Managing stroke in individuals with disabilities: ethical considerations in care delivery

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Persons with disabilities, while constituting around one in four in the general populace,[1] have historically made up less than 10% of those given intravenous thrombolysis for acute ischemic stroke (AIS), despite comprising 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 amongst patients receiving the standard of care in AIS, namely thrombolytics or endovascular treatment. This systematic exclusion of persons with disabilities from stroke care has also been present in interventions in persons suffering from other chronic diseases including heart failure, diabetes mellitus, dementia etc.[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 utilization, 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 non-disabled 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 healthcare costs, and a much higher incidence of chronic conditions, compared to those without disabilities.[7] Additionally, they also 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 aged 65 years and older, who have the unfortunate distinction of having the highest incidence of stroke, with two of every five persons being disabled.[1] Often, trials for new therapies exclude stroke patients having some degree of pre-morbid functional dependence based on the premorbid modified Rankin scale score, despite lack of clear pathophysiologic rationale. This results in a vicious cycle wherein persons with disabilities find themselves less reflected amongst the target groups for novel therapies and recent advances in the field, resulting in lack of clarity in their optimal management, which then amplifies the dearth of research in them. This is unfortunate, as prior literature has not provided building blocks for future studies. The scarcity of research, that proves (or disproves) the non-disturbance of trial

homogeneity by inclusion of persons with disabilities, deters further trials from including them. Investigators thus tend to gravitate towards keeping strict exclusion criteria in order to maintain high internal validity.

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 unmistakeable 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 Americans with Disabilities Act, the Rehabilitation Act of 1973 and National Institutes of Health (NIH) policy on inclusion of minorities in research.[7,8] Those with disabilities may well be considered a minority that has 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 emphasised the continuing magnitude of the problem.[9,10] It would also have been of value for the paper to have further considered how clinicians could ensure that their biases do not hinder them from delivering non-discriminatory, ethically-resilient care.

Overall, this paper is a sign of the worldwide movement of clinical medicine coming to terms with its past unethical or biased behaviour, 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 mRS,[5] in order for trials to better capture the post-treatment improvement in the disabled.

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