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Examining Anosognosia of Neglect

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Abstract

Background—Unilateral neglect (neglect) and anosognosia often co-occur post-stroke. It is unknown whether anosognosia of neglect varies for different types of **daily** activities.

Objectives—To examine the frequency of anosognosia of neglect for items on the Catherine Bergego Scale (CBS) and determine the level of agreement between participant/assessor item ratings and total scores.

Methods—Secondary analysis of data. We conducted descriptive analyses and inter-rater reliability analyses (Cohen's kappa) to determine the level of agreement between assessor and participant item ratings. A paired t-test was conducted to compare assessor and participant total scores.

Results—The frequency of anosognosia amongst items varied (29.2%-83.3%), and Kappa statistics ranged from −0.07 (no agreement) to 0.23 (fair agreement) for item ratings. There was a significant difference $t(36) = 3.02$, $p \leq .01$) between assessor (M=8.0, SD= 5.2) and participant-rated (M=5.3, SD=4.5) total CBS scores.

Conclusion—Anosognosia is prevalent among those with neglect. Findings highlight the importance of assessing for anosognosia.

Stroke survivors frequently experience unilateral neglect, hereafter referred to as neglect (Hreha et al., 2017). Due to their inattention to one side of their body or space, stroke survivors with neglect are often unable to independently perform basic (e.g. dressing,

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bathing, grooming) and instrumental activities of daily living (e.g. meal preparation, driving) (Buxbaum et al., 2004; Chen, Hreha, Kong, & Barrett, 2015; Corbetta, 2014; Katz, Hartman-Maeir, Ring, & Soroker, 1999). Anosognosia frequently co-occurs with neglect and both are particularly common among individuals with right hemisphere lesions (Appelros, Karlsson, & Hennerdal, 2007; Appelros, Karlsson, Seiger, & Nydevik, 2002). Anosognosia refers to a lack of insight or awareness of impairments (e.g. hemiparesis, neglect, hemianopia) (Nurmi Laihosalo & Jehkonen, 2014). Estimates of the prevalence of neglect and anosognosia vary considerably. However, it has been estimated that 30-70% of stroke survivors with right hemisphere lesions have neglect and 20-60% of stroke survivors with left hemisphere lesions have neglect (Hreha et al., 2017). The vast majority of studies conducted with stroke survivors have focused on *anosognosia of hemiparesis*, which is estimated to affect ~30% of stroke survivors (Kortte & Hillis, 2009; Nurmi Laihosalo & Jehkonen, 2014). However, it is well recognized clinically that stroke survivors with neglect often have limited insight to their neglect and how neglect affects their ability to perform daily activities (Corbetta, 2014; Prigatano, 2014). Hence, this study uniquely focuses on *anosognosia of neglect*.

Anosognosia is a significant predictor of disability and there are major safety concerns (e.g. falls) associated with anosognosia (Dai et al., 2014; Vossel, Weiss, Eschenbeck, & Fink, 2013). However, relatively few studies have examined anosognosia of neglect (Azouvi, 1996; Azouvi et al., 2006) and the majority of those studies have examined participants' awareness of their performance on paper and pencil based neglect assessments (Vossel et al., 2013; Vossel et al., 2012) rather than their awareness of their performance of daily activities (Azouvi, 1996). It is important to use a more ecologically valid assessment (i.e. performance of daily activities) rather than paper and pencil based assessments so that we can better understand awareness of impairments demonstrated in the real world. In an ecologically valid assessment, the task demands resemble activities performed in everyday life (Chaytor & Schmitter-Edgecombe, 2003). To our knowledge, no studies have examined whether anosognosia of neglect varies for different types of activities. Different subtypes of neglect have been identified (e.g. personal, peripersonal, extrapersonal) and stroke survivors with neglect may have one or more of these neglect subtypes (Buxbaum et al., 2004; Committeri et al., 2007). These subtype classifications are used to describe the types of activities (e.g. occurring on body, near space, far space) where neglect is observed. However, it is unknown how much insight stroke survivors with neglect have regarding their performance of daily activities and whether they have greater insight to different types of neglect (e.g. personal neglect versus peripersonal neglect). This information can be used to help develop critically needed evidence-based interventions targeting anosognosia of neglect (Bowen, Hazelton, Pollock, & Lincoln, 2013). Studies testing interventions for neglect rarely consider or report anosognosia of neglect (Azouvi, Jacquin-Courtois, & Luaute, 2016). However, an increased understanding anosognosia of neglect may help explain why stroke survivors with neglect do/do not respond to an intervention.

The Catherine Bergego Scale (CBS) (Azouvi, 1996; Azouvi et al., 2006; Azouvi et al., 2003) is a functional neglect assessment that also has a parallel questionnaire, administered to stroke survivors, to determine whether they have anosognosia of neglect. The purpose of this study was to examine the frequency of anosognosia of neglect for CBS items and to

determine the level of agreement between participant and assessor CBS item ratings and total scores. We also examined whether stroke survivors with neglect have greater awareness of their impairments for certain types of activities tested on the CBS. We hypothesized that there would be a significant difference between participant and assessor total CBS scores and that participants would rate themselves significantly ($p<.05$) lower (i.e. less neglect) than assessors. We also hypothesized that there would be slight to fair ($_K$=0.1-0.40) agreement (McHugh, 2012) between participant and assessor ratings for all items on the CBS.

Methods

We conducted a secondary analysis of data collected from two post-stroke neglect rehabilitation studies. One study was a cross-sectional study that examined measurement of neglect. The other study was a single group repeated measures study that examined the feasibility and preliminary efficacy of repetitive task-specific practice for individuals with neglect. Pre-intervention data from the single group repeated measures study were included in the analysis. Data from the two studies could be combined since the studies shared similar inclusion criteria (e.g. unilateral stroke). Combining the datasets was advantageous since it provided a more heterogeneous sample representing a wide range of impairment levels (CBS). For example, participants in the cross-sectional study had greater impairment (i.e. neglect) on average than participants in the single group repeated measures study.

Participants in the cross-sectional study were eligible to participate if they were ≥18 years old, experienced a unilateral hemispheric stroke, were able to follow 2-step commands (based on clinical judgement of participants' ability to complete 5 standard commands such as close your eyes and then touch your head) 80% of the time and did not have any other neurological disease that might affect their perception. Participants were eligible for the single group repeated measures study if they met the following criteria: ≥18 years old; ≥6 months post unilateral hemispheric stroke; demonstrated neglect (impairment on ≥ 1 of the conventional subtests from the Behavioral Inattention Test (Halligan, Wilson, & Cockburn, 1991)); mild to moderate upper extremity paresis (Motricity Index scores 48-92 (Collin & Wade, 1990)); able to follow one-step commands 80% of the time (based on clinical judgement of participants' ability to complete 5 standard commands such as touch your nose); not receiving therapy for the paretic upper extremity. Participants were recruited for both studies from local stroke support groups, local academic registries, and through therapist referrals. All procedures were followed in accordance with ethical standards of the Institutions and in accordance with the revised Declaration of Helsinki. The parent studies were approved by their respective local Institutional Review Boards. All participants were informed of the study risks and benefits and provided informed consent. Data were stored in a secure manner to protect confidentiality.

Measures

Assessments were administered by trained study assessors and inter-rater reliability was established for the measures (intraclass correlation coefficient, ≥0.95). Descriptive data were

collected. The methods described were used with participants in both studies except the measures used to measure cognitive impairment differed.

We administered the 11-item National Institutes of Health Stroke Scale (NIHSS) (Adams et al., 1999; Brott et al., 1989) to measure the severity of stroke-related impairments as per the sum score: higher scores (Range: 0-42; Mild: 0-5; Moderate: 6-13; Severe: 14-42) indicate greater impairment (Rundek et al., 2000; Sacco, DeRosa, Haley, Jr, & et al., 2001; Schlegel et al., 2003). The validity and reliability of the NIHSS is established in the stroke population (Adams et al., 1999; Brott et al., 1989; Goldstein & Samsa, 1997).

The Montreal Cognitive Assessment (MoCA) (Chiti & Pantoni, 2014; Cumming, Churilov, Linden, & Bernhardt, 2013; Nasreddine et al., 2005) was administered to participants in the cross-sectional study. The MoCA has been established as a valid and reliable assessment of post-stroke cognitive impairment (Chiti & Pantoni, 2014; Koski, 2013; Toglia, Fitzgerald, O'Dell, Mastrogiovanni, & Lin, 2011). The MoCA contains items assessing 8 cognitive domains: visuospatial/executive function, naming, memory, attention, language, abstraction, delayed recall, and orientation. Scores range from 0-30, with scores <26 indicating impaired cognition. We applied the 1-point correction to the total score for individuals with ≤12 years of education (Nasreddine et al., 2005).

The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) (Larson, Kirschner, Bode, Heinemann, & Goodman, 2005; Randolph, Tierney, Mohr, & Chase, 1998; Wilde, 2006) was administered to participants in the single group repeated measures study to assess cognition. The RBANS is a valid and reliable measure of cognitive impairment post-stroke and assesses attention, immediate recall, delayed recall, language processing, and visuospatial and constructional processing (Larson et al., 2005; Randolph et al., 1998; Wilde, 2006). We used the age-adjusted total index scores (normal M=100; SD=15) to determine if participants were cognitively impaired. An age-adjusted total index score <85 indicates impairment. The MoCA and RBANS demonstrate concurrent validity ($r=.56$, $p\leq.01$) (Paul et al., 2011).

We administered the Catherine Bergego Scale (Azouvi, 1996; Azouvi et al., 2006; P. Azouvi et al., 2003) to measure neglect. The CBS is a valid, reliable, and sensitive measure of post-stroke neglect (Azouvi, 1996; Azouvi, 2016; Azouvi et al., 2006; Azouvi et al., 2002; Azouvi et al., 2003; Luukkainen-Markkula, Tarkka, Pitkanen, Sivenius, & Hamalainen, 2011). Specifically, it has good internal consistency, inter-rater reliability, concurrent validity and convergent validity (Azouvi, 1996; Azouvi et al., 2006; Azouvi et al., 2002; Azouvi et al., 2003; Luukkainen-Markkula et al., 2011). The CBS is a functional neglect assessment because it assesses neglect through observation of activities such as eating and locomotion (i.e. collisions, navigation items). The CBS has items that assess for personal, peripersonal, and extrapersonal neglect and the type of neglect each item assesses has been delineated (Grattan & Woodbury, 2017; Plummer, Morris, & Dunai, 2003). Assessors score 10 items using a 4-point scale (Azouvi, 1996). We computed two sets of scores from the CBS. We used the assessor summed item scores to determine the presence and severity of neglect. Higher CBS scores (range: 0-30) indicate more severe neglect (Azouvi, 1996). Traditionally, items scores are simply summed (Azouvi, 1996). However, we also dichotomized the scores

on each item (i.e. assessor rated impaired [Item rating score 1, 2, or 3], assessor rated not impaired [Item rating score 0]) in order to examine the responses at the item level and determine the level of awareness of their impairments.

The CBS has a parallel anosognosia questionnaire (Azouvi, 1996). We administered the questionnaire to participants following the CBS to determine the participants' level of awareness of their impairments (i.e. neglect). The questionnaire asks the participant to rate themselves on each of the 10 CBS items using the same 4-point scale. Thus, participants are asked to select a rating scores (0: No neglect/difficulty; 1: Mild neglect/difficulty; 2: Moderate neglect/difficulty; 3: Severe neglect/difficulty). We computed two sets of scores from the anosognosia questionnaire. We used summed scores to determine the participants' self-assessment CBS score which is traditionally performed (Azouvi, 1996). We also dichotomized the score for each item (i.e. participant rates self impaired [Item rating score 1, 2, or 3], participant rates self not impaired [Item rating score 0]).

Analyses

The data (descriptive, NIHSS, MoCA, RBANS, CBS) were combined and analyzed using IBM SPSS Statistics v23. Descriptive analyses characterized the sample. The dichotomized CBS scores were used to calculate the frequency of impairment (ratings=1, 2, or 3) for each item according to assessors and according to participants. Similarly, the dichotomized CBS and anosognosia questionnaire scores were used to calculate the frequency of participants who did not identify any impairment (i.e. rating=0) when the assessor did identify impairment (ratings=1, 2, or 3) (anosognosia measure). A paired t-test was used to determine if there was a significant difference ($p<.05$) between assessor and participant summed scores. We also used the Pearson correlation to examine the relationship between assessor and participant summed scores. We interpreted the correlation results using the following criteria: 0.0-0.25 little to no relationship; 0.25-0.50 fair relationship; 0.50-0.75 moderate to good relationship; >0.75 good to excellent relationship (Portney & Watkins, 2009). Inter-rater reliability analyses using Cohen's Kappa were conducted to determine the level of agreement between the assessor and participant item ratings. We interpreted the kappa results using the following criteria: ≤0 no agreement; 0.01-0.2 no to slight, 0.21-0.40 fair, 0.41-0.60 moderate, 0.61-0.80 substantial; 0.81-1.0 almost perfect (McHugh, 2012).

Results

Data from 37 participants were analyzed (Table 1). Participants were an average of 63.6 years old (SD=14.5). The majority of participants were males who experienced a right hemisphere ischemic stroke. On average, participants demonstrated moderate (Rundek et al., 2000; Sacco et al., 2001; Schlegel et al., 2003) stroke-related impairments and were cognitively impaired (MoCA/RBANS).

Participants demonstrated neglect most frequently (86.5%) on the limb awareness item and least frequently (0.05%) on the auditory awareness item (Table 2). Anosognosia of neglect was common, however the frequency varied greatly depending on the item (29.2%-83.3%) (Table 2). Kappa statistics ranged from −0.07 to 0.23 thus indicating no agreement to fair agreement for the items. There was a significant difference ($t(36) = 3.02$, $p \leq .01$) between

assessor (M=8.0, SD= 5.2) and participant-rated (M=5.3, SD=4.5) summed scores. Participants rated themselves significantly lower (i.e. perceived less neglect) than assessors. There was a fair positive correlation (r=.35, p=.03) between assessor and participant-rated summed scores.

Discussion

To our knowledge, no studies have reported on the prevalence of anosognosia of neglect for performance of daily activities. Our data indicate that anosognosia is extremely pervasive among stroke survivors with neglect and support the findings of Appelros et al. (2007) who found that approximately 42% of individuals with neglect also had anosognosia for hemiplegia, hemianopia, or sensory impairment. We found that greater than half of the participants demonstrated neglect on assessor-rated items such as dressing, collisions, limb awareness, personal belongings, and gaze. Yet, 29.2 (personal belongings) to 64.0% (dressing) of participants who had neglect were unaware (i.e. had anosognosia) that they demonstrated impairment on these five items (Table 2).

On average, participants did have some insight to their neglect. Although the participant and assessor total CBS scores were statistically different from one another, the mean participant score was greater than zero and the strength of the association between participant and assessor total CBS scores was fair. These results suggest that participants recognize some of their impairments but are not aware of others. The results also suggest that even when participants recognize their neglect, they may rate the severity of the impairment very differently from assessors.

This study also contributes to the literature because it examined whether anosognosia of neglect varies for different types of activities, which has not been previously studied. There was considerable variability in the frequency (29.2-83.3%) of anosognosia for different activities. In this sample, anosognosia of personal neglect was most common. Participants frequently lacked insight to neglect demonstrated during activities such as dressing, grooming, and cleaning up after a meal. Anosognosia of peripersonal (e.g. personal belongings) and extrapersonal neglect (e.g. collisions) were still prevalent but were less common. The highest level of agreement was for the personal belongings and collision items. Participants were also more aware when they demonstrated impairment on these items. One reason for these findings may be that when participants demonstrate neglect during these behaviors, they receive immediate implicit feedback regarding their performance. For example, if a stroke survivor with neglect collides into a doorway they receive immediate sensory input that may cue them to his/her impairment. Similarly, if a participant struggles to locate personal belongings, they may have greater insight to the fact that they either did not locate the item they were looking for at all or that it took them considerable time to do so. Conversely, anosognosia of neglect during performance of an activity such as grooming may be higher because a stroke survivor’s perception may be that they comprehensively and successfully completed the task even if they failed to attend to one side of his/her face.

Cognitive impairment is common post stroke (Sun, Tan, & Yu, 2014) and likely contributes to anosognosia of neglect. In our sample, all but 3 of the 36 participants (unable to calculate total index score for 1 participant since not all subtests were administered) were cognitively impaired (i.e. scored below cut-offs on the MoCA/RBANS). Our findings suggest that the majority of stroke survivors with neglect demonstrate cognitive impairment. However, the MoCA cut-off score has been debated and there is some evidence to suggest that the cut-off should be lower (Rossetti, Lacritz, Cullum, & Weiner, 2011). A lower cut-off score would mean that fewer stroke survivors would be considered as having cognitive impairment. The relationship between anosognosia of neglect and cognitive impairment is not well studied. However, there is some evidence that anosognosia is correlated with cognitive impairment (Appelros, Karlsson, Seiger, & Nydevik, 2003) and that stroke survivors with anosognosia have greater impairments in executive functioning than those without anosognosia (Starkstein, Jorge, & Robinson, 2010). It is logical that impairments in problem solving and self-monitoring in particular would contribute to anosognosia of neglect; however, we did not administer a comprehensive neuropsychological battery to confirm this hypothesis. Future studies should be conducted to examine factors that contribute specifically to anosognosia of neglect.

A limitation of our study is that we did not investigate whether lesion location affects anosognosia of neglect. Studies indicate that there are regions of the brain that are associated with different types of anosognosia (Pia, Neppi-Modona, Ricci, & Berti, 2004; Rousseaux, Allart, Bernati, & Saj, 2015; Starkstein et al., 2010; Vocat, Staub, Stroppini, & Vuilleumier, 2010; Vossel et al., 2012). Neuroanatomical relationships to neglect subtypes (e.g. personal, peripersonal) have also been identified (Corbetta & Shulman, 2011; Rousseaux et al., 2015). It is possible that neuroanatomical correlates exist for different subtypes of anosognosia of neglect as well. This warrants investigation in future studies. Another limitation of this study is that participants were assessed at different time points post stroke. However, the vast majority of our participants (81.1%) were greater than six months post stroke at the time they were evaluated which is often considered the chronic stage of stroke recovery. Approximately 1/3 of stroke survivors with acute neglect have neglect that persists into the chronic stage of stroke (i.e. 6 months) (Karnath, Rennig, Johannsen, & Rorden, 2011). It is possible that participants in our sample experienced less neglect recovery due to their anosognosia. Additional studies should be conducted that examine the trajectory of anosognosia over time and whether anosognosia of neglect for different types of activities are more/less common at different stages of stroke recovery. Future studies should also examine anosognosia of performance of daily activities not assessed by the CBS (e.g. bathing, meal preparation).

Conclusion

These findings highlight the importance of assessing for anosognosia of neglect in stroke rehabilitation. Stroke survivors with neglect have greater disability (Jehkonen, Laihosalo, & Kettunen, 2006) compared to other stroke survivors and their caregivers have higher levels of burden and stress (Chen, Fyffe, & Hreha, 2017). Anosognosia is also associated with disability (Vossel et al., 2013). If a stroke survivor lacks insight to his/her neglect, it is likely more challenging for the individual to address his/her own performance deficits, and/or

recognize the need for caregiver assistance (cues or physical assist) to complete daily activities. The relationship between anosognosia of neglect and caregiver burden and stress should be explored in future studies.

Findings also underscore the need for evidence based interventions for anosognosia of neglect. Given the prevalence of anosognosia among stroke survivors with neglect, we would argue that unless anosognosia of neglect is addressed (i.e. assessed for, identified, treated), interventions aimed at reducing disability for individuals with neglect may be less effective. There are very few studies that have tested interventions designed specifically to improve awareness or that have examined the impact of neglect rehabilitation interventions on improving awareness (Beschin, Cocchini, Allen, & Della Sala, 2012; Ronchi et al., 2013; Soderback, Bengtsson, Ginsburg, & Ekholm, 1992; Tham, 2001; Kerstin Tham & Tegnér, 1997). We found that individuals with neglect frequently lacked insight to their performance of daily activities. Thus, additional research is clearly needed to identify evidence based interventions that improve awareness of performance of daily activities (e.g. dressing). Occupational therapy practitioners must be cognizant of the prevalence of anosognosia of neglect and takes steps to not only assess for anosognosia of neglect but also consider its impact when planning treatment.

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Table 1

Descriptive Statistics and Catherine Bergego Scale Scores (N=37)

Male, *n* (%)	23 (60.5)
Age, years, *M* (*SD*)	63.6 (14.5)
Non-Hispanic White, *n* (%)	26 (70.3)
African American, *n* (%)	11 (29.7)
Chronicity, months, median (interquartile range)	13.0 (7.0-52.8)
Right hemisphere, *n* (%)	27 (73.0)
Ischemic, *n* (%)	26 (72.2)
NIHSS, M (SD)	7.4 (3.8)
MOCA, M (SD), (n=21)	20.0 (5.4)
RBANS, M (SD), (n=**15**)*	70.3 (11.9)
CBS Assessor Total Score, M (SD)	8.0 (5.2)
CBS, Participant Total Score, M (SD)	5.5 (4.5)

Note. NIHSS=National Institutes of Health Stroke Scale; MOCA=Montreal Cognitive Assessment; RBANS=Repeatable Battery for the Assessment of Neuropsychological Status; CBS=Catherine Bergego Scale.

Table 2

Inter-rater Reliability and Anosognosia

CBS Item	Participants Demonstrating Impairment (Assessor Rating), n (%)	Participants Demonstrating Impairment (Participant Rating), n (%)	Anosognosia† n (%)	Cohen's Kappa‡
Personal Belongings	24 (64.9)	17 (45.9)	7 (29.2)	0.20
Gaze	22 (59.5)	12 (32.4)	10 (45.5)	0.16
Limb Awareness	32 (86.5)	21 (56.8)	11 (34.4)	0.14
Auditory Awareness	2 (0.05)	1 (0.03)	1 (50.0)	−0.01
Grooming	12 (32.4)	5 (13.5)	7 (58.3)	−0.07
Dressing	25 (67.6)	9 (24.3)	16 (64.0)	0.13
Eating	9 (24.3)	5 (13.5)	4 (44.4)	0.02
Cleaning after Meal	6 (16.2)	1 (0.03)	5 (83.3)	−0.06
Collisions	25 (67.6)	17 (0.46)	8 (32.0)	0.23*
Navigation	14 (37.8)	9 (24.3)	5 (35.7)	0.11

Note. CBS=Catherine Bergego Scale;

*p<.05;

†Participants who did not Identify Impairment when Assessor Did, Participant rating/Assessor Rating;

‡Agreement between assessor and participant raw item score ratings.