



Contents lists available at ScienceDirect

Journal of the Formosan Medical Association

Journal homepage: <http://www.jfma-online.com>

Brief Communication

Establishment of Electronic Chart-based Stroke Registry System in a Medical System in Taiwan

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To establish a prospective, real-time, self-sustainable stroke registry system, we incorporated a registry with an electronic chart to create an electronic chart-based stroke registry system in November 2006. The International Classification of Diseases Ninth Revision code (430-437) was used to auto-enroll stroke patients admitted to neurology departments. Clinical information was written by doctors, nursing information was recorded by nurses, and basic patient information was entered by administrative departments. Numerical data and the date and time of any studies were auto-downloaded from the hospital computer. In total, 212 items were auto-downloaded, including basic patient information, laboratory blood test and examination results, and the date and time of imaging and special intervention. The stroke scales (121 items, National Institutes of Health Stroke Scale, Barthel index, and modified Rankin scale) were designed to be auto-adjusted to reduce incompatibility. The 95 items with pull-down options were used to specify the contents. This registry system can be time-, labor- and money-saving with secured data accuracy.

Key Words: cerebrovascular disease, electronic chart system, stroke registry

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Received: July 19, 2010

Revised: October 20, 2010

Accepted: October 27, 2011

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Disease registries that collect ongoing data about aspects of the illness of individual patients can provide information about disease burden, patient characteristics, patterns of care, and outcomes. These registered data can be used to study disease etiology, evaluate intervention programs, improve quality of care, and help decision-making on health policy. It is recommended that data be collected as soon as they are available (prospective and real-time collection) as a means to improve their quality.¹ At present, all such registry systems use web-based or hospital-based technologies. These systems collect data retrospectively and manually by study coordinator from the medical chart records after patients are discharged, and there are difficulties with data collection in an emergency setting.² There is also a challenge with funding to support the cost of data collection and acquiring significant investment of resources to sustain the registry system.

The Chang Gung Medical System (CGMS) has established a paperless framework to maintain all medical records in an electronic medical chart system. To establish a prospective, real-time, self-sustainable stroke registry system with the lowest possible funding and investment, we have incorporated the stroke registry system with the electronic medical chart system (electronic chart-based stroke registry system).

Methods

In 2006, we first developed registry data elements and designed registry prototypes. Then, we collaborated with computer program designers to build the infrastructure. Prototype development workshops were conducted to establish a consensus on case definition, inclusion criteria, refinement of data elements, expansion of data elements, and development of concise data definitions. A preliminary list of data elements was concluded in accordance with professionally developed, widely accepted clinical practice guidelines. Various resources were reviewed, including journal articles, scientific statements,

and educational materials from major professional organizations.³⁻⁷

Consensus meetings were held to review and discuss stroke registry items in prototype and to make recommendations. After finalizing the stroke registry items, meetings with computer programmers from the Department of Information Management in CGMS were held to design the computer programs and construct the infrastructure of registry system.

The CGMS Stroke Registry Task Force comprised doctors and nurses with a specialty in stroke, statisticians from Chang Gung University, and computer programmers from the Department of Information Management in CGMS. The task force organized a committee to write stroke management guidelines and a registry operation manual. Regular meetings were held by the CGMS Stroke Registry Task Force to evaluate the accuracy and completeness of the registry data and to seek improvement of the registry system.

All participants in the CGMS registry were obliged to attend training in data collection and stroke scale scoring. A continuing education program was held every year and the contents included basic stroke concepts, stroke management, and evaluation of stroke outcome.

After a patient is enrolled into the registry system, a standard medical order for acute stroke management is suggested. Stroke management guidelines that deal with acute stroke management, rehabilitation to discharge planning,⁸ and a registry operation manual that contains definitions of all data items⁹ are implemented in the registry system for doctors to have a quick review of evidence-based guidelines and item definition. The stroke outcome using the National Institutes of Health Stroke Scale, Barthel index, and modified Rankin scale was evaluated at the emergency department, admission, discharge, and outpatient clinic. After completion of registry data entry, the records are auto-transformed to a medical chart format, and a printout fulfills the standard medical chart accreditation.

To secure the least interference in doctors' daily work, descriptive items such as chief complaints,

Table 1. Distribution of registry items in ischemic stroke registry system^a

Number of item	Subsystem				Total
	Emergency department	Admission	Discharge	Outpatient	
Auto-download	10 (28.6)	42 (29.2)	129 (57.6)	31 (48.4)	212 (45.4)
Pull-down option	2 (5.7)	63 (43.8)	25 (11.2)	5 (7.8)	95 (20.3)
Auto-adjust	16 (45.7)	30 (20.8)	49 (21.8)	26 (40.6)	121 (25.9)
Free-typing	7 (20.0)	9 (6.3)	21 (9.4)	2 (3.1)	39 (8.4)
Total	35	144	224	64	467

^aData are presented as n or n (%).

present illness, and hospital course are preserved as usual and the following procedures are constructed to minimize registration labor and errors.

- (1) Auto-enrollment of stroke patients using International Classification of Diseases Ninth Revision (ICD9) codes (430–437) to secure the completeness of stroke patient enrollment.
- (2) Auto-download of existing data in the hospital computer system to prevent typing errors and human negligence.
- (3) Auto-download of date and time of any procedure related to the index stroke, except the stroke onset time, which needs manual entry by a doctor.
- (4) Auto-classification of ischemic stroke subtype according to the TOAST (Trial of Org 10172 in Acute Stroke Treatment) criteria¹⁰ to reduce inter-observer differences.
- (5) Auto-adjustment of stroke scale score to prevent inter-scale inconsistency.
- (6) Pull-down option system to prevent typing errors and to secure the consistency of data quality.

Results

The prototype of the electronic chart-based, stroke registry system was first established in Linkou CGMH on 2 November 2006, and was extended to the other three branch hospitals from March 2007. From 9 January to 6 March 2007, a total of five workshops for developing stroke registry prototypes were held. From July 2006, an education

program and certification examination for National Institutes of Health Stroke Scale, Barthel index and modified Rankin scale were held twice yearly. From 28 July 2007, regular consensus meetings were held among CGMS Stroke Centers four times yearly. From 9 April 2008, regular meetings with computer programmers from the Department of Information Management in CGMS were held once every 2–4 weeks. From 17 February 2009, every stroke patient admitted to the neurology department in the four branch hospitals was compelled to be registered in this registry system, and the registry rate was over 95% in 2009. Stroke is a major disease and documentation with the ICD9 codes 430–437 is needed to obtain full health insurance support after diagnosis is made; therefore, these patients are compelled to be registered if the diagnosis is 430–437.

Table 1 shows the number of item in the four registry subsystems including emergency department records (35), admission summary (144), discharge summary (224), and outpatient follow-up records (64).

Discussion

Black et al¹¹ have suggested that there are five characteristics of a high-quality clinical database: completeness of recruitment; completeness of data; use of explicit definitions of variables; independence of observation of outcomes; and data validation. The CGMS possesses a powerful electronic medical chart system that is used as the

Table 2. Comparison of electronic chart-based and web-based stroke registry systems

	Electronic chart-based	Web-based
Operation method	Prospective real-time auto-enrollment	Retrospective manual enrollment
Characteristics	Time-, labor- and money-saving	Time-, labor- and money-intensive
Maintenance of registry	Sustainable along with the hospital electronic chart system	Need budget to maintain registry system
Data collection	Auto-download in 45.4% of items	Manual
Integrity of registry data	Secured by real-time auto-audit system and data manager	Secured manually
Observation of outcome	Electronic follow-up system at outpatient clinic and by stroke case manager	Manual follow-up
Integration among different registry systems	Operable inside CGMS	Difficult to integrate among different registry systems
Hospital computer system	Need powerful hospital computer system	No need of hospital computer system
Integration among different medical systems	Inoperable	Operable through web program

CGMS = Chang Gung Medical System.

framework of the stroke registry system. To secure the completeness of stroke patient recruitment, every patient diagnosed with the ICD9 code 430–437 is automatically enrolled into the registry system. To secure the completeness of data collection, every item must be entered before exit from the registry system. For the explicit definitions of variables, the stroke registry operation manual and stroke guidelines are implemented in the registry system as a data dictionary for item definition. The independent observation of outcomes is accomplished by a follow-up computer system at the outpatient clinic. For patients who are absent from hospital after discharge, manual follow-up by post or telephone is carried out by stroke case managers or doctors. Data validation is performed instantly by a real-time automatic audit system (auto-download of existing data, auto-adjustment of stroke scales, and auto-classification of stroke subtypes) during data entry to prevent human negligence, and is further audited by a stroke data manager with assistance from statisticians from Chang Gung University.

The main difference between electronic chart-based and web-based stroke registry systems is described in Table 2. In web-based registry systems, the registry data are obtained from medical charts and entered by study coordinators. Validation is

needed to secure the reliability of the data. However, in electronic chart-based registry systems, all the information is downloaded automatically into the registry system during chart writing. There is no need for data re-entry by study coordinators, which can improve the accuracy of data entry and prevent manual errors.

There are some limitations with this registry system. After the computer program of an electronic chart system is upgraded, there is a need to adjust the registry system to adapt to the new computer program. Only stroke patients with ICD9 codes 430–437 who are admitted to a neurology department are registered at present; therefore, if stroke patients are not admitted or are admitted to non-neurology departments, they may not be enrolled. There is also a need to collaborate with other departments for data sharing to secure good registry quality. Clinical follow-up of registered stroke patients is a major problem if patients do not return to our hospitals. In this situation, manual follow-up with telephone contact or home visiting by stroke case managers is needed.

This electronic chart-based stroke registry system is established and designed not only to meet the needs of clinical research and medical teaching, but also to maintain the quality of medical

services and to fulfill the requirements of hospital accreditation. This registry system is time-, labor- and money-saving, and is now functioning in the four branch hospitals of CGMS.

Acknowledgments

The authors would like to thank Chang Gung Memorial Hospital under the Medical Research Projects (Contract No. CMRPG35072, CMRPG-35073 and CMRPG390821) for financially supporting this research.

References

1. Arts D, de KN, Scheffer GJ, de JE. Quality of data collected for severity of illness scores in the Dutch National Intensive Care Evaluation (NICE) registry. *Intensive Care Med* 2002;28:656–9.
2. Columb MO, Haji-Michael P, Nightingale P. Data collection in the emergency setting. *Emerg Med J* 2003;20:459–63.
3. Measuring and improving quality of care: a report from the American Heart Association/American College of Cardiology first scientific forum on assessment of healthcare quality in cardiovascular disease and stroke. *Stroke* 2000;31:1002–12.
4. Alberts MJ, Hademenos G, Latchaw RE, et al. Recommendations for the establishment of primary stroke centers. Brain Attack Coalition. *JAMA* 2000;283:3102–9.
5. Arts DG, De Keizer NF, Scheffer GJ. Defining and improving data quality in medical registries: a literature review, case study, and generic framework. *J Am Med Inform Assoc* 2002;9:600–11.
6. Kennedy L, Craig AM. Global registries for measuring pharmaco-economic and quality-of-life outcomes: focus on design and data collection, analysis and interpretation. *Pharmacoeconomics* 2004;22:551–68.
7. Schwamm L, Reeves MJ, Frankel M. Designing a sustainable national registry for stroke quality improvement. *Am J Prev Med* 2006;31:S251–7.
8. Available at: <http://lnkwww.cgmh.org.tw/intr/stroke/03-6-2.htm>
9. Available at: <http://lnkwww.cgmh.org.tw/stroke/manu/13.htm>
10. Adams HP Jr, Bendixen BH, Kappelle LJ, et al. Classification of subtype of acute ischemic stroke. Definitions for use in a multicenter clinical trial. TOAST. Trial of Org 10172 in Acute Stroke Treatment. *Stroke* 1993;24:35–41.
11. Black N, Barker M, Payne M. Cross sectional survey of multicentre clinical databases in the United Kingdom. *BMJ* 2004;328:1478–81.