12-31-2020

# The Relationship between Narrative Informativeness and Psychosocial Outcomes in Chronic Stroke-Induced Aphasia

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THESIS
Submitted in Partial Fulfillment of the
Requirements for the Degree of

**Master of Science**

**Speech-Language Pathology**

The University of New Mexico
Albuquerque, New Mexico

**July 2020**

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ABSTRACT

Currently there is a gap in the literature in understanding the relationship between the newly categorized primary outcome measure of discourse and secondary outcomes related to psychosocial impact, such as participation, psychological impact, social well-being, or mood. In a large sample of persons with stroke-induced aphasia (N=115), this study analyzed discourse samples using main concept analysis to determine how discourse performance correlates with the secondary outcome measures ALA, CCRSA, GDS, and CIQ. As a secondary research question, the differences in these relationships dependent on severity was also explored. Results showed statistically significant positive correlations between main concepts (MCs) and ALA (overall), CCRSA, and CIQ (overall), with effect sizes ranging from weak to moderate strength. This study provides novel insights into the relationship between the newly categorized primary outcome measure of discourse and secondary outcomes related to psychosocial impact.

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CHAPTER 1

INTRODUCTION

Aphasia is an impairment of an established language system that affects

production and comprehension of language. Aphasia is most often caused by stroke,

though it can be caused by other brain damage (e.g., brain injury, brain tumor) or

deterioration (e.g., primary progressive aphasia). Simmons-Mackie (2018) estimates that

the prevalence of aphasia due to stroke in the United States ranges from 2,210,000 to

2,550,000. Persons with aphasia (PWAs) report difficulties recalling once familiar words

in conversation, reading written words and/or letters, writing, and/or understanding

spoken language. These language difficulties negatively impact the ability to share

feelings and ideas, make comments, or ask questions, restricting communication

opportunities with family members, friends, and broader social and community networks

(Davidson, Howe, Worrall, Hickson, & Togher, 2008). PWAs are often unable to fulfill

pre-stroke life roles and responsibilities, and experience restricted community

participation and increased reliance on others. This affects their autonomy and their

ability to independently navigate society. Additional consequences include financial

strain from decreased vocational opportunities and increased medical costs (Ellis,

Simpson, Bonilha, Mauldin, & Simpson, 2012; Ganzfried, 2018). The negative

consequences related to aphasia for PWAs, their families, and society at large highlight

the importance of effective management and rehabilitation of aphasia (Brady, Kelly, Godwin, Enderby, & Campbell, 2016).

Aphasia therapy targets maximizing language abilities post-stroke, and participants in programs show more improvements as compared to those who do not (Brady, et al., 2016; Papathanasiou, Coppens, & Davidson, 2016). Confidence in aphasia treatment efficacy is based on decades of research that has focused on impairment-based measures as primary outcomes, aligned with the body structure and function domain within the World Health Organization International Classification of Functioning (WHO-ICF). There is abundant evidence of treatment-induced change in measures such as naming, receptive abilities (e.g., following directions), and overall aphasia severity. Such measures have been enjoyed and utilized for their ease of administration and interpretation as well as their psychometric properties. A focus on these outcomes have thus shaped clinical practice, including reimbursement practices and research directions. However, recent studies have called into question the usefulness of such measures. For example, studies have shown a lack of significant correlation between naming and real-world communication abilities (e.g., having a conversation, telling a story, participating in social gatherings), and caution the use of this measure as predictive of speaker's discourse performance (Mayer & Murray, 2003; Fergadiotis & Wright, 2015). Correlations between naming and discourse abilities may be present, but only for some subtypes - Richardson et al. (2018) found strong correlations between naming (object and verb) and narrative "gist", but only for persons with Broca's and Wernicke's aphasia. Taken together, these findings confirm the notion that naming and other measures of

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discrete language impairment are not strong measures for predicting functional

communication for all PWAs.

Given the devastating impacts of aphasia described above, it is critical to focus on

outcomes that matter to PWAs and their families, and what matters to PWAs is not

necessarily in alignment with the measures that have historically been used to indicate

improvement. For example, Wallace et al. (2017) found that PWAs desire most to

communicate functionally with a variety of communication partners, reintegrate and

participate in community/society, and improve quality of life (psychosocial well-being).

While impairment-based measures are certainly reliable indicators that can reveal one

aspect of aphasia recovery, there are other equally, or even more, important areas to

consider in the WHO-ICF framework, including activity (e.g., functional communication,

conversational abilities) and participation (e.g., interpersonal interactions). In response to

repeated and more frequent calls to address the desires of PWAs and their families with

aphasia treatment, the Cochrane review working group has recategorized outcome

measures, so that impairment-based measures such as naming, receptive abilities, and

aphasia severity, are now relegated to secondary outcome status (Brady et al., 2016).

Primary outcome measures now focus on characterization functional communication

abilities, beyond communication of the most basic wants and needs. This is in line with

the WHO-ICF emphasis on activity and participation, that inspired the life participation

approach to aphasia (LPAA) (Chapey, et al., n.d.; Elman, 2016). This recategorization

also resonates with guidance by Aura Kagan and Nina Simmons-Mackie (2007) to

remember that "the choice of aphasia assessment and intervention strategies should be

directly influenced by outcome goals related to life participation in its broadest sense" (p. 309). Functional communication measures should address the ability to convey a meaningful message to a listener in everyday exchanges (Brady et al., 2016). Brady and colleagues acknowledge what is readily understood by clinicians and researchers worldwide - evaluation and treatment of functional communication is not straightforward. They suggest inclusion of measures such as the Communicative Abilities of Daily Living (CADL), the Communicative Effectiveness Index (CETI), and discourse, and state that development of functional communication measures is an area in need of much more attention and research.

Discourse is defined as "any language that is beyond the boundaries of isolated sentences" (Ulatowska & Olness, 2004, p. 300) and reflects a complex activity of combining linguistic elements into a coherent and meaningful message (Wright, 2011). Focus on discourse measurement has been steadily growing since Elizabeth Armstrong's seminal paper that examined the many different types of discourse measures and their theoretical underpinnings (Armstrong, 2000). Since that time, there has been the creation of a standardized discourse protocol with normative references (AphasiaBank; https://aphasia.talkbank.org), a focus on psychometric development of discourse measures (Pritchard, Hilari, Cocks, & Dipper, 2018), and even a movement to establish a core outcome set of discourse measures (D-COS) for worldwide utilization and dissemination (e.g., de Riesthal & Diehl, 2018; Dietz & Boyle, 2018; Wallace et al., 2018). Common discourse elicitation techniques include picture description, story retelling, procedural descriptions, and unstructured topic-related or open-ended conversations (Bryant,

Ferguson, & Spencer, 2016). The structured discourse tasks included on AphasiaBank include sequential picture description (Broken Window, Refused Umbrella), complex single picture description (Cat Rescue), story (re)telling (Cinderella story), and procedural memory (How to Make a Peanut Butter and Jelly Sandwich - hereafter referred to as Sandwich). There is some evidence that discourse abilities measured in structured clinical settings may be more representative of real-world conversational abilities (Mayer & Murray, 2003; Richardson & Dalton, 2015). This aligns well with the new primary aphasia treatment outcomes, previously mentioned by Cochrane, focused on maximizing functional communication abilities.

There are well-known and significant barriers to incorporating discourse into clinic and research. One barrier is the extensive time and energy required of clinicians to transcribe, code, and analyze, which is one of the main reasons discrete language tasks have received more focus compared to dynamic speech production (Johnson, Kurland, Parker, Fromm, & MacWhinney, 2012). The sheer number of available elicitation techniques and measures is also daunting for clinicians and researchers. Bryant et al. (2016) reported that over 500 different discourse measures were included in their review of 165 studies that included discourse outcomes. However, Pritchard et al. (2018) encourage usage and continued forward progress of discourse measurement, as their review of the psychometric properties of discourse measures in aphasia indicated "high level of acceptability, inter- and intra-rater reliability, and had good content… and construct validity" (p. 1086). Further, concerted efforts are being made to make discourse analysis more clinician-friendly (e.g., Dalton, Hubbard, & Richardson, 2020). For

example, clinicians can use checklists of main concepts for multiple standardized discourse tasks to assess whether discourse skills are effectively conveying the appropriate message to the listener (Nicholas & Brookshire 1995; Richardson & Dalton, 2015, 2019). Main concept analysis seems to be useful for characterizing deficits and detecting differences in performance between typical and clinical populations, and identifying differences between aphasia subtypes (Kong, Whiteside, & Bargmann, 2016; Dalton & Richardson, 2015; Dalton & Richardson, 2019). Additionally, clinicians can use checklists of words typically used to describe certain pictures or tell stories, called a core lexicon, to assess how well PWAs are able to tap into typical lexical usage (Dalton & Richardson, 2015; Kim & Wright, 2020). Importantly, these and other measures in development can be completed without time-consuming phonetic transcription. Still, because discourse sampling obtained in a controlled clinical or laboratory environment is usually semi-spontaneous in nature, it is not known with certainty that such samples predict successful conversational abilities in the real-world. This a future direction for research, looking directly into the predictive relationship between, for example, picture description and spontaneous conversational abilities.

While treatment studies have increasingly added discourse measures, participation measures, and quality of life measures as secondary research questions or generalization outcomes, no published works examine the relationship between discourse and other pertinent secondary outcome measures such as participation, psychological impact, social well-being, or mood. These measures reflect the personal and contextual domains of the WHO-ICF and can have a significant impact on the PWA as well as the caregiver, who

may influence communication success and who also experience negative consequences of the stroke and aphasia. There is no standard battery of assessment tools to measure activity and participation impact due to a lack of comprehensive, reliable, valid, and globally accepted tools. However, a recent international survey of different stakeholders (patients, caregivers, providers) emphasized that a core outcome set should include measures of emotional wellbeing, patient reported satisfaction, and quality of life, in addition to measures of language and communication (Wallace, Worrall, Rose, & Le Dorze, 2019b). Certain measurement instruments were even suggested based upon consensus (Wallace et al., 2019a). Currently, it is up to the clinician's discretion to choose appropriate assessments that will reflect accurate management and rehabilitation of a PWA's language and communication abilities, activity, and participation (Brady et al., 2016). Some commonly used (clinically and research) formal measures include the Assessment for Living with Aphasia (ALA), Communication Confidence Rating Scale (CCRSA), Geriatric Depression Scale short form (GDS-SF), and Community Integration Questionnaire (CIQ). There is a gap in the literature in understanding relationships between discourse abilities and these secondary psychosocial measures.

The ALA is a pictographic, self-report measure of aphasia-related quality of life with strong psychometrics that captures key aspects of living with aphasia (Simmons-Mackie, 2014). The CIQ is a patient-reported questionnaire on the social role, limitations, and community interaction of people with an acquired brain injury. It is another one of the few formal assessments looking at participation in PWAs with appropriate psychometric properties (Dalemans, de Witte, Lemmens, van den Heuvel, & Wade, 2008;

Dalemans, de Witte, Beurskens, van den Heuvel, & Wade, 2010). The CCRSA is a questionnaire that measures PWAs levels of confidence in various communication environments and activities. It is a psychometrically sound tool for assessing participants' self-report of communication confidence (Babbitt, Heinemann, Semik, & Cherney, 2011). The GDS-SF is used to identify depression in older adults and can be administered to PWAs with appropriate accommodations (e.g., use of informants, modifying questions, visual mood scales, etc.) (Townend, Brady, & McLaughlan, 2007). While there is research studying quality of life and psychosocial well-being in those with aphasia, there is no research that investigates the relationship between discourse and such measures (Cruice, Hill, Worrall, & Hickson, 2008; Cruice, Worrall, & Hickson, 2011). There is a single study that investigated the relationships between impairment-based and psychosocial measures as a secondary research question (Chiou & Yu, 2018). Main findings showed strong correlations between the ALA, CCRSA, and certain cognitive abilities. Importantly, there was not a significant correlation between the WAB-R and ALA, supporting the argument that a PWA's life participation perspective is not best revealed through an impairment-based measure (Chiou & Yu, 2018).

Currently there is no research that investigates the potential relationship between the newly categorized primary outcome measure of discourse and secondary outcomes related to psychosocial impact in a large sample of persons with stroke-induced aphasia. The purpose of this study is to analyze discourse samples using main concept analysis to gather information on micro- and macro-linguistic discourse abilities and determine how discourse performance correlates with the secondary outcome measures ALA, CCRSA,

GDS, and CIQ. As a secondary research question, we will explore the differences in these relationships by severity.

CHAPTER 2

METHODS

**Participants**

Participants included males and females 18 years of age and older who acquired

aphasia as a result of a stroke. Persons under the age of 18 were not included because

speech and language deficits due to neurological injury present and recover in

fundamentally different ways in children and adults. All participants had adequate

auditory and visual acuity to consent to the research and participate in assessment tasks.

Specifically, they were able to hear well enough to understand verbal instructions and

repeat words and sentences from an auditory cue, and could see well enough to complete

subtests of the speech and language testing that required interpretation of pictorial and

written material. All participants reported proficiency in English prior to the onset of

stroke. Proficiency was defined as primary use of English in one or more of the following

settings: home, work, community, and school. This language requirement was necessary

because the spoken language tasks were presented in English. Participants had a history

and confirmed diagnosis, per a neurologist, of stroke affecting language. A stroke

etiology allowed the study of a more homogeneous population, as people with other

etiologies (e.g., brain tumor, multiple sclerosis, progressive aphasia) may respond in

unique ways that could impact analysis. Additional exclusionary criteria included a

primary diagnosis of dementia based on a review of the medical records and/or patient

report. Participants were not excluded based on race, gender, or ethnicity.

Data from 228 PWAs was collected from a study titled "Communication, Activity, and Life Participation in Aphasia" (CALPA) that is being conducted at two primary sites - University of New Mexico (PI: Richardson) and University of North Carolina - Chapel Hill (PIs: Jacks, Haley). Several data reduction procedures were carried out to reduce a portion of the heterogeneity present in the large sample. First, a stroke etiology of the aphasia was required for inclusion. Second, they had to have completed three discourse production tasks (DPT) that covered different genres: 1) sequential picture description (Broken Window), 2) story retell (Cinderella), and 3) procedural discourse (PB&J Sandwich). Finally, participants had to have completed at least one of the appropriate psychosocial measures (ALA, CCRSA, GDS, and/or CIQ). Consistent with current research (Dalton & Richardson, 2015; Dalton & Richardson, 2019), the discourse performance of individuals who scored above the WAB cut-off (not aphasic by WAB; NABW) was investigated as a group distinct from PWA and other aphasia subtypes. This resulted in 115 (40 female, 75 male) PWAs. There were 41 Anomic, 22 Broca, 18 Conduction, 28 NABW, 2 Transcortical Motor, 1 Isolation, 1 Wernicke's, and 2 unclassified aphasics in the sample. See Figure 1 for details regarding data reduction. See Table 1 for complete demographics by group and subtype. See Table 2 for the number of participants included in each analysis.

**Figure 1.** Recruitment Breakdown
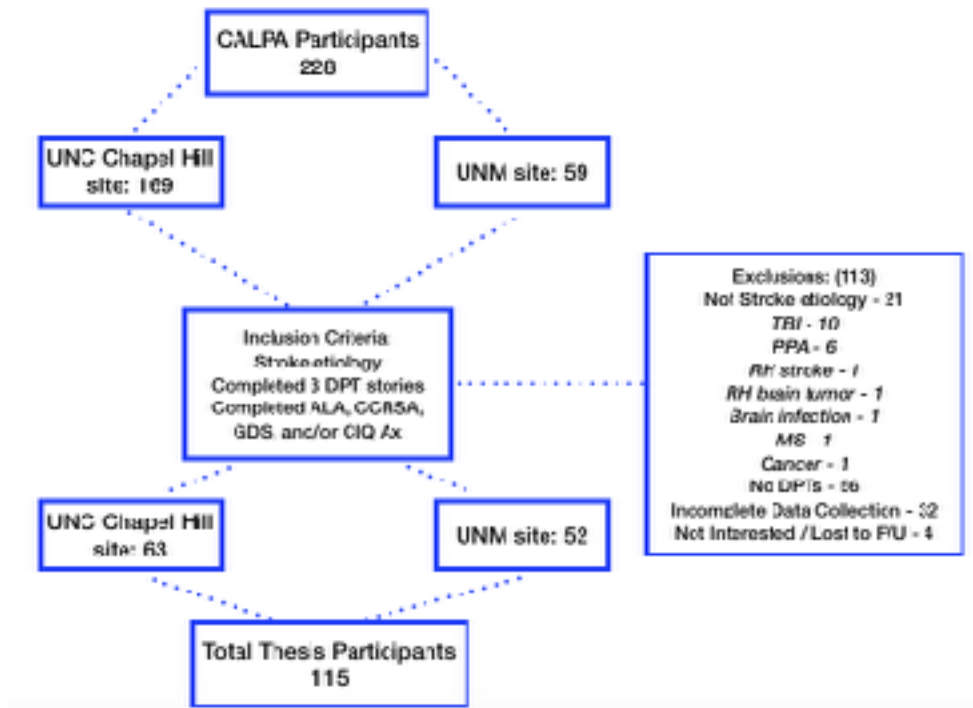


**Table 1.** Demographic information for all participants*

|  | All PWAs | Anomic | Broca's | Conduction | NABW | Transcortical Motor |
|---|---|---|---|---|---|---|
| **Age (years)** | 60.0 (±14.3) 18 - 88 | 62.5 (±14.0) 18 - 80 | 54.3 (±15.6) 19 - 82 | 63.2 (±12.7) 41 - 83 | 59.0 (±14.1) 25 - 88 | 56.5 (±13.4) 47 - 66 |
| **Aphasia Duration (months)** | 49.4 (±63.8) 2 - 352 | 57.3 (±79.2) 3 - 352 | 59.5 (±66.4) 4 - 252 | 44.4 (±48.1) 2 - 180 | 35.3 (±48.8) 3 - 180 | NA |
| **WAB Aphasia Quotient \*\*** | 79.0 (±18.0) 29.8 - 100 | 87.0 (±5.1) 71.4 - 93.7 | 53.6 (±11.6) 29.8 - 71.6 | 69.3 (±7.0) 52.3 - 80.1 | 96.8 (±1.8) 94 - 100 | 79.0 (±1.9) 77.6 - 80.3 |
| **Gender** | 40 Female 75 Male | 13 Female 28 Male | 10 Female 12 Male | 5 Female 13 Male | 11 Female 17 Male | 0 Female 2 Male |

| Table 1. [cont.] | | | | | | |
|---|---|---|---|---|---|---|
| **Education (years)**** | 14.8 (±2.9) 7 - 22 | 16.5 (±3.0) 12 - 22 | 13.3 (±1.9) 9 - 16 | 13.1 (±2.9) 7 - 16 | 15.6 (±3.0) 12 - 22 | NA |
| **Race/ Ethnicity**** | 83 Caucasian 11 African American 1 Native American 13 Hispanic/ Latino 4 Multiple 1 Other 1 N/A | 31 Caucasian 6 African American 1 Native American 2 Multiple (W/EA & AA; EA & Swedish) | 13 Caucasian 3 African American 5 Hispanic/ Latino | 16 Caucasian 1 African American 1 Hispanic/ Latino | 20 Caucasian 5 Hispanic/ Latino 1 Other 2 Multiple (EA/HIS) | 1 Caucasian 1 African American |

\* Did not report demographics for subtypes with N=1 (Isolation & Wernicke's)
\*\* 2 participants did not complete WAB
\*\*\* 53 missing observations
\*\*\*\* 1 missing observation

**Table 2.** Test pairings

| Discourse & ALA | Discourse & CCRSA | Discourse & GDS | Discourse & CIQ |
|---|---|---|---|
| N=106 | N=113 | N=101 | N=96 |

**Assessments**

*Main Concept Analysis*

Main concept analysis (MCA) has been described an approach that can evaluate the micro- and macro-structure of language (Armstrong, 2000), as it highlights deficits and performance differences at the word and sentence level, as well as information related to discourse abilities, specifically whether or not speakers communicate essential concepts needed to express the overall "gist" of the main ideas in a picture, story, or procedure in which speakers share knowledge (Nicholas & Brookshire, 1993a). A main concept (MC) is defined as an utterance that contains a subject, main verb, and an object, if appropriate. Multiple studies have identified MCA as a stable and sensitive measure for discourse, with strong inter- and intra-rater reliability across raters and testing sessions (Boyle, 2014; Hopper, Holland, & Rewega, 2002; Kong, 2009; 2011; Nicholas & Brookshire, 1993a; 1995). Additionally, MCA provides information about communication adequacy and is correlated with listener ratings of overall communication abilities (Ross & Wertz, 1999). MCA has been used to analyze the MC production differences between controls and PWAs (Kong, 2009; Nicholas & Brookshire, 1993a, 1995; Richardson & Dalton, 2015) and between persons with fluent versus nonfluent aphasia types (Kong, 2009).

Transcripts were scored for main concepts (MCs) using a closed list created from the narratives of 92 control speaker's transcripts retrieved from the AphasiaBank database (Richardson & Dalton, 2015). Narratives included Broken Window, Cinderella, and Sandwich, and were elicited according to standardized AphasiaBank procedures

(MacWhinney, Fromm, Forbes, & Holland, 2011). Stories were scored for the presence or absence of MCs, and for the accuracy and completeness of MCs that were present. Coding procedures were adapted from Nicholas and Brookshire (1995), where missing MCs were coded as absent (AB) and MCs that were present could receive one of four codes based on accuracy and completeness: accurate and complete (AC), where all essential information is accurate and complete; accurate but incomplete (AI), where part of the essential information is accurate but one or more essential parts are missing; inaccurate but complete (IC), where all required elements are present but one or more parts of the essential information are inaccurate; and inaccurate and incomplete (II), where one or more required elements contains inaccurate essential information and has missing essential information (see Table 3). MC codes were transformed to numeric scores using the formula: $AC(3) + AI(2) + IC(2) + II(1) + AB(0) = MC$ score. Scores for each MC were summed within stories to yield an MC composite score. Finally, the number of MCs a participant attempted to produce for each story (MC attempts) was calculated by adding the number of statements receiving AC, AI, IC, and II codes. See Table 3 for examples of main concept coding.

**Table 3.** Main Concept Codes, Definitions, and Examples.

| Cinderella Main Concept: ***She[1] ran[2] down the stairs[3].*** | | |
|---|---|---|
| Code | Definition | Example |
| AC | <u>Accurate/Complete:</u> All required elements are present and accurate. | "She[1] was running[2] down the stairs[3]." |
| AI | <u>Accurate/Incomplete:</u> One or more required elements missing, all required elements that are produced are accurate. | "She[1] had to run[2]." |
| IC | <u>Inaccurate/Complete:</u> All required elements are present, one or more are inaccurate. | "So he[1] gets[2] out[3]." |
| II | <u>Inaccurate/Incomplete:</u> One or more required elements missing, one or more of the required elements produced are inaccurate. | "He[1] run[2]." |

*Assessment for Living with Aphasia*

The Assessment for Living with Aphasia (ALA) (Kagan et al., 2010) is a 45-item

pictographic questionnaire of self-reported perceptions on aphasia-related quality of life

measures that captures qualitative and quantitative data. Quantitative questions involve

frequency counts and a rating scale, where patients are asked to respond to questions

(e.g., "How would you rate your talking?" "Are you satisfied with the number of days

you go out?") using a scale of 0-4 (0 reflecting most negative/definitely no, 4 reflecting

most positive/definitely yes) to inform on impact. This self-report captures key aspects of

living with aphasia within 5 sub-domains: Aphasia, Participation, Environment, Personal,

and Wall (Simmons-Mackie, 2014). Test-retest reliability of the instrument is strong, with

moderate to high intraclass correlations (ICC) for the ALA overall score (0.87) and

individual sub-domain scores (0.66 to 0.84). There is high internal consistency of items

according to Cronbach's alpha (0.592 to 0.891). This assessment's construct or

concurrent validity resulted in a significant and moderately strong correlation compared

to measures believed to assess similar constructs including the Stroke and Aphasia

Quality of Life scale-39 (SAQOL-39) ($r$ = 0.65; p<0.001); the Visual Analogue Self-

esteem Scale (VASES) ($r$ = 0.63; p<0.001); the Communication-Associated

Psychological Distress Scale of the Burden of Stroke Scale (BOSS CAPD) ($r$ = -0.63; p<

0.001). Overall, the ALA is a psychometrically sound assessment tool built on the

expressed needs and concerns of key stakeholders, including people with aphasia, family

members, and speech-language pathologists.

*Communication Confidence Rating Scale for Persons with Aphasia*

The Communication Confidence Rating Scale for Persons with Aphasia (CCRSA)

(Babbitt & Cherney, 2010) was originally developed as an 8-item questionnaire of self-

reported confidence for various conversational environments. It was based off the

American Speech-Language-Hearing Association Quality of Communication Life Scale

(ASHA-QCL) (Paul, Frattali, Holland, Thompson, Caperton, & Slater, 2004) and Self-

Efficacy Scale for Adult Stutterers (SESAS) (Ornstein & Manning, 1985) to address

confidence specifically, an area deemed important by patients. The questions from the

ASHA-QCL were adjusted to focus on whether a patient was confident in a

communicative act, as compared to the original wording regarding whether or not they

participated in a specific communicative act (e.g., "I use the telephone," shifted to "How

confident are you about your ability to speak on the telephone?"). A horizontal response

scale (0 to 100) was incorporated from the SESAS. A psychometric properties study

showed statistically significant results and findings supported the reliability and sensitivity of the CCRSA in assessing participants' self-report of communication confidence. However, there were many subtly different communication opportunities to choose from and room for interpretation, which suggested the need for further evaluation with a larger and more diverse sample size (Cherney, Babbitt, Semik, & Heinemann, 2011). A revised 10-item CCRSA questionnaire was evaluated with a rating scale analysis (Rasch) performed by Babbitt, Heinemann, Semik, & Cherney (2011), which showed significant Person and item reliability (0.81 and 0.96 respectively) using Cronbach's alpha of 0.80. Findings support the reliability and sensitivity of the 10-item CCRSA in assessing participants' self-report of communication confidence, evidenced by the improved psychometrics as compared to the original (Babbitt, Heinemann, Semik, & Cherney, 2011). The CCRSA is the only published confidence measure designed for use with people who have aphasia. Modifications were made to the CCRSA (e.g., large print, large 1-100 scale, adding practice questions to orient patients to the task and confirm understanding, etc.) to ensure participant comprehension of the questions and the task.

*Geriatric Depression Scale Short Form*

The Geriatric Depression Scale Short Form (GDS-15) (Sheikh & Yesavage, 1986) is a 15-item yes/no questionnaire designed to identify the presence and severity of depression on a scale that ranges from 0-15, specifically for the elderly. This scale is described as a valid screening instrument as it correlates well ($r$=.82 and $r$=.78) with scores on the Montgomery Asberg Depression Rating Scale (MADRS) in 2 separate studies (Almeida & Almeida, 1999; Herrmann et al., 1996). GDS-15 scores also correlate

with scores from the original 30-item GDS ($r$=.84; Herrmann et al., 1996; Sheikh &

Yesavage, 1986), which reports internal consistency of .94, test-retest reliability of .85,

and high criterion-related validity with the Zung Self-Rating Depression Scale ($r$=.84)

and the Hamilton Rating Scale for Depression ($r$=.83) (Yesavage et al., 1982).

Modifications were made to the GDS-15 (e.g., large print, large yes/no icons available for

pointing, etc.) to ensure participant comprehension of the questions and the

task. Questions were presented in a powerpoint format, one at a time, in order to reduce

complexity of task (i.e., allow for participants to focus on one question at a time with no

other questions present as possible distractions).

*Community Integration Questionnaire*

The Community Integration Questionnaire (CIQ) (Willer, Rosenthal, Kreutzer,

Gordon, & Rempel, 1993) is a 15-item questionnaire that assesses the social role,

limitations, and community interaction of people with acquired brain injury. Dalemans,

de Witte, Beurskens, van den Heuvel, and Wade (2010) conducted a cross-sectional,

interview-based psychometric study on 150 people with a range of aphasia severity

(minimal to severe). Results indicated good internal consistency with a standardized

Cronbach's alpha of 0.75, excellent test-retest reliability (ICC = 0.96), and moderate

correlations with the Barthel Index (Mahoney & Barthel, 1965), the Dartmouth Coop

Functional Health Assessment (COOP) Charts - World Organisation of Family Doctors

(WONCA) Charts (COOP-WONCA) (Van Weel, 1993), and the Life Satisfaction

Questionnaire (Endicott, Nee, Harrison, & Blumenthal, 1993) with regard to construct

validity. Significant relationships were found with regard to age and aphasia severity

(Dalemans, 2010). The CIQ adjusted for people with aphasia is a feasible instrument that is adequate in assessing participation in this particular population. Modifications were made to the CIQ (e.g., large print, pictures to enhance questions) to ensure participant comprehension of the questions and the task.

**Data Analysis**

Each participant was grouped into test pairings for analysis, dependent on which assessments were completed (e.g., discourse and ALA; discourse and CCRSA, etc.). See Figure 1 and Table 2 for details. Although there are many reports on discourse, as well as on activity and participation measures, reported in people with chronic stroke-induced aphasia, no studies have examined the relationships between these measures. Our primary research question sought to determine the relationship between overall Main Concept (MC) scores and the overall scores of the selected psychosocial measures. Two of these measures, the ALA and the CIQ, also have several subtests. Following calculation of overall correlations, we also conducted tests between the overall MC scores and each of the ALA and CIQ subtests to determine if specific subtests were more notable than others. Bivariate correlations using Pearson product-moment coefficients measures the strength and direction of association that exists between two variables. Data were screened to ensure assumptions of Pearson's correlation analysis were met: (1) the two variables measured are continuous, (2) there is a linear relationship between the two variables, (3) there are no significant outliers, and (4) the variables are approximately normally distributed. Our data did not meet the first assumption of being continuous variables, as some are ordinal measurements. A Spearman's rank-order correlation

(Spearman rho) is a nonparametric measure of the strength and direction of association that exists between two variables measured on at least an ordinal scale. Spearman's two assumptions are (1) that the two variables should be measured on an ordinal, interval, or ratio scale, and (2) there is a monotonic relationship between the two variables. This statistical approach was appropriate for many of our comparisons because of its decreased sensitivity to populations that do not have normal distributions or populations that contain outliers, which were characteristics of our data set. For one assessment (GDS), our data did not show a monotonic relationship between variables (a violation of Spearman's second assumption), so a Kendall's tau-b was run as an alternative. Kendall's assumptions are (1) that the two variables measured are on an ordinal or continuous scale, and (2) Kendall's tau-b determines if there is a monotonic relationship between the variables, however, this is not a strict requirement. The level of significance was set a priori at $p \leq .05$ for all analyses in order to identify significant correlations. Statistical Package for the Social Science (SPSS) version 26.0 (Chicago, IL) was used to generate descriptive statistics and perform statistical analyses.

To explore our secondary question regarding potential differences in relationships by severity, participants were sorted into bins based on their WAB AQ scores (0-25 = very severe, 26-50 = severe, 51-75 = moderate, 76-93.8 = mild, 93.9+ = NABW). Kendall's tau-b values are reported due to the more restricted sample sizes and the expected lack of consistent linear or monotonic relationships between variables due to severity bins.

CHAPTER 3

RESULTS

**Reliability**

To measure reliability of MC coding based on Nicholas and Brookshire protocol

(Nicholas & Brookshire, 1995), the author re-scored 20% of randomly selected

transcripts for intra-rater reliability, which resulted in 87.63% consistency. A speech-

language pathology graduate student re-scored a separate 20% of randomly selected

transcripts for inter-rater reliability, which resulted in 83.36% consistency.

**Correlations between Main Concepts and Psychosocial Measures**

A Spearman's rho examined the relationship between MC composite scores and

the four assessments of interest (ALA, CCRSA, CIQ, GDS) (see Table 4). A Spearman's

rank-order correlation determined a weak to low, positive correlation with the ALA total

($r_s(106) = .218$, p = .025) (see Figure 2), a low to moderate, positive correlation with the

CCRSA ($r_s(113) = .397$, p = .000) (see Figure 3), and a weak to low, positive correlation

with the CIQ ($r_s(96) = .268$, p = .008) (see Figure 4). A Kendall's tau-b correlation was

run to determine the relationship between MC composite and the GDS since the

assumptions were not met for a Spearman's rho; no monotonic relationship was present

between the two variables.

**Table 4.** Descriptive Statistics for MC Composite and Assessment Totals

|       | N   | $r_s$        | p    |
|-------|-----|--------------|------|
| ALA   | 106 | .218         | .025 |
| CCRSA | 113 | .397         | .000 |
| CIQ   | 96  | .268         | .008 |
| GDS   | 101 | -.044 (τb)   | .532 |

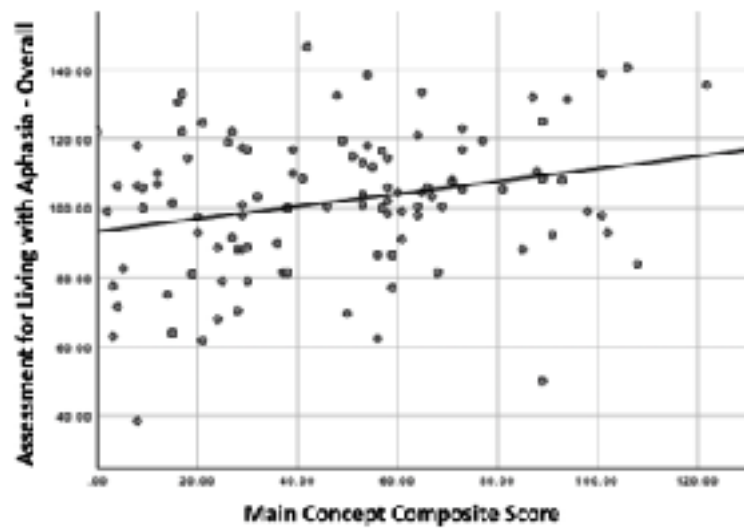**Figure 2.** ALA Correlation Graph



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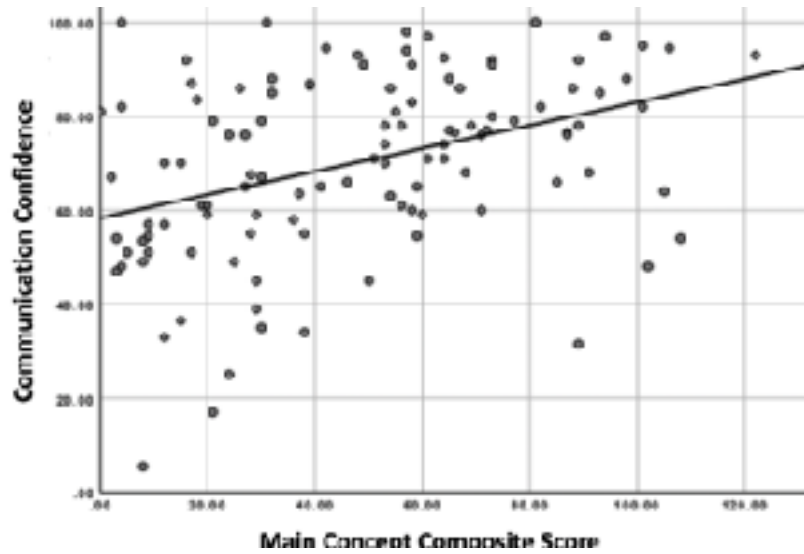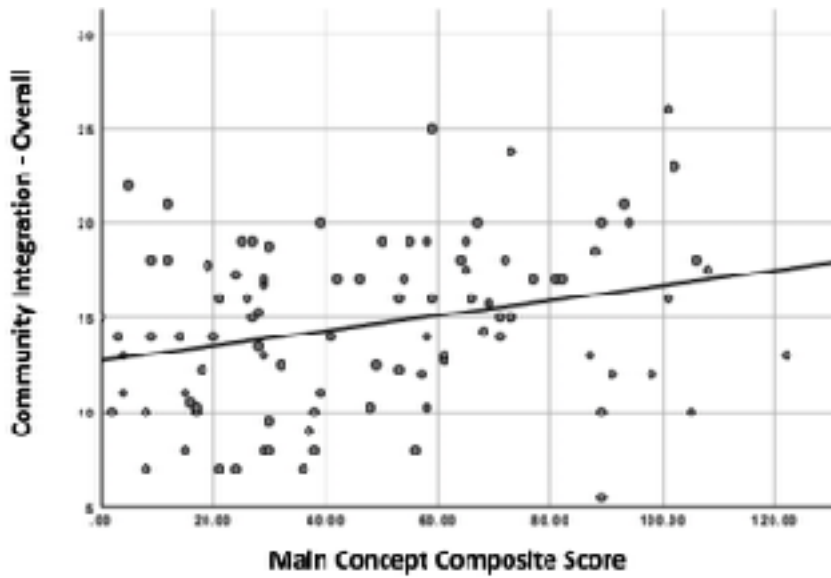**Figure 3.** CCRSA Correlation Graph



**Figure 4.** CIQ Correlation Graph



Because two outcome measures had subtests (ALA, CIQ), it was further explored

whether certain subtests were correlated more or less strongly with the MC composite

score, compared to the overall scores. A Spearman's rank-order correlation was run to

determine the relationship between MC composite score and ALA subtest scores (see

Table 5). There was a low to moderate, positive correlation between MC composite score and ALA-Aphasia score ($r_s(106) = .393$, p = .000) (see Figure 5), a weak to low, positive correlation between MC composite score and ALA-Participation score ($r_s(106) = .194$, p = .046) (see Figure 6), and a low to moderate, positive correlation between MC composite score and ALA-Environment score ($r_s(106) = .402$, p = .000) (see Figure 7).

**Table. 5** Descriptive Statistics for MC Composite and ALA Subtest Scores

|  | N | $r_s$ | p |
|---|---|---|---|
| Aphasia | 106 | .393 | .000 |
| Participation | 106 | .194 | .046 |
| Environment | 106 | .402 | .000 |
| Personal | 106 | .017 | .859 |
| Wall | 106 | -.066 | .500 |

**Figure 5.** ALA - Aphasia Subtest Correlation Graph
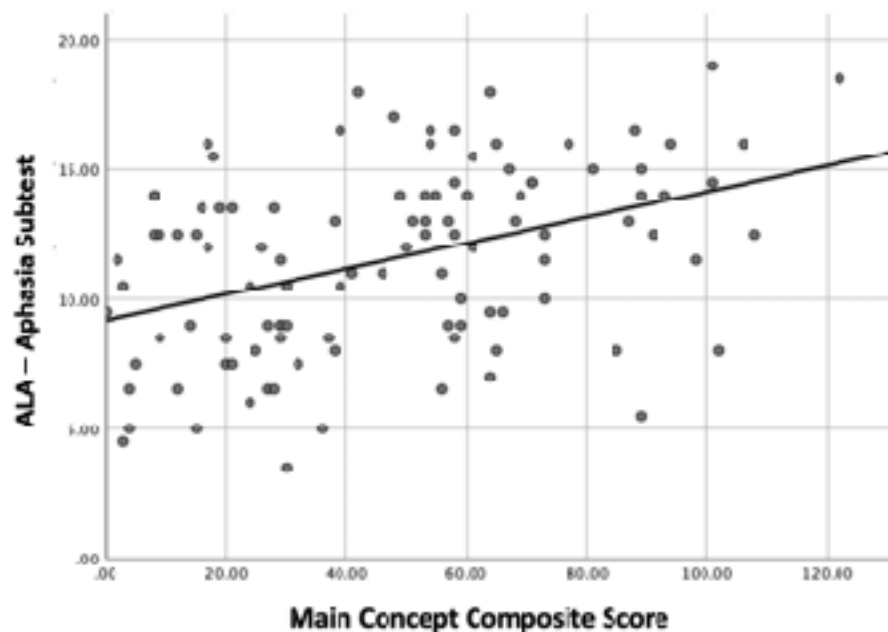


Main Concept Composite Score

**Figure 6.** ALA - Participation Subtest Correlation Graph
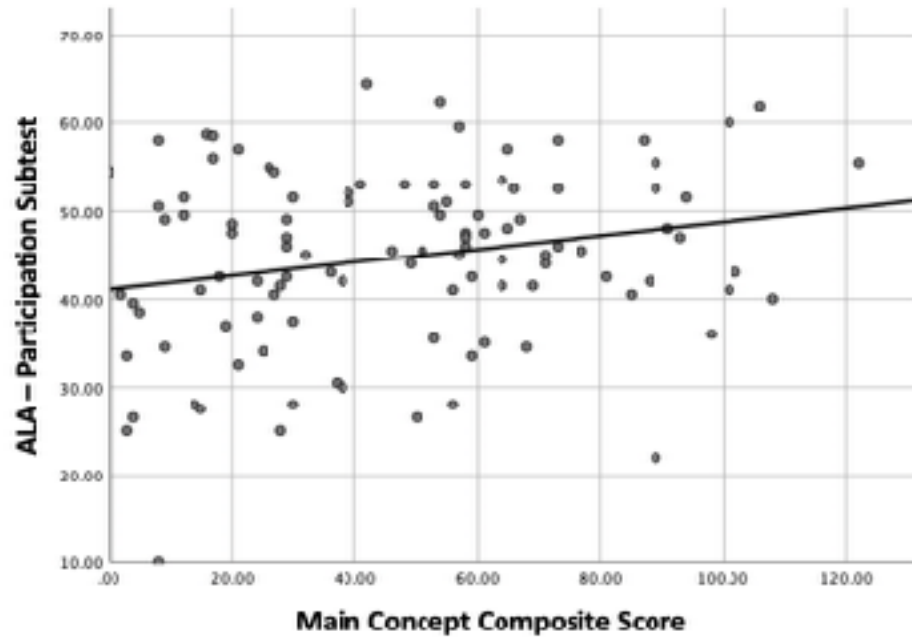


**Figure 7.** ALA - Environment Subtest Correlation Graph
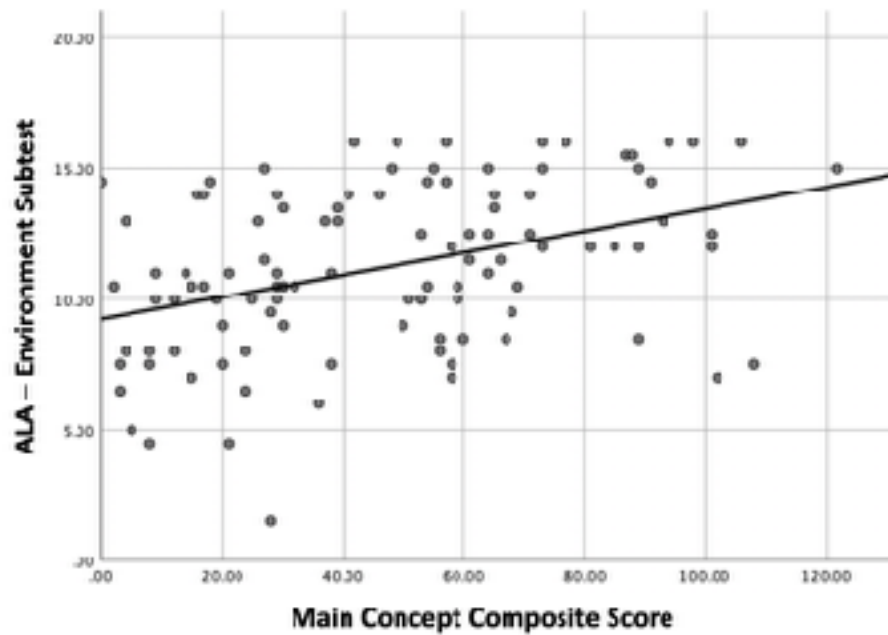
A Spearman's rank-order correlation was run to determine the relationship between MC composite score and CIQ subtest scores (see Table 6). There was a weak to low, positive correlation between MC composite score and CIQ Social score ($r_s(96) = .253$, $p = .013$) (see Figure 8), and a low to moderate, positive correlation between MC composite score and CIQ Productivity score ($r_s(96) = .307$, $p = .002$) (see Figure 9).

**Table. 6** Descriptive Statistics for MC Composite and CIQ Subtest Scores

|  | N | $r_s$ | p |
|---|---|---|---|
| Home | 96 | .058 | .574 |
| Social | 96 | .253 | .013 |
| Productivity | 96 | .307 | .002 |

**Figure 8.** CIQ - Social Subtest Correlation Graph
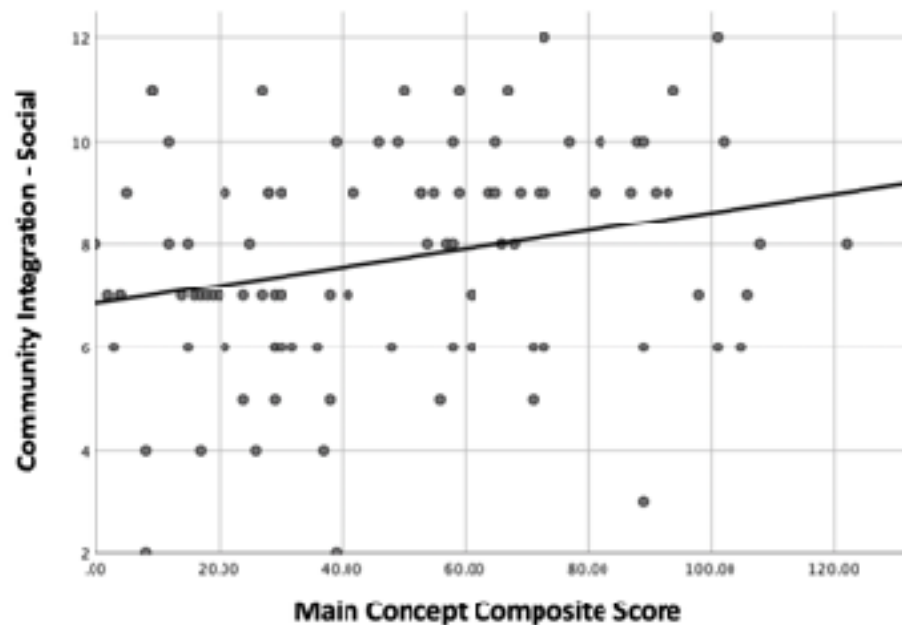
**Figure 9.** CIQ - Productivity Subtest Correlation Graph
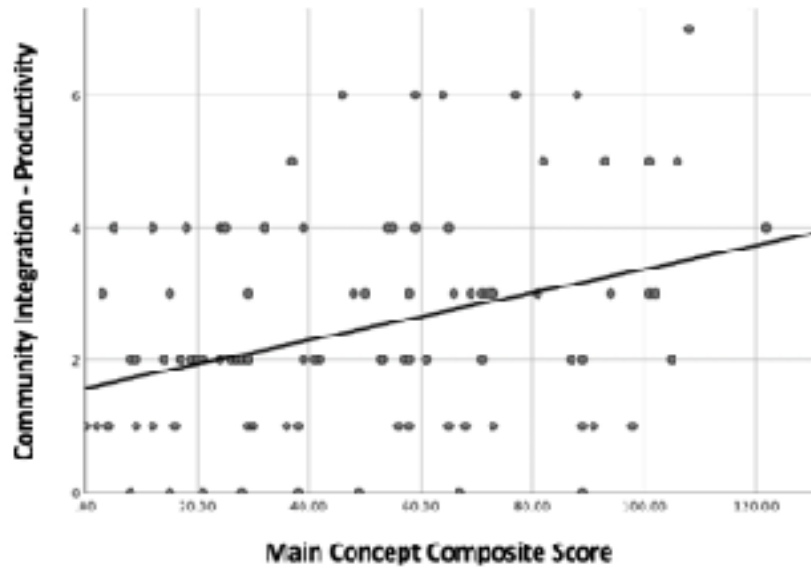


Correlations were also examined according to WAB severity, with the Mild

category (AQ score 76 and above) further subdivided into Mild (AQ score 76-93.7) and

NABW, those above the WAB cutoff  (AQ score greater than 93.8). A Kendall's tau-b

examined the relationship between MC composite scores and the assessments of interest

(ALA, CCRSA, CIQ, GDS). There were no statistically significant findings based on

severity (see Table 7).

**Table. 7** Descriptive Statistics for MC Composite and Assessment Totals based on

Severity

|  |  | N | τb | p |
|---|---|---|---|---|
| Severe | ALA | 9 | .000 | 1.000 |
|  | CCRSA | 11 | -.299 | .209 |
|  | CIQ | 7 | .098 | .761 |
|  | GDS | 8 | .036 | .901 |
| Moderate | ALA | 26 | .025 | .860 |
|  | CCRSA | 28 | .147 | .276 |
|  | CIQ | 25 | -.059 | .689 |
|  | GDS | 24 | -.050 | .744 |
| Mild | ALA | 44 | .111 | .292 |
|  | CCRSA | 43 | .115 | .285 |
|  | CIQ | 37 | .200 | .088 |
|  | GDS | 40 | -.095 | .419 |
| NABW | ALA | 26 | .084 | .551 |
|  | CCRSA | 28 | .048 | .722 |
|  | CIQ | 25 | .184 | .205 |
|  | GDS | 27 | -.006 | .966 |

Because two outcome measures had subtests (ALA, CIQ), it was further explored whether certain subtests were correlated with the MC composite score. A Kendall's tau-b examined the relationship between MC composite scores and the subtests. There were no statistically significant findings based on severity.

CHAPTER 4

DISCUSSION

To our knowledge, this study included the largest sample of persons with stroke-induced aphasia to examine the relationship between the ability to convey a narrative gist and measures of psychosocial functioning. We demonstrated here that main concept (MC) scores are significantly related to several psychosocial measures with effect sizes (i.e., correlation strengths) ranging from weak to moderate strength. The positive correlations between MCs and ALA (overall), CCRSA, and CIQ (overall) scores indicated that as the ability to express essential elements in narrative increases, so did overall patient-reported quality of life, confidence in overall communicative abilities in various conversational environments, and patient-perceived participation ability (i.e., their social role, limitations, and community interaction).

A relationship between narrative abilities and depression was not observed in our sample. One explanation for the lack in relationship postulates that additional factors have influence on how a person responds to depression and how it manifests itself in someone's life. Personal factors (e.g., disposition towards facing challenges of life) and contextual factors (e.g., established support systems) can influence and impact a person, and that impact can influence other areas, like depression. Narrative abilities are just one aspect or ability that may influence depression. There is also a difference between having depression caused by a brain injury (i.e., the medical diagnosis) and how someone copes with their brain injury. The presence of more intact or functional narrative abilities does not guarantee the absence or lessened degree of depression. For example, those classified

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as having Mild aphasia, considered higher functioning patients, may have adequate narrative abilities. However, the negative impacts of aphasia can still be seen (i.e., inability to work, decrease in autonomy and independence, etc.). Further, a possible hyper awareness of these limitations could result in the PWA feeling depressed, despite their high narrative scores. Narrative abilities do not safeguard against depression. Further research on depression in this population is needed.

Our selected narrative measure was most strongly correlated with the CCRSA, followed by the CIQ and then the ALA. Questions on the CCRSA addressed a PWA's confidence in communicating in different situations (e.g., speaking on the telephone, being included in conversations, being understood, etc.). The strong correlation strength may be due to the fact that the questions were specifically related to discourse opportunities (e.g., talking on the phone, engaging in discussions, advocating to others, etc.). The ALA and CIQ tapped into multiple and varied topics, beyond the more straightforward assessment of confidence in communicating, where the majority of the questions also involved discourse opportunities. Some questions from the ALA and CIQ that focused on communication and interaction involved situations or contexts that may or may not rely primarily on discourse. For example, the ALA inquired about "satisfaction in how often you go out" and "satisfaction in doing what you want and with whom". Similarly, the CIQ inquired about "how often do you travel outside of home". Some of these questions addressed situations that may not require intact conversational abilities, yet those situations can still be meaningful to the individual and provide a setting for the individual to feel like a valuable, involved community member.

Results from the ALA and CIQ subtests revealed a more detailed perspective regarding the relationship between discourse abilities and psychosocial functioning. Areas with low to moderate correlation included the ALA-Aphasia, ALA-Environment (see Table 5; see Figures 5, 7) and CIQ-Productivity subtests (see Table 6; see Figure 9). The ALA-Aphasia subtest questions related to personal reflections regarding a PWA's own capabilities (e.g., talking, understanding, reading, writing, etc.). The ALA-Environment subtest questions asked specifically about communication breakdown strategies and supports. Since discourse abilities are direct reflections of talking and are directly related to successful communication and strategy use with helpful supports in conversations for both the listener and speaker, it was not surprising to see some of the strongest correlations between these measures. The CIQ-Productivity subtest questions addressed participation in various life roles and being engaged in active roles as a member of society. Work, school, and vocational opportunities are all settings that connect to others, and discourse is most often the vehicle used to interact with others in these settings.

Areas with weak to low correlation included the ALA-Participation (see Table 5; see Figure 6) and CIQ-Social subtests (see Table 6; see Figure 8). ALA-Participation subtest questions addressed community involvement and conversational abilities and identified activities the PWA was currently involved in, rather than their capabilities or impairments. The CIQ-Social questions inquired about the people involved in a PWA's life and how that was related to independence and living in community. Correlations with main concepts are logical here since discourse plays a significant role when interacting

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with the community because it allows a person to build relationships with communication partners through simple and complex conversations and discussions of specific topics. What was somewhat surprising was the reduced strength of these correlations, given the importance of discourse abilities for social participation. This indicated that there are other factors that also contribute a great deal to social participation.

Across different levels of severity, there were no statistically significant relationships between MCs and psychosocial measures. However, this is only exploratory data, due to the great differences in sample sizes. More research with a larger sample size is needed. One explanation postulates that the sorting of our sample set into severity bins created isolated observations of the different groups in the sample. This, in essence, reduced our ability to see a linear relationship along a continuum, as compared to the entire sample that allowed for a reflection of the continuum of results, where low narrative scores were typically related to more severe participants.

Assessment is the gateway to understanding a patient's current level of abilities as well as their personal future goals. This drives treatment to be patient-centered in order to maximize their overall communication abilities. Knowledge of factors that are connected or influenced by other areas can give a fuller picture of the possible influences on therapy success. We know that PWAs desire to communicate functionally and to reintegrate back into society and their communities. Discourse assessment is a useful tool to gain insights into outcomes that are pertinent and meaningful to the patients. Discourse abilities are related to other outcomes that are important to PWAs and their families. Given these correlations, there is reason to expect work on discourse would increase psychosocial

functioning, especially those constructs measured by ALA-Aphasia, Environment, and CIQ Productivity subtests. This is valuable because patients deserve to be provided therapy that has global benefits to life participation. When patient's needs are addressed, there can be a positive impact on patient autonomy (i.e., their personal goals and preferences), communication opportunities, networking, and communal living.

**Limitations and Future Directions**

The sample size and composition is somewhat limited, preventing broad generalization and warranting further research. The overall sample size included data from 115 PWA, however, the categories based off of severity included data from only 7-11 for Severe, 24-28 for Moderate, 37-44 for Mild, and 25-28 for NABW, depending on the psychosocial measure under study. The small sample size could only give exploratory information on the relationships based off of severity bins. The sample of participants was slightly gender-biased, with more males than females represented. The sample is not racially/ethnically diverse, with the majority identifying with a white/ European descent. This may not be an appropriate comparison group for all races and ethnicities.

Additional research with a larger and more diverse sample set could help establish confidence in the generalization of the findings to more patients of various backgrounds. A larger sample set could also allow for more insights into potential relationship differences based on severity. We only examined a single discourse measure in this study - main concepts. There are many other discourse measures that could be explored to see if they predict psychosocial outcomes. For example, microlinguistic measures such as

lexical diversity and propositional density may show that one's ability to produce more typical and complete utterances is important for communication confidence, participation, or some other construct. Additionally, macrolinguistic measures such as story grammar and coherence may show that one's ability to produce complete and organized episodes during narratives predicts participation or satisfaction. The relationships between other discourse measures and psychosocial outcomes should be explored. Additionally, other contextual factors should be explored to understand their influence on social participation, as narrative abilities are just one aspect with influence. Finally, further research is needed to confirm if discourse sampling does predict real-world conversational abilities, in order to have confidence that discourse samples obtained clinically or in a research setting can give accurate representations of patient's conversations in a real-world setting.

**Conclusions**

Spoken discourse is the main mode of human communication, and involves much more than just naming objects around us. It is integrated into all of our interactions with others. Discourse abilities impact activities and participation opportunities (e.g., talking with family members and coworkers, reminiscing about old stories, sharing about an event that happened at work, socializing and relationship building, expressing your needs in the community, etc.). This study provides novel insights into the relationship between the newly categorized primary outcome measure of discourse and secondary outcomes related to psychosocial impact in a large sample of persons with stroke-induced aphasia. We observed relationships between discourse performance and the psychosocial measures

ALA, CCRSA, and CIQ. There was no correlation between discourse and GDS measures. For this study, we selected a reliable, valid, and clinically friendly measure of discourse - main concepts - that captures narrative gist, or the ability to convey the essential elements of a story. Our findings indicate that intervention approaches that focus on improving one's ability to convey gist might also result in improvements in psychosocial outcomes. Given the ease of administration and coding, it also means that discourse can be readily assessed and tracked throughout intervention. It is clear other factors also contribute to psychosocial functioning, as our correlations, though significant, were not strong. While narrative measures selected here can give some predictive insight into psychosocial functioning or adjustment, there are likely other contributory factors that explain additional variance in functioning. These other factors, which may include other discourse measures as well as contextual factors, need to be explored and identified so they can be optimized.

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