Stroke in persons with disability

Need for ethically resilient care

Ahmad Ozair, MBBS, and Ravindra K. Garg, MD, DM

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Persons with disabilities, while constituting ≈1 in 4 in the general populace,1 have historically made up <10% of those given IV thrombolysis for acute ischemic stroke, despite being a much larger percentage of cases of the same.2,3 Across the world, persons with disabilities continue to face a disproportionately lower representation not only in clinical trials but also among patients receiving the standard of care in acute ischemic stroke, namely thrombolytics or endovascular treatment. This systematic exclusion of persons with disabilities from stroke care has also been present in interventions in persons with other chronic diseases, including heart failure, diabetes mellitus, and dementia.4 In this issue of Neurology®, Young et al.5 provide an excellent review of ethical issues surrounding the provision of stroke care in persons with disabilities. Using principles of bioethics, health law, cognitive psychology, and recent research in rights of persons with disabilities, they highlight considerable areas of improvement for practicing neurologists.

Clinical medicine, including neurology, has increasingly recognized the impact of inherent cognitive biases and paternalistic approaches. These lead to diagnostic inaccuracies, medical mismanagement, and poor resource use, resulting in overall poor patient care.6 Here, Young et al. explain well how the ineffectual bias, fragility bias, and catastrophe bias together affect clinical decision-making in providing care for stroke in persons with disabilities. Clinicians frequently equate disability with poor health, perceive the disabled at higher risk for complications from aggressive management, and believe them susceptible to “magnified suffering” from complications compared to nondisabled persons. This leads to withholding of essential treatment from persons who would physiologically benefit from them, resulting in a large number of people with needlessly decreased quality of life, who must now spend additional resources to manage this deterioration in their level of functioning. Thus, these biases further amplify the well-known phenomenon of persons with disabilities having poorer health, greater health care costs, and a much higher incidence of chronic conditions compared to those without disabilities.7 In addition, these biases compromise patient autonomy by substituting decision-making on behalf of persons with disabilities and assuming the undesirability of interventions due to their disability.

The authors also highlight how both clinical trials and standard care practices tend to exclude the disabled. This disparity especially affects people ≥65 years of age, who have the unfortunate distinction of having the highest incidence of stroke, with 2 of every 5 persons being disabled.1 Often, trials for new therapies exclude patients with stroke with some degree of premorbid functional dependence based on the premorbid modified Rankin Scale score, despite a lack of clear pathophysiologic rationale. This results in a vicious cycle wherein persons with disabilities find themselves less reflected among the target groups for novel therapies and recent advances in the field, resulting in a lack of clarity in their optimal management, which then amplifies the dearth of research in them. This is unfortunate because prior literature has not provided building blocks for future studies. The scarcity of research that proves (or disproves) the nondisturbance of trial homogeneity by the inclusion of persons with disabilities deters further trials from including them. Investigators thus tend to gravitate toward keeping strict exclusion criteria to maintain high internal validity.

Department of Neurology, Faculty of Medical Sciences, King George’s Medical University, Lucknow, Uttar Pradesh, India.

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Importantly, the authors also examine the inequity and injustice that arise from excluding the disabled from interventions. In depriving persons with disabilities of the standard of care, despite established and unmistakable benefits, both clinicians and trial investigators tread an unethical path. Such discriminatory care is evidently unjust in the face of clear legal and moral guidance in the form of the Americans with Disabilities Act, the Rehabilitation Act of 1973, and NIH policy on inclusion of minorities in research.7,8 Those with disabilities may well be considered a minority who historically had unjust, systematic exclusion from both clinical practice and research.

The authors could have additionally looked at the current trial registrations on ClinicalTrials.Gov and highlighted those with the issues they have raised, especially for the trials yet to start recruiting. A search for interventional studies in stroke that exclude disabled participants could have emphasized the continuing magnitude of the problem.9,10 It would also have been of value for the article to have further considered how clinicians could ensure that their biases do not hinder them from delivering nondiscriminatory, ethically resilient care.

Overall, this article is a sign of the worldwide movement of clinical medicine coming to terms with its past unethical or biased behavior, thereby providing a corrective future course of action. Trial investigators for interventions in stroke need to shift, in particular, from an approach of exclusion to a methodology of inclusivity. This may well be reflected in using better functional outcomes such as the modified Rankin shift or the weighted modified Rankin Scale5 for trials to better capture the posttreatment improvement in the disabled.

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