

Patients' perceptions on outcomes after mechanical thrombectomy in acute ischemic stroke

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Abstract

Background: The modified Rankin Scale (mRS) is a clinician-reported scale that measures the degree of disability in patients who suffered a stroke. Patients' perception of a meaningful recovery from severe stroke, expected value of a stroke intervention, and the effect of disparities are largely unknown.

Methods: We conducted a survey of patients, their family members, and accompanying visitors to understand their personal preferences and expectations for acute strokes potentially eligible for acute endovascular intervention using a hypothetical scenario of a severe stroke in a standardized questionnaire.

Results: Of 164 survey respondents, 65 (39.6%) were the patient involved, 93 (56.7%) were a family member, and six (3.7%) were accompanied visitors (friends, other). Minimally acceptable disability after a stroke intervention was considered as mRS 2 by 42 respondents (25.6%), as mRS 3 by 79 (48.2%), and as mRS 4 by 43 (26.2%) respondents. Race was associated with different views on this question ($p < 0.001$; Hispanic and Black patients being more likely to accept disability than Caucasian and Asian patients), while sex ($p = 0.333$) and age ($p = 0.560$) were not. Sixty-three respondents (38.4%) viewed minimally acceptable probability of improvement with an intervention as over 50%, 57 (34.8%) as 10–50%, and 44 (26.8%) as less than 10%.

Conclusions: A wide range of acceptable outcomes were reported regardless of gender or age. However, race was associated with different acceptable outcome. This is an important finding to demonstrate because of the persistent racial and ethnic disparities in the utilization of endovascular therapy for acute stroke in the United States.

Keywords

mRS, outcome, stroke, thrombectomy

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Introduction

The modified Rankin Scale (mRS) is a clinician-reported scale measuring the degree of disability in patients who have suffered a stroke, ranging from 0 to 6.¹ mRS is the primary outcome measure for the majority of acute stroke clinical trials.^{2,3} Its utilization currently extends to daily clinical practice, quality improvement initiatives, regulatory approval, and hospital certifying pathways.⁴ An mRS score of 0–2 (less commonly, 0–1 or 0–3) is often defined as a “good” or “favorable” outcome, whereas a higher score corresponds to a “poor” or “unfavorable” outcome.^{3,5} Criticism of this dichotomous approach includes the possibility of missing clinically important treatment effects and inability to capture important patient-centered improvements in certain functional domains.^{3,5}

Accurately defining outcomes that are meaningful to patients or their families can be challenging, especially in critically time-dependent emergency, such as in cases

of acute ischemic stroke (AIS).⁶ Physicians may choose not to recommend a certain intervention such as thrombolysis or thrombectomy in a setting of acute stroke if the

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likelihood of a “good” outcome is perceived to be low. However, patients’ perception of a meaningful recovery from severe stroke, expected value of a stroke intervention, and how racial, gender, or age disparities affect these choices are largely unknown. We conducted a survey of patients, their family members, and accompanying visitors, to understand their personal preferences and expectations for treatment of AIS potentially eligible for an acute endovascular intervention using a hypothetical scenario of a severe stroke in a standardized questionnaire.

Methods

Study design

This study was approved by the local institutional review boards with a waiver for informed consent. Between 1 January 2023 and 30 April 2023, 172 surveys were distributed and collected in the inpatient and outpatient setting by members of stroke teams in three distinct geographical regions of the United States (Midwestern, Southeastern, and Southcentral states). Consecutive patients who were seen by the corresponding center’s stroke team for any cerebrovascular diagnosis were approached. We intentionally attempted to exclude patients or family members in the acute stroke window setting to minimize delays to treatment and distress. We did not collect any information regarding the underlying admitting diagnosis given the sensitive nature of the survey. No patient identifying information was collected as a part of the survey. All three participating centers were comprehensive stroke centers that offer a wide range of treatments for ischemic and hemorrhagic strokes.

The questionnaire described a clinical scenario of a major ischemic stroke with high likelihood of long-term severe disability without treatment, a schematic to help illustrate the seven mRS health states from the consensus recommendations from stroke therapy academic industry roundtable XI,² five questions describing individual characteristics of survey respondent and two questions describing possible outcomes of the clinical scenario with a thrombectomy procedure (see the Supplemental Data). The survey was developed with an interactive process. The initial version was reviewed with patients/clinicians and their feedback was incorporated in the final version.

The first outcome (minimally acceptable degree of outcome expected after an intervention) listed three outcome scenarios: mRS 2 (“slight” disability), mRS 3 (“moderate disability”), and mRS 4 (“severe” disability). The second outcome (minimally acceptable probability of a clinical improvement with an intervention) listed three probabilities: >50%, 10–50%, and <10%. The questionnaire was administered by the members of multidisciplinary stroke teams to adult patients, their family members, and accompanying visitors who were receiving care in clinics (outpatient setting) or admitted to the hospital (inpatient setting). Once the scope of the survey was explained by the research team, respondents were

asked to provide verbal consent in order to continue with survey. If multiple family members were present, every member willing to participate filled out a separate survey form with instructions to describe their personal opinion only.

Statistical analysis

Survey responses were recorded and entered into IBM SPSS Statistics Version 27 (IBM Corp., Armonk, NY) for compilation and statistical analysis. A *p*-value of less than 0.05 was used to indicate statistical significance. The main outcomes measured were regarding opinions on minimally acceptable disability and minimally acceptable probability of improvement. These variables each had three possible responses. We treated both variables as ordinal variables graded in a stepwise fashion with a one-point difference between each step. Distributions were generated using numbers and frequencies. The relationship between our demographic variables and outcomes was assessed using Mann–Whitney U tests, Kruskal–Wallis tests, analysis of variance tests with post-hoc Fisher’s Least Significant Difference tests, and Pearson correlation tests where appropriate.

Results

A total of 172 surveys were collected; eight had incomplete data and were excluded from analysis leaving a total of 164 surveys for final analysis. Demographics are summarized in Table 1. Of respondents, 65 (39.6%) were the patient involved, 93 (56.7%) were a family member, and six (3.7%) were accompanied visitors (friends, other). Forty respondents (24.4%) were <50 years old, 114 (69.5%) were 51–80 years old, and 10 (6.1%) were >80 years old. Sixty-four (39%) were male. Caucasian ethnicity was the most common (103 respondents; 62.8%) followed by Hispanic ethnicity (47; 28.7%). One-hundred forty-one respondents (86%) either suffered a stroke in the past or knew someone who had had a stroke.

Outcomes

Outcomes and their relationship with demographic variables are presented in Table 1 and Figure 1. Of the first outcome, minimally acceptable disability after a stroke intervention, 42 respondents (25.6%) viewed their answer as mRS 2, 79 (48.2%) as mRS 3, and 43 (26.2%) as mRS 4. Race was found to be associated with different views on this question (*p*=0.008; Figure 1(a)). Specifically, a higher proportion of Hispanic and Black patients were more likely to choose a more disabled outcome than Caucasian patients (*p*=0.001) and Asian patients (*p*=0.040). Hispanic and Black patients had similar views (*p*=0.269). Sex (*p*=0.333), age (*p*=0.560), and prior experience with strokes (*p*=0.197) were not associated with a different choice of minimally acceptable disability.

Table 1. Characteristics of study respondents and their preferences for outcomes of stroke treatment.

Characteristics	N/total (%)	Acceptable minimal benefit with treatment				p-value	p-value
		Slight disability, mRS 2	Moderate disability, mRS 3	Severe disability, mRS 4	>50%	10–50%	<10%
Respondents	Total = 164	42 (25.6%)	79 (42.8%)	43 (26.2%)	63 (38.4%)	57 (34.8%)	44 (26.8%)
Patient	65/164 (39.6%)	17/65 (26.2%)	31/65 (47.7%)	17/65 (26.2%)	25/65 (38.5%)	20/65 (30.8%)	20/65 (30.8%)
Family member	93/164 (56.7%)	24/93 (25.8%)	46/93 (49.5%)	23/93 (24.7%)	35/93 (38.7%)	22/93 (23.7%)	22/93 (23.7%)
Friend, other	6/164 (3.7%)	1/6 (16.7%)	2/6 (33.3%)	3/6 (50.0%)	2/6 (33.3%)	2/6 (33.3%)	2/6 (33.3%)
Age							
<50	40/164 (24.4%)	7/40 (17.5%)	24/40 (60.0%)	9/40 (22.5%)	12/40 (30.0%)	20/40 (50.0%)	8/40 (20.0%)
50–80	114/164 (69.5%)	32/114 (28.1%)	50/114 (43.9%)	32/114 (28.1%)	48/114 (42.1%)	35/114 (30.7%)	31/114 (27.2%)
>80	10/164 (6.1%)	3/10 (30.0%)	5/10 (50.0%)	2/10 (20.0%)	3/10 (30.0%)	5/10 (50.0%)	2/10 (20.0%)
Gender							
Female	100/164 (61.0%)	21/100 (21.0%)	53/100 (53.0%)	26/100 (26.0%)	40/100 (40.0%)	31/100 (31.0%)	29/100 (29.0%)
Male	64/164 (39.0%)	21/64 (32.8%)	26/64 (40.6%)	17/64 (26.6%)	23/64 (35.9%)	26/64 (40.6%)	15/64 (23.4%)
Race/ethnicity							
White	103/164 (62.8%)	30/103 (29.1%)	54/103 (52.4%)	19/103 (18.4%)	51/103 (49.5%)	41/103 (39.8%)	11/103 (10.7%)
Hispanic	47/164 (28.7%)	9/47 (19.1%)	15/47 (31.9%)	23/47 (48.9%)	6/47 (12.8%)	12/47 (25.5%)	29/47 (61.7%)
Black	8/164 (4.9%)	1/8 (12.5%)	6/8 (75.0%)	1/8 (12.5%)	3/8 (37.5%)	1/8 (12.5%)	4/8 (50.0%)
Asian	6/164 (2.3%)	2/6 (33.3%)	4/6 (66.7%)	0/6 (0%)	3/6 (50%)	3/6 (50%)	0/6 (0%)
Other/mixed race	0	0	0	0	0	0	0
History/knowledge of stroke							
Yes	141/164 (86.0%)	34/141 (24.1%)	68/141 (48.2%)	39/141 (27.7%)	0.197	52/141 (36.9%)	47/141 (33.3%)
No	23/164 (14.0%)	8/23 (34.8%)	11/23 (47.8%)	4/23 (17.4%)		11/23 (47.8%)	10/23 (43.5%)
						2/23 (8.7%)	2/23 (8.7%)

Abbreviations: mRS: modified Rankin Scale.

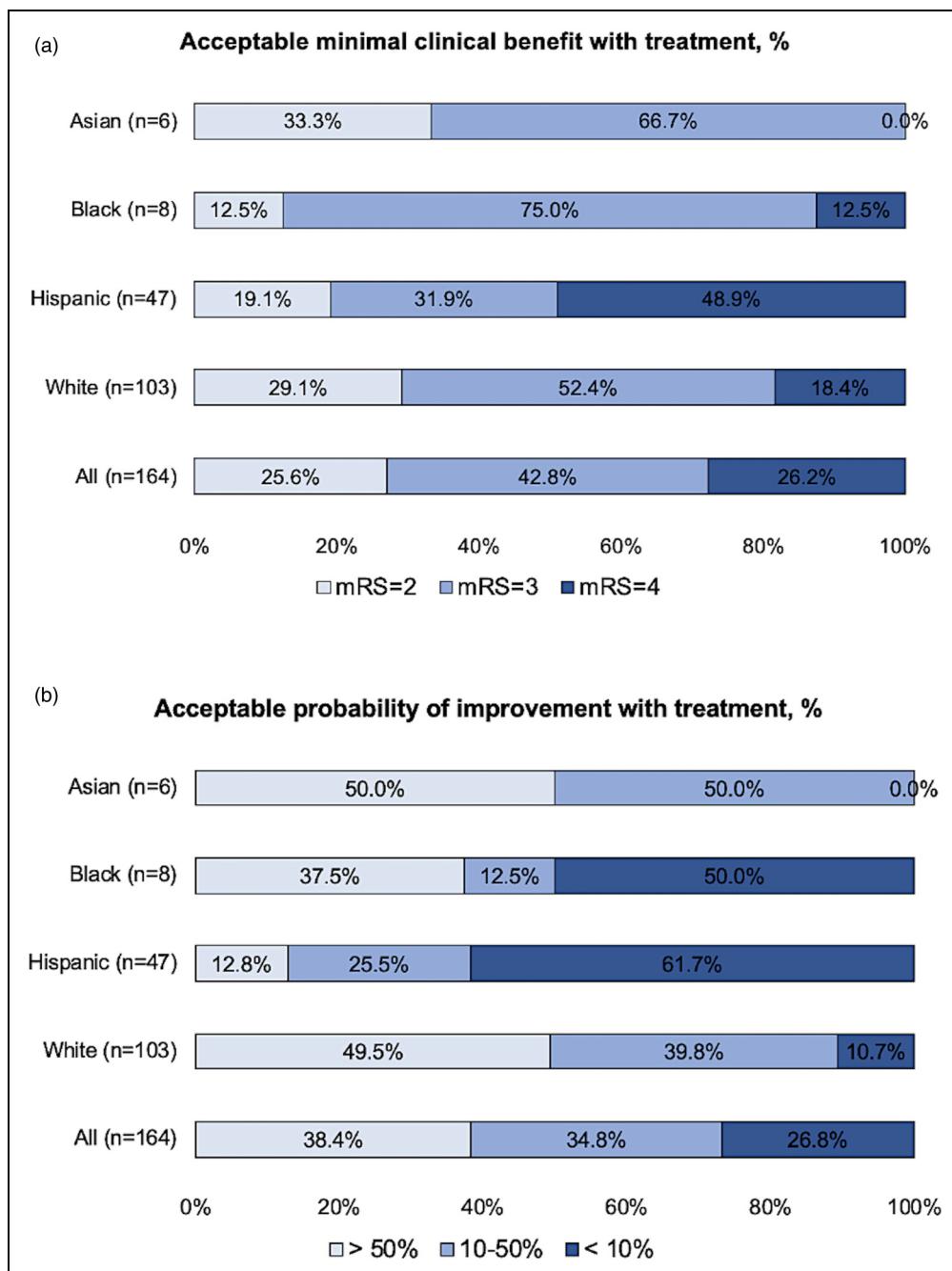


Figure 1. Preferences for outcome of stroke treatment according to race. (a) An association of race with minimally acceptable disability after a stroke intervention. (b) An association of race with minimally acceptable probability of improvement with an intervention.

For the second measured outcome, minimally acceptable probability of improvement with an intervention, 63 respondents (38.4%) viewed their answer as over 50%, 57 (34.8%) as 10–50%, and 44 (26.8%) as less than 10%. Race was found to be associated with different views on this question ($p < 0.001$; Figure 1(b)). Specifically on post-hoc testing we found that Hispanic patients were more willing to rank acceptable a lower likelihood of clinical benefit than Caucasian patients ($p < 0.001$) and Asian patients ($p = 0.001$); similarly on post-hoc testing we found that Black patients were more likely to choose a lower likelihood of clinical benefit than Caucasian patients ($p = 0.048$) but not Asian patients ($p = 0.101$). Gender ($p = 0.958$), age

($p = 0.638$), and prior experience with of strokes ($p = 0.086$) were not associated with different views on minimally acceptable probability of improvement. Supplemental Tables S1 and S2 report outcomes for patients and family/ visitors separately.

Discussion

This study reported patients' and family members' preferences regarding a minimal acceptable outcome after stroke thrombectomy in a hypothetical case of AIS with severe deficits. The main findings were that a wide range of acceptable outcomes were reported regardless of gender

or age. In fact, the majority of respondents considered moderate or severe disability (mRS 3 and 4, respectively) to be an acceptable outcome to justify an endovascular intervention. Differences in race were associated with different acceptable outcomes. A higher proportion of patients of Hispanic ethnicity and Black race accepted an outcome with higher degree of disability. This is an important finding to demonstrate, especially because of the persistent racial and ethnic disparities in the utilization of endovascular therapy for AIS in the United States. A study of 206,853 admissions to 173 endovascular centers showed that endovascular therapy utilization was lower in patients who defined themselves as Black and Hispanic compared to white/non-Hispanic patients (7.0% versus 9.8%).⁷ While our study measured patients'/families' perceptions, a recent study was published that analyzed prognostic discordance between physicians and families in severe brain injury (entailing ischemic stroke, intraparenchymal hemorrhage, subarachnoid hemorrhage, traumatic brain injury, or hypoxic ischemic encephalopathy after cardiac arrest). Kiker et al. found that a discordance occurred for 61% of patients/families, oftentimes because of over-optimism.⁸ We hope that by surveying patient/family perceptions in this case, a physician will be better able to reach a mutual understanding with patients and their families.

With expanding indications for endovascular therapy in AIS, such as in patients with large core strokes, there are concerns whether at some point an intervention becomes a futile procedure.^{9–11} At the same time, evidence from a prospective study where neurointerventionalists' ability to predict clinical outcome after thrombectomy was evaluated showed that physicians performed poorly in prognosticating patient 90-day outcomes.¹² In a study of 299 patients undergoing thrombectomy, Fargen et al. showed that physician interventionalists correctly predicted the patient's 90-day mRS tertile (0–2, 3–4 or 5–6) in only 44% of patients.¹²

Our study has some limitations. To avoid distress in the setting of AIS, we intentionally did not approach patients and families in the “acute” window. Thus, while our survey results are representative of a general population of patients treated by inpatient and outpatient stroke teams, it is not reflective of true emergency setting when decisions about acute stroke treatments are made. This study also may lack generalizability geographically and culturally given the limited number of centers included. Third, we did not include the option of intravenous thrombolysis in our survey option, as we wanted to keep the survey as brief and simple as possible. The “threshold” for accepting thrombolysis and its outcomes might differ than what our survey data showed. Fourth, there may have been selection bias. Our process was to offer the survey to all consecutive inpatients and outpatients who had “any cerebrovascular diagnosis”. We did not specify this further and did not record the number of patients who did not want to participate, possibly introducing bias. Another bias worth discussing is the underrepresentation of Black patients in this survey. Finally, we did not

collect data on pre-stroke disability which may influence procedural outcome and the degree of acceptable post-stroke disability. Hispanics and Blacks are more likely to live with a disability within the US, which may contribute to their higher tolerance to post-stroke disability.¹³

Conclusions

Based on our cross-sectional survey, patients and families demonstrated that after a large ischemic stroke, there was a wide range of acceptable outcomes were reported regardless of gender or age. In fact, the majority of respondents considered moderate or severe disability (mRS 3 and 4, respectively) to be an acceptable outcome to justify an endovascular intervention. However, race was associated with different acceptable outcome. This is an important finding to demonstrate because of the persistent racial and ethnic disparities in the utilization of endovascular therapy for acute stroke in the United States.

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Supplemental material

Supplemental material for this article is available online.

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