Future of Quality and Outcomes Research in Stroke

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Stroke is a common and costly condition that affects 15 million people worldwide each year. Globally, stroke results in nearly 6 million deaths, and another 5 million people are permanently disabled by stroke each year. Stroke is the fourth leading cause of death, the second most common reason for hospitalization in older adults, and the most common cause of long-term disability in the United States. Although there have been important advances in stroke treatment and rehabilitation over the past few decades, stroke patients, care partners, and clinicians frequently still have too little information to determine which diagnostic tests, treatments, and strategies to apply and which to avoid in specific instances. There remain critical voids in knowledge about which approaches to stroke care are likely to produce optimal clinical outcomes for the greatest number of patients. In addition, despite well-developed repositories for the assessment of neurological quality of life and other patient-reported outcomes, the field of cerebrovascular disease has been slow to incorporate these measures into care planning and shared decision-making. Even when strong evidence exists, there are frequently gaps, variations, and disparities in how that evidence is applied in clinical practice. Challenges remain in accurately capturing and reporting quality and outcomes, including functional outcomes, that are properly risk adjusted. Quality and outcomes research in stroke is essential to bridging these substantial gaps in knowledge, better informing clinical decision making, and driving further improvements in stroke care and outcomes.

With the significant disease burden and existing gaps in knowledge in stroke care, stroke quality and outcomes research has been increasingly recognized as a key priority for both researchers and knowledge users. The Institute of Medicine has highlighted stroke as one of the highest priority conditions for clinical and comparative effectiveness research. Comparing the safety and effectiveness of various prevention, diagnosis, and treatment options for stroke has been identified by the Patient-Centered Outcomes Research Institute as one of the 5 national priorities for research.

To better inform clinical decisions, there is an urgent need for better and more personalized ways to gauge prognosis and response to treatments. It is also essential to better understand how demographics, comorbid conditions, and other factors interact to influence health, access to care, and response to therapies in people with stroke. There is a need for enhanced approaches to detecting potential safety issues with drugs and devices for patients with stroke. It has also been increasingly recognized that there is value in incorporating patient preferences and values at all stages of clinical decision making, including research, and in improving integration of patient-centered measures of longitudinal functional outcomes and direct patient-reported outcomes into research.

The development of stroke registries has been instrumental in measuring and improving the quality of stroke care by providing tools that improve patient assessment, clinical decision support, delivery of evidence-based therapies, and timely benchmarked performance feedback. National-level improvements in stroke quality of care and outcomes have been achieved through these registries, as well as through focused initiatives, to improve specific aspects of stroke care. Stroke quality of care and outcomes research is increasingly drawing on the vast amount of data continuously generated from stroke patients by leveraging existing data infrastructure of clinical registries, electronic health records, administrative claims, and other sources to serve as data sources for examining the clinical effectiveness of a variety of diagnostic tests, therapies, strategies, and delivery systems in stroke care. In addition, there are increasing opportunities to integrate information that is generated from stroke patients’ own experiences and that reflects the health outcomes that they most value.

With increasing pressures to reduce costs and streamline healthcare operations and the implementation of electronic health records that are consistent with Centers for Medicare and Medicaid Services Meaningful Use requirements, eliminating inefficiencies in the collection and analysis of health outcome data will be vital to supporting health outcomes research in stroke. Efforts to foster more routine deterministic and probabilistic linkages between clinical registries, administrative claims data, and electronic health records data will be required. In addition, alternative strategies to develop poststroke functional outcome measures that do not require direct patient interviews will be necessary, and innovative research strategies will likely leverage sources, such as administrative data (eg, claims for use of assistive devices, rehabilitation services, home healthcare), digital health monitoring devices (eg, activity trackers, arrhythmia detection), and novel patient-reported outcome methodologies (eg, analysis of social media postings, targeted surveys, online transaction activity).
Health outcomes research in stroke also has an important role to play in informing federal policy related to quality, privacy, and reimbursement. Through partnerships between multiple professional societies and organizations that work with the Centers for Medicare and Medicaid Services, new methods for incorporating measures of stroke severity into administrative claims through added fields in the International Classification of Diseases-10th edition will allow encoding of the National Institutes of Health Stroke Scale. This will permit a new generation of stroke quality measures to be appropriately risk adjusted and available for use by federal and private payer population health management and risk-based contracts that will adjust reimbursement to be aligned with the highest quality of care and outcomes.

Insights into the importance of including stroke severity measures into stroke mortality models were made possible through health outcomes research derived from clinical registries that demonstrated these important relationships. Pivotal research into the impact of Canadian privacy regulations that required written informed consent for inclusion of cases into a national stroke registry revealed that such a requirement introduced substantial selection bias and underreporting of poor outcomes, ultimately leading to a revision in the privacy regulations.

Finally, the burden of stroke is not equally distributed, and it is increasingly disproportionately felt by low-income countries. The International Consortium for Health Outcome Measurement recently published a Standard Set for Stroke (http://www.ichom.org/medical-conditions/stroke/), which reflects the consensus of leading stroke physicians, health outcomes measurement experts, and patients. It is designed to represent the outcomes that matter most to patients who have experienced a stroke and is suitable for collection in all countries. Only through international collaboration, benchmarking, and sharing of best practices can we make progress in improving the lives of all individuals across the globe who experience a stroke.

This stroke-themed issue of *Circulation: Cardiovascular Quality and Outcomes* provides outstanding examples of the types of vibrant quality and outcomes research taking place in stroke. It is our hope that this progress will accelerate, and the critical research necessary to meet the needs of stroke patients, care partners, clinicians, and healthcare systems globally will be produced and implemented.

**Disclosures**

Dr Fonarow reports serving as a member of the Get With The Guidelines (GWGT) steering committee; receiving significant research support from the Patient-Centered Outcomes Research Institute (PCORI); serving as an expert consultant to YALE-CORE in its work as a CMS contractor in measure development and risk-based contracts that will adjust reimbursement to be aligned with the highest quality of care and outcomes. Insights into the importance of including stroke severity measures into stroke mortality models were made possible through health outcomes research derived from clinical registries that demonstrated these important relationships. Pivotal research into the impact of Canadian privacy regulations that required written informed consent for inclusion of cases into a national stroke registry revealed that such a requirement introduced substantial selection bias and underreporting of poor outcomes, ultimately leading to a revision in the privacy regulations.

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**References**


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