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Methodological Issues in Monitoring Health Services and Outcomes for Stroke Survivors: A Case Study

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Abstract

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Authors' contributions

Mary Stuart initiated the study, had overall responsibility for the study design and data analysis, and drafted the manuscript. Donato Papini participated in the design of the study, designed the data retrieval requests for AUSL 11, reviewed and translated the all of the data headings, played a key role in data analysis and help prepare the manuscript. Francesco Benvenuti participated in the design of the study, reviewed the data, participated in the data analysis and interpretation of data, and edited the manuscript. Marco Nerattini participated in the design of the study, designed the data retrieval requests for AUSL 10, and participated in the data analysis. Enrico Roccato, Velio Macellari, Steven Stanhope, and Richard Macko participated in the design of the study, reviewed the data analysis and edited the manuscript. Michael Weinrich participated in the design of the study, assisted in data analysis and helped prepare the manuscript.

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Background—Obtaining comprehensive health outcomes and health services utilization data on stroke patients has been difficult. This research grew out of a memorandum of understanding between the NIH and the ISS (its Italian equivalent) to foster collaborative research on rehabilitation.

Objective—The purpose of this study was to pilot a methodology using administrative data to monitor and improve health outcomes for stroke survivors in Tuscany.

Methods—This study used qualitative and quantitative methods to study health resources available to and utilized by stroke survivors during the first 12 months post-stroke in two Italian health authorities (AUSL10 and 11). Mortality rates were used as an outcome measure.

Results—Number of inpatient days, number of prescriptions, and prescription costs were significantly higher for patients in AUSL 10 compared to AUSL 11. There was no significant difference between mortality rates.

Conclusion—Using administrative data to monitor process and outcomes for chronic stroke has the potential to save money and improve outcomes. However, measures of functional impairment and more sensitive outcome measures than mortality are important. Additional recommendations for enhanced data collection and reporting are discussed.

Keywords

stroke; outcomes; equity; administrative data

Background

The American Recovery and Reinvestment Act of 2009 (ARRA) will result in a remarkable infusion of \$19 billion into the US health care system for the adoption of health information technology (HIT), including electronic health records (EHRs) [1], increasing hope that HIT will improve the quality and cost-effectiveness of chronic care management [2]. However, it is not a foregone conclusion that such benefits will occur despite this substantial investment [3]. Furthermore, most commercially available EHR systems have not demonstrated the ability to adequately support population management systems [4]. In this context, lessons from a pilot study conducted in Italy should be useful.

In September 2003, the National Institutes of Health (NIH), in conjunction with its Italian counterpart, the Istituto Superiore di Sanità (ISS), convened an international working group to consider health outcomes for stroke survivors as a measure of health equity. Equity in health has been defined as “the absence of potentially remediable, systematic differences in one or more aspects of health across socially, economically, demographically or geographically defined population groups or subgroups[5].” While acute stroke has previously been identified as a health disparity in the U.S.[6], the NIH/ISS workgroup was particularly interested in increasing the awareness of clinicians, administrators and policy makers on quality of life, health services utilization and outcomes for what they termed “chronic stroke”. The concept of chronic stroke was loosely defined—it could be conceived as anything “after the acute admission” and certainly would be applied to the period following the natural trajectory of recover (6–9 months post-stroke). A methodology for monitoring access to health services and health outcomes for chronic stroke was identified as a priority and two local health authorities in Italy volunteered to serve as pilot sites.

The importance of chronic disease—which accounts for 78% of health expenditures in the U.S. [7] -- is increasingly recognized as a significant issue, highlighting the need for more effective population based monitoring. For a number of reasons, stroke is an especially appropriate condition to examine for variations in health care utilization and outcomes. It is among the leading causes of adult death and disability in all industrialized nations [8]. More than half of

stroke victims will have residual motor deficits as well as other sequelae with potentially disabling and costly implications [9–11]. The implications of stroke and the sequelae can be devastating for care-givers as well as patients and have a major impact on health and long term care costs [8,12]. The prevalence of stroke is expected to increase in concert with the growing percentage of elderly [13,14].

Among chronic diseases, stroke outcomes are particularly promising as an indicator of the overall quality of health-related services for several reasons: a) the relatively high incidence and prevalence of stroke [15]; b) our knowledge of the natural history of recovery from the acute stage [9,11,16–18]; c) stroke's link to lifestyle, socio-economic, and health care dimensions, including uncontrolled hypertension, smoking, poor diet, and lack of exercise [19], provides a gauge that spans both the health and social sectors; and, perhaps most importantly, because d) timely acute care, rehabilitation and community based services have the potential to return people to active lives and to prevent or delay subsequent disability and death associated with the chronic stage of stroke [20–28].

In this latter context, rehabilitation for chronic stroke can play a key role. While we know that rehabilitation in the acute stage makes a difference in returning a portion of stroke victims to active lives, relatively little is known about the cost-effectiveness of differences in the timing, amount, duration, and setting of rehabilitation services needed to optimize this percentage in the chronic phase [29]. Current belief is that this group continually recycles through traditional health care services in an attempt to manage the impairments, co-morbidities, and state of systematic disablement associated with chronic stroke [30]. This systematic disablement is theorized to be the result of the sedentary lifestyle that follows stroke and the rapid cardiovascular and strength deconditioning process [31,32]. There is growing evidence that deconditioning is not inevitable, and that maintenance rehabilitation in the chronic phase can improve function and quality of life for stroke survivors [33–35]

Italy has one of the highest percentages of elderly individuals in its population, making it among the highest in Western Europe in the incidence and prevalence of stroke [36]. The World Health Organization has ranked the Italian health system among the best in the world [37]. Local health authorities in Italy have relatively sophisticated computerized administrative databases offering potential for monitoring and feedback. Florence (AUSL 10) and Empoli (AUSL 11), the two local health authorities in Tuscany that volunteered as pilot sites for this project are geographically adjacent and yet have distinct differences. AUSL 10 includes the historic city of Florence and has the health resources associated with a large urban area. By contrast, neighboring Empoli (AUSL 11) is characterized by small towns, a largely rural economy, and more modest health resources. This diversity, it was thought, could provide insight into community-level factors that might facilitate (or hinder) comparison of health services access, utilization and outcomes for chronic stroke.

In a recent reform of the National Health Services, Italy has adopted a semi-federal organization of health services. Italy is subdivided into 20 regional administrative authorities called “Regions”. . In the recent reform, Regions gained more autonomy from central government in the financing and planning of health care. Each Region was further subdivided into one or more AUSL, operating with a fixed budget and responsibility for the organization and delivery of health services for a defined population. Person-based health services utilization data are routinely maintained because each AUSL is required to report a standard set of data on the performance of its health system.

While the AUSLs' performance reports did not include information specific to chronic stroke, the availability of inpatient utilization and diagnostic data suggested that such reporting might be feasible if a useful and simple to administer methodology were developed. The pilot study

described in this report represents the first step in the development and utilization of a methodology that could be used by the various AUSL in Tuscany, and potentially by other political jurisdictions or health plans to monitor the factors and outcomes of care for people with chronic stroke. This paper presents the results of the Empoli-Florence pilot study, comparing health resources available in the community and utilized by stroke patients during the first 12 months post-stroke as well as outcomes (e.g. mortality). In addition, methodological issues in making comparisons of this type are discussed and recommendations are made for enhanced data collection.

Methods

Our goal was to develop a methodology that could guide health policy and management decisions, yet be simple and relatively inexpensive to administer. Consequently, we wanted to limit the need for multivariate analysis, reduce variation due to case-mix and severity of stroke as much as possible, and use routinely collected data. Specific objectives of this pilot study were: 1) To compare the general health resources available to the populations living in two Italian AUSL; 2) To compare the utilization of health services in the first year following stroke for patients in each AUSL; 3) To compare chronic stroke mortality rates in each AUSL and 4) To make recommendations for improving administrative data bases to monitor and compare health outcomes as well as the efficiency and effectiveness of services for people with chronic stroke in different AUSL, political jurisdictions, health plans, or countries.

The study used both qualitative and quantitative research methods. In phase one of the study, we conducted a series of site visits and interviews with senior health officials and clinicians in AUSL 10 and 11 to determine the organization and availability of health services and to identify the availability of relevant data. In phase two, we conducted a retrospective analysis of administrative data one year post-stroke for all patients in AUSL 10 and 11 who met study criteria during the calendar year 2002. In phase three, a working group was convened to review the data and make recommendations for ways the methodology could be improved in the future.

The study population was a defined subset of all individuals registered for health care in AUSL 10 and 11 who were admitted to the hospital with a stroke in 2002. The study population was selected using DRG 14 (stroke) from the inpatient databases for AUSL 10 and 11. In order to reduce variation due to differences in the case-mix or severity of stroke and make comparison groups more homogeneous, people were then excluded from the study population if they had a hospital admission for a previous stroke within the prior two years; had a primary or secondary diagnosis that indicated hemorrhagic or “rule out” stroke (e.g. all codes other than ICD9-CM 437.0, 437.4, 433.*, 434.*, 438.*); or died before hospital discharge. Since our intent was to compare the process and outcomes of care for two local health authorities, people were excluded when their index hospitalization was provided outside the health authority responsible for their care. Thus only residents of AUSL 10 and 11 who were treated within their respective region were included in the study.

The year 2002 was selected as the index admission for this chronic stroke cohort because, due to changes in the AUSLs' data systems, it was the first year that certain data elements were available in both health authorities. Utilization was then summarized for the study population for a one year period subsequent to the index admission. To test the statistical significance of differences between AUSL 10 and 11 for proportions involving the study population we used the test for two independent proportions. The T-test was used to test for statistical significance in means between the two groups.

Results

Health resources

Table 1 compares the population demographics, health budget and general health resources in AUSL 10 and 11. In 2002, AUSL 10 had 797,737 citizens, a population 3.6 times the size of AUSL 11. The age and gender distributions were similar in the two AUSL Income distributions and percent of individuals at risk for poverty were similar in both AUSL [38]. The health operating budget of AUSL 10 was approximately 1.2 billion euros, or 4.3 times the health operating budget of AUSL 11.

Both AUSL 10 and 11 spent approximately the same proportion of their budget on general practitioners (5% and 5.5% respectively) and hospitals (45.6% and 45.7% respectively). In each AUSL, the largest category of expenditures was for hospital services (which includes specialists). In Empoli (AUSL 11), these services were largely provided by public general hospitals. In Florence (AUSL 10), these services are provided by public general hospitals as well as Careggi, a large University teaching hospital.

In each AUSL a separate budget covered community social services, including subsidies for home services, food, assisted living, and nursing homes. These social services were available on a sliding scale basis, so the individual paid only part of the cost. The AUSL covered medical services (“quota sanitaria”) in nursing homes, but not the food and accommodation expenses.

Table 1 also compares general health resources—that is the hospital beds, clinics, and health professionals sometimes referred to as the “structure” of a health system. AUSL 10 had 6.9 times the hospital bed capacity of AUSL 11. While this may seem excessive, the circumstances are more complex than might be immediately evident. In addition to serving Florence, Careggi serves as a tertiary specialty hospital for the Tuscan region and is paid on a DRG basis by other AUSL whose patients come for care. Careggi is an independent hospital and, while AUSL 10 is its major client, it is important to recognize that it admits patients from all of Tuscany.

Table 2 compares relevant health resources in AUSL 10 and 11. Most notably, AUSL 10 provided substantially more inpatient rehabilitation and nursing home capacity, while AUSL 11 served more people on an outpatient basis. In 2002, AUSL 10 had 9 hospitals with inpatient rehabilitation services (total of 302 beds --3 hospitals did not have night-time physician coverage on site) while AUSL 11 had one hospital with 8 beds. AUSL 10 also had a rehabilitation day hospital capacity--there was no comparable day hospital service in AUSL 11. AUSL 10 had a 231 bed long-term care hospital (similar in concept to the US chronic hospital) and 3,100 nursing home beds while AUSL 11 had 477 nursing home beds. AUSL 11 recorded 35,734 personal assistance contacts (estimated at 30 minutes/contact). No comparable figures on personal care were available for AUSL 10.

Both health authorities provided in-home rehabilitation care regarding activities of daily living and physical therapy. AUSL 10 reported 2697 individuals who received on average 2.4 visits per person per year. AUSL 11 reported 454 patients with an average of 14.7 visits per person per year. Community based out-patient teams (physician, physical therapist, speech therapist, occupational therapist) in AUSL 10 reported 95,000 visits/year. In AUSL 11, outpatient rehabilitation provided an estimated 70,000 services to 4000 individuals per year (an average of 17.5 services per person), including physiotherapy, speech therapy, and physical therapy.

Three of the five hospitals in AUSL 10 had a stroke unit, whereas none in Empoli had a stroke unit. One in Empoli had a stroke team. All emergency departments in both health authorities had stroke protocols. Average travel time from home to the hospital was fifteen minutes in

AUSL 10 and ten minutes in AUSL 11. Both health authorities had smoking cessation programs in place as part of stroke prevention strategies.

Utilization of services and mortality in the first year after stroke

The stroke pilot study population included 751 stroke patients in AUSL 10 and 223 in AUSL 11. In 2002, there were 2092 people hospitalized with DRG 14 for stroke in AUSL 10 and 499 in AUSL 11. Of these, 1341 in AUSL 10 and 276 in AUSL 11 were excluded for not meeting study criteria. This included stroke patients who died before discharge, received inpatient or rehabilitation services outside the local health authority, had a hospital admission for stroke in the previous 2 years or had ICD9-CM codes indicating anything other than an ischemic stroke (e.g. intracerebral hemorrhage, TIA, acute but ill-defined cerebrovascular disease, etc.) As indicated in Table 3, the study population was evenly divided between males and females. Differences in the age and gender distribution between AUSL 10 and 11 were modest and not statistically significant.

Table 4 reports utilization of institutional and community health services as well as mortality for the study population during the year following the first stroke. There were no significant differences in mean inpatient days/person for the index admission (8.7 versus 9.5 for AUSL 10 and 11 respectively) or for the percentage of stroke patients with a readmission (42% versus 39% for AUSL 10 and 11 respectively). However, the average number of readmissions per user was significantly higher ($p<.01$) for AUSL 10 when compared to AUSL 11 (1.69 versus 1.51 readmissions/user respectively). Differences in mean days for hospital readmissions was also statistically significant ($p<.001$) for AUSL 10 and 11, with 20.92 versus 11.43 days per person respectively. Differences in the percentage of the study population with admission to a rehabilitation hospital was also statistically significant ($p<.002$) with 27.1% versus 8.5% receiving rehabilitation admissions in AUSL 10 and 11 respectively. Mean days per person were also significantly higher for rehabilitation admissions in AUSL 10 compared to AUSL 11. The cumulative differences in the index hospitalization, readmissions, and rehabilitation hospitalizations resulted in a significantly higher mean for total hospital days ($p<.001$) for AUSL 10 (28.4 days/person/year) when compared to AUSL 11 (17.0 days/person/year).

The comparison of community-based services was limited in that administrative data were not available for many services. For example, general practitioners were paid by capitation and the number of visits or services provided during a visit were not included in the AUSL data bases. Nursing home data were available from AUSL 11 but not from AUSL 10. Two areas where data were available from both AUSL were visits to specialists visits and pharmaceuticals. Of the study population, 44% in each AUSL made at least one visit to a specialist. Differences in pharmacy usage were significant. In AUSL 10, 79.2% of the study population received a pharmaceutical prescription compared to 89.2% in AUSL 11 ($p=.001$). The mean number of pharmaceuticals was 80.3 in AUSL 10 vs. 61.8 in AUSL 11 ($p<.001$). This translates into a cost difference of 970 Euro per person in AUSL 10 compared to 551 Euro per person in AUSL 11.

Mortality rates appear to be lower in AUSL 10 than in AUSL 11 (19.4% versus 24% of the study population died during the first year in AUSL 10 and 11 respectively). However, these differences were not statistically significant.

Discussion

Inpatient acute and rehabilitation services

The most striking finding is the much higher mean number of hospital inpatient days for the study population in AUSL 10 compared to AUSL 11. This is largely an issue of hospital

resources. AUSL 10 had a population 3.6 times that of AUSL 11, a health-operating budget 4.3 times that of AUSL 11 and hospital bed capacity 6.9 times that of AUSL 11 when Careggi Hospital is included; 4 times that of AUSL 11 if Careggi is excluded. Hospitalization rates in Florence are influenced by the presence of Careggi, the university teaching hospital located in AUSL 10. Careggi has longer length of stays for stroke than other hospitals in the Tuscan Region. Arguably, case-mix and severity are factors—presumably, the most severe cases are referred to Careggi from other health authorities. However, because Careggi is located in Florence, a disproportionate share of patients from Florence are admitted there. Since severity is unmeasured in this study, it is not possible to say whether stroke patients from AUSL 10 were more severe than from AUSL 11, highlighting the difficulty in interpreting variation in service use obtained solely from administrative data.

Although we attempted to control for variation due to differences in the case-mix or severity of stroke and to make comparison groups more homogeneous through the exclusion of patients with hemorrhagic stroke, these methods are insufficient in controlling for the significant heterogeneous nature of outcomes. Without doubt, there remain unmeasured differences in case-mix and severity between the two health authorities. The categories of stroke are not only of academic and clinical interest; the different types of stroke and the location of the stroke in the brain determine the degree of disability and the amount of care required long-term. [39]

Administrative data alone cannot address these issues. Once noteworthy differences in utilization or outcomes have been identified with administrative data, there are several approaches that can be used to interpret the variation. For example, the administrative data can serve as a sampling frame to identify a subset of cases for further review. A study design in which case records, or case summaries, are reviewed by a study neurologist using standard criteria for classification of stroke would allow more meaningful interpretation of differences. Without this additional step, it is not possible to control for “severity” and interpretation of the data will be of questionable value. The NIH stroke scale provides one option for classification of stroke. There is no single standard to predict future utilization or measure all dimensions of recovery and disability after acute stroke [40]. Selection of the best “next step” in interpreting the data depends on how the study will be used.

Socio-economic factors, including age, gender, educational status, income, and race have also been associated with disparities in health status and utilization in other studies [41]. These variables, along with stroke severity and patient’s co-morbidities, can be included in multivariate analytic models when the populations being compared are large enough to provide adequate statistical power. Multivariate analysis was not considered a viable option for this project. In addition to the absence of person-based data on income, education, and stroke severity in the administrative database, the local health authorities lacked the resources to undertake multivariate data analysis. The challenges facing the local administrators who supported this project was further highlighted by the recognition that, despite positive intentions, they were unable to continue to follow the cohort identified for this study longitudinally as planned, due to changes in staff and economic conditions.

Stroke patients in AUSL 10 had routine access to acute inpatient rehabilitation, while in AUSL 11 access to these services was extremely limited at the time of this study. Although we were unable to obtain data on the use of in-home rehabilitation services by the stroke study population, we note that AUSL 11 was providing greater access to in-home rehabilitation services in general when compared to AUSL 10. Absence of this type of detail is a major limitation of this study, and one that could be corrected in the future if the AUSL would maintain personal identifiers in their databases to facilitate data linkage in the construction of person-based analytic files.

Changes in stroke services implemented by AUSL 10

At the time of this study, the virtual absence of in-patient rehabilitation for stroke patients in AUSL 11 was a cause of considerable concern to the local health authority. Since 2002, AUSL 11 has reorganized rehabilitation and geriatric services and increased access to inpatient rehabilitation services for stroke patients, among other reforms. In 2002, AUSL 11 had 8 inpatient rehabilitation beds; this was increased to 16 beds by 2003 and a day-hospital program was started. A 15-bed rehabilitation nursing home has been established, with an average length of stay of 29 days. In 2004 AUSL 11 opened a stroke area for acute stroke in the internal medicine department. In 2005, AUSL 11 began development of a program for stroke patients, which includes a community-based Adaptive Physical Activity (APA) program for chronic stroke, with classes held 3 times a week in community gyms [42]. There are now 452 participants enrolled in 35 courses in 29 gymnasiums in 13 out of 15 municipalities in AUSL 11.

It is fair to say that these changes did not occur as a result of this pilot data study, but rather both the study and the changes resulted from a strong leadership team in AUSL 11, committed to using data and empirical evidence to improve services for a geographically defined population with chronic diseases. The determination and success of this team in accomplishing their goals and objectives was a privilege to observe, but that is another story involving personalities and politics, and beyond the scope of this paper.

Pharmaceuticals

Another significant difference between the two health authorities identified by this study was the prescribing patterns for pharmaceuticals. Patients in AUSL 10 were significantly less likely to receive prescriptions, but the mean number of pharmaceuticals was significantly higher, as was the first year cost per person. These differences may be the result of aggressive management of pharmaceuticals by AUSL 11, where staff work closely with general practitioners to assure the appropriateness of pharmaceuticals and that the least expensive drugs appropriate to patient needs are prescribed. Alternatively, they could be associated with unmeasured differences in patient severity. Because different types of strokes result in different prescriptions, without appropriate clinical classification of stroke, differences in prescription patterns are clinically meaningless. For example, differences in prescription patterns could be to some degree an indication of differences in the frequency of different types of stroke in different regions, although data from neighboring regions in Italy [43] suggests that this variation is much smaller than the variation seen across major regions in the U.S. [41] and is thus unlikely to explain the differences observed between the two regions in this study. However, as noted earlier, the presence of Careggi, the large teaching hospital in Florence, is likely to contribute to differences in case-mix and severity and may also influence prescribing patterns independent of case-mix and severity in the two regions. Administrative data can provide a sampling frame for clinical review and interpretation.

Use of administrative data

With the exception of specific issues noted in the following discussion, the administrative data provided a good starting point for comparing the care provided to stroke survivors following their index hospital admission. For administrators and policy makers to make informed decisions regarding planning, quality improvement, and resource allocation it is important that they have adequate information with which to monitor utilization and outcomes associated with chronic stroke. In an attempt to determine the types of data most useful for effective decision making, the results from this pilot study were reviewed by a multidisciplinary team of US and Italian stroke researchers that included the disciplines of epidemiology, economics, health services research, and neurology. Their recommendations are as follows:

Recommendations for data enhancement for monitoring chronic stroke

1. *Clinical Information System Upgrades.* The AUSLs, like many US providers, are in the process of upgrading and computerizing their clinical information systems. A number of stroke registries are available that offer examples of the type of clinical information that, if collected in a computerized information system, would provide an efficient means for augmenting the health authority's outcomes-related metrics in the administrative stroke data base. Examples for further consideration include the Copenhagen stroke registry, the "Stroke Tool Kit," the NIH stroke scale.
2. *Standardizing Data.* The more attention that can be given to standardization of data collection for stroke patients in different populations, the easier and more reliable comparisons using these data will be. Although early attempts at making comparisons with administrative data can be fraught with unintended pitfalls, experience with profiling and other management applications of health administrative data provide evidence that these problems can be overcome.
3. *Enhancing Existing Data.* The value of a stroke database such as the one used for this study would be considerably enhanced by the addition of measures of stroke severity and functional impairment. Even collection of a limited set of indicators, such as the 3-item Barthel (pre and post stroke), would be very useful. Consideration should be given to where in the system the additional data would be most useful to practitioners and whether it can be collected as part of routine patient management. For example, the Stroke Impact Scale (SIS) may be most useful for patients with mild stroke and could be collected as part of discharge planning or by social services personnel in developing a service plan. The SIS has been translated into many languages, and the telephone SIS has been found to be a reliable and efficient alternative to an on-site interview [44].
4. *Measuring Functional Impairment.* Alternatives to the SIS include the Functional Impairment Measure (FIM) or Extended Barthel Index (EBI). These measures are widely used throughout the world in rehabilitation settings and are frequently collected before hospital discharge as measures of disability and stroke severity for stroke patients in some countries. Their limitation is that they do not adequately measure the mild and severe ends of the continuum of disability (i.e. "floor and ceiling effects"), a significant problem for chronic stroke measurement. [45] For this reason, the stroke team preferred the SIS to the FIM and EBI for a stroke database. However, as previously noted, even the short 3-item Barthel would significantly enhance the utility of administrative data such as that reported in this paper.
5. *Primary Care and Rehabilitation Data.* Another missing element in the AUSL database is data on general practitioners (GPs). In the AUSL, the GPs are paid under a capitation scheme and the AUSL receives no patient specific data on utilization or the preventive care provided by the GPs. These data would be useful in linking primary care utilization patterns with patient outcomes and for monitoring provider specific practice patterns. The inclusion of detail on rehabilitation services would also make the data base more useful. See references [46–48] for reviews of current issues in measurement and methodology for effectiveness research on rehabilitation in the U.S.
6. *Outcome Measures.* The team recommended nursing home admissions, hospital readmission rates, recurrent stroke rates, and mortality rates as good outcome measures that can be generated with administrative data. The rate of nursing home admissions has proven useful as an outcome measure in other stroke studies because it reflects the combined effectiveness of acute care, rehabilitation, home care, social supports and environmental considerations. Other desirable outcome measures for

chronic stroke include mobility, caregiver burden, prescription of anti-hypertensives at 6 months and one-year, and follow-up at six and one year intervals with the telephone SIS.

7. *Durable Medical Supplies and Equipment.* Data on durable medical supplies and equipment was not available for this study. Because of the increasing role postulated for adaptive technology in improving functional independence and the associated costs, inclusion of data on durable medical supplies and equipment in a stroke database and periodic analysis of this data will help inform future coverage decisions.
8. *Prescription Drugs.* Because the strongest and most reliable components of the databases in the AUSLs are for inpatient and prescription drugs, the team recommended further analysis of co-morbidities using inpatient ICD and drug codes. As noted in the discussion section, administrative data alone cannot adequately interpret the differences in prescribing patterns between the two health authorities. It can, however, provide an excellent sampling frame for further clinical review. The value of using drug codes to monitor medication compliance and potential drug-interactions was also noted.
9. *Recommendations for future analysis.* A database such as the one developed by AUSL 10 and 11 can be used to identify priorities and develop strategies to improve patient outcomes, reduce inpatient or nursing home admissions and increase access to certain services. In interpreting comparisons across political regions, care should be taken to consider differences in patient co-morbidity and severity. The type of data outlined here offers a starting point for the process of quality improvement and cost containment. Differences among political jurisdictions offer an opportunity to determine how regional variation may be contributing to inpatient readmissions, nursing home admissions, types of co-morbidity, compliance with medication guidelines and potential to reduce drug interactions. Sub-studies comparing the management of patients with the following co-morbidities are recommended: depression, hypertension, diabetes, COPD, and decubitus ulcers. Interventions that reduce functional dependence, improve mobility, increase fitness and medication compliance, and reduce caregiver burden may reduce preventable hospital or nursing home admissions and home health utilization. Definition and monitoring of quality indicators for statins, aspirin, warfarin, anti-depressants, and hypertensives may also be useful to reduce preventable hospital and nursing home admissions.
10. *Resources needed to develop useful data on chronic stroke.* Person-based fixed-length analytic files are needed to convert data on chronic stroke into useful information for policy makers, managers, clinicians, and consumers. To develop, maintain, and analyze a stroke database, an organization will need to allocate staff or contract for this service. The cost of this activity must be considered in light of the potential for savings--chronic stroke patients are among the most costly for a health care system [49].

For further discussion of indicators, methods, and conceptual issues in measuring health equity and disparities, readers are referred to Macinko and Starfield[50] and Carter-Pokras and Baquet [51]. A comparison of costs was beyond the scope of this study. For methods in health care costing, readers are referred to a recent *Medical Care* supplement on this topic [52]. Examples of cost studies pertaining to long term costs for stroke survivors are also available [53–55]

Conclusion

Given the high hospital readmission rates and long-term care costs associated with chronic stroke, reducing health inequities has the potential both to save money and improve outcomes. However, a reliable data-driven system for monitoring the process and outcomes of care is

needed to provide feedback to decision makers. Of particular note is the need for measures of stroke type, severity, and functional impairment. Without access to such measures, it is difficult to determine whether the longer stays and higher cost prescriptions in AUSL 10 are associated with better outcomes. The utility of the SIS for this purpose is highlighted because 1) it is more sensitive than other widely used measure for people with severe or mild impairments; 2) it has been translated into many languages; and 3) the telephone SIS provides a feasible option for ongoing follow-up.

Great care must be taken in comparing utilization data and outcomes of health services across political or organizational boundaries. At the micro-level, adequate attention must be paid to the consistent definition of variables and standardization of data to assure reliability and validity of measurement. At the macro level, differences in culture, policy, and practice can influence outcomes not only among countries, but within them, and at the level of the hospital or community as well. While these factors are cause for caution, it is these very differences that make the systematic monitoring of chronic stroke promising from a policy perspective.

Much can be learned through the identification and study of natural experiments in the management of chronic stroke. What we learn can guide the systematic improvement of chronic care management. This is not a trivial issue--Today the number of stroke survivors with disabilities exceeds 5 million people in the United States alone and the direct and indirect costs of stroke have been estimated at \$65.5 billion annually [56]. Reflecting the demographics of aging, the number of strokes per year in the US is expected to double over the next 50 years [57]. While one of the major challenges of health care systems is to provide cost-effective acute care and rehabilitation to minimize the disability associated with chronic stroke, it is also important to identify the needs for patients suffering with chronic stroke conditions and better define the benefits of long-term continuity and coordination of care. In this process, service providers that monitor and use data to improve the efficiency and effectiveness of chronic stroke care, should benefit from their investment.

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Table 1

Population Demographics, Health Budget and General Health Resources for AUSL 10 and 11

	AUSL 10	AUSL 11
<i>Demographics¹</i>		
Total population	797737	221787
% female	52%	51%
% age 65–74	12%	11%
% age 75–84	8%	8%
% 85 and older	3%	3%
<i>Health Budget²</i>		
Total operating budget for AUSL	1154660000 Euro	269898775 Euro
% general practitioners	5%	5.5%
% public general hospitals ³	21%	44%
% private hospital	4.6%	1.7%
% prescription drugs ⁵	12%	15%
% durable medical supplies & equip	.3%	1%
% prevention	3%	5%
% university hospital ⁶	20%	--
<i>General Health Resources⁷</i>		
Public general hospitals	5 (1316 beds)	5 (596 beds) ⁵
University hospital (Careggi) ⁸	1 (1866 beds)	0
Private hospitals ⁹	15 (1358 beds)	1 (60 beds)
Ambulatory specialty clinics	80	19
General practitioners ¹⁰	802	187
Salaried health professionals(11)	4709	1657
Administration	791	295
Technicians	1330	465

¹ Source: AUSL administrative data (2003). Note there is a separate budget for community social services that is administered by the local government. The social services budget subsidizes home services, food, assisted living residences and nursing homes. These services are available on a sliding scale basis. In the nursing homes, the AUSL covers only medical services, not room and board.

² includes prescription drugs used in hospital

³ excludes prescription drugs used in hospital

⁴ includes children's hospital

⁵ AUSL 10 has 4 hospitals but one has 2 sites.

⁶ Source: AUSL administrative data (2003)

⁷ "Careggi" University Hospital is an independent hospital in the metropolitan area of Florence and its beds cannot be attributed to AUSL 10. It works on a fee basis (DRG payment) and AUSL 10 is its major client (in this sense can be seen as a AUSL 10 resource), however it admits patients from all Tuscany AUSLs.

⁸ Of the 15 private hospitals in AUSL 10, 2 have private patients, the remaining 13 have contracts with the AUSL 10. The private hospital in AUSL 11 contracts with the AUSL.

⁹ Excludes pediatricians, Includes MDs, physical therapists, nurses, etc in public hospitals and clinics

¹⁰ Source: AUSL administrative data (2002)

Table 2Health resources relevant to acute and chronic stroke in AUSL 10 and 11^{1,3}

	AUSL 10	AUSL 11
Community prevention		
Smoking cessation	Yes	Yes
Exercise	Yes	Yes
Diet	Yes	Yes
Emergency Dept. (ED)		
Ave. travel time to hospital ²	15min	10min
EDs w/stroke protocol	5	2
EDs w/imaging equipment	5	2
Inpatient acute and subacute		
Hospitals with stroke units	3	0
Hospitals with stroke team	0	1
Rehabilitation post acute inpatient		
Inpatient beds-24 hr MD	302	8
Inpatient beds-w/o 24 hr MD	179	0
Rehabilitation day hospital		
Capacity per day w/MD	110	6 (activated in 2004)
Capacity per day w/o MD	56	0
Rehabilitation home care⁴		
No. of persons served/yr	2697	454
Ave. no. of visit/person	2.4	14.7
Rehabilitation outpatient		
No. of persons served	N/A	4000 ⁵
No. of visits	95000	70000 ⁵
Chronic care professionals		
Physical therapists	129	44
Speech therapists	47	5
Occupational therapists	0	1
Other therapists	32	6
Long-term care hospitals		
No. beds	231	0
Nursing homes		
No. beds	3100	477
Personal assistance		

	AUSL 10	AUSL 11
No. of visits/year	N/A	35734 (ave. 30 min.)

¹ Source: AUSL administrative data (2002 unless otherwise specified);

² Time from stroke to ED is based on estimates by Emergency Departments.

³ Children's rehabilitation and psychiatric rehabilitation services are not included.

⁴ Data may underestimate services and is not considered as inpatient and pharmaceutical.

⁵ Source: AUSL 11 rehabilitation service estimates

Table 3Gender and age of study population in AUSL 10 and 11¹

	AUSL 10 N=751	AUSL 11 N=223	Statistical Significance
Gender			
% male	50%	51%	NS
% female	50%	49%	NS
Mean age	77 years	77 years	NS
Age distribution			
% age 65–74	23%	17%	NS
% age 75–84	36%	44%	NS
% age 85 and older	27%	27%	NS

¹In 2002, there were 2092 people hospitalized with DRG 14 for stroke in AUSL 10 and 499 in AUSL 11. Of these, 1341 in AUSL 10 and 276 in AUSL 11 were excluded for not meeting study criteria. This included stroke patients who died before discharge (14% in both AUSL 10 and 11), received inpatient or rehabilitation services outside the local health authority (4% in AUSL 10 compared to 16% in AUSL 11), had a hospital admission for stroke in the previous 2 years (2% in AUSL 10 compared to 5% in AUSL 11) or had ICD9-CM codes indicating anything other than an ischemic stroke (e.g. intracerebral hemorrhage, TIA, acute but ill-defined cerebrovascular disease, etc.--39% in AUSL 10 and 43% in AUSL 11). Only individuals with ICD9-CM codes 437.0, 437.4, 433.*, 434.*, 438.* in the main or secondary diagnosis were selected for the study population. Individuals were also excluded if their index admission for stroke was to the University Teaching Hospital (Careggi).

Table 4Utilization of health services and mortality for study population in year following index stroke¹

	AUSL 10 N=751	AUSL 11 N=223	Significance
<i>Index hospital admission(1ststroke)</i>			
Mean days/person	8.70±11.2	9.52±7.61	NS
<i>Acute hospital readmissions</i>			
% with readmission	42%	39%	NS
Ave. no. readmits/user	1.69±1.10	1.51±0.83	p<.01
Mean days/user	20.92±30.4	11.43±10.03	p<.001
<i>Rehabilitation hospital admission</i>			
% with admission	27.1%	8.5%	p<.002
Mean days/user	39.8±28.4	35.3±17.8	p<.005
<i>Total hospital days²</i>			
Mean days/person	28.4±36.6	17.0±17.6	p<.001
<i>Long-term care hospitals</i>			
% using service	5.5%	0	
Mean no. days/user	37.58± 27.10	0	
<i>Nursing homes</i>			
Mean no. day/user	Not available	135±167.20	
<i>Emergency dept. visits</i>			
Mean no. visits/person	Not available	2.7	
<i>General practitioner</i>			
Mean no. visits/person	Not available	Not available	
<i>Specialty visits</i>			
% with visit	44%	44%	NS
<i>Rehabilitation outpatient visits</i>			
Mean no. visits/person	Not available	1.4	
<i>Durable medical equipment</i>			
	Not available	Not available	
<i>Pharmaceuticals</i>			
% with pharmaceuticals	79.2%	89.2%	p=.001
Mean no./year/user	80.3±40	61.8±32	p<.001
Mean 1st yr. cost/person	970 Euro	551 Euro	
<i>Ambulatory Procedures³</i>			
% with procedure	Not available	75%	
First yr. cost/person	Not available	234 Euro	

	AUSL 10 N=751	AUSL 11 N=223	Significance
<i>Home health visits</i>	Not available	Not available	
<i>Personal assistance</i>	Not available	Not available	
<i>Mortality</i>	19.4%	24%	NS

¹ The study population was defined to include only individuals who survived the index stroke admission. Persons refers to all individuals in the study population. User refers to only those people who used the designated service. Except for mean days for the index (first) admission, all rates reported are for services following the index discharge until one year post stroke. Mortality rates were derived from the archives of the municipalities and do not include people who moved out (about 4% in each AUSL).

² Includes index admission, acute hospital readmission and rehabilitation

³ Ambulatory procedures include radiology, blood analysis, etc.