

Unilateral Spatial Neglect May Not Be Detected by Performance-Based Functional Neglect Assessment

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Importance: Unilateral spatial neglect (neglect) poststroke is disabling. It is critical that people with neglect are identified so that treatment can be provided to maximize independence. However, there is some evidence to suggest that existing assessments may not adequately measure neglect. It is unclear whether assessments also fail to identify people with neglect entirely.

Objective: To determine whether there are stroke survivors who self-report neglect symptoms that are not detected by therapist-rated assessments and to compare self-report and therapist-ratings.

Design: Cross-sectional study.

Setting: U.S. university research center.

Participants: Unilateral stroke survivors ($N = 133$).

Intervention: Not applicable.

Outcomes and Measures: The Catherine Bergego Scale (CBS) was administered to participants and scored by a trained occupational therapist. The parallel self-evaluation anosognosia form was also administered to participants to self-report and rate neglect symptoms.

Results: Forty-eight participants (36.1%) were classified as without neglect on the basis of therapist-rated total CBS scores, yet 30 (62.5%) of these 48 participants reported symptoms of neglect on the CBS self-evaluation anosognosia form. There was a significant difference ($p < .001$) between therapist-rated and self-rated total CBS scores.

Conclusions and Relevance: Our results indicate that many stroke survivors report some level of disability associated with neglect yet do not meet the criteria to be classified as having neglect according to a commonly used therapist-rated performance-based measure.

Plain-Language Summary: The findings of this study contribute to the evidence that existing assessments used by occupational therapists to measure performance-based neglect may not always detect neglect symptoms comprehensively in people poststroke. The finding also suggests that we may be missing neglect symptoms entirely. Occupational therapists should consider using various methods to assess for neglect, including patient self-report and comprehensive occupational profiles. Clinicians should also thoroughly screen all clients with stroke for neglect, regardless of lesion location.

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Unilateral spatial neglect (neglect) is a common neurocognitive impairment that is characterized by difficulty in responding; orienting; or reporting to people, objects, or stimuli in the contralesional side of space (Heilman et al., 2000). Neglect is often referred to as a disconnection syndrome (Bartolomeo et al., 2007;

Lunven & Bartolomeo, 2017), because it occurs when there is disruption to the dorsal or ventral attention networks in the brain (Alves et al., 2022; Bartolomeo et al., 2007; Lunven & Bartolomeo, 2017). Given the extensive number of brain regions (cortical and subcortical) associated with these networks, neglect can occur as a result

of lesions in many different areas (Alves et al., 2022; Corbetta et al., 2005; Corbetta & Shulman, 2011). It is important to note that neglect is more common and more severe after right hemisphere lesions (i.e., left neglect), but it also affects approximately 18% of people with left hemisphere lesions (i.e., right neglect; Esposito et al., 2021). Neglect is complex, and people may neglect one side of their body (personal neglect), neglect one side of space within reaching distance (peripersonal neglect), or neglect one side of space beyond reaching distance (extrapersonal neglect; Buxbaum et al., 2004). Neglect affects approximately one-third of stroke survivors and is associated with greater disability, poorer functional recovery, and greater sensorimotor impairments (Bosma et al., 2020; Esposito et al., 2021; Hammerbeck et al., 2019). Thus, it is important that clinicians are able to identify people with neglect to address their rehabilitation needs.

Although numerous assessments are available for clinicians to use in screening and assessing for neglect, the majority are impairment-based, paper-and-pencil assessments (e.g., line bisection, letter cancellation, star cancellation, copy or draw a figure), and although they are easily administered, they are limited in relevance and sensitivity (Grattan & Woodbury, 2017; Plummer et al., 2003). For example, paper-and-pencil assessments lack ecological validity and the ability to inform how neglect affects daily life (Azouvi, 2017; Grattan & Woodbury, 2017; Pedroli et al., 2015). Therefore, it is challenging for these assessment results to be used to plan rehabilitation targeting the patients' re-engagement at home and in the community. In addition, pencil-and-paper assessments are less sensitive at detecting neglect when compared with functional assessments (i.e., assessments for neglect in the context of daily activities) and more variable, even when a battery of paper-and-pencil assessments is administered (Azouvi et al., 2006; Bonato, 2012; Luukkainen-Markkula et al., 2011). Thus, current evidence supports the use of functional measures over impairment-based, paper-and-pencil assessments.

Although the limitations of paper-and-pencil assessments are well studied, less research has been conducted to examine the potential limitations of existing functional neglect assessments. However, there is some evidence to suggest that some functional neglect assessments, such as the Behavioral Inattention Test, only assess for a single type of neglect (e.g., peripersonal neglect; Hartman-Maeir & Katz, 1995; Wilson et al., 1987) and may lack sensitivity at detecting neglect compared with pencil-and-paper assessments. In contrast, the Catherine Bergego Scale (CBS; Azouvi et al., 2003) assesses for multiple types of neglect (Grattan & Woodbury, 2017; Plummer et al., 2003) and, hence, may be more sensitive at detecting neglect. The CBS is one of the most commonly used functional neglect assessments and is the only one, to our knowledge, that contains items that assess for personal, peripersonal, and extrapersonal neglect (Azouvi, 2017; Grattan & Woodbury, 2017; Plummer et al., 2003).

Despite the fact that the CBS has many strong psychometric properties and includes items that can assess for various types of neglect, it still may have limitations (Azouvi et al., 2003). A mixed-methods study by Klinke et al. (2016) found that the CBS was unable to fully identify challenges related to safety and independence that people with neglect were experiencing. These findings highlight that functional performance in daily life may fluctuate for people with neglect and depend on various environmental or personal factors (e.g., visual distractions, noises, fatigue, anxiety). For example, a person with neglect may be able to avoid collisions that are due to their neglect while ambulating in their own familiar quiet home environment but may be unable to avoid collisions in a busy shopping mall that is full of auditory and visual distractors and with a greater variety of physical obstacles. It also leads us to question whether people with mild neglect, or perhaps those whose performance fluctuates under various task demands and environmental conditions, could have their neglect go undetected by a commonly used functional neglect measure during an evaluation session.

The CBS also has a parallel patient self-evaluation form that was originally developed to assess for anosognosia (Bosma et al., 2020) but it is not as commonly used as the performance-based, therapist-rated CBS items. Therapist-rated scores can be compared with patient-reported scores to assess for agreement and whether a patient with neglect lacks insight into their neglect. However, we were interested in examining the potential disparity between patient-reported scores and therapist-rated scores to determine whether there are some people who recognize neglect behaviors in their own daily life that clinicians are not detecting during an evaluation session. To our knowledge, a patient-reported outcome measure that comprehensively captures the lived experiences of people with neglect does not exist. Thus, the purpose of our study was to compare therapist-rated CBS assessment scores to participant self-evaluation scores to determine whether these scores align and whether there are people who self-report neglect symptoms yet would have gone undiagnosed with neglect if traditional therapist-rated methods alone had been used.

Method

This study was a descriptive secondary analysis of data ($N = 133$) from a cross-sectional neglect measurement study that took place at two institutions. All research procedures were approved by the institutional review boards at the University of Pittsburgh and the Medical University of South Carolina. All participants provided informed consent and understood the risks and benefits in participation in the study, that participation was voluntary, and that their identities would not be disclosed. The procedures followed were in accordance with the ethical standards of the institutional review boards and were consistent with the revised Helsinki

Declaration of 2000. Data were stored in a secure manner and confidentiality was maintained.

Participants

Participants included people who were ages 18 yr and older, had a unilateral stroke, could follow one-step directions 80% of the time, and did not have any other neurological disease that might affect their perception. Participants were recruited from stroke support groups, therapist referrals, and through several academic research registries.

Procedures

Study assessors underwent training, using cases in accordance with the study's manual of procedures. Interrater reliability ($\kappa > 0.9$) was established before the start of the study and was maintained throughout the course of the study. The assessors administered a battery of assessments, and descriptive data were also collected.

We administered the CBS to assess for neglect. The validity and reliability of the CBS are well established. The CBS has excellent interrater and intrarater reliability, as well as good internal consistency, criterion validity, and concurrent validity (Azouvi et al., 1996, 2003; Luukkainen-Markkula et al., 2011). Assessors rated performance through observation of participants' performance on various daily tasks (Azouvi et al., 2003). Items include personal belongings, gaze, limb awareness, auditory awareness, grooming, dressing, eating, cleaning after meal, collisions, and navigation. The 10 items were scored on a 4-point scale ranging from 0 (*no neglect*) to 3 (*severe neglect*), with possible total scores ranging from 0 to 30. We used the total score to categorize participants as having or not having neglect. Total scores that were equal to 0 indicated no neglect and scores of 1 or higher indicated neglect.

The CBS also contains an anosognosia questionnaire that parallels the items that are functionally assessed. Participants were asked to rate their perceived level of difficulty with each of the 10 items. The assessment was administered in a standardized manner by a trained evaluator. The standard assessment procedures guide the evaluator to refrain from using emotion in one's voice when acknowledging the participant's response to an item (i.e., expressing that the response was good or bad), thereby controlling for social desirability bias (Althubaiti, 2016). In addition, recall bias was controlled because the recall period was short (i.e., participants recalled their performance of events in the past week). On the rating scale, scores were 0 (*no neglect or difficulty*), 1 (*mild neglect or difficulty*), 2 (*moderate neglect or difficulty*), and 3 (*severe neglect or difficulty*). Self-ratings were summed to determine a participant's self-assessment score, with a possible range of 0 to 30; higher numbers indicate more severe neglect. We examined the total scores to

determine whether participants reported some level of difficulty on any of the 10 items in their daily life (total score, ≥ 1).

Analyses

Data were analyzed using IBM SPSS Statistics (Version 28). Descriptive analyses were used to characterize the sample. We then used descriptive statistics to determine the number and percentage of participants who were classified by therapists as having neglect (therapist-rated total score, ≥ 1) versus without neglect (therapist-rated total score, 0) using established CBS cutoff scores. We calculated the number and percentage of participants who reported neglect-related disability (participant-rated total score, ≥ 1) yet were classified as without neglect (therapist-rated total score, 0). For this subsample of participants, we then examined participant scores for each item. We also used a paired *t* test to determine whether there was a significant difference ($p < .05$) between therapist and participant summed scores. Finally, we used a paired *t* test to examine whether there were significant differences ($p < .05$) in the self-report items or total scores between participants with left and right hemisphere lesions.

Results

Of the 133 participants in the parent study, 48 (36.1%) participants were classified as without neglect and 85 (63.9%) were classified as with neglect on the basis of therapist-rated total CBS scores. In the subsample of 48 participants (who self-reported neglect symptoms yet were classified as without neglect) who were analyzed further (Table 1), the average age was 59.5 yr ($SD = 13.8$). The majority of participants were Caucasian men who experienced a right hemisphere ischemic stroke an average of 61.0 mo ($SD = 55.7$) before enrollment. On average, participants self-reported mild neglect symptoms, with a mean CBS anosognosia score of 2.6 ($SD = 3.1$).

Table 1. Descriptive Statistics

Characteristic	n (%)
Age, <i>M</i> (<i>SD</i>)	59.5 (13.8)
Male	26 (54.2)
Caucasian	37 (77.1)
Black	9 (18.8)
Asian	1 (2.1)
More than one race	1 (2.1)
Ischemic	38 (79.2)
Right hemisphere affected	20 (41.7)
Months since stroke, <i>M</i> (<i>SD</i>)	61.0 (55.7)
CBS anosognosia total score, <i>M</i> (<i>SD</i>)	2.5 (3.1)

Note. *n* = 48. CBS = Catherine Bergego Scale.

Thirty (62.5%) of the 48 participants classified as without neglect still reported symptoms of neglect on the CBS self-evaluation scale. The percentages of participants who indicated some level of impairment (score ≥ 1) on items ranged from 6.3% (grooming item) to 35.4% (limb awareness; Table 2). Participants most commonly self-reported the neglect symptoms “limb awareness,” “collisions when ambulating,” and “difficulty locating personal belongings” when therapists did not identify disability. Ratings of 1 (mild neglect) were most commonly reported and ratings of 3 (severe neglect) were rarely reported. There was a significant difference between assessor-rated ($M = 0.0$, $SD = 0.0$) and participant-rated ($M = 2.6$, $SD = 3.1$) total CBS scores, $t(47) = 5.7$, $p < .001$. Participants rated themselves significantly higher (i.e., perceived greater neglect) than assessors. There were no significant differences ($p < .05$) for any of the self-report item scores or total scores between participants with left and right hemisphere lesions.

Discussion

The purpose of our study was to determine whether there are people who self-report neglect symptoms but do not demonstrate neglect on the therapist-scored CBS. Our results indicate that many people report some level of disability associated with neglect yet do not meet the criteria to be classified as having neglect according to a commonly used performance-based measure. The CBS self-evaluation anosognosia scale is typically used to measure a client’s lack of awareness of neglect deficits; hence, the patient-reported score should be lower than the therapist-administered score. Previous studies have found that patient-reported CBS scores are significantly lower (i.e., they report less neglect, anosognosia is present) compared with therapist-administered CBS scores (Azouvi et al., 2003; De-Rosende-Celeiro et al., 2021; Grattan et al., 2018). However, it is interesting that our analysis revealed a

group of people who demonstrated a patient-self-reported score that was higher than the therapist score; that is, these individuals reported higher neglect levels than indicated by the scores obtained by the therapists. This suggests that, perhaps in using this assessment, therapists are not capturing the full scope of a client’s lived experience with neglect when performing.

Our findings contribute to the evidence that functional neglect assessments may not always detect comprehensive neglect symptoms poststroke. Moreover, the results suggest that we may be missing neglect symptoms entirely. A previous mixed-methods study of people who had been diagnosed with neglect found that the CBS did not fully capture neglect-related disability or safety issues that the people with neglect were experiencing (Klinke et al., 2016). If people are not identified by functional neglect assessments, it is unlikely that they will receive adequate treatment to allow for safe participation in daily activities. Without proper intervention, people with neglect may be at a greater risk for injuries and may experience less recovery.

Overall, when participants in the present study reported difficulty in completing tasks, they typically reported mild difficulty rather than moderate or severe. It is interesting to note that our sample included a slightly larger percentage of people who reported right side neglect (left hemisphere lesion), which is known to be associated with milder neglect symptoms (Ten Brink et al., 2017). Milder symptoms of neglect may go unnoticed by therapists, because they may not be as evident within a more controlled clinical assessment environment. Previous studies in the field of stroke rehabilitation have also found discrepancies between patient-reported outcomes and assessor-rated assessments (Maaijwee et al., 2014; Stewart & Cramer, 2013; van Delden et al., 2013). Often, patients report greater poststroke symptoms than functional assessments indicate. For example, Stewart and Cramer

Table 2. Self-Reported Ratings on Anosognosia CBS Items for People Categorized by Therapists as “Without Neglect”

CBS Anosognosia Item	n (%)			
	No Neglect	Mild Neglect	Moderate Neglect	Severe Neglect
Personal belongings	35 (72.9)	9 (18.8)	3 (6.3)	0 (0.0)
Gaze	38 (79.2)	8 (16.7)	1 (2.1)	1 (2.1)
Limb awareness	31 (64.6)	12 (25.0)	5 (10.4)	0 (0.0)
Auditory attention	39 (81.3)	6 (12.5)	3 (6.3)	0 (0.0)
Grooming	45 (93.8)	3 (6.3)	0 (0.0)	0 (0.0)
Dressing	40 (83.3)	7 (14.6)	1 (2.1)	0 (0.0)
Eating	41 (85.4)	4 (8.3)	3 (6.3)	0 (0.0)
Cleaning face	44 (91.7)	2 (4.2)	1 (2.1)	1 (2.1)
Collisions	34 (70.8)	11 (22.9)	2 (4.2)	1 (2.1)
Navigation	40 (83.3)	7 (14.6)	1 (2.1)	0 (0.0)

Note. $N = 48$. The 10 items were scored as 0 (no neglect), 1 (mild neglect), 2 (moderate neglect), and 3 (severe neglect). CBS = Catherine Bergego Scale.

(2013) discovered that a large number of people who had little to no disability, according to assessor-rated functional assessments, reported reduced use and difficulty with hand movements on patient-reported outcome measures. Van Delden et al. (2013) found that even when minimal clinically meaningful changes on upper extremity function assessments were detected, patients did not always report perceiving a clinically significant change. Similar findings have been reported regarding cognition poststroke. Maaijwee et al. (2014) revealed that people in the acute and subacute phases poststroke report cognitive impairments that do not correlate strongly with performance on cognitive measures. Failure to detect mild neurological symptoms tends to be a theme across assessor-rated assessments.

Findings highlight the importance of measuring neglect symptoms in a variety of modes (e.g., self-report, performance based) and with several items having various levels of complexity to capture the fluctuating levels of neglect that a patient may experience in both their simple and their complex daily routines. The demands of a task increase or decrease depending on the context within which it is performed; therefore, existing functional neglect assessments may not be sufficiently challenging, because they are typically performed in only one context (Sarri et al., 2009). For example, someone may have a more difficult time finding their car keys on the left side of their kitchen table when the television is on and people in the next room are conversing than when home alone in a quiet environment. These external distractors are prevalent in everyday life and often increase the cognitive demand for completing even seemingly simple tasks. In addition, studies have shown that tasks that require dual attention increase the cognitive load required for performance and are more likely to reveal a patient's neglect (Andres et al., 2019). For example, the cognitive load can be increased through combining tasks that are both physically and cognitively challenging, such as navigating a busy grocery store while recalling ingredients for a meal. Thus, it is possible that for participants in this sample, the assessors did not detect neglect on the CBS because the items did not fully replicate various levels of complexity with the environment or task demands experienced in their own daily life.

Although there are certainly merits to using the self-report, it is also important to recognize that people with neglect often have anosognosia where they lack insight or awareness into their disability and, therefore, underreport neglect symptoms. It is possible that, although participants in this study did self-report neglect symptoms, they were actually experiencing a disability that was even greater than they knew. This is why it is important for clinicians to incorporate both performance-based assessments and conduct personalized client interviews to determine the extent to which neglect may be affecting a client's performance in daily activities poststroke.

A limitation of this study is that participants who reported neglect symptoms may have overreported symptoms. For example, a person may report difficulty with collisions, but these challenges could also be attributed in part to decreased balance. A study by Tobler-Ammann et al. (2020) found that some people with neglect have difficulty distinguishing between neglect and other impairments (e.g., nonuse because of hemiparesis), which often coexist. Although it is possible that some people are reporting difficulty with certain daily activities because of impairments other than neglect, this alone is unlikely to account for the entirety of the substantial number of people reporting neglect-related disability. Given the nature of the self-report, there is some potential subjectivity with participants' perceived level of difficulty. Therefore, we believe that the most compelling finding is that people reported some level of difficulty or disability that was not identified by the performance-based measure. Findings also may be attributed to the assessments used in this study. However, there is evidence that the CBS is more sensitive than other neglect assessments (Chen et al., 2012; Gillen et al., 2021), and, to our knowledge, it is the only assessment that has a self-report measure that is parallel to the performance-based, assessor-rated version. In addition, it is the only performance-based neglect assessment that includes items that address personal, peripersonal, and extrapersonal neglect (Grattan & Woodbury, 2017). Virtual reality assessments may offer the opportunity to sensitively identify neglect-related disability and could potentially be paired with real-world self-report (Buxbaum et al., 2012; Ogourtsova et al., 2017).

Another limitation of the study is that we did not randomize the order of the assessments, because the self-evaluation anosognosia form is intended to be administered after the performance-based assessment. We did not anticipate that this would affect our findings, but it is possible that this primed participants to think more about how neglect affects them on a daily basis. Although we used methods to try to prevent or minimize self-report bias, it is possible that the self-report bias (Althubaiti, 2016) still affected findings. It is also possible that these findings would not generalize to a more acute population. On average, participants in this study were in the chronic stage of stroke recovery and reported mild symptoms of neglect. Neglect is more common early after stroke, but it is estimated that approximately one-third of people with acute neglect continue to have chronic neglect (Karnath et al., 2011; Marchi et al., 2017). People who are in the acute stage of stroke recovery typically have more severe neglect (Moore et al., 2021) that may be more likely to be captured and detected by the assessor-rated CBS. Our findings may be attributed to the participants' stage of stroke recovery. It is also likely that a self-report measure would be less useful in determining whether a person has neglect in the acute and subacute stages of stroke recovery, given the high rates of anosognosia

earlier after stroke (Starkstein et al., 2010). Future studies should explore potential predictors of perception of neglect, including chronicity.

Implications for Occupational Therapy Practice

It is currently recommended that occupational therapists use functional neglect assessments rather than paper-and-pencil assessments to determine whether clients have neglect. However, our research suggests that even a functional neglect assessment may lack sensitivity and that clients who are experiencing mild neglect symptoms may not be identified. It is vital to identify even mild neglect symptoms accurately early after stroke so that we may treat these symptoms, because they are associated with higher rates of occupational dysfunction. Practitioners in acute care settings must assess for neglect and be cognizant of the impact that neglect can have on occupational performance. The findings of this study have the following clinical implications for occupational therapy practice:

- Occupational therapists should be aware that performance-based assessment may fail to identify mild neglect in clients who report neglect symptoms in their daily life.
- In addition to functional assessments, occupational therapists should consider using various modes to assess for neglect, including patient self-report and comprehensive occupational profiles.
- Clinicians should thoroughly screen all clients with stroke for neglect, regardless of lesion location. Although people with right-sided lesions typically experience greater symptoms of neglect, those with left-sided lesions also experience neglect and may go undetected because they exhibit more minor symptoms.

Conclusion

Our findings suggest that a commonly used neglect measure may fail to identify people with neglect, but additional investigation is warranted. A mixed-methods study may provide further insight into how people perform on a breadth of neglect measures compared with their account of their experience in daily life. If limitations are revealed, it is possible that a new measure may need to be developed. Our findings emphasize the need for clinicians to carefully screen and assess people for neglect, because even milder symptoms have the potential to cause occupational dysfunction. To accurately identify these people, clinicians should complete a comprehensive interview and occupational profile to assess areas of performance that may be affected by neglect. 🏠

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