

Original Article

Imperfect Patients: Disparities in Treatment of Stroke Patients with Premorbid Disability

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ABSTRACT: *Background:* Despite the high proportion of stroke patients with a pre-existing impairment, patients with disabilities are often excluded from stroke treatment trials. Trials are designed for "perfect patients": patients who are functionally independent and thus generally younger with fewer comorbidities; ironically, such patients are less likely to experience stroke than those with premorbid disability. Exclusionary practices in trials may translate into disparities in stroke care in practice. Through a review of literature, our purpose is to illuminate how people with disabilities are treated across the care continuum following a stroke. *Methods:* We completed a qualitative systematized review of articles pertaining to the care of patients with premorbid disability and stroke and their outcomes. Using a critical disability studies' theoretical lens, we analyzed inequity across the stroke care continuum. *Findings:* Among 24 included studies, we found evidence that people with disabilities did not receive equitable access to treatment ranging from being admitted to stroke units to receiving post-stroke rehabilitation. However, observational studies suggest that stroke therapies may be beneficial in selected patients with disabilities when measures of success are framed more achievable (e.g. return to pre-stroke status). This leaves us concerned about how people with pre-existing impairments might be structurally disabled within current systems of stroke care. *Conclusion:* We use our critical disability studies' theoretical lens to argue that an intersectional approach to stroke treatment is much needed if we are to remedy structural inequities embedded throughout the care continuum.

RÉSUMÉ: Des patients « imparfaits » : disparités dans les traitements de patients victimes d'un AVC qui présentent une invalidité prémorbide. Contexte: Malgré la proportion élevée de patients victimes d'un AVC qui présentent une déficience ou une invalidité préexistante, ces derniers sont souvent exclus des essais visant à trouver des traitements destinés aux AVC. Ces essais sont alors conçus pour des patients dits « parfaits », à savoir autonomes sur le plan fonctionnel et donc généralement plus jeunes et présentant moins de comorbidités. Ironiquement, rappelons que ces patients sont pourtant moins susceptibles de subir un AVC que ceux qui présentent une invalidité pré-morbide. Il s'ensuit que ces pratiques d'exclusion dans les essais peuvent se traduire dans la pratique par des disparités dans les soins destinés aux AVC. Au moyen d'une revue de la littérature, notre objectif est donc de mettre en lumière la façon dont les personnes atteintes d'une invalidité sont traitées en lien avec le continuum des soins post-AVC. *Méthodes*: Pour ce faire, nous avons effectué un examen qualitatif systématisé d'articles portant, d'une part, sur les soins destinés aux patients souffrant d'une invalidité pré-morbide et victimes d'un AVC, et, d'autre part, sur l'évolution de leur état de santé. À l'aide d'une approche théorique basée sur des études critiques de l'invalidité, nous avons ainsi analysé l'iniquité présente dans le continuum des soins post-AVC. Résultats: Parmi 24 articles inclus, nous avons trouvé des preuves que les personnes atteintes d'une forme d'invalidité ne bénéficiaient pas, de l'admission dans les unités de soins des AVC à la réadaptation post-AVC, d'un accès équitable à des traitements. Cependant, des études axées sur l'observation suggèrent que les thérapies de l'AVC peuvent être bénéfiques chez certaines de ces personnes lorsque les mesures de réussite sont formulées de manière plus réaliste (p. ex. : le retour à un état antérieur à l'AVC). Nous sommes donc préoccupés par la manière dont ces personnes peuvent être structurellement handicapées dans le cadre des systèmes actuels de soins de l'AVC. Conclusion: Nous avons utilisé une approche théorique basée sur des études critiques du handicap pour faire valoir qu'une approche inter-sectionnelle du traitement de l'AVC est indispensable si nous voulons remédier aux inégalités structurelles qui sont ancrées dans le continuum des soins prodigués.

Keywords: Stroke; Pre-existing impairments; Disability; Care; Critical disability studies

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Introduction

Stroke often occurs in patients who are already living with some degree of physical or cognitive impairment in their daily life. Physicians consider different factors in deciding whether a patient is eligible or ineligible for acute stroke therapies, including time since stroke onset as well as stroke severity, which is most often measured by the modified Rankin Scale (mRS). The mRS ranges from 0 (perfect health) to 6 (death). The score is informed by motor function and ability to complete activities of daily living (ADLs) and is also used to assess recovery post-stroke.² This paper is about the treatment of people with pre-existing impairments presenting with stroke in medical facilities. Using a critical disability studies' theoretical lens and understanding impairment according to the human rights model of disability, we analyze inequity across the stroke care continuum through a review of the literature. Our purpose is to illuminate how people with disabilities are treated across the care continuum following a stroke.

We aim to understand how pre-existing impairment impacts the treatment of stroke as well as the decision-making process that determines the amount and type of care a patient receives. We define people with disabilities as "those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others." Disability is understood to be a result of environmental barriers: individuals with an impairment are disabled by a lack of accessibility in the services they use and the communities they live in.3,4 Thus, individuals with impairment such as post-stroke neurological deficits are not inevitably disabled but are rendered disabled by our technological and societal limitations in integrating individuals with impairment into our communities. The Convention on the Rights of Persons with Disabilities³ is built on a human rights model of disability which "focuses on the inherent dignity of the human being and subsequently, but only if necessary, on the person's medical characteristics." This concept in the human rights model implies not only that medical intervention is necessary and something to be desired in the case of a medical emergency such as stroke, but also that "people are to be valued not just because they are economically or otherwise useful but because of their inherent self worth."5

Heterogeneity in patients who have been given the same mRS score is great including in relation to patients with pre-existing impairments, and this leads us to examine the utility of mRS application in determining likelihood of 'success' in treatment. Between 12.5 and 33% of people who have a stroke have a pre-existing impairment as measured by the mRS, with the proportion increasing to between 24.8 and 65% in patient cohorts over the age of 80.6,7 Despite the high proportion of stroke patients with a pre-existing impairment, patients with pre-existing disabilities are often excluded from treatment trials.8 This leaves us concerned about how people with pre-existing impairments might be structurally disabled by acute care environments prior to even requiring care for stroke. Our literature review focuses on articles that discuss the treatment of people with disabilities who have a stroke and the decision-making process of providing or withholding stroke care along the care continuum for individuals with pre-existing impairments. We first present our literature review methodology, followed by the findings from our review. We conclude with a discussion on the ramifications and limitations of our findings, touching upon how privilege and colonialism are embedded along the stroke care continuum. Our theoretical anchoring in critical

disability studies as evidenced by our use of the human rights model of disability leaves us concerned that people with disabilities may experience exclusion along the stroke care continuum due to their pre-existing medical conditions, a theme found throughout the medical care system.^{9–12}

Methods

Anchored in our human rights model of disability and our corresponding aim of illuminating differences in stroke treatment for people with and without pre-existing impairments, we conducted as systematized review to collect and examine studies reporting on treatment and treatment outcomes for stroke patients with and without pre-existing impairments. We chose to utilize a qualitative evidence synthesis methodology to aggregate the processes which directed health care providers' decisions about how to treat their patients with disabilities. Following Booth's direction, we attempt to ensure that multiple perspectives were represented in our selected studies for review. We sought to elaborate our interpretation of studies of treatment and treatment outcomes by including studies reporting on treatment decision-making for stroke patients. We examined studies for detailed and reoccurring themes regarding the stroke treatment, outcomes, and decisionmaking for patients with and without pre-existing impairments.

Treatment is understood to consist of the evaluation of the patient, the immediate treatment, and post-stroke care. Authors C.C. and N.M.M. searched four databases: PUBMED, Web of Science Core Collection, Ovid Healthstar, Ovid Medliner, and EBSCO. Within EBSCO we used Academic Search Complete, CINAHL Plus with Full Text, Health Source: Nursing/Academic Edition, and Family and Society Studies Worldwide to search the literature. Our search terms were "stroke" or "cerebrovascular accident" or "cerebral vascular event" or "transient ischemic attack" AND "disability evaluation" or "dementia" or "cognitive disorders" or "cognitive dysfunction" or "intellectual disability" or "cognitive impairment" or "intellectual impairment" or "cognitive disability" or "major neurocognitive disorder" or "minor neurocognitive disorder" AND "pre-existing." We also ran a search in each of the databases using the above terms in addition to the terms "qualitative" or "action research" or "case study" or "content analysis" or "discourse analysis" or "ethnographic" or "focus group" or "grounded theory" or "interview" or "narrative" or "observational" or "phenomenological." Our inclusion criteria were that articles needed to contribute to (a) an understanding of the decision process of professionals to intervene when people with disabilities have a stroke, and/or (b) how interventions provided to patients with disabilities differed from interventions offered to patients without

We assessed the difference in interventions that used a propensity score-matched analysis to share findings of the effectiveness and use of interventions for people with and without disabilities, as well as studies that solely focused on people with disabilities. See Figure 1.

We used a consensus-based approach to consolidate included studies. Our team is comprised of a stroke physician (A.G.), a medical student (N.M.M.), and two disability studies scholars (B.L. and C.C.). A total of 131 articles were selected by C.C. and N.M.M. for further screening. Duplicates were removed, and the abstracts of the remaining 65 articles were reviewed using our inclusion criteria. We selected nine studies that came from our initial search strategy. Articles found using our search strategy failed to discuss the decision-making process of health practitioners, and we relied on snowballing to increase the number of

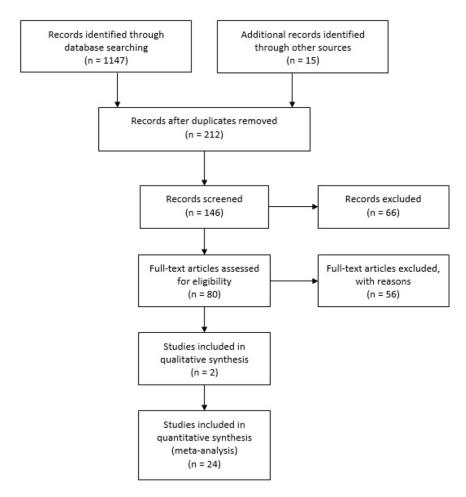


Figure 1: Selection process for reviewed studies.

articles reviewed as the search term "pre-existing" limited our initial search results significantly. Snowballing led to a further 16 studies being included in our qualitative analysis. We are concerned by this problematic pattern within the stroke literature given the demographics of the population that has stroke is primarily people with pre-existing impairments. A strength of our selection of literature is the heterogeneity of approaches taken by studies. They include evidence of the impact of disability along the stroke care continuum and thus provide us with a fairly encompassing understanding of the ways in which health care providers understand how to best serve their patients with impairments. Critical disability studies anchored our analysis and left us concerned about the potential inequities that may persist in stroke treatment, stroke outcome, and the decision-making process of health practitioners regarding patients with disabilities.

Findings

These 24 studies encompass the participation of 80,100 people with disabilities with stroke, 155,255 people without disabilities with stroke, 33 family caregivers, and 79 health care providers, leading to a total of 235,437 participants informing our review. See Table 1.

From this literature review, we generated four themes: 1 – differences in outcomes for patients with versus without disabilities; 2 – differences in treatment for patients with versus without disabilities; 3 – definitions of "successful" treatment; and 4 – treatment practices for patients with versus without disabilities. We use each theme to illustrate the extent that disability influences the

treatment of people presenting with stroke in an acute care setting. We begin by presenting differences in outcome, and we follow by presenting treatment given our assessment that health practitioner views of the likelihood of successful outcomes are informed by the presence of pre-existing disability, and this plays a role in determining who gets treatment or how much treatment they receive. Following our findings on differences in outcome and treatment between people with and without disabilities, we share our theme of differences in understandings of "successful" outcomes in stroke treatment. We conclude by sharing the practices of health care professionals when treating people with stroke.

Difference in Outcomes for Patients with Versus Without Disabilities

The literature supplies evidence that people with disabilities, as measured by the mRS, benefit from treatment for stroke at the same rate as those without disabilities. Studies differ in their definition of disability: one study²³ defined disability as an mRS ≥ 1 ; mRS ≥ 2 was used to differentiate those with and without disabilities in six studies 1,6,7,29,32,35 ; while seven studies 18,20,21,24,25,31,36 defined disability and dependence as an mRS ≥ 3 . Regardless of definition of disability, individuals treated with intravenous thrombolysis (IVT) and endovascular therapy (EVT) experienced a similar rate of a return to their baseline functioning as those without disabilities, with the exclusion of people with an mRS of 5 as identified by Gumbinger et al. $^{22,1,7,8,18,20,21,23,24,29,31,34-36}$.

Table 1: Characteristics of included studies

Study	Study Design	Patient Population	Post-stroke Disability Outcomes	Mortality Outcomes	Other Comments
Alshekhlee et al., 2011 ⁽¹⁴⁾	Retrospective Cohort Study	United States • 36,178 patients with stroke; 35,350 patients with dementia not treated with IVT, 207 patients with dementia who received IVT, 621 patients without dementia treated with IVT	Thrombolysis did not increase the rate of in-hospital mortality or risk of ICH in comparison to the matched control subset	In-hospital mortality and ICH was higher in the thrombolysis group compared to those who didn't receive thrombolysis	Thrombolysis rate was lower among patients with dementia in comparison to the national sample.
Bunn et al., 2016 ⁽¹⁵⁾	Mixed-Methods; Scoping Review, In-depth Interviews, and Focus Group Interviews	United Kingdom • 8 community-dwelling people with dementia; 33 family carers; and 56 HCPs • Scoping review of 76 studies	People with dementia were found less likely to have the same level of access to or quality of care compared to people without dementia		Emergency departments in the UK lack strategies for acute stroke care for people with pre-existing cognitive impairments There was little follow-up for patients following discharge and outcomes of dementia case findings are poorly reported to general practitioners.
Busl et al., 2013 ⁽¹⁶⁾	Retrospective Cohort Study	United States • 153 acute stroke patients over the age of 80 who received either intravenous (IV) or intra-arterial reperfusion therapy; 132 without dementia and 21 with dementia. 135 of 153 patients were white.	The odds of favorable discharge decreased with admission of NIHSS score.	 In-hospital mortality rate was 35%. The rate was 57% for those who received IV tPA, 54% for IAT, and 11% for both. Dementia and NIHSS independently predicted in-hospital mortality. The odds of in-hospital mortality was associated with an increased NIHSS score, IAT, and dementia. 	
Callisaya et al., 2021 ⁽¹⁷⁾	Retrospective Cohort Study	Australia • 7070 patients; 693 with a history of dementia and 6,377 without dementia	Patients with dementia were less likely to receive care from an allied health care team within 48 hours of admittance No association between dementia status and the majority of complications during acute hospital stay		Management plans were more likely discussed with patients and family members but they were less likely to receive information about stroke Patients with dementia and no other comorbidities who received treatment were less likely to experience stroke progression or sent to palliative care
Caruso et al., 2020 ⁽¹⁾	Retrospective Cohort Study	Italy • 282 patients treated with rt-PA; 35 with mRS \geq 2, 247 with mRS \leq 2	Patients with mRS of 2 and 3 may benefit from thrombolytic therapy with moderate risk of symptomatic intracranial hemorrhage and mortality	 Mortality was higher in patients with premorbid mRS scores of 4 or 5 than in patients with an mRS of 2 or 3 In patients who survived with a mRS ≤ 2, NIHSS score was similar to those with a mRS ≥ 2 	
Cooray et al., 2020 ⁽¹⁸⁾	Retrospective Cohort Study	Multinational • 88,094 patients treated with IVT; 83,528 without a disability, 4566 patients had pre-stroke disability, defined as an mRS of 3 to 5.	Risk of symptomatic intracranial hemorrhage stroke was not higher in patients with pre-existing disability than patients without pre-existing disability.	Pre-stroke disability was associated with a higher risk of early mortality	Intravenous thrombolytic in acute ischemic stroke was not associated with an increased risk of symptomatic intracranial hemorrhage or parenchymal hemorrhage.

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Table 1: (Continued)

Study	Study Design	Patient Population	Post-stroke Disability Outcomes	Mortality Outcomes	Other Comments
Foell et al., 2003 ⁽¹⁹⁾	Retrospective Cohort Study	Canada • 112 patients treated with IVT; 88 patients without pre-existing disability, 24 patients with a disability	Patients with disabilities returned to pre-stroke function as often as patients without disabilities	Three-month mortality was higher for patients with disabilities than those without	Patients treated with IVT returned to their pre-stroke level of function as often as patients without pre-existing disability despite an overall higher mortality rate
Gensicke et al., 2016 ⁽²⁰⁾	Retrospective Cohort Study	Multinational 7430 patients treated with IVT, 6941 patients were previously independent and 489 were dependent before stroke	The frequency of symptomatic intracranial hemorrhage was comparable in both groups	IVT-treated dependent stroke patients had an increased mortality risk compared to independent patients and were as likely to have an intracranial hemorrhage	Patients who were previously dependent were two times as likely to die within the next three months in comparison to the previously independent patients
Goldhoorn et al., 2018 ⁽²¹⁾	Retrospective Cohort Study	The Netherlands • 1441 patients; 1284 with an mRS ≤ 2 and 157 patients with an mRS ≥ 3	Occurrence of ischemic stroke progression and symptomatic intracranial hemorrhage was similar in both groups	Favorable outcome was seen in 27% of patients with disabilities and 42% of patients without disabilities	
Gumbinger et al., 2019 ⁽²²⁾	Retrospective Cohort Study	Germany • 52,741 patients with ischemic stroke; 12,406 with mRS ≥ 2, 40,335 mRS ≤ 1	In the group of patients with an mRS of 5, there was no association between IVT treatment and successful outcome Among patients with an mRS score of 0 to 4, favorable outcome was achieved more often for patients treated with IVT compared to those not treated		IVT can be effective in patients with severe pre- existing disabilities as long as they are not bedridden, and withholding IVT on the grounds of pre-existing disability is not justified
Karlinski et al., 2014 ⁽²³⁾	Retrospective Cohort Study	Multinational – Eastern Europe • 7250 patients; 5995 with no disability (mRS 0), 791 mRS 1, 293 mRS 2, 171 mRS ≥ 3	 Increased intracranial hemorrhage was not associated with patients with a pre-existing disability (mRS ≥ 1) 	 Patients with mRS ≥ 2 had similar vascular profile and favorable outcome despite higher mortality for patients with an mRS ≥ 3 	There did not appear to be an independently increased risk of symptomatic intracranial hemorrhage after IVT 1 in 3 patients with disabilities may return to their pre-stroke mRS
Larsson et al., 2020 ⁽²⁴⁾	Retrospective Cohort Study	Sweden • 591 patients treated with EVT; 90 had pre-stroke disability, defined as an mRS ≥ 3, 501 with no pre-stroke disability	Recanalization rates and return to mRS did not differ between those with and without pre-stroke disability	Mortality at 3 months was higher for patients with disabilities than those without 20% of patients with pre-stroke disability treated with a thrombectomy returned to their pre-stroke functional level	Recanalization rates and return to mRS did not differ between those with and without pre-stroke disability
Leker et al., 2017 ⁽²⁵⁾	Retrospective Cohort Study	Israel • Total of 131 patients; 108 with an mRS ≤ 2 and 23 with an mRS ≥ 3	 Patients with a pre-stroke mRS ≥ 3 were older and more likely to have had a previous stroke Despite EVT patients with a pre-stroke mRS ≥ 3 were more likely to have an unfavorable outcome, defined as an mRS ≥ 4 after day 90 post-stroke. 		Patients with disabilities are less likely to benefit from EVT treatment, defined as maintaining an mRS score ≤ 4 90 days poststroke but this should not be a justification for exclusion from treatment as some patients do benefit from intervention

(Continued)

Table 1: (Continued)

Study	Study Design	Patient Population	Post-stroke Disability Outcomes	Mortality Outcomes	Other Comments
Longley et al., 2018 ⁽²⁶⁾	Qualitative Interview Study	United Kingdom • 23 stroke specialist health care practitioners who worked with patients treated for stroke	Participants with pre-existing cognitive impairment receive less rehabilitation than participants without pre-existing cognitive impairment, unknown if that has an impact on outcome		Understanding a patient as an individual, knowledge of dementia, and perceptions of role within their healthcare team were factors found to influence whether a patient's needs are accommodated in rehabilitation or if rehabilitation efforts are ended.
Longley et al., 2019 ⁽²⁷⁾	Retrospective Cohort Study	United Kingdom • 139 stroke patients receiving rehabilitation; 106 without pre-existing cognitive impairment, 33 with pre-existing cognitive impairment	People in stroke rehabilitation with pre-existing cognitive impairment receive less therapeutic intervention and patient facing therapy sessions		Participants with pre-existing cognitive impairment received 40 physio- and occupational therapy sessions compared to the 56 sessions those without pre-existing cognitive impairment received
Merlino et al., 2019 ⁽⁸⁾	Retrospective Cohort Study	Italy • 110 patients with a prestroke mRS of 3 or 4; 36 who received IVT, and 74 who did not receive IVT	Prevalence of three-month mortality, intracranial hemorrhage, and symptomatic intracranial hemorrhage did not differ between the two groups	Patients treated with IVT had higher rates of favorable outcome and major neurological improvement compared to non-treated patients	Disability alone should not be considered as a contraindication to IVT treatment
Murao et al., 2013 ⁽²⁸⁾	Retrospective Cohort Study	France • Total of 99 patients; 68 without pre-existing cognitive impairment; 31 with cognitive impairment, no dementia	Patients with cognitive impairment, no dementia, who were treated with IVT had similar outcomes to cognitively normal patients		No clinical reason is observed in this preliminary study to exclude a patient from IVT on the basis of cognitive impairment, no dementia
Salwi et al., 2020 ⁽²⁹⁾	Retrospective Cohort Study	United States • Total participants were 791; 532 with an mRS 0-1, 259 with an mRS 2-3.	Other indicators of treatment success did not point to a justified exclusion from treatment with mechanical thrombectomy on the basis of disability	Death by 90 days post- stroke was higher in patients with a pre-stroke mRS of 2 to 3	Insufficient evidence that functional and procedural outcomes were different between patients with and without pre-stroke disability who were treated with mechanical thrombectomy
Saposnik et al., 2010 ⁽³⁰⁾	Retrospective Cohort Study	Canada • Total patients was 1754; 877 with pre-existing dementia and 877 with no pre-existing dementia	Patients with pre-existing dementia had similar disability at discharge and home disposition, while in the subgroup of patients who received thrombolysis there was no difference regarding risk of intracerebral hemorrhage	Dementia itself does not explain that 80% of patients with dementia had greater disability and a need for institutionalization following a stroke, rather associated comorbidities explain this outcome as well as the 50% mortality rate one-year post-stroke	Pre-existing dementia is not independently associated with morality, disability, or institutionalization after ischemic stroke Pre-stroke dementia may not preclude access to IVT or specialized care following a stroke
Seker et al., 2019 ⁽³¹⁾	Retrospective Cohort Study	Germany • 136 patients with premorbid mRS 3 and 4 treated with mechanical thrombectomy. 111 with an mRS of 3 and 25 with an mRS of 4	Good outcomes are less likely in patients with an mRS of 3 or 4 when compared to patients with an mRS ≤ 2 but are still achievable Approximately 20% of stroke patients with an mRS of 3-4 return to pre-stroke functional status		Successful recanalization is the most important predictor of good outcome Low NIHSS scores, high ASPECTS, and TICI 2b-3 are all independent predictors of a good outcome post- stroke

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Table 1: (Continued)

Study	Study Design	Patient Population	Post-stroke Disability Outcomes	Mortality Outcomes	Other Comments
Slawski et al., 2018 ⁽³²⁾	Retrospective Cohort Study	United States • 96 patients treated with a mechanical thrombectomy who were over 80 years old; 50 with an mRS 0-1 and 46 with an mRS 2-4	No significant difference in good outcome between patients who have an mRS of 0-1 and patients who had an mRS of 2-4 ASPECTS and NIHSS predicted good outcome regardless of premorbid disability		Redefining good outcome to include return to baseline functioning demonstrates that a third of patients over the age of 80 benefit from mechanical thrombectomy
Zerna et al., 2018 ⁽³³⁾	Retrospective Cohort Study	Canada • 21.788 patients with premorbid dementia	Patients with dementia were less likely than patients without dementia to be discharged to a rehabilitation facility or a home setting Old age and greater number of vascular risks did not explain the higher morality of patients with dementia compared to those without	Patients with ischemic stroke and concurrent dementia have higher mortality, face significantly more dependence after stroke and utilize greater healthcare resources than stroke patients without dementia	Significant difference in terms of baseline status between patients with dementia and patients without dementia
Zhang et al., 2018 ⁽⁷⁾	Retrospective Cohort Study	Australia • 820 patients presenting with acute stroke treated with IVT; 680 with no pre-existing disability and 140 with pre-existing disability	Patients with pre-existing disability were older and had more vascular risk factors as well as more severe strokes on presentation compared to patients without disabilities	Death at 90 days was more likely for patients with pre- existing disabilities (35.7%)	IVT should be considered in patients with mild to moderate pre-stroke disability
Zupanic et al., 2017 ⁽³⁴⁾	Retrospective Cohort Study	Sweden • Total participants were 8111; 6755 without dementia and 1356 with dementia	mRS score and accommodation status were worse among patients with dementia after 3 months	In those who had IVT, the incidence of symptomatic intracerebral hemorrhage and death at three months was not significantly different between patients with and without dementia	 Patients with dementia were less likely than patients without dementia to receive IVT In younger populations with dementia, there is no significant difference in risk with IVT when compared to patients without dementia

Stroke treatment entails risk for symptomatic intracerebral hemorrhage (sICH), but people with disabilities were not found to be more likely to experience sICH than those without disabilities. 1,8,16,20,23,29,34,36,37. Higher mortality of people with disabilities was associated with older age, increased stroke severity, and comorbidities that led to their impaired state rather than due to the disability itself. 7,25,35 Throughout the sources reviewed, patients with a higher mRS were typically older, had more comorbidities, had had more severe strokes, had had previous strokes, had diabetes mellitus, experienced atrial fibrillation, and were more likely to catch pneumonia. 16,22,33

Busl et al. ¹⁶ found that patients ≥80 with AIS treated with IVT had a decreased likelihood of death, illustrating that age as a single variable does not limit the benefit of intervention for individuals. The finding of age not predicting stroke outcome was replicated by Murao et al., ³⁵ who additionally found that cognitive impairment, no dementia (CIND), and onset to needle time were not associated with a positive outcome. A retrospective study design from Italy consisting of 2037 patients compared patients with mRS 3 or 4 who received IVT to patients with disabilities who did not receive IVT. Patients with a disability who received IVT were found to have more than seven times the odds of a favorable outcome

(return to the pre-stroke mRS 3 months after stroke) and three times the odds of a neurological improvement than the patients with a disability who did not receive IVT.⁸

Nearly 42% of patients with mRS score of 3 returned to the prestroke state when treated with IVT. Merlino et al.¹ also found the three-month mortality rate to be comparable in both patient groups. There was no associated benefit of IVT therapy for patient outcome for patients with an mRS of 5 found by Gumbinger et al.²² Mortality rate of patients with an mRS \geq 3 was equal in Gumbinger et al.'s²² study between those who were treated with IVT and those who were not, yet patients with mRS 3 and 4 were more likely to have a successful outcome than those without a pre-stroke impairment (mRS \leq 2). Zhang et al.² looked at rt-PA's effectiveness in those with an acute ischemic stroke admitted to a stroke unit with an mRS \geq 2. Patients with mRS 2 and 3 were found to benefit from rt-PA.

Busl et al.¹⁶ found that patients with dementia ≥80 years old did not benefit from reperfusion therapy due to an increase in inhospital mortality and unfavorable discharge, which was understood to be discharged to residential care facility. Favorable discharge was a return to the patient's home or rehabilitation facility. NIHSS score and dementia were found to independently predict in-hospital mortality for patients over 80 years of age.

As stroke severity, measured by NIHSS or CNS, increased, so did mortality, and NIHSS also served to predict successful outcomes post-stroke. 16,35,36 On the other hand, Murao et al. 35 found that the outcome of patients with CIND treated with rt-PA compared to patients without pre-existing cognitive impairment did not significantly differ, with favorable outcome defined as mRS \leq 1. These findings in the literature suggest that the presence of impairment itself does not constitute clinical justification for patient exclusion from stroke treatment.

Differences in Treatment for Patients with Versus Without Disabilities

Disability seemed to serve as a basis for exclusion from thrombolysis treatment, with none of the patient participants with dementia in Zhang et al.'s⁷ study who had a mRS of 5 receiving treatment and over 60% of those with mRS 3 and 4 being excluded from treatment. Caruso et al. observed that people with severe dementia and people with physical disabilities are often excluded from IVT treatment following an AIS. Of the 530 patients with a premorbid mRS between 2 and 4 in the Oxford Vascular study, only two patients received thrombolysis.⁶ Three months poststroke, 421 of the 530 patients with a disability were still alive. This study also illustrates that each increment of post-stroke disability among patients with premorbid disability is associated with worse 5-year mortality, institutionalization, and health care costs. Therefore, we may infer that successful treatments that mitigate post-stroke disability in patients with pre-existing disability may have long-term benefits. The study also illustrates how treatment leads to cost savings in the long term.

Echoing Caruso et al., Bunn et al. 5 found that people with dementia were less likely to be treated with thrombolysis compared to the overall ischemic stroke population. Bunn and colleagues¹⁵ reported that emergency departments in the UK did not have any strategies for acute stroke care tailored for people with pre-existing cognitive impairments. In their initial scoping review of 76 articles, Bunn et al. 15 found that in ten of the eleven articles that compared access to treatment between people with and without dementia, people with dementia were less likely to have the same level of access to or quality of care. These findings were replicated in Australia by Callisaya et al. 17 While patients with dementia in Australia were thrombolyzed more often within 60 minutes than patients without dementia, patients with dementia were less often admitted to stroke units and less likely to be treated with IVT for ischemic stroke. Being admitted to a stroke unit made it more likely for a patient with dementia to receive rehabilitation and decreased the mortality rate.¹⁷ Busl et al.'s study¹⁶ found dementia in patients older than 80 to be grounds for exclusion from treatment with IVT. However, this finding has not been replicated in other studies that analyze the effectiveness of stroke treatment for patients with disabilities.

Saposnik et al.³⁶ counter Busl et al.'s¹⁶ findings and claim that dementia diagnosis ought not preclude stroke treatment. Patients with dementia experienced the same rate of 30-day mortality, disability at discharge, and change in disposition as patients without dementia when using propensity-matched methods.³⁶ No differences were found in terms of thrombolysis-caused risks between the two populations.

Definitions of Successful Treatment: Reliance on Dichotomized mRS

In the studies reviewed, the mRS was used to determine the extent of disability in individuals presenting with stroke. Some studies utilized an ordinal understanding of the mRS to define successful post-stroke outcomes as the maintenance of pre-stroke mRS score for those with an mRS \geq 3 and a post-stroke mRS \leq 2 for those with a pre-stroke mRS of ≤ 2.725 While this understanding allows for impaired individuals to have their treatment deemed successful, Gumbinger et al.²² acknowledge that those with mRS 5 will, by default, have high levels of success in maintaining mRS score as the only way for them to increase their score is through death. Other studies defined successful treatment in narrow terms as a dichotomous phenomenon.³⁶ Post-stroke mRS \leq 2 or mRS 3 for all patients was defined as successful while everything else was unsuccessful.⁷ Patients with disabilities will rarely experience successful treatment with this measure. Busl et al. 16 also adopted a dichotomous understanding by determining successful treatment according to the discharge destination of patients. "Favorable" destinations were home or rehabilitation facilities while "unfavorable" destinations were skilled nursing facilities, hospices, or death. The authors did not indicate if they recorded details about patients' prior living situation which could impact the validity of their findings as one's home can be a skilled nursing facility.

Zhang et al.⁷ have observed that the pre-stroke mRS of a patient can be over-estimated, leading some individuals with a cognitive disability to, paradoxically, recover from a stroke with a lower mRS than when they were first ranked on the scale. This is of consequence because the mRS of a patient in acute care can influence the treatments that physicians use to treat the stroke.¹ Even when guidelines allow for a patient to be eligible for an intervention, Callisaya et al.¹⁷ found that physicians have a large amount of independence to determine whether or not to perform the intervention and that mRS measurement of a patient can impact physicians' decisions.

Treatment Practices for Patients with Versus Without Disabilities

Qualitative data from health care provider participants were collected by Longley et al.²⁶ to gain insight into how clinicians determine which stroke patients with a pre-existing cognitive impairment receive stroke rehabilitation. Longley et al. conducted semi-structured interviews with a range of health care practitioners including physicians and occupational therapists. Participants expressed the importance of understanding the extent of a patient's cognitive impairment prior to the stroke in order to determine the goals of rehabilitation. Family members were considered an important source of information to health care provider participants as family input was triangulated by formal assessments during admission and prior assessments if relevant. Longley et al.²⁶ discuss the role of informal factors in shaping how physiotherapists predict stroke patient's rehabilitation potential. In describing the process of determining rehabilitation potential, a physiotherapist noted: "I think it's been so difficult for me to describe who has got rehab potential . . . sometimes it is a gut instinct." Perceived rehabilitation potential influences how participants made decisions regarding their patients' treatment, with patients who participants felt had no ability to "carry over" knowledge from previous sessions being recommended for discharge rather than continued rehabilitation. A lack of knowledge about dementia and cognitive impairment was expressed by participants as leading them to rely on mentorship from senior health care providers and also to rely on their own "common sense." Stroke rehabilitation in the UK is limited to a period of weeks and goals of rehabilitation are made within days of the patient being admitted. Participants pointed to the physical environment as posing a barrier for success for patients: "I am very conscious of the fact that it's a very busy, noisy environment and it's horrendous for a cognitive patient (34, p.1140). Participants felt that management of abilities, rather than improvement, ought to be the goal for patients with pre-existing cognitive impairments. Participants carried heavy caseloads and recognized that they prioritized the rehabilitation of individuals who made quick progress in their programs. The prioritization of rehabilitation of individuals who made quicker progress may result in the exclusion of individuals with pre-existing dementia from additional treatment and rehabilitation following a stroke.

Longley et al.²⁷ evolved their work with prospective observational cohort study where they used the total number of therapy sessions (physical and occupational therapy) over an eight-week period to determine if pre-existing cognitive impairment influenced clinical rehabilitation decisions for stroke patients. When the analysis was adjusted for National Institutes of Health Stroke Scale (NIHSS), sex, and age, Longley et al.²⁷ reported that the group with pre-existing cognitive impairment had 14 fewer therapy sessions per person than participants with no pre-existing cognitive impairment. The mean difference between the two groups for attendance of physiotherapy sessions was 9.2 fewer sessions for the participants with pre-existing cognitive impairments with a 95% confidence interval ± 3.7 sessions. Difference in attendance of occupational therapy sessions was not statistically significant but participants with a pre-existing cognitive impairment had, on average, nine fewer "patient facing" sessions and two more "non-patient facing" sessions than participants with no pre-existing cognitive impairment. Patient facing sessions are sessions in which the patient is directly interacting with the occupational therapist while non-patient facing sessions can take place in the form of family meetings, phone calls, and other nonpatient interacting activities. The authors note that because they only recruited participants who were admitted to rehabilitation programs, their findings may be skewed given that rehabilitation program gatekeeping influenced their recruitment. Individuals with pre-existing cognitive impairments, notably dementia, may be excluded from rehabilitation programs.²⁷ Callisaya et al.¹⁷ found that despite legislation mandating equal levels of care for all individuals with stroke, people with dementia received poorer quality care and little access to rehabilitation programs in Australia. Goals were set less often for patients with dementia, with treatment being deemed as "futile" in 50.8% of files with documented reasoning.

Discussion

By illuminating structurally disabling features within the ischemic stroke acute care system, our goal is to contribute to decolonizing and transforming health care practices within a system where individual treatment plans hinge on understanding individuals who often have been reduced to the level of their (clinically perceived) disability. We draw from a critical disability studies perspective to focus on humans as more than their capacity for economic engagement and we ally with decolonizing mandates in a quest to acknowledge biases that can be subconscious. We argue for reflecting on how practices such as relying on "gut feeling" regarding a patient's likelihood of successful treatment can inadvertently facilitate disparities in treatment based on non-medically relevant patient characteristics. We recognize that acute care settings are working under circumstances of perceived resource scarcity and that this scarcity incentivizes the use of quantitative and dichotomous determinants of stroke treatment success such as the mRS scale, age, or the presence of comorbidities. Yet healthcare providers have the responsibility to resist working conditions that dehumanize patients and to collaborate towards healthcare systems where all kinds of patients are at the center of evidence-informed care.

Three decades ago, before IVT became the standard of care as the first reperfusion therapy for AIS, patients presenting with severe deficits essentially had no acute options to reverse their deficits. This was the case when Dr John Rankin first formulated his eponymous scale to evaluate post-stroke disability in 1957.³⁸ Today, IVT and EVT are powerful treatment options that allow physicians to dramatically change the fates of their patients, with up to one in two to one in four otherwise-healthy patients achieving excellent outcomes. Our therapeutic privilege as stroke health care practitioners – a privilege to dramatically change the course of our patients' lives with reperfusion therapies – remains exceptional in the field of neurology. This constitutes a paradigm shift that has been accompanied by a focus on identifying ideal candidates for these treatments in the form of candidates who are best able to achieve these excellent outcomes - even though stroke still disproportionately affects elderly patients and patients with premorbid disability who are least likely to achieve such excellent outcomes. With our newfound therapeutic privilege, our desperate search for effective stroke therapies has shifted in routine practice to a search for "perfect patients."

The "perfect patient" is functionally independent (translating in trials into an mRS between 0 and 2, young, physically fit, and has no comorbidities. Ironically, this segment of the population is least likely to experience stroke. Yet this is the segment of the population on which treatment trials are tested and whose needs are best met by institutional protocols.³⁹ We found evidence that people with disabilities did not receive equitable access to treatment ranging from being admitted to stroke units to receiving post-stroke rehabilitation. ^{17,27,40} There is no convincing evidence of increased risk of hemorrhage or specific stroke treatment associated complications for people with disabilities, yet disability is often an exclusion criterion in treatment trials; thus, physicians lack high-quality data to guide treatment decisions for their patients who have disabilities/pre-existing impairments. 41,42 Stroke therapies must be developed in consideration of the target population. Currently, the lack of inclusion of people with pre-existing impairments in Phase 4 trials for stroke therapies limits the evidence available to physicians and healthcare practitioners in making decisions regarding stroke therapies for people with disabilities and their associated comorbidities. On the one hand, there remains a paucity of high-quality literature regarding the efficacy of acute stroke therapies in patients with pre-stroke disability or dementia. On the other hand, there is considerable evidence from observational studies indicating no significantly increased risk from such therapies in these patients with pre-stroke disability or dementia. 41,42 This leaves us concerned that people with disabilities are being structurally disabled by acute care environments. Although some studies reported exclusion from treatment as justified on the basis that intervention was "futile" or too dangerous, most often no justification for inequitable access to treatment was given.¹⁷

Post-stroke rehabilitation requires repetitive actions from patients. Admittance to rehabilitation programs is often based on evidence from randomized control trials (RCTs), but Nelson et al.³⁹ observe that participants in these trials are younger, disproportionately male, and have far fewer comorbidities than the average stroke patient. This leads to patients with disabilities being excluded from rehabilitation programs because they cannot meet the standards of improvement set by people without disabilities.

Ability to remember movements or to "carry over" knowledge from previous sessions is considered a prerequisite for patients to be eligible for rehabilitation yet the prerequisite is not founded on any medical logic.⁴⁰

We found a large variety of definitions of "successful" treatment and propose that having a universal, dialectical understanding of "success" would be of most benefit to patients and would serve to deconstruct the disabling structures and processes we observed. A universal understanding allows for the standardization of findings along the care continuum and better serves policy makers, health care practitioners, and patients. 41,42 Using a critical disability studies lens illuminates that an individual with an mRS of two can be more disabled than an individual with an mRS of four. Compare an individual with paraplegia who owns a wheelchair-accessible home, has a well-paying job with benefits, and a large social support system to an individual who has an intellectual disability, multiple part-time minimum wage jobs, rents an apartment, and a limited social support system. Both individuals have a stroke. While medically, the individual in the wheelchair appears to have a more "severe" disability, there is little they are unable to do, while the individual with an intellectual disability has many barriers to their participation in society. Additional social determinants of health such as social support, ethnicity, income, and employment shape an individual's recovery and risk of recurrence following a stroke. 41,42 From an ethical perspective, treatment may seem justifiable on the basis of preventing additional disability - but the extent to which treatment can avert such additional disability remains unknown. The shared experiences of patients with disabilities within the ischemic stroke acute care system emphasizes the need to decolonize healthcare practices and healthcare provider's definitions of successful treatment.

We advocate that investment in research and programming that is accessible for *all* stroke patients is necessary and that "successful" treatment of stroke ought to be understood using an intersectional lens. The use of stroke assessment scales fails to capture a holistic understanding of patients' lives. We are encouraged by the American Heart Association's scientific statement calling for the incorporation of ordinal analyses of stroke outcomes to facilitate enrollment of patients with premorbid disability into Phase 4 and other trials, which we have identified as a way in which to improve the access of people with disabilities to stroke treatment as well as to improve health care providers' knowledge of, and access to, treatments for their patients.⁴³ Health equity across the stroke care continuum is possible with innovation, and we hope that readers take responsibility to ally with their marginalized patients along the care continuum.

Limitations

Our findings are limited by not having found literature discussing how physicians make decisions to treat patients with disabilities. Without an understanding of the process of treatment decision-making for patients with disabilities, it is difficult to meaningfully inform quality improvement for stroke care in patients with pre-existing impairments. Informal decision-making processes allow for physician or caregiver/proxy biases to impact patient wellbeing and reinforce prevailing cultural narratives that define wellbeing and what a 'good' life looks like. The informal decision-making processes may include additional non-medical factors such as living situation and family knowledge of medical history which extend beyond noted measurements of patient's feasibility for specific treatments.⁴⁰

Conclusion

In our analysis of the stroke treatment system in terms of disparities between people with and without pre-existing impairments, we found evidence that structural disablement is embedded in the stroke care continuum. Exclusion from treatment trials leads to patients with pre-existing impairments not having easy access to both IVT and EVT treatments, thus becoming disabled. Physicians have wide discretionary power over whether to proceed with treatment based on clinical evidence that includes diverse findings depending on the definition of "success" in post-stroke outcomes. We believe physicians have a proclivity to use "perfect patients" as a measure of "success." Further research into how physicians make the decision to treat patients is much needed. Neither physicians nor their "imperfect" patients are best served by the current state of the stroke care, and we propose that by using a human rights model of disability, both structural and individual biases are revealed across the stroke care continuum.

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