Health policy research and its kin, outcomes research, are primarily aimed at informing policy decision-makers. Although we know of no clear line separating these 2 types of research, an apparent convention is to term research performed specifically for policy decisions and typically reported in nonacademic publications as "health policy research," whereas outcomes research is the more academic counterpart. Outcomes research has been defined as follows: the study of "... the impact of health care on the health outcomes of patients and populations... in general, real-world settings... (measuring) a wide range of outcomes, including mortality, morbidity, functional status, mental well-being, and other aspects of health-related quality of life... (and) may entail any in a range of primary data collection methods and synthesis methods that combine data from primary studies." Whatever term one wishes to use, this report focuses on several studies published in peer-review journals in the past year that are of potential importance to the thinking and actions of policy decision-makers.

Policy decision-makers can be said—at the risk of oversimplifying—to be driven by 2 dominant questions. The first question is, does a particular problem deserve my attention? The second question is, is there any solution to the problem that is credible, practical, and otherwise politically attractive? Does Stroke Deserve the Policy Maker’s Attention?

A condition deserving of a policy maker’s attention is one that affects many worthy individuals in disconcerting ways and consumes large volumes of shared resources. Several recent studies reinforce the contention that by this metric, stroke deserves attention.

Health Burden of Stroke

Particularly salient is a study by Elkins and Johnston in which demographic projection techniques are used estimate that in the US, the number of deaths from stroke will double by the year 2032. This burden will be (and indeed is) unevenly distributed in the population. Confirming previous studies, the black population (particularly noted the young and middle aged) and the elderly incur a disproportionate share of the burden of stroke, with more frequent and more severely disabling strokes. Recent evidence further reinforces the observation that patients with atrial fibrillation incur worse strokes, as do patients with diabetes.

Although comprising a relatively small number of stroke victims, children represent a particularly troubling issue that has been neglected in clinical practice and research. A recently published epidemiological study has shown that the US states with high adult stroke mortality rates also have high stroke mortality rates in people younger than age 20 years, suggesting that atherosclerosis per se is only a part of the explanation for variations in stroke burden. Steinlin et al followed-up 20 children with ischemic stroke and report that in many there were often long-term neuropsychological consequences that significantly affect the lives of the children and that require long-term follow-up and support. Friefeld et al used the Pediatric Quality of Life 4.0 Generic Inventory Scale, a promising assessment tool. Their results indicate that severity of neurological outcome only accounts for a small proportion of variance in quality-of-life scores. Emotional and social function are of greater independent importance for children with stroke.

Economic Burden of Stroke

As shown in an international comparison of stroke cost studies across the developed world, stroke is associated with high cost—typically 3% of national health care costs and 25% of the gross domestic product (or $100 per capita). Several recent studies add nuance to the basic message that stroke is costly. One nuance is that the cost of stroke is highly variable, depending substantially on patient features (severity and stroke type) and system features (especially tendencies to use inpatient rehabilitation services as an extension of acute care or other regional idiosyncrasies). Costs of stroke are apparently quite changeable as evidenced by broad temporal shifts in location, type, and intensity of services after stroke. One issue the fluidity of cost raises for policy makers is that stroke cost estimates require some degree of tailoring to local circumstances, including local demographics and practice style. It also suggests that programs aimed at specific aspects of stroke care could have unpredictable effects on resource use.

A further nuance to the message that stroke imparts a large societal burden is that much of this burden is associated with reversible risk factors. Based on analyses of data from the

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Second National Health and Nutrition Examination Survey (NHANES)\textsuperscript{16} Qureshi et al\textsuperscript{15} point out that depending on risk category, 4\% to 14\% of stroke risk (and cost) is attributable to reversible factors and these factors are associated with a decrease in life expectancy of 2 to 10 years. Although attributable risk is not the same as reversible risk (e.g., never having had hypertension is not the same as having effectively treated hypertension), it does suggest that risk factor management could have a large aggregate effect and thus is worthy of being on the policy maker’s “radar.”

**What Actions Should Health Policy Makers Promote?**

Three major sets of stroke guidelines have been produced in 2003 and 2004 from the American Stroke Association,\textsuperscript{17} European Stroke Initiative (EUSI),\textsuperscript{18} and the second edition of the National Clinical Guidelines for Stroke from the Royal College of Physicians, London, United Kingdom.\textsuperscript{19} There is remarkable concordance between the documents. The UK guidelines are the widest ranging, covering not only acute care, organization of care, and prevention but also many aspects of rehabilitation and longer-term care. In addition, for the first time in the United Kingdom, specific guidelines for the management of stroke in children have been published.\textsuperscript{20}

As with most guidelines, stroke guidelines highlight the need for more research to fill in the gaps in evidence. This is unlikely to happen unless spending on stroke-related research increases substantially. An article Pendlebury et al\textsuperscript{21} examined the amounts spent on stroke research in 9 European countries, with cancer research funding often 10-times as much. Similar findings have previously been shown in the US, suggesting that this is a worldwide phenomenon that needs to be urgently addressed.

One recent notable study addresses a troubling problem for many clinicians (and hence a respectable topic for a clinical policy)—how to manage warfarin at the time of endoscopy. Using cost-effectiveness analysis, Gerson et al\textsuperscript{22} estimate that withholding warfarin before endoscopic surgery either dominates (is more effective and less expensive) or is cost-effective when compared with various alternatives.

Two recent studies examine the cost-effectiveness of treatments applied after the stroke. Patel et al\textsuperscript{23} analyze data from a trial of caregiver training and estimate that this intervention is cost-saving and does not worsen patient survival or the quality of life of either patient or caregiver. In line with the notion that stroke interventions can have surprising (and unintended) effects, the investigators note that the principle reason for the cost-saving was because of decreased hospitalization costs, not decreased cost of other postacute care services. A second study\textsuperscript{24} used Markov modeling, applying a Cochrane Review estimate of the efficacy of stroke units and French data on care patterns and costs. They conclude that stroke units would improve survival by nearly 1 year. With a modest ongoing cost, they conclude such units are highly cost-effective. Conspiciously, French stroke units provide short-term care, whereas the studies that form the basis of the analysis mostly provided longer-term care, including rehabilitation.

**Methodological Issues**

The recent stroke policy literature raises a variety of other technical issues that are worth general note. Mathematical modeling of disease development and outcome is becoming increasingly common in the stroke policy literature.\textsuperscript{13,14,24–27} One report by Moodie et al\textsuperscript{25} describes a model based on an Australian stroke data\textsuperscript{24} developed for use in national policy priority setting. The basic notion is that such population-based model can provide a standard foundation for priority setting (i.e., allowing various “what if” exercises for policy makers to compare different strategies across different segments of the population). Although the article serves only as a basic proof of concept, further efforts, including validation and testing of portability, are warranted.

Patel et al\textsuperscript{28} supplement a report of results of a trial of alternative strategies for stroke care with a cost analysis. Whereas the principal objective of the article is to examine the value of stroke units compared with an organized program of domiciliary care, of particular interest is the authors’ use of a technique termed “cost-effectiveness acceptability curves.” Used increasingly in clinical policy analyses outside of stroke, this form of analysis asks the question, for a given willingness to trade-off money for health outcomes, how likely is it that one treatment strategy will be the preferred choice? Because costs measures tend to have greater variance than health measures, a typical trial is unlikely to achieve “statistical significance” for cost-effectiveness measures. A cost-effectiveness acceptability curve allows a policy maker to decide if the evidence is strong enough for practical purposes.

Several recent studies have shed light on methodological issues in assessment of health outcomes. The Atherosclerosis Risk in Communities Study\textsuperscript{29} of nearly 15,000 subjects attempted to improve on existing models by including 22 nontraditional factors. Improvements were very modest and unlikely to improve clinical and public health efforts to reduce the community burden of stroke. The Charlson Index\textsuperscript{30} has been used before in conditions other than stroke and has now been shown to be valid as a measure of comorbidity for use in ischemic stroke, with every 1-point increase associated with a 15\% increase in the odds of a poor outcome at discharge. Quantifying disability is most frequently performed using the Barthel Index, motor component Functional Independence Measure, and the categorical disability measure of the modified Rankin score. Kwon et al\textsuperscript{31} examined the predicting ability of ADL measures to the modified Rankin score using a categorization scheme minimizing the false-positive response rate. All 3 measures were highly correlated. Both the Barthel Index and motor component Functional Independence Measure differentiated disability better in lower than higher disability; however, because of the ceiling effect of Barthel Index and motor component Functional Independence Measure, the translation between the scores could not be completed for all 6 levels of the Functional Independence Measure.

Interventions targeting mood and handicap have the potential to improve quality of life independent of impairment and disability. Measures of quality of life often exclude patients with aphasia. Hilari et al\textsuperscript{32} adapted the Stroke-Specific
Quality of Life Scale for use with people with aphasia to produce the Stroke and Aphasia Quality of Life Scale. It demonstrated high acceptability, with 87% of patients able to self-complete the score and appeared reliable and valid but needs further testing to evaluate responsiveness. The Burden of Stroke Scale is also reported to give valid and reliable estimates of functioning in stroke survivors with communication disorders in the areas of physical activity limitation, cognitive activity limitations, and psychological distress.  

Comment

Despite the clear policy implications of stroke, research relevant to stroke policy continues to be an activity that occurs relatively apart from stroke policy formation. Improved coordination between the research and policy-making occurs relatively apart from stroke policy formation. Irrelevant to stroke policy continues to be an activity that needs further testing to evaluate responsiveness. The Burden of Stroke Scale is also reported to give valid and reliable estimates of functioning in stroke survivors with communication disorders in the areas of physical activity limitation, cognitive activity limitations, and psychological distress.  

References


Key Words: Advances in Stroke ■ health burden ■ health economics ■ health policy ■ health outcomes ■ outcomes research ■ stroke