The Colorado Stroke Registry

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Overview

Stroke is common, tragic, and expensive. It is within our capability to lessen the burden of stroke for all Coloradans. In fact, there are few areas in medicine where the opportunity for progress is so great, but little progress is being made. Closing the gap – between where we are now and where we wish to be – requires a mechanism for working together to promote systematic quality improvement. The Colorado Stroke Registry (CSR) will be an important component of that mechanism. In the remarks below, we will summarize the Registry's development to date and our view of its future.

Introduction and Background

Stroke imperils life, mobility, communication, employment, and even one's sense of self. Few survivors escape without lasting scars. Stroke is our primary cause of long term disability and the third leading cause of death. Although it hasn't been estimated recently, the cost of stroke more than a decade ago was said to be more than $40 billion, with the average lifetime per person cost of a first stroke coming to more than $100,000.[1]

Encouraging medical advances have been achieved in recent years. The cause of stroke is understood. Effective treatments are available. Risk factors are well known, and altering risks can prevent strokes. Why then does stroke remain common, tragic, and expensive?

This gap between what we actually do and what we could achieve is not unique to stroke. The Institute of Medicine has pointed out that the gap is present throughout our medical system.[2] It is estimated that actual practice conforms with best achievable practice only about half the time. This realization, combined with knowledge of unacceptable disparities in the delivery of quality care and an uncomfortably high frequency of medical errors, has led to call for a transformation of our present system of care.[3]

The creation of higher quality, more equitable, safer, and more efficient systems is a goal with which few would disagree. But, systems of care, like other complex dynamic systems, are not easy to program. Tinkering with them can lead to large and negative unintended consequences. Perhaps this partly explains medicine's slowness in entering the age of assessment and accountability that has been heralded for more than two decades.

The current system of stroke care is inadequate. It is too sluggish, too fragmented, and too inconsistent to treat stroke effectively.[4] Given the widespread availability of computerized data tracking and analysis, it is becoming possible to see in nearly-real-time how adjustments to a medical system affect the system's performance. With this sort of feedback, institutions and care providers are becoming more confident of their ability to tune their systems on the fly, without crashing. Continuous quality improvement is on the verge of becoming a reality, not just a slogan.

The CSR is a part of a broader quality improvement (QI) movement in medicine. It will provide the data that will inform the effort to improve stroke care throughout our state. Nationally, accumulating evidence affirms the value of a broad QI approach. For example, the Institute for Healthcare Improvement recently announced that more than 122,000 lives had been saved over an 18 month period, during which hospitals undertook an unprecedented campaign of internal QI in the areas of infection control, medication-error prevention, and management of cardiac/critical care patients.[5] Furthermore, adherence to recommended process has been shown to result in improved survival rates for heart attack patients.[6]

The Origin and Current Status of the CSR

In recognition of the importance of stroke – and of the gap between potential and practice – the Colorado Legislature created the Colorado Stroke Advisory Board (CSAB) in 2002. Board members were recruited by public announcement and were selected from a variety of disciplines by the executive director of the Colorado Department of Public Health and Environment. Their mandate was to examine and report on the problem of stroke as it exists in Colorado. This report was issued in October of 2003.[7]

The report noted the lack of a statewide feedback mechanism for decision making about QI for stroke. Among the report's recommendations were that Colorado should establish a stroke registry, "for the purpose of guiding recommendations to facilitate continuous quality improvement of stroke care in Colorado".

The report's recommendations were unfunded until 2006, when a three-year grant was awarded for a pilot statewide stroke registry. Funding came from the Amendment-35 tobacco tax increase. Although the CSAB mandate ended with the publication of the 2003 report, some original members of the board continued to serve, joined by other volunteers concerned about the problem of stroke, in a reconstituted CSAB. This new board was brought under the umbrella of the Colorado Cardiovascular Disease & Stroke Prevention Program, a volunteer group endorsed by the Department of Public Health and Environment. Currently more than 20 organizations are represented in the new CASB. Membership is open to all Colorado stake-holders in stroke.

The CASB and CSR are unique projects. Unlike other initiatives, they are not a state-mandated, regulation-driven projects. Rather, they are bottom-up, grassroots undertakings. The database for the registry is Get-With-The-Guidelines, a quality improvement tool from the American Stroke Association (ASA) that is widely used by hospitals across the country. In addition to giving ready access to best-practice guidelines, the tool allows institutions to compare their adherence to recommended quality indicators with national benchmarks.

The CSR is the nation's first "superuser" of Get-With-The-Guidelines, with access to patient level data across all participating hospitals in Colorado. To allay concerns about privacy and competitiveness, the data supplied to the CSR is de-identified for individual patients and for treating hospitals. We are able see a global picture of stroke in Colorado, but no hospital is able to use the data for competitive advantage. As we discover deficiencies in care, we will work through the ASA to encourage individual hospitals to see how they can improve quality in the identified areas.

The initial focus of the CSR is on the use of clot-dissolving agents in acute stroke. These agents have the potential to completely reverse the ill effects of a stroke, if given quickly to appropriate patients. Yet, in its 2003 report the CSAB found that their use in Colorado was very low, only about 1% – about half the national average at that time.

Effective use of clot-dissolving agents depends on a high level of public awareness, rapid transport to a hospital, prompt evaluation, and judicious selection of candidates for treatment. We aim to understand Colorado's performance in this area by tracking several key variables: time from onset of symptoms to hospital arrival; the percentage of stroke patients given clot-dissolving treatment; the incidence of complications and the outcome of care (discharge destination) for those so treated.

The Future of the CSR

In years two and three of this pilot registry, we will examine and work to improve adherence to consensus quality indicators for stroke treatment and prevention. Funding for the CSR is guaranteed only until mid 2008. It is the hope of the CSAB that the Registry will have shown sufficient merit by then that funding will continue, but that remains to be seen.

It is the belief of many on the CSAB that over the long term, the volunteer status of the CSAB membership could prove to be a handicap. It might legitimately be asked, "By what authority does the CSAB assume the role of overseer, analyst, and QI coordinator concerning statewide issues in stroke?" Authority and accountability for system-reform initiatives will likely need to be incorporated into existing public health structures, perhaps via an appointed board, acting with the Colorado Department of Public Health and Environment. Further legislative action by the state will likely be necessary for this to come to pass.

A model for the CSR is NRMI, the National Registry of Myocardial Infarction, a registry that gathers information about treatment of heart attack. In so doing, NRMI is thought to have contributed to a dramatic reduction in mortality from coronary heart disease.[8]

Summary

It has been said that, "Building stroke systems throughout the United States is the critical next step in improving patient outcomes in the prevention, treatment, and rehabilitation of stroke. The current fragmented approach to stroke care in most regions of the United States provides inadequate linkages and coordination among the fundamental components of stroke care. Providers and policymakers at the local, state, and national levels can make significant contributions to reducing the devastating effects of stroke by working to promote coordinated systems that improve patient care." [4]

We in the "stroke community" recognize that stroke care can be improved by better use of the knowledge and tools that are currently at our disposal. Getting from where we are to where we wish to be is not so much a technological problem as it is a sociological one.

Stroke is a complex condition with many variations. Stroke care involves many health care providers across a range of disciplines. Competition for stroke "business" is keen among institutions, providers, professional associations, government agencies, and nonprofit

organizations. Long established patterns of referral and outmoded ideas about stroke retard innovation in the delivery of stroke care. Corralling these elements in a cooperating, efficient, and effective system is a challenge, but the CSR is an important tool in the work to meet that challenge.

References:

1. Taylor TN, Davis PH, Torner JC, Holmes J, Meyer JW, Jacobson MF. Lifetime cost of stroke in the United States. Stroke. 1996 Sep;27(9):1459-66.

2. Corrigan JM, Donaldson MS, Kohn LT, eds. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academy Press; 2001.

3. McGlynn EA, Asch, SM, Adams J, et al. The quality of health care delivered to adults in the United States. N Engl J Med. 2003;348:2635-2645

4. Schwamm, et al. Recommendations for the Establishment of Stroke Systems of Care. Stroke. 2005; 36: 0001-0014

5. IHI announces that hospitals participating in 100,000 lives campaign have saved an estimated 122,300 lives. Available online at: http://www.ihi.org/IHI/Programs/Campaign/

6. Peterson, et al. Association Between Hospital Process Performance and Outcomes Among Patients With Acute Coronary Syndromes. JAMA. 2006;295:1912-1920

7. Stroke in Colorado: A Report to the Colorado Legislature from the Colorado Stroke Advisory Board. October 2003. Available online at: http://www.cdphe.state.co.us/pp/cvd/Stroke_Rpt.pdf

8. Jha, AK. Measuring Hospital Quality. JAMA 2006; 296:95-97