

Patient-Informant Agreement in Reported Activities and Participation Depends on Aphasia Severity

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INTRODUCTION

Aphasia, an impairment that most commonly occurs after stroke, is commonly operationalized as a linguistic impairment affecting expressive or receptive language, with the possible presence of deficits in various cognitive domains. Impairments resulting from aphasia have been conceptualized using the World Health Organization's International Classification of Functioning, Disability, and Health (WHO-ICF; Simmons-Mackie & Kagan, 2007; WHO, 2002). The WHO-ICF defines disability as a composition of multiple interdependent domains: 1) body functions and structures, 2) activities and participation, and 3) environment and personal factors. The intention of the WHO-ICF framework is to allow for clinical comparison between different conditions and the impact they have on these domains. The body functions and structures domain refer to the anatomy and physiology of the body that may be impaired. The activities and participation domain refers to the execution of and involvement in activities of daily living that may be limited due to the impairments described in the first domain. Environment and personal factors combine to create the third domain, including contextual factors such as that may include social attitudes, legal and social structures, social background, etc.

Aphasia has most commonly been assessed and treated at the impairment level, or in the WHO-ICF domain of body functions and structures. However, stroke, aphasia, and rehabilitation is not strictly limited to this level of impairment (i.e., body functions and structures), but also strongly involves the activities and participation domain of the ICF (Schumacher et al., 2020). The participation and activities domain of the WHO-ICF focuses on a person's ability to engage in

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selected activities and complete tasks in the context of day-to-day life. Evidence shows that individuals living with a language impairment, such as aphasia, and their care partners acknowledge that conversations and social situations are sources of stress (Cruice et al., 2003; Laures-Gore & Buchanan, 2015). *Functional communication* is the ability to communicate effectively with any communication modality in a patient's everyday environment, not bounded by the controlled nature of a therapy or research session (Frattali et al., 1995; Hula et al., 2015). While functional communication relates a patient's impairment level to their ability to complete daily activities, language severity alone is not often an accurate depiction of ability to functionally communicate, but heavily relies on the communication environment and support (Irwin et al., 2002; Schumacher et al., 2020). *Communicative participation*, a similar, yet distinct construct, can be operationalized as taking an active participatory role in daily situations that require any means of communication (Eadie et al., 2018), seeking to explore the context of engagement as opposed to effectiveness in communicating. Additionally, the ability to participate within a patient's previous *social roles* is often affected by aphasia. People with aphasia (PWA) often report reductions in friendships, changes in quality of marital relationships, employment, and limitations in general social networks (Pike et al., 2017; Therrien et al., 2021). Relationships between performance-based language severity and measures of participation have been reported as weak to moderate, proposing that individual factors beyond impairment severity propel reductions in participation (Baylor & Darling, 2020; Eadie et al., 2018). Moreover, PWA often identify participation in social activities as an ultimate outcome in aphasia rehabilitation, with the self-reported goals of many PWA being related to the activities and participation domain (Dijkers, 2010; Worrall et al., 2011). The aforementioned supports and extends Ross and Wertz (2003) who examined the different components in positive quality of life (QoL) in persons with and without

aphasia. The authors concluded that societal participation and situation specific communication may have the greatest role in enhancing the QoL in PWA. As such, the assessment and treatment of activities and participation has accumulated increased interest in clinical and research settings.

Patient outcomes can be assessed objectively with usage of performance-based measures or subjectively with usage of internal appraisals by the patient or key stakeholders, such as clinicians or care partners (van der Zee et al., 2013). Objective assessments are of value in terms of measuring observable behavior at the impairment level which often helps guide treatment planning, though many health professionals have implemented subjective assessments as part of routine practice as well (Kimonides et al., 2018). Guiding intervention regimens exclusively on the severity of impairments to body functions and structures can lead to mistreatment and a lack of patient-centered care, specifically when measuring constructs that are often unobservable to the observant eye, but the inclusion of subjective measures help to avoid this problem (Cohen & Hula, 2020). Additionally, objective and subjective measures are often weakly correlated with each other (van der Zee et al., 2013; Yorkston et al., 2008). For example, frequency of participatory events does not necessarily associate with patients satisfaction of participation and engagement (Baylor & Darling, 2020). To preserve patient autonomy and patient-centered care, advocacy for documenting the patient perspectives of all health domains is critical in ensuring personally-relevant rehabilitation goals and positive outcomes (Baylor & Darling, 2020; Doedens & Meteyard, 2020; Perenboom & Chorus, 2003). Accordingly, the assessment of participation and activities is commonly completed utilizing patient-reported outcome measures (PROMs). PROMs are subjective assessments that grant space for standardized evaluations of health constructs from the perspective of the patient themselves (Bingham et al., 2017; Cohen et al., 2021). The

introduction of PROMs into routine clinical practice provides PWA with an opportunity to endorse their beliefs regarding the individual's perspective of functioning and desired outcomes.

Some PWA may be unable to provide responses to some PROMs due to the severity of their cognitive-linguistic impairment (Cohen & Hula, 2020). In these cases, a person who is close to the patient may be asked to supply an informant-reported evaluation of the patient (Hilari et al., 2007), providing their perspective of the patient (Roydhouse et al., 2022). Informant-reports are often not in full agreement of PWA reports, including ratings of PROMs exploring activity limitations and participation restrictions (Ashaie & Cherney, 2021; Cruice et al., 2005). For post-stroke individuals, patients and care partner reports have been found to agree to a greater degree on constructs that are observable in nature, such as degree of language severity, in comparison to constructs that are harder to gather via observation, such as mood or perceptions of well-being. Likewise, care partners present with a tendency to report patients as more severely impacted than patients themselves (Dorman et al., 1997; Doyle et al., 2013; Lapin et al., 2021). Overrating the severity of a patient's impairment has also been found to increase as the severity of impairment following stroke increased (Duncan et al., 2002). Studies investigating PWA and informant agreement, specifically, in measures of participation and activities for PWA have reported similar findings. The Aphasia Communication Outcome Measure (ACOM; Hula et al., 2015), a measure of functional communication, demonstrated moderate to strong correlations between PWA and informant reports, but with significant disagreements in multiple individual cases (Doyle et al., 2013). Authors conclude that PWA-informant reports are not interchangeable for the given measure, with a future aim of developing an informant-report version of the ACOM to produce stronger agreement with PWA appraisals. Moreover, during validation of the Communicative Participation Item Bank (CPIB; Baylor et al., 2017), authors report a low correlation between

PWA-informant reports on the outcome measure, with informants rating PWA participants as more severe than the patient would rate themselves and a suggestion to utilize caution when interpreting informant ratings in place of PWA. Kozlowski and colleagues (2015) investigated the agreement between post-stroke adults and informants on reports of The Quality of Life in Neurological Disorders measurement system, a set of standardized PROMs designed to measure domains of physical, mental, and social functioning in individuals with acquired neurological impairments (Cella et al., 2012). Authors reported that while informant reports are beneficial in their own respect, informant reports cannot replace patient responses.

Reports provided by informants may differ from that of the patient due to a variety of factors. One possible reason is that the patient's communication impairment makes it difficult for the informant to be in tune with the patient's perspective, especially their experience of difficult-to-express health constructs. This may exacerbate the known discrepancy that the reports of patients and informants are more similar for constructs that are observable than unobservable (Kozlowski et al., 2015). For example, it is likely that informants are more likely to rely on observable, performance-based domains, such as language severity, when rating functional communication whereas PWA may rely on behaviors such as mood and depression, that are not directly observed or experienced by others (Doedens & Meteyard, 2020). A second possible reason for patient-informant discrepancies is a difference in perspective or interpretation of the health construct. For example, depressive symptoms are known to affect the "lens" through which one perceives, experiences, and reports on health constructs (Howland et al., 2017). Thus, the depressive symptoms of the PWA and/or informant may influence their experience and/or report of activities and participation.

Considering the increased usage and importance of PROMs assessing activities and participation in clinical research settings, further research into the agreement of PWA-informant ratings on measures of participation and activities is warranted. In particular, the present study sought to investigate whether the agreement between PWA-informant ratings on PROMs of participation and activities is systematically affected by the degree of the patient's language severity and the patient's experiences of depressive symptoms. We specifically analyzed the ACOM, CPIB, and Neuro-QoL Social Roles and Activities, PROMs relevant to the activities and participation domain with known PWA-informant discrepancies. We hypothesized that performance-based language impairment and degree of depressive symptoms would positively associate with PWA-informant discrepancies. In line with previous research, we further posited that informant-reports would be significantly associated with performance-based language severity and present with a systematic impact of PWA-informant discrepancies across measures of activities and participation.

METHOD

Participants

The present study is a secondary analysis of data collected for the development of establishing severity levels for patient reported outcome measures, obtained by Cohen et al. (2023). Whereas the original sample included adults with acquired cognitive/language disorders caused by stroke, Parkinson's disease, or traumatic brain injury (TBI), the sample in the present study consisted of 29 dyads of post-stroke PWA and their selected informant respondent. PWA were eligible for study inclusion if they were (1) at least 18 years of age, (2) English speaking, (3) 6 months post-stroke, (4) have a diagnosis of aphasia, and (5) identified an informant respondent willing to participate who had at least weekly contact with the individual before and after the onset of the

condition. PWA were administered a series of yes/no comprehension questions to ensure their cognitive/linguistic capacity to provide informed consent. Each eligible PWA who agreed to participate was asked to identify a care partner, such as a spouse, parent, or child, to participate in the study. Eligible informants were those who were (1) 18 years or older, (2) able to understand spoken and written English, (3) have no reported history of progressive neurological disease and major psychiatric illness, and (4) produce normal scores on the Montreal Cognitive Assessment (Freitas et al., 2013), a cognitive screening test for mild forms of cognitive impairment. PWA were compensated for their time and informants participated without compensation.

Demographic and clinical characteristics of participants with aphasia ($n = 29$) are presented in Table 1. PWA had a mean age of 56.3 (SD = 12.5) years, the majority were male (68%), and with a mean year's post onset of 4.5 (SD = 3.6) years. Seven PWA presented with severe aphasia and 12 PWA presented with moderate aphasia as determined by the Quick Aphasia Battery (QAB; Wilson et al., 2018), a brief, multidimensional screening instrument of performance-based language severity. Severity of language impairment was characterized by the performance-based measure as being within normal limits, mild, moderate, or severe. Individuals scoring less than moderate on the QAB ($n = 10$) were identified as having mild aphasia, verified by multiple other factors. Informant characteristics are presented in Table 2. Informants had a mean age of 59.1 (SD = 12.9) years and reported knowing the PWA for a mean of 32.2 (SD = 14.4) years. The informant sample was predominantly female (79%) and spouses (69%) of the PWA.

Table 1.

Demographic characteristics of PWA sample ($n = 29$)

Age (M, SD)	56.3 (12.5)
Sex (%)	

Female	31
Male	65.5
Race (%)	
White	72.4
Black/African American	20.7
Asian	3.4
Other	0
Education Level (%)	
Highschool graduate	13.8
Some college, no degree	20.7
Associate degree	6.9
Bachelor's degree	31.0
Master's degree	24.1
Years Post Diagnosis (M, SD)	4.4 (3.6)
Aphasia Severity (%)	
Mild	34.5
Moderate	41.4
Severe	24.1

Note. M = Mean, SD = Standard deviation. Sex, age, race, and education level from one PWA is missing.

Table 2.

Demographic characteristics of informant sample (n = 29)

Age (M, SD)	59.1 (13.0)
Sex (%)	
Female	75.9
Male	20.7
Race (%)	

White	69.0
Hispanic	3.4
Black/African American	20.7
Asian	3.4
Other	3.4
Education Level (%)	
Some Highschool, no degree	3.4
Highschool graduate	6.9
Some college, no degree	24.1
Trade Tech	3.4
Associate degree	6.9
Bachelor's degree	27.6
Master's degree	27.6
Years Known (M, SD)	32.2 (14.4)
Caregiver Relationship (%)	
Spouse	69.0
Child	10.3
Parent	6.9
Other	13.8

Note. M = Mean, SD = Standard deviation. Sex of one informant is missing.

Procedures

The study was approved by the Institutional Review Boards at the University of Delaware and The Ohio State University prior to participant enrollment. All participants were provided written information explaining the project, which was also discussed with them, and written consent was obtained. Following consent, PWA and informants completed a single, in-person session in which

they could participate simultaneously or sequentially. If the informants were not available for the same session as the PWA, they were able to schedule a separate session. The measures were administered in a quiet room by trained study team members. All PWA and informant pairs individually completed three PROMs related to participation restrictions and activity limitations. Informants were asked to answer the assessment questions as they think their partner with aphasia would answer. PWA and informant pairs that were missing any assessment data were excluded from the present study.

Behavioral Measures

Three activity and participation constructs served as outcome measures for this study: communication participation, functional communication and social roles and activities. Communicative participation was collected via administration of the *Communicative Participation Item Bank short form* (CPIB; Baylor et al., 2013). The CPIB is a 10-item patient or informant outcome measure of communicative participation, or “taking part in the communication aspects of life situations” (Baylor & Darling, 2020). The CPIB was developed with the intent of being appropriate for adults with a variety of communication disorders, and has been validated for PWA (Baylor et al., 2017). The *Aphasia Communication Outcome Measure short form* (ACOM; Hula et al., 2015) was administered to measure self-reported functional communication. The ACOM short form is a reliable, 12-item self-report measure of functional communication, defined as “the ability to receive or to convey a message, regardless of mode, to communicate effectively and independently” (Frattali et al., 1995). To address communication modes, the ACOM assesses spoken language expression and comprehension, reading, writing and number use. Lastly, social roles and activities were measured by the *Neuro-QoL Cognitive Ability to Participate in Social Roles and Activities short form* (v1.0)(NQ-SRA; Cella et al., 2012; Gershon et al., 2012). The NQ-

SRA short form is an 8-item self-report measure that examines the amount of participation or involvement in social roles and/or activities. Lastly, to measure depressive symptoms, *Neuro-QoL Depression short form* (NQ-Depression; Cella et al., 2012) was administered. The NQ-Depression short form is a self-report of attitudes and symptoms of depression.

The measures are expressed as T-scores with a mean of 50 and standard deviation (SD) of 10. A higher t-score indicates a higher presence of the concept being measured. The NQ-SRA is a positively worded measure, such that a t-score of 60 (i.e., 1 SD above the mean), indicates a higher perception of positive functioning (i.e., greater satisfaction with social roles and activities). In contrast, the NQ-Depression measure is a negatively worded concept, such that a t-score of 60 indicates a higher perception of negative functioning (i.e., greater perception of depressive symptoms). The ACOM and CPIB are measured similarly as the NQ-SRA – higher scores indicate more positive perceptions of perceived functioning. CPIB, ACOM and Neuro-QoL SRA severity level cut-off points are interpreted as reported by Cohen et al. (2023). NQ-Depression severity level cut-off points are based upon distance from normative group means (HealthMeasures, n.d.). See Table 3.

Table 3.

Severity Level Cut-off Scores for PROMs and QAB t-scores.

Assessment	WNL	Mild	Mild - Moderate	Moderate	Severe
ACOM*	-	62.5 - 75	52.5 – 62.5	37.5 – 52.5	25 – 37.5
CPIB	62.5 - 75	52.5 – 62.5	-	37.5 – 52.5	25 – 37.5
NQ-SRA	47.5 – 52.5	42.5 – 47.5	-	37.5 – 42.5	30 – 37.5
NQ-Depression	20.0 – 55.0	55.0 – 60.0	-	60.0 – 70.0	70.0 – 80.0

QAB 8.90 – 10.00 7.50 – 8.89 5.00 – 7.49 0.00 – 4.99

Note. QAB cut-off scores reflect the QAB overall scores, which is derived from the seven summary measures of the screener. All other cut-off scores reflect the t-scores of each measure. *ACOM cut-off scores does not include a “WNL” range because every participant in the reference range had aphasia (See Cohen et al. (2023) for more).

Statistical Analyses

Descriptive statistics were used to examine participant characteristics. To investigate PWA and informant score differences as a function of performance-based language severity and depressive symptoms, difference scores, which will be the term to reference PWA-informant ratings from this point forward, were computed by subtracting an informant's t-score from the PWA's t-score. Negative difference scores indicate informants rate the PWA higher than the PWA report themselves, whereas positive difference scores indicate that the PWA rates themselves higher than the informant reports. Three dependent variables are examined in this study: CPIB difference scores, ACOM difference scores, and Neuro-QoL SRA difference scores.

To examine the influence of aphasia severity on the outcome variables, three hierarchical regressions were conducted – one for each outcome variable. In preparation for regression analyses, the independent variables (i.e., QAB; NQ-Depression) were correlated with the dependent variables utilizing Pearson's product moment correlations. No association between the depression scores and any dependent variable was identified (see Table 5), so only regression analyses with the QAB are conducted. The first block of each regression assessed the variance accounted for by performance-based aphasia severity alone. The second block of each regression addressed the unique and additive variance explained when the informant-report version of each measure was added to the model. Informant-report versions were included in the regression model due to the relationship between informant reports and performance-based language severity. To further explore the influencing factors of difference scores, Pearson's correlations are conducted

across each outcome variable and the informant-report of the corresponding PROM. Using Cohen’s convention, Pearson’s correlation coefficient results were interpreted as follows: $|r| \leq .30$ weak/small correlation; $.30 < |r| < .50$ moderate/medium correlation; $|r| > .50$ strong/large correlation (Cohen, 1992).

RESULTS

Participant Characteristics

PWA yielded a mean ACOM t-score of 52.53, mean CPIB t-score of 43.10, mean NQ-SRA t-score of 46.42, and mean NQ-Depression t-score of 47.62. Informants yielded a mean ACOM t-score of 48.74, mean CPIB t-score of 41.91, mean NQ-SRA t-score of 48.15, and mean NQ-Depression t-score of 50.14. Table 4 presents group-level statistics and difference scores across the three outcome variables.

Table 4.

Summary of Group Descriptive Statistics.

Assessment	PWA	Informant	PWA - Informant difference ¹
ACOM	52.53 (9.60) (37.76 – 75.33)	48.74 (14.10) (26.81 – 78.66)	3.79 (11.76) (-22.11 – 32.08)
CPIB	43.10 (6.98) (28.20 – 60.6)	41.91 (10.18) (24.20 – 71.00)	1.19 (9.51) (-18.70 – 23.80)
NQ-SRA	46.42 (4.61) (34.00 – 53.40)	48.15 (8.34) (31.80 – 60.20)	-1.73 (8.61) (-19.60 – 12.40)

NQ- Depression	47.62 (6.53) (36.90 – 68.30)	50.14 (7.23) (36.90 – 67.30)	-2.51 (6.41) (-13.70 – 9.90)
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Notes. All statistics are reported as (Mean (SD)) (range). ¹Positive scores indicate the patient produced a higher score. Negative scores indicate the proxy produced a higher score.

To examine relationships between language severity, group-level means, and difference scores, Pearson’s product-moment correlations were conducted between the outcome variables and PWA QAB t-scores (see Table 5). Correlations revealed that language severity scores were strongly correlated with ACOM mean difference scores ($r = -.523, p < .01$), and moderately correlated with CPIB mean difference scores ($r = -.438, p < .05$) and Neuro-QoL SRA mean difference scores ($r = -.387, p < .05$). No significant correlations noted between QAB t-scores and PWA or NQ-Depression reports.

Table 5.

Relationships between language severity and PROM ratings.

	ACOM	CPIB	NQ-SRA	NQ-Depression
PWA	.161	.279	.188	-.194
Informants	.545**	.600**	.504**	-.216
Difference Scores	-.523**	-.438*	-.387*	.046

Notes. PROM measures correlated with QAB t-scores.

* $p < .05$, ** $p < .01$

Hierarchical multiple regressions were run across each outcome variable to determine if the addition of performance-based language severity and informant rating of outcome measure improved the prediction of PWA-informant agreement. See Table 6 for full details of each regression model. Across all three regression models, the full model of aphasia severity and

informant report (Model 2) explained 53-71% of the variance ($p < .001$). The addition of informant reports predicted 29 – 56% of unique variance in the difference score ($p < .001$).

Table 6.

Hierarchical Multiple Regressions Predicting PWA-Informant Agreement with Aphasia Severity and Informant Reports.

<i>Outcome Variable: Communication Participation</i>				
Variable	Model 1:		Model 2:	
	Language Severity		Language Severity and Informant Rating	
	B	β	B	β
Constant	11.61*		30.53**	
QAB total score	-1.67*	-.44	.072	.019
CPIB Informant			-.71**	-.76
R^2	.16		.53	
F	6.41*		22.06**	
DR^2	.16		.37	
DF	6.41*		16.74**	
<i>Outcome Variable: Functional Communication</i>				
Variable	Model 1:		Model 2:	
	Language Severity		Language Severity and Informant Rating	
	B	β	B	β
Constant	19.16**		35.13**	
QAB total score	-2.46*	-.52	-.79	-.17
CPIB Informant			-.54**	-.65
R^2	.25		.54	

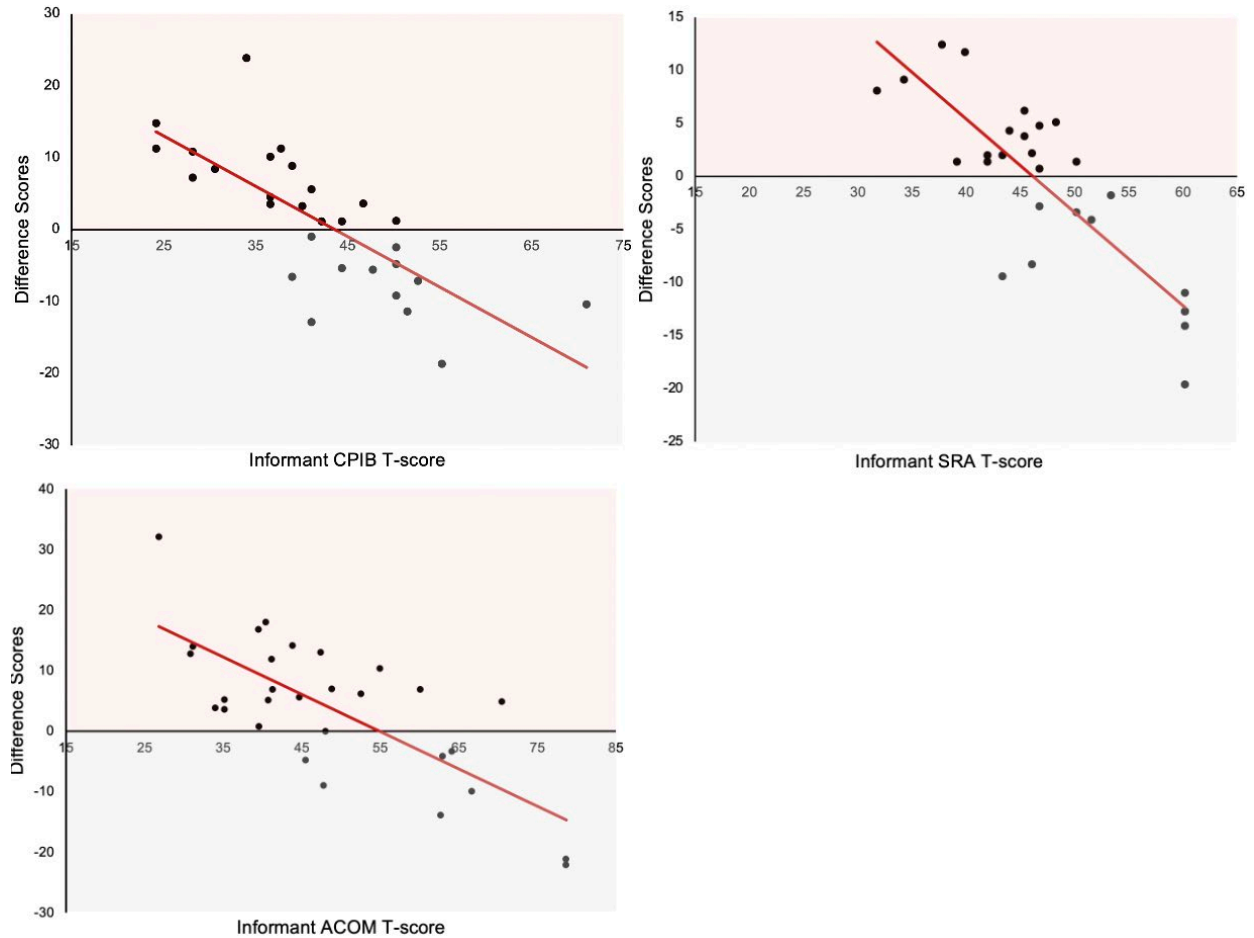
<i>F</i>	10.16*		17.15**	
<i>DR</i> ²	.25		.29	
<i>DF</i>	10.16*		17.82**	
<hr/> <i>Outcome Variable: Social Roles and Activities</i> <hr/>				
	Model 1:		Model 2:	
	Language Severity		Language Severity and Informant Rating	
Variable	B	β	B	β
Constant	11.61*		30.53**	
QAB total score	-1.67*	-.44	.072	.019
CPIB Informant			-.71**	-.76
<i>R</i> ²	.12		.71	
<i>F</i>	4.75*		34.94**	
<i>DR</i> ²	.12		.59	
<i>DF</i>	4.75*		55.55**	

Note. * $p < .05$, ** $p < .001$

To visually inspect the systematic variation in PWA agreement as a function of informant ratings, modified Bland-Altman plots were created (Figure 2). Informant ratings are statistically significantly associated with ACOM agreement ($r = -.750, p < .001$), CPIB agreement ($r = -.741, p < .001$), and NQ-SRA agreement ($r = -.852, p < .001$).

Figure 2.

Modified Bland-Altman Plots



Note. Red shading (above the x-axis) indicates that PWA provided a higher PROM report. Gray shading (i.e., below the x-axis) indicates that informants provided a higher PROM report. For all PROMs presented a here, a higher report is indicative of greater perceived functioning. Bland Altman plots presented here are modified. A traditional bland-altman plot presents difference scores on the y-axis and mean scores on the x-axis. Instead of mean scores, the x-axis in the presented plots depict informant reports.

An ad hoc analysis was conducted to determine the degree to which years-post-onset related to PWA reports, informant reports, and PWA-informant difference scores. Table 7 presents the results. Pearson’s rank-order correlations identified no statistically significant results.

Table 7.

Relationships between patient age, years’ post-onset, and PROM reports

	ACOM	CPIB	NQ-SRA	NQ-Depression
Age				
PWA	-.310	-.005	.026	-.022
Informants	-.134	.028	-.118	.061
Difference Scores	-.090	-.033	.127	-.093
Years Post Onset				
PWA	-.132	.100	.231	-.236
Informants	.113	.127	.218	-.223
Difference Scores	-.243	-.063	-.087	.023

Discussion

While discrepancies amongst patients and their care partners on PROM reporting is appreciated, it remains unclear how the degree of language severity may systematically affect PWA-informant discrepancies on PROMs measuring constructs within the WHO-ICF activities and participation domain. With the increasing acknowledgement of participation as a key outcome following aphasia rehabilitation, it remains critical to identify factors that may influence a PWA or care-partners perception of a patient's level of participation and activity functioning to best guide patient-centered care and outcomes. Thus, the aim of the present study was to investigate whether the agreement between PWA-informant ratings on PROMs of participation and activities is systematically affected by the degree of the patient's language severity and the patient's experiences of depressive symptoms.

Patient-informant difference scores were found to be highly variable, with some difference scores reflecting dramatic differences in reported function or participation. As a group, informants rated

patients as more severe than patients themselves on all outcome variables excluding social roles and activities (NQ-SRA), meaning informants perceived PWA as having more positive and functional social roles than PWA reported themselves. This result is surprising considering the general trend for informants to perceive patients as more impaired than patients themselves. An explanation for this finding is perhaps PWA are more critical of the social consequences, such as negative changes in social roles secondary to their communication impairments, as opposed to the impairment themselves. PWA often report experiencing greater difficulty in participating in social experiences and roles that they once had due to the presence of their acquired language deficits (Alary Gauvreau & Le Dorze, 2022). In a qualitative study, Dalemans et al. (2010) reported that PWA often do not speak of communicative participation in the same light as clinicians and researchers. Rather, PWA speak of social participation as engagement, involvement, and contribution to the community. Thus, social roles and activities may serve as a construct that better resonates with PWA perspectives of perceived functioning and impairments as opposed to the underlying communicative components. Moreover, the number of activities completed by a PWA has been found to not associate with perceived engagement (Baylor & Darling, 2020; Dalemans et al., 2010). Given the known difficulty of care partners understanding internal, unobservable constructs experience by PWA, it is possible that care partners misinterpret the number of social participation and activity attempts with true satisfaction and engagement with the individual with aphasia desired social roles.

Consistent with our hypothesis, results of the present study identified no significant associations between PWA PROM reports and performance-based language severity. This means that performance-based language severity did not appear to have an impact on how PWA report their ability to participate in activities and social roles, suggesting other physical or psychological

constructs may play a role in PWA reporting of participation and activities. Moreover, informant reports across all outcome measures were statistically significantly correlated with a patient's performance based language severity. Specifically, informants were more likely to report that individuals with more severe language severity are more likely to have greater difficulty participating in desired activities and social roles, whereas individuals with mild language severity present with the least difficulty participating in desired activities and social roles. Results of this study also identified statistically significant relationships between performance based language severity and PWA-informant difference scores, such that, as language severity increased, informants were significantly more likely to rate the patient as functionally more impaired than the patient themselves. The results replicate and extend previous aphasia literature that has identified a similar trend in which informant reports align with performance based language severity, as well as informants tending to report PWA as more impaired than patients themselves on measures of functional communication, communicative participation, and depression (Cruice et al., 2005; Doyle et al., 2013; Fucetola & Tabor, 2015; Hilari et al., 2007).

Regression models that included both performance-based language severity and informant-report accounted for 53 – 71% of the variance in outcome measure difference scores. Informant-reports alone predicted 30 – 56% of unique variance in the difference scores. The unique variance provided by informant reports is illustrated on the modified bland-altman plots (Figure X), revealing that as informant reports increase (i.e., informant perceives the patient is more functional than the PWA themselves), the difference score increases at a negative rate, signaling a lack of agreement with PWA reporting worse perceived functioning across all constructs. Similarly, as informant reports decrease (informant perceives the patient is less functional than the PWA themselves), the difference scores increase at a positive rate, suggesting a lack of agreement with

PWA reporting greater perceived functioning across all constructs. In other words, the difference scores on the selected outcome measures of can be systematically and significantly predicted by performance-based language severity and informant-reports.

Results suggest that some PWA and their informants report very different perceptions of functional participation and activity engagement. As discussed, one possible explanation for this finding is the reliance informants place on observable constructs as opposed to unobservable constructs when providing reports for PWA. While degree of language severity can be predictive of outcomes during recovery, a variety of other constructs that may be less present to the observer have a lasting effect on a PWA's personal perception of well-being. In other words, degree of language impairment is not the sole driving factor of perceptions of functional communication, engagement in social activities, and general life satisfaction in individuals living with aphasia. While the extent of literature surrounding individuals with mild aphasia is minimal, the present study and a few previous studies have identified that aphasia across all severities has a direct impact on life participation (Armstrong et al., 2013; Cavanaugh & Haley, 2020; Fox et al., 2009). In fact, research has also suggested that individuals with milder impairments may be more sensitive to the subtle differences in their communication given their ability to self-monitor language accuracy and effectiveness in comparison to individuals with greater impairments (Cavanaugh & Haley, 2020). The self-awareness of language difficulties may have a direct impact on language confidence, which is often considered a prerequisite for participating in daily activities and various social situations (Niemi & Johansson, 2013). While the presence of aphasia commonly creates a negative impact on activity limitations and participation restrictions across all severity ranges, self-awareness of mild language impairments may serve as an explanation as to why individuals with seemingly mild aphasia exhibit more critical self-perceptions of self.

Emotional distress, such as depressive symptoms, can have an impact on an individual's perception of experiences and overall well-being. Literature has supported a strong relationship between depressive symptoms and participation in desired activities, rehabilitation outcomes, and overall QoL (Hinckley & Packard, 2001; Lee et al., 2015; Rowlands et al., 2020). Moreover, literature has suggested that depressive symptoms may serve as a mediator of patient and informant discrepancies (Howland et al., 2017; Tay et al., 2014; Williams et al., 2006). However, depression scores did not significantly associate with performance-based language severity, PROM ratings provided by PWA and informants, or PWA-informant difference scores. The lack of relationship is suspected to be secondary to the lack of depressive symptoms reported by both PWA and informants in the present sample. The mean depressive score for PWA was 47.62 and the mean depressive score for informants was 50.14 (WNL: 20.0 – 55.0; See Figure X for distribution). This means that there was a relatively low reporting of depressive symptoms in the present sample. The lack of depressive symptom variability may have inhibited the ability to detect relationships between increased depressive severity with measures of participation and activities. Given the use of convenience sampling for the present study, it is possible that depression was accurately reported, and the selected population represents a sample with, on average, depressive symptoms that are within normal limits. However, methodological issues may have impacted accurate reporting of depressive symptoms. For one, the Neuro-QoL PROM forms were developed for people with acquired neurological impairments in mind, but not specifically validated on PWA. Critically, a PROM score is interpreted best when the interpretation criteria is in line with a specific population, such as PWA (Revicki et al., 2008). A method to interpret scores that are clinically relevant to a specific population is through a bookmarking procedure, a process that engages stakeholders in developing criteria for how PROMs should be interpreted. Recently, Cohen and

colleagues (2023) performed PRO-bookmarking procedures on several PROMs, including NQ-SRA. Regarding the NQ-SRA, results of the study indicated discrepancies in the threshold for severe deficits in social roles such that the study reported severe cut off scores (t-scores 30 – 37.5) for PWA that healthmeasures.net would have classified as moderate. Unfortunately, the Neuro-QoL Depression form has yet to undergo PRO-bookmarking processes for the clinical population of aphasia. Thus, the norm-referenced standardized scores utilize to interpret NQ-Depression scores may not be fully accurate for PWA considering the discrepancies noted with the NQ-SRA. Second, research has suggested mood constructs be measured using pictural and visual stimuli. Visual processes are commonly isolated to right hemisphere (Barrows et al., 2021; Brown & Thiessen, 2018). PWA often process visual stimuli to the same degree as neurotypical populations by maximizing functions of the unimpaired contralateral hemisphere (Griffith et al., 2014). The present study did not utilize visual aids or supports in supplement with the depression measure, which may have hindered accurate mood reporting. However, this explanation does not explain why informants, who do not have language impairments, also provided depressive scores on average that are within normal limits. Another possible reason for the lack of relationship between depression and outcome variables was the lack of informant self-reports of depressive symptoms, as only informant reports of depressive symptoms for the patient were provided. Family members and care partners of people with aphasia are also susceptible to experiencing negative alterations in psychological well-being and developing depressive symptoms (Grawburg et al., 2013). Given the acknowledgement that depressive symptoms can impact perceptions of self and others, it is possible that informant's personal depressive symptoms may have correlated with informant reports of PWA functioning or systematically impact PWA-informant discrepancies.

The present study identified no significant relationships between time post onset or age with the selected outcome measures or difference scores. This means that years post onset and age were not related to perceptions of activity restrictions or participation limitations in PWA or their informants in this sample. There has been mixed reports on the influence of time post stroke on participation satisfaction in post-stroke adults. Quique et al. (2023) found that PWA who are longer time post-stroke reported higher levels of social participation. Though, van der Zee and colleagues (2013) found that a longer time post stroke was a significant predictor of lower satisfaction with participation, suggesting that not all post stroke individuals adapt and/or accept their impairment over time. Similar results have been found with depressive symptoms, with depressive symptoms failing to diminish over time following a diagnosis of aphasia (Pompon et al., 2022). Results of the present study supports and extends findings of the latter reports, with perceptions of psychosocial domains not altering as time post-diagnosis extends. This suggests that PWA require ongoing support as time surpasses to actively engage and participate in desired activities. Age not being correlated to participation confirms previous research that has also reported that younger and older adults report similarly on measures of communicative participation frequency (Toglia et al., 2019). The results also suggest that age and time post onset to not relate to the degree of PWA-informant difference scores. This finding is in contrary to literature that suggests agreement between post-stroke adults and informants tends to increase as time passes given the allotted time offered for informants to be exposed to patient perceptions (Ignatiou et al., 2012; Pickard et al., 2004). The difference may lie in that this study investigated post-stroke adults with aphasia, whereas previous findings is based on post-stroke adults, but not exclusively those with aphasia. It is possible that the contribution of a language impairment may disable PWA from articulating

their perceptions of activity restrictions, participation limitations, and other difficult to express constructs.

Clinical Implications

The administration of PROMs to capture personal perceptions of activity limitations and participation restrictions following impairment is central in guiding clinical goal setting and assessing outcomes that are valued by the individual. However, accurate interpretation of PROM measures is crucial to ensure proper goal setting and outcome measurement. Results of the present study suggest that scores supplied by informants and PWA are not consistently interchangeable, and like previous studies, informants are more likely to rate PWA more negatively than PWA rate themselves. Results of this study also suggest that informants may rate PWA more positively on constructs relating to social roles than PWA themselves. Clinicians must be aware of the unobservable constructs that may guide an individual's attitude towards their own participation and activity restrictions but may evade informant recognition according to our findings. Results of the present study may indicate a greater need for speech language pathologists to provide greater aphasia education and communication skills training to caregivers. Providing caregivers with a better understanding of the concomitant psychosocial effects aphasia may have on their loved ones, as well as the less salient components of language as reported by Fucetola and Tabor (2015) could help bridge the discrepancies between perspectives on measures of quality of life.

The present research provides evidence that PWA with less severe language deficits are likely to perceive themselves as having worse activity limitations and participation restrictions than individuals with more severe language deficits. Clinically, it is critical to ensure that patients have adequate emotional support to navigate the new normality of living with aphasia. The implementation of psychosocial support to bolster emotional support and redirect negative images

of self may be warranted for these individuals with aphasia. Northcott and colleagues (2018) operationalized psychosocial support to help manage negative reactions through counseling and address the participation and activity consequences associated with aphasia. Through implementation of interventions targeting psychosocial support, individuals across all aphasia severities may learn to accept their new normality and perceive one's capabilities and functioning through a more positive lens. However, the implementation of psychosocial interventions for people with aphasia presents with numerous barriers. One clear barrier is the cognitive-linguistic impairments that often hinders PWA from expressing difficult-to-express constructs.

Second, the assessment and treatment of psychological and psychosocial symptoms are most traditionally provided by an allied health professional with suitable licensure and/or credentials to provide evidence-based mental health treatments. However, many allied health professionals report no experience working with PWA, decreased confidence in providing adequate psychological services to this population, and feeling under-skilled in mood-screening and providing these individuals with appropriate emotional support (Morrow-Odom & Barnes, 2019; Rowland & McDonald, 2009). Moreover, there is currently uncertainty regarding the speech-language pathologists (SLPs) role in providing mental health services for patients. The American Speech-Language-Hearing Association outlines counseling as one of the eight service deliveries of SLPs and 97-98% of SLPs endorse that it is within their scope to address emotional well-being (American Speech-Language-Hearing Association, 2016; Brumfitt, 2006; Sekhon et al., 2019). Though, only 42% of SLPs report being confident in addressing the psychosocial needs of their patients and reports of utilizing strategies to avoid addressing difficult emotions during patient sessions (Northcott et al., 2018; Simmons-Mackie & Damico, 2011). Clearly, there is a critical gap in assisting with well-being and valued living in people with aphasia, evident by the

lack of confidence in providing psychosocial support across mental health professionals and SLPs. To provide support for all PWA, but specifically those with mild language severity, future research should endeavor to explore psychosocial intervention strategies that health professionals endorse confidence in implementing.

Limitations

The present study presents with several limitations. Previous studies have reported that various psychosocial factors, such as depression, mood, care-partner strain, and general life satisfaction may influence the way PWA and informants rate questions on self-report measures (Doedens & Meteyard, 2020; Grawburg et al., 2013; Ignatiou et al., 2012; Williams et al., 2006). Aside from depressive symptoms of the patient, the present study did not record and analyze any psychosocial constructs which may have key implications in the discrepancy between PWA and care partner reports. As mentioned, a diagnosis of aphasia has precipitating effects on care partner well-being, and psychological and emotional symptoms can impact an individual's perspective of their experiences and surroundings. Future research should identify psychosocial constructs that may influence PWA and informant perceptions of activity limitations and participation restrictions to better assess these variables that may influence PWA-informant discrepancies in PROM reports. Our study utilized the informant perspective, in which the person close the PWA reports on the PROM from *their personal perspective* as opposed to taking the perspective of the PWA (Roydhouse et al., 2022). Perhaps if care partners were asked to respond to the PROMs utilizing a proxy rating, or *taking the perspective of the PWA*, they would be more aligned with the patient's perspective. Lastly, the present study consists of a relatively small sample size, despite adequate statistical power, corresponding with a lack of cultural diversity, inhibiting the ability to translate results of patient-informant ratings in aphasia to the greater population. As with all research in the

field of aphasiology, future work should strive to include diverse samples that encapsulate the accurate demographic scope of individuals in the community living with aphasia.

Conclusion

This study sought to explore whether the agreement between PWA and informants on measures of participation and activities is systematically affected by the degree of a patients' language severity. Performance-based language severity was significantly associated with informant reports, but not PWA. Moreover, performance-based language severity and informant reports were found to predict the discrepancy of PWA-informant difference scores statistically significantly. Age and time post-onset were not significant predictors of any outcome variables. The findings of this study suggest that PWA with mild language severity report worse functioning (i.e., activities and participation) than their informant, whereas people with more severe language severity report better functioning than their informants. The findings suggest a greater need for speech-language pathologists to provide education and communication skills training to care partners to help foster closer communication about difficult-to-express thoughts and feelings related to participation and quality of life.

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