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Suzanne Perea Burns
Medical University of South Carolina

Brandi M. White
University of Kentucky, brandi.white50@uky.edu

Gayenell Magwood
Medical University of South Carolina

Charles Ellis
East Carolina University

Ayaba Logan
Medical University of South Carolina

See next page for additional authors

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Authors

Suzanne Perea Burns, Brandi M. White, Gayenell Magwood, Charles Ellis, Ayaba Logan, Joy N. Jones Buie, and Robert J. Adams



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Racial and ethnic disparities in stroke outcomes: a scoping review of post-stroke disability assessment tools

Suzanne Perea Burns^a, Brandi M. White^b, Gayenell Magwood^{a,c}, Charles Ellis^d, Ayaba Logan^e, Joy N. Jones Buie^a, Robert J. Adams^{a,f}

^aWISSDOM Center, Medical University of South Carolina, Charleston, SC, USA;

^bCollege of Health Sciences, University of Kentucky, Lexington, KY, USA;

^cCollege of Nursing, Medical University of South Carolina, Charleston, SC, USA;

^dDepartment of Communication Sciences and Disorders, East Carolina University, Greenville, NC, USA;

^eDepartment of Library Science and Informatics, Medical University of South Carolina, Charleston, SC, USA;

^fDepartment of Neurology, Medical University of South Carolina, Charleston, SC, USA

Abstract

Purpose: To identify how post-stroke disability outcomes are assessed in studies that examine racial/ethnic disparities and to map the identified assessment content to the International Classification of Functioning, Disability, and Health (ICF) across the time course of stroke recovery.

Methods: We conducted a scoping review of the literature. Articles published between January 2001 and July 2017 were identified through Scopus, PubMed, CINAHL, and PsycINFO according to predefined inclusion and exclusion criteria.

Results: We identified 1791 articles through database and hand-searching strategies. Of the articles, 194 met inclusion criteria for full-text review, and 41 met inclusion criteria for study inclusion. The included studies used a variety of outcome measures encompassing domains within the ICF: body functions, activities, participation, and contextual factors across the time course of stroke recovery. We discovered disproportionate representation among racial/ethnic groups in the post-stroke disability disparities literature.

Conclusions: A wide variety of assessments are used to examine disparities in post-stroke disability across the time course of stroke recovery. Several studies have identified disparities through a variety of assessments; however, substantial problems abound from the assessments used including inconsistent use of assessments, lacking evidence on the validity of assessments

CONTACT Suzanne Perea Burns sburns@twu.edu WISSDOM Center, Medical University of South Carolina, 99 Jonathan Lucas, Suite 508, MSC 160, Charleston, SC 29425, USA.

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among racial/ethnic groups, and inadequate representation among all racial/ethnic populations comprising the US.

Keywords

Stroke; disability evaluation; health status disparity; minority health; patient outcome assessment

Introduction

Stroke is considered a chronic health condition that contributes to persistent and unmet long-term needs in the context of the community [1,2]. Adults with stroke often experience residual disability, participation limitations, and a range of personal, social, and economic hardships [3]. Recent evidence suggests that racial and ethnic minorities in the United States (US) are disproportionately affected by stroke and have a greater burden of post-stroke disability across the time course of stroke recovery (i.e., pre-stroke, acute, early recovery, long-term/community) [4–8]. Although a majority of studies have discovered disparities in stroke recovery outcomes among racial/ethnic minorities, inconsistencies in the findings exist. Variation in tools used to examine disparities in post-stroke disability may contribute to the inconsistent findings reported in the literature. For instance, studies that examine disparities in activity limitations across the time course of stroke recovery have demonstrated conflicting findings. Burgess et al. [8] describe how disparities in activity limitations measured by two different tools, the Barthel Index and modified Rankin Scale, have shown a range of findings (i.e., worse outcome, better outcome, and no difference in outcome) in racial minorities compared to non-Hispanic whites when examining short- and long-term outcomes.

Post-stroke functioning and disability is variable, complex, and may be influenced by residual impairments and a range of personal and contextual factors [9]. The World Health Organization's International Classification of Functioning, Disability, and Health (ICF) [10] is an internationally accepted framework that provides a common language for individual and population-level disability and functioning across the lifespan (Figure 1). The ICF aids in the conceptualization of interactions between functioning, activities, participation, and contextual influences (i.e., personal and environmental) pertaining to post-stroke disability [9]. The framework is built upon the International Classification of Impairments, Disability, and Handicaps (ICIDH) [11] which applied different basic principles and terminology but had similar aims. For instance, the ICIDH used impairment, disability, and handicap terminology which are referred to as body functions and structures, activities, and participation in the ICF, respectively. Additionally, the ICF introduced environmental factors that comprise the physical, social, and attitudinal environment [12]. Herein, we applied the ICF to review the literature on assessments used to examine disparities in post-stroke disability among a variety of racial/ethnic minority groups residing in the US.

When studying assessments used to examine disability among persons with stroke, it is inherently useful to work within a framework to categorize and classify data [13]. The ICF components correspond with functional outcome measures used in stroke recovery research and may be particularly useful in understanding disparities in functioning and disability.

Furthermore, understanding the variability in assessments used to examine disparities in post-stroke disability throughout the literature may provide insight on the validity of reported disparities. The objectives of this review are three-fold: (1) identify assessments used in racial/ethnic disparities in post-stroke disability literature, (2) use the ICF as a frame of reference for mapping the contents of the identified measures, and (3) evaluate the time points of measured outcomes and racial/ethnic representation within the identified studies.

Methods

Search strategy

A scoping review of the literature was conducted to identify assessments that address domains of the ICF to examine racial/ethnic disparities in the US. We conducted a scoping review because it is useful in mapping fundamental concepts and identifying gaps in the literature by systematically examining, selecting, and integrating existing research [14]. The lead author and the research librarian conducted the initial search within PubMed, Scopus, CINAHL, and PsycINFO, and included the following terms MeSH and natural language terms: *stroke, cerebral vascular disease, transient ischemic attack, outcome, outcome measure, outcome assessment, evaluation studies, impact, recovery, rehabilitation, restore, regain, resume, continental population groups, population, race, ethnology, ethnic groups, African American, Hispanic American, Latino/a, Mexican American, American Indian, Native American, Alaskan Native, Asian, ancestry, Pacific Islander, Native Hawaiian, people of color, black*.

First, titles and abstracts were reviewed for inclusion for full-text review. Two authors independently reviewed the articles for inclusion and exclusion for data extraction. The authors also engaged in hand-searching which involved searching reference lists of included manuscripts and review articles, first author names of included studies, and search with terminology in Google Scholar. A dichotomous ‘no’ or ‘maybe’ scoring system for article inclusion was used. When reviewer disagreement on inclusion occurred, they convened to discuss and reach a consensus on inclusion. Abstracts that did not explicitly state the specific outcome measures used were reviewed during the full-text review.

Inclusion and exclusion criteria

Inclusion criteria consisted of the following items: (1) empirical research studies, (2) participants reported therein were aged 18 years or older, (3) objectives therein were to examine disparities in functional outcomes, and (4) studies were published between January 2001 and July 2017. Exclusion criteria for publications consisted of the following items: (1) did not exclusively focus on stroke, (2) did not focus on racial/ethnic disparities, (3) were not conducted at least partially in a US population, (4) described instrument development or psychometric analysis only, (5) did not report outcomes related to disability and functioning, (6) were not in English language, (7) focused on the stroke caregiver only, (8) ICD-9 codes as outcome or disability measure, and/or (9) were dissertation, commentary, blogs, conference proceedings, book chapters, case-studies, predictive modeling, or not comparative in focus. If literature reviews emerged in our search, we examined the reference list, located the publications, and screened for inclusion. Articles published prior to 2001

were excluded because the ICF was published in this year and we expect it had a substantial impact on how disability and functioning are assessed in the literature. Finally, only published articles that compared outcomes among racial/ethnic groups were included. We did not include studies that used predictive modeling unless the articles also reported differences between groups.

Data extraction and classification

Once all of the publications that met inclusion criteria were identified, we extracted and recorded relevant information that matched the aims of this study: outcome measures used, assessment content type, racial/ethnic representation, and time points across the time course of stroke recovery when outcomes were assessed. The contents of outcome measures used within the identified studies were extracted and classified using the ICF browser (<http://apps.who.int/classifications/icfbrowser/>). Race/ethnicity were categorized using minimum designations for race and ethnicity [15,16]. Time points for assessment across the time course of stroke recovery were broadly classified using pre-stroke, acute stroke (including hospitalization and rehabilitation), early recovery, and community living/long-term outcomes terminology as described by Skolarus and Burke [17]. For purposes of this study, early recovery outcomes included assessments administered 90 days since the stroke. Additionally, if the studies used repeated measures for multiple points in time, we collected this information and categorized within both time points.

Results

Literature search

We identified 1791 articles through database and hand-searching strategies. One hundred and ninety-four articles met inclusion criteria for full-text review, and 41 met inclusion criteria after full-text review. Refer to Figure 2 for detailed depiction of inclusion and exclusion criteria application.

Outcome measures

The 41 included studies used a variety of assessments encompassing domains within the ICF: body functions, activities, participation, and contextual factors (Table 1). Two activity measures were the most frequently used: Functional Independence Measure (FIM) and modified Rankin Scale (mRS). Several studies used survey data from national data sources (e.g., National Health Interview Survey, Health and Retirement Study) that included self-report questions about difficulty and capacity with body functions, activities, and participation. Additionally, two assessments used in the identified studies examined contextual factors. The majority of the assessments identified were only used by a single study.

Assessment across the time course of stroke recovery

Assessments for examining disparities in post-stroke disability were assessed across the time course of stroke recovery. The assessments were used at all pre-identified time points: pre-stroke ($n = 9$), acute stroke ($n = 10$), early recovery ($n = 14$), community living/long-term ($n = 33$). Some studies used repeated outcomes at more than one time point across the time

course of stroke recovery and this information was collected and reported in Table 1. A majority of studies examined racial/ethnic disparities during community living/long-term with national data set and survey methodology. Refer to Figure 3.

Racial/ethnic representation

The included studies were comprised of four primary racial/ethnic groups: white ($n = 41$), black or African American ($n = 36$), Hispanic or Latino ($n = 16$), and Asian ($n = 6$).

Although the category of ‘other’ was used for several studies, few articles described the racial/ethnic representation in categories labeled as ‘other’. We only factored participants described within the ‘other’ categories when the study itself delineated the composition.

Only one study in our review described the ‘other’ as being comprised of American Indian or Alaska Native and Native Hawaiian or Pacific Islander (Figure 4).

Discussion

A large number of outcome measures with a varied nature exist to support the assessment of disability and functioning across the time course of stroke recovery. The ICF presents a conceptual framework to convey the interactive effects that contribute to disability and functioning. Although the ICF domains may appear mutually exclusive, they often interact to create feedback loops which may be attributed to the complex nature of measuring stroke outcomes [82]. For instance, ischemic stroke may cause executive dysfunction and subsequent limitations in completing household activities (i.e., cooking and medication management) or engaging in work social activities in the community.

We categorized the assessments broadly with the ICF framework and found that most research examines disparities in the body functions domain. Although this focus contributes to our understanding of disparities in post-stroke disability and functioning, few studies have included assessments that examine personal and environmental factors important for contextualizing outcome differences. By including assessments that measure domains across the ICF, we may gain a more comprehensive understanding of racial/ethnic disparities in post-stroke disability.

We discovered a lack of consistency among the assessments used to examine post-stroke disability. The most frequently used tools were the FIM, mRS, and self- or proxy-report on abilities through national interview surveys. Although self-report type assessments are valuable in understanding disability, performance-based measures are inherently important when attempting to understand true-to-life disability, particularly among adults with stroke [83]. It was not surprising that the FIM appeared most frequently in our search as this tool is widely used in practice, particularly in inpatient rehabilitation, as it is a standard instrument for the Centers for Medicare and Medicaid Services (CMS). Additionally, the Uniform Data System for Medical Rehabilitation (UDSMR) incorporates this tool to examine racial/ethnic disparities in stroke outcomes and this may influence the frequency of FIM use [84].

Despite the projected growth in racial/ethnic representation, relatively few outcome measures have been validated among racial/ethnic populations that comprise the US [85].

Although some investigators have developed culturally tailored measures or separate normative data, this approach is limited in that differences in outcomes may remain unexplained and unexamined [85]. However, integrating assessments that are sensitive and conceptually relevant to unique cultures may support an enhanced understanding of disparities in post-stroke disability [86]. In general, the studies included in our review did not describe the validity of the selected instruments among the population of interest. In fact, it is possible, that the identified disparities in the literature are perpetuated by the outcome measures used. As the US becomes more diverse, it is essential that outcome assessments are validated with the same 'fervor' as used when examining other psychometric characteristics [86].

A striking finding in this review was the lack of representation among specific racial/ethnic groups in the US. As expected, we found that most studies have examined disparities in African Americans followed by Hispanics or Latinos then Asians. Interestingly, we found only one study that examined disparities among two specific populations: American Indian/Alaska Native and Native Hawaiian/Pacific Islander. Examining disparities in both populations is important for several reasons. First, American Indians/Alaska Natives may have the highest stroke mortality rates among all US racial/ethnic groups with recent corrections of racial misclassification and non-representative sampling [87]. Most of the research on both American Indian/Alaska Native and Native Hawaiian/Pacific Islander have focused primarily on mortality rates, hospitalization, age, and comorbidity burden/risk. It is important to note that although several investigators examine disparities using a single population lens, this study aimed to examine outcome measures used with a comparative approach and other studies may exist among these populations that are not comparative in nature. Nonetheless, it is essential that future studies examine potential disparities in post-stroke disability and functioning outcomes to support the elimination of health disparities among all racial/ethnic populations that comprise the US.

To mitigate disparities in post-stroke disability and functioning, it is crucial to understand underlying contributors across the time course of stroke recovery. Skolarus and Burke [17] describe four time points where differences in disability may arise: pre-stroke, acute stroke period, early stroke recovery period, and the community living/long-term outcome period. This is a noteworthy observation as differences in post-stroke disability may be viewed from a life course perspective where racial/ethnic differences in pre-stroke functioning and disability may have existed prior to the stroke. Additionally, across the time course of stroke recovery, outcomes may be influenced by a range of personal and environmental factors which are less studied and therefore not well-understood.

The majority of the studies we reviewed examined disparities in community living/long-term outcomes. However, we have determined the reasoning for the focus on disability in the context of the community is due to the nature of national data sets which are available for analysis to researchers. Several of the studies used survey methodology which may capture the lived experience post-stroke, but may not be adequate for capturing the complexities associated with post-stroke performance. Furthermore, few longitudinal studies have examined disparities by integrating performance-based measures that may capture true-to-life disability in the lived environment. We posit that future studies examining disparities in

the context of the community integrate outcome measures that examine real-world contributors to disability through performance-based testing and examination of personal and environmental factors that may influence post-stroke disability outcomes.

Limitations

Despite a comprehensive search strategy, the primary limitation of this study is that we may have missed published articles that met inclusion criteria that did not emerge with our search strategy in the databases we selected. Additionally, this review only included studies that were comparative in nature and excluded studies that involved predictive modeling and qualitative research questions. The decision to limit the review to studies published in the US is another limitation; however, we made this decision as we expect that healthcare delivery systems likely influence outcome measures to some capacity. Lastly, it is noteworthy that some studies used outcome measures as stroke severity indicators and vice versa. For this study, we only included articles that explicitly identified each assessment as a contributor to overall disability and functioning versus a measure of stroke severity. However, this may have impacted our final assessment list and frequencies reported.

Conclusions

In research and practice, a wide variety of assessments can be used to examine post-stroke disability across the time course of stroke recovery. Several studies have identified disparities in functional outcomes; however, substantial problems abound from the identified assessments including a (1) lack of consistency in timing and type of outcome assessed and (2) lack of presented evidence of assessment validity among the targeted population. Moreover, representation amongst all US racial/ethnic groups, and emphasis on disparities in personal and environmental factors that contribute to disability are insufficient to draw inference. Additionally, few studies examine disability beyond 12-month outside of self-reported survey data. Although negative long-term outcomes may be attributed to aging or the presence of comorbidities, we urge researchers to further examine long-term disability outcomes in persons with stroke to better understand this problem. The key inference from this review is that future studies on disparities in post-stroke disability should consider integrating consistent use of similar assessments and a comprehensive disability framework as the lack of consistency complicates the identification and interpretation of racial/ethnic disparities across the time course of stroke recovery.

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IMPLICATIONS FOR REHABILITATION

- An enhanced understanding of racial/ethnic disparities in post-stroke disability outcomes is inherently important among rehabilitation practitioners who frequently engage with racial/ethnic minority populations across the time course of stroke recovery.
- Clinicians should carefully consider the psychometric properties of assessment tools to counter potential racial bias.
- Clinicians should be aware that many assessments used in stroke rehabilitation lack cultural sensitivity and could result in inaccurate assessment findings.

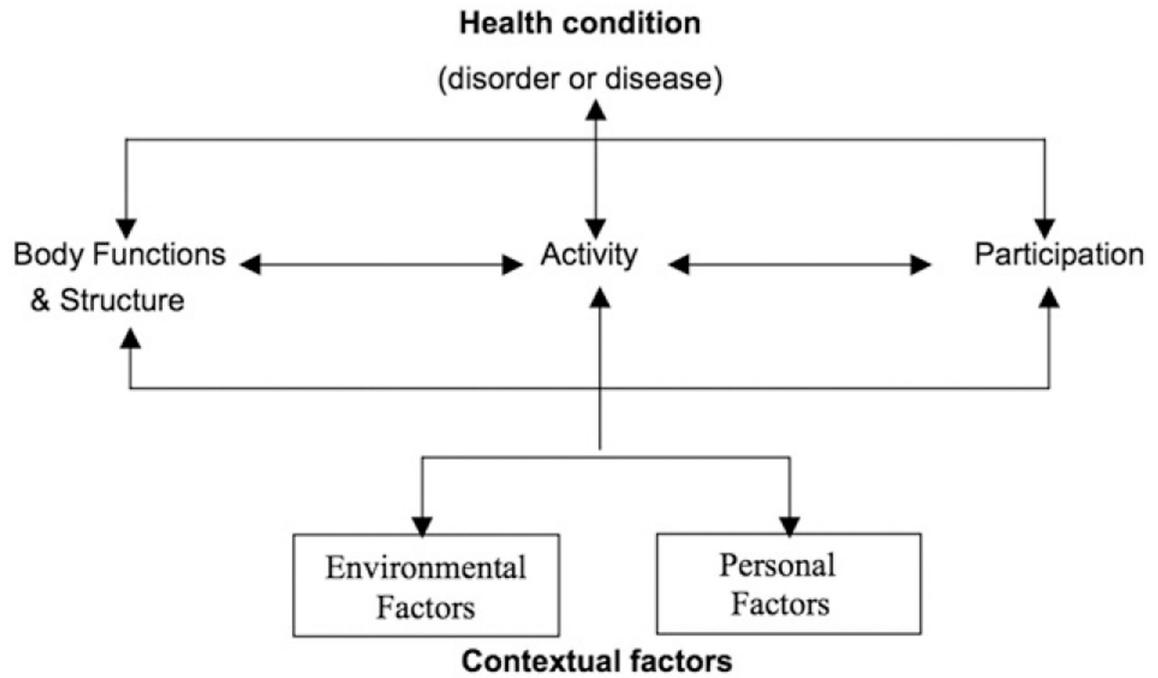


Figure 1. International classification of functioning, disability and health. Note: Reprinted from World Health Organization, Geneva, Towards a Common Language for Functioning, Disability, and Health ICF, Page 9, Copyright 2002.

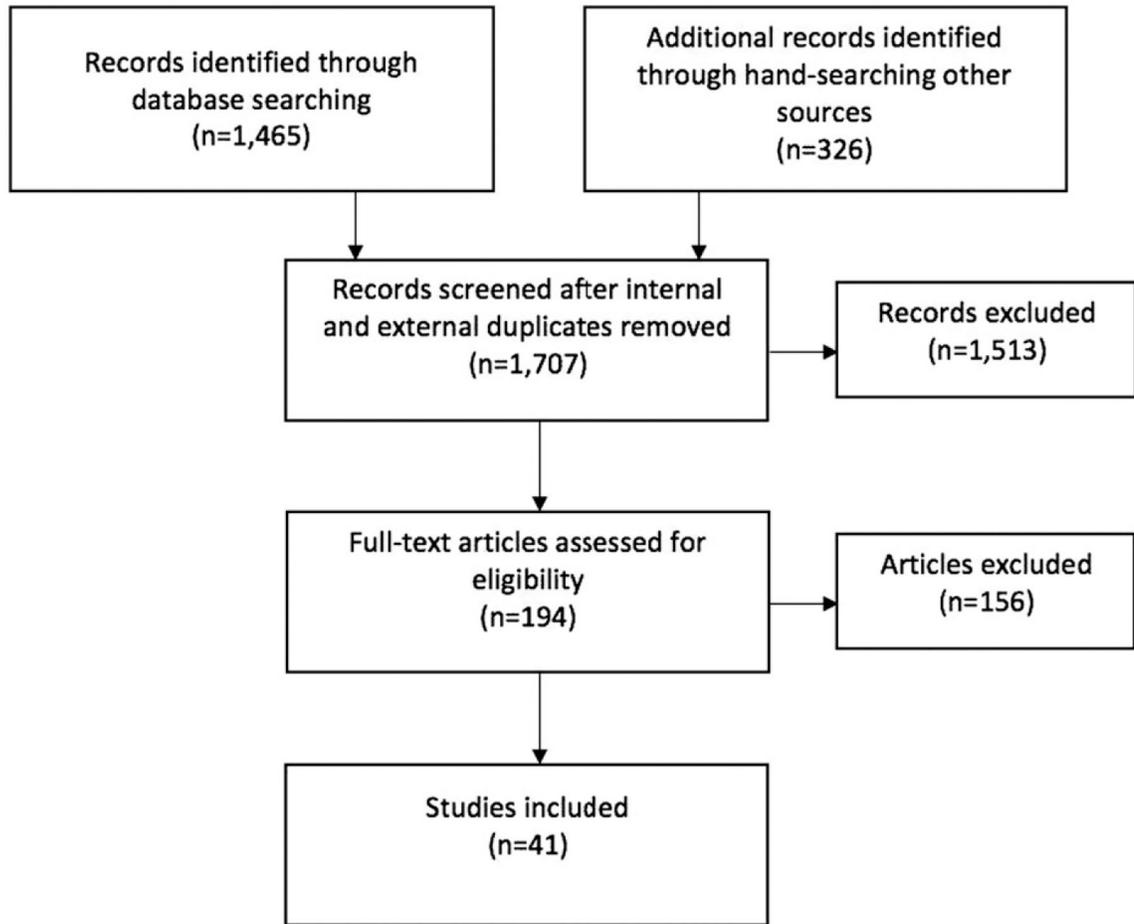


Figure 2.
Decision making process for study inclusion.

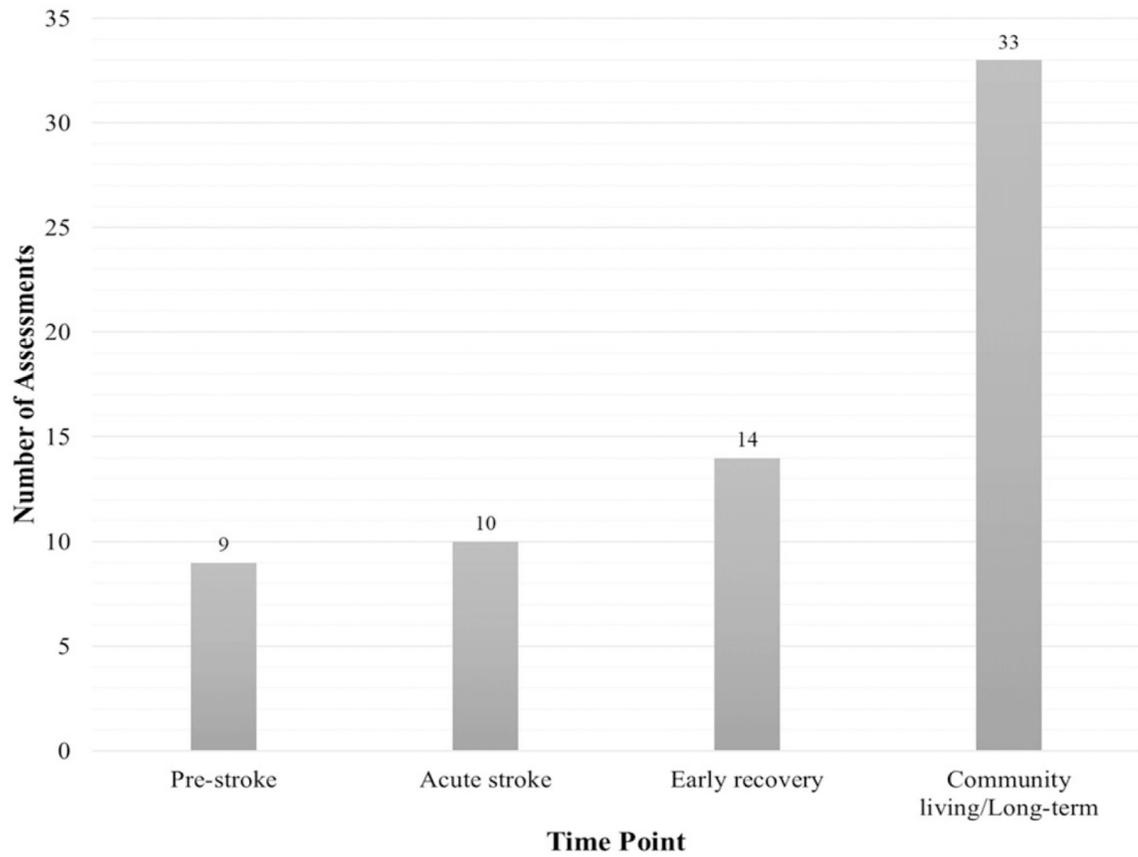


Figure 3.
Outcomes measured across the time course of stroke recovery.

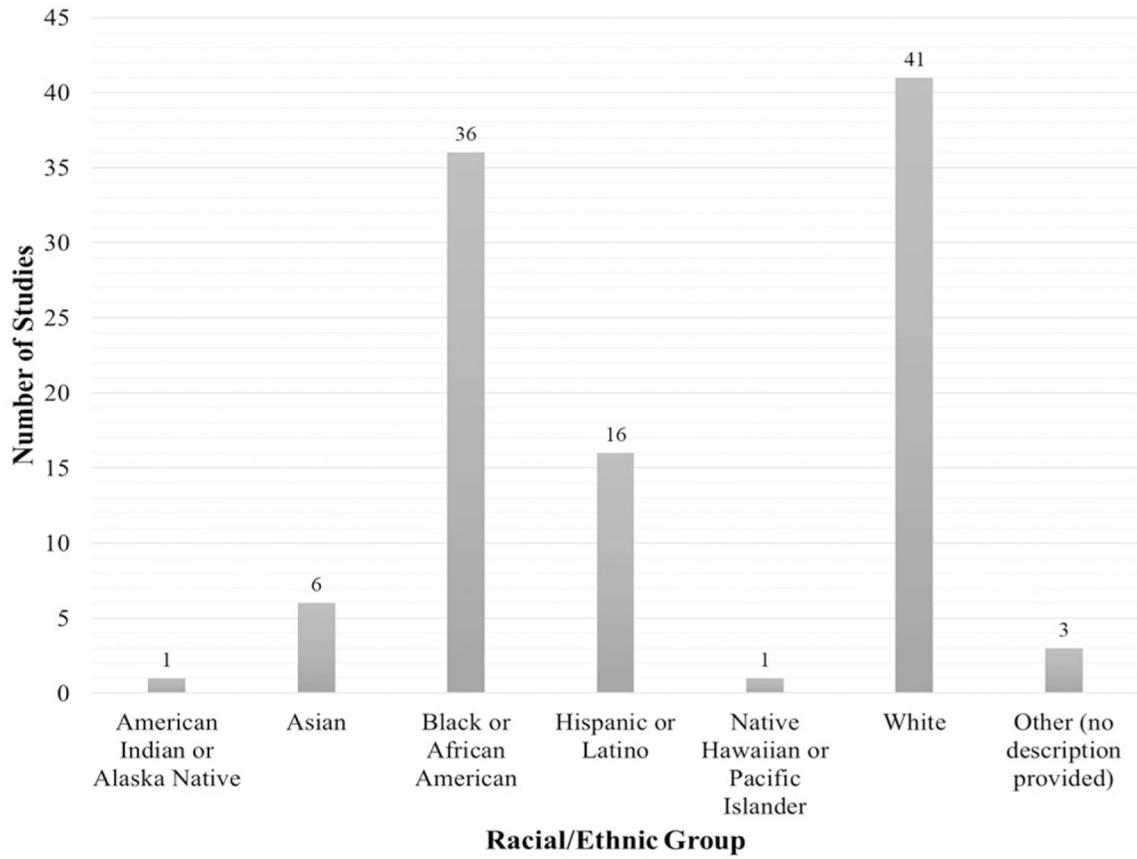


Figure 4. Racial/ethnic representation within the included studies.

Table 1.

Disparity study assessment tools and description of use

Assessment tools	ICF code and description	Number of times used	Time point measure used	Racial/ethnic representation	References
Functional Independence Measure (FIM) [18]	Body Functions B1. Mental Functions B5. Functions of the digestive system B6. Genitourinary function <u>Activities and Participation</u> D3. Communication D4. Mobility D5. Self-care	11	Acute stroke, Early recovery, Community living/long-term	White, African American, Hispanic, Asian, Other with description of American Indian or Alaska Native, Pacific Islander or Hawaiian Native	[19–29]
Katz ADL Scale * [30]	<u>Body Functions</u> B5. Functions of the digestive system B6. Genitourinary function <u>Activities and Participation</u> D4. Mobility D5. Self-care	1	Community living/long-term	White, African American	[31]
Barthel Index [32]	<u>Body Functions</u> B5. Functions of the digestive system B6. Genitourinary function <u>Activities and Participation</u> D4. Mobility D5. Self-care	2	Acute stroke, Early recovery, Community living/long-term	White, African American	[33,34]
Frenchay Activities Index [35]	<u>Activities and Participation</u> D4. Mobility D6. Domestic life D7. Interpersonal interactions and relationships D8. Major life areas	2	Early recovery, Community living/long-term	White, African American, Hispanic	[27,36]
modified Rankin Scale * [37]	<u>Activities and Participation</u> D2. General tasks and demands D4. Mobility	7	Pre-stroke, Acute stroke, Early recovery, Community living/long-term	White, African American, Hispanic, Asian	[6,33,34,38–41]
Glasgow Outcome Scale [42]	<u>Activities and Participation</u> D2. General tasks and demands	1	Early recovery	White, African American	[43]
Instrumental Activities of Daily Living - survey questions	<u>Activities and Participation</u> D6. Domestic life D8. Major life areas	6	Pre-stroke, Early recovery, Community living/long-term	White, African American, Hispanic	[4,6,8,44–46]
Basic Activities of Daily Living/ survey questions	<u>Activities and Participation</u> D4. Mobility D5. Self-care	5	Pre-stroke, Early recovery, Community living/long-term	White, African American, Hispanic	[4,6,8,44,46]
Short Physical Performance Battery	<u>Body Functions</u> B7. Neuromusculoskeletal and movement-related function <u>Activities and Participation</u> D4. Mobility	1	Community living/long-term	White, African American	[8]

Assessment tools	ICF code and description	Number of times used	Time point measure used	Racial/ethnic representation	References
Patient Health Questionnaire* [47]	Body Functions B1. Mental functions	3	Pre-stroke, Community living/Long-term	White, African American, Hispanic	[8,46,48]
Generalized Anxiety Disorder Questionnaire [49]	Body Functions B1. Mental functions	1	Community living/Long-term	White, African American	[8]
Mental Adjustment for Stroke Scale [50]	Body Functions B1. Mental functions	1	Pre-stroke	White, Hispanic	[48]
Kessler K6 Scale [51]	Body Functions B1. Mental functions	1	Community living/Long-term	White, African American, Hispanic, Asian	[52]
Western Aphasia Battery-Revised [53]	Body Functions B1. Mental functions	1	Community living/Long-term	White, African American	[54]
Immediate and Delayed Recall	Body Functions B1. Mental functions	3	Community living/Long-term	White, African American	[8,55,56]
Clock Drawing Test [57]	Body Functions B1. Mental functions	2	Community living/Long-term	White, African American	[8,55]
Mini-Mental Status Examination* [58]	Body Functions B1. Mental functions	3	Acute stroke, Early recovery, Community living/Long-term	White, African American, Hispanic, Asian	[6,28,34]
Telephone Interviews for Cognitive Screening [59]	Body Functions B1. Mental functions	1	Community living/Long-term	White, African American	[60]
National Institute of Health Toolbox-Cognition Battery [61]	Body Functions B1. Mental functions	1	Community living/Long-term	White, African American	[62]
Questionnaire for Cognitive Decline [63]	Body Functions B1. Mental functions Activities and Participation D1. Applying Knowledge	2	Pre-stroke	White, African American, Hispanic	[6,56]
Cognitive Capacity-survey questions	Body Functions B1. Mental functions Activities and Participation D1. Applying Knowledge	2	Community living/Long-term	White, African American	[31,46]
Visual Field - Confrontation Testing	Body Functions B2. Sensory functions	1	Acute stroke	White, African American, Hispanic, Asian	[28]
Motricity Index [64]	Body Functions B7. Neuromusculoskeletal and movement-related functions	1	Acute stroke	White, African American, Hispanic, Asian	[28]
Timed Walk Test (2- or 6-minute) [65,66]	Body Functions B7. Neuromusculoskeletal and movement-related function Activities and Participation D4. Mobility	3	Acute Stroke, Community living/Long-term	White, African American, Hispanic, Asian	[28,67,68]
Proprioception-Limb Placement Task	Body Functions B2. Sensory functions	1	Acute Stroke	White, African American, Hispanic, Asian	[28]
National Institute of Health Stroke Scale (NIHSS) [69]	Body Functions B1. Mental functions B2. Sensory functions	2	Early recovery, Community living/Long-term	White, Hispanic	[6,34]

Assessment tools	ICF code and description	Number of times used	Time point measure used	Racial/ethnic representation	References
30-Foot Walk Velocity (Self-selected and fast)	B3. Voice and speech functions B7. Neuromusculoskeletal and movement-related function Body Functions B7. Neuromusculoskeletal and movement-related function Activities and Participation D4. Mobility	2	Community living/Long-term	White, African American	[67,68]
VO2 Peak with Graded Treadmill Testing	Body Functions B4. Functions of cardiovascular system	2	Community living/Long-term	White, African American	[67,68]
Concentric and Eccentric Torque and Muscle Quality	Body Functions B7. Neuromusculoskeletal and movement-related function	1	Community living/Long-term	White, African American	[68]
Ambulatory Status	Activities and Participation D4. Mobility	1	Pre-stroke, Acute stroke	White, African American, Hispanic, Asian	[70]
Physical Capacity or Mobility - survey questions	Activities and Participation D4. Mobility	6	Community living/Long-term	White, African American	[8,31,46,55,71,72]
Participation survey questions	Activities and Participation D7. Interpersonal interactions and relationships D8. Major life areas D9. Community, social, and civic life	3	Community living/Long-term	White, African American	[8,71,72]
Medical Outcomes Study Short Form [71]	Body Functions B1. Mental functions B2. Sensory functions and pain Activities and Participation D2. General tasks and demands D4. Mobility D5. Self-care	1	Community living/Long-term	White, African American	[46]
Return to Driving - survey questions	Activities and Participation D4. Mobility	1	Community living/Long-term	White, African American	[4]
Resuming valued life activities - survey questions	Activities and Participation D2. General Tasks and demands	1	Community living/Long-term	White, African American	[4]
Stroke-Specific Quality of Life [74]	Body Functions B1. Mental functions B2. Sensory functions B3. Voice and speech functions Activities and Participation D4. Mobility D5. Self-care D6. Domestic life D7. Interpersonal interactions and relationships D8. Major life areas D9. Community, social, and civic life Environmental factors E3. Support and relationships	1	Early recovery	White, Hispanic	[75]
Return to Work - survey questions	Activities and Participation D8. Major life areas	1	Early recovery	White, Hispanic	[5]
Connectedness-Isolation Scale	Environmental factors E3. Support and relationships	1	Early recovery, Community living/Long-term	White, African American, Hispanic	[36]

Assessment tools	ICF code and description	Number of times used	Time point measure used	Racial/ethnic representation	References
Caregiver Time	Environmental factors E3. Support and relationships	1	Community living/Long-term	White, African American	[55]
Life Orientation Test [76]	Body Functions B1. Mental functions	1	Pre-stroke	White, Hispanic	[48]
Pearlin Scale [77]	Body Functions B1. Mental functions	1	Pre-stroke	White, Hispanic	[48]
Geriatric Depression Scale [78]	Body Functions B1. Mental functions	2	Early recovery, Community living/long-term	White, African American, Hispanic	[27,36]
Center for Epidemiologic Studies Depression [79]	Body Functions B1. Mental functions	1	Acute stroke, Early recovery, Community living/Long-term	White, African American, Hispanic	[80]
Stroke Impact Scale [81]	Body Functions B1. Mental functions B3. Voice and speech functions B5. Functions of the digestive system B6. Genitourinary function B7. Neuromusculoskeletal and movement-related functions Activities and Participation D1. Applying knowledge D2. General tasks and demands D3. Communication D4. Mobility D5. Self-care D6. Domestic life D7. Interpersonal interactions D8. Major life areas D9. Community, social, and civic life	1	Community living/Long-term	White, African American	[34]

* Indicates the assessment used in at least one of the studies was a modified version. Note: The broader mental functions category includes both cognitive and emotional functions as described within the ICF Browser.