	4.81	4.13	60	76	98	71	88	88	18	14	73.1	76.2
PER	63	61	3.88	4.5	3.94	4.25	63	60	110	146	63	61	21	12	34.1	56.7
ROM	56	78	4.13	4.25	4.25	4.19	46	63	73	62	91	94	57	55	85.3	84.4
SCH	84	86	4.5	4.88	4.5	4.71	90	95	57	55	87	92	47	44	76.8	81.2
Mean	61	74	4.16	4.27	4.24	4.31	64	75	87	74	85	86	35	36	69.7	74.8
SD	14	11	.63	.5	.61	.5	18	16	42	35	10	11	15	17	16	10
% Change	21%		3%		2%		17%		-14%		2%		3%		7%	

Key: CCRS – Communication Confidence Rating Scale

QCL-8 – ASHA, Quality of Communication Life Scale, 8 questions modified for CCRS

QCL-17 – ASHA Quality of Communication Life Scale, all 17 items

CETI – Communication Effectiveness Index

BOSS – Burden of Stroke Scale

CADL-2 – Communication Activities of Daily Living, second edition

BNT – Boston Naming Test

WAB-AQ – Western Aphasia Battery- Aphasia Quotient