Hospital-based Stroke Registry in Taiwan

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Although randomized controlled trials provide the highest level of evidences in stroke medicine, the value of observational data from the stroke registry should not be overlooked. The former helps to determine the effect of an intervention under an optimal situation that baseline characteristics of individuals between groups were comparable, while the latter might be useful for identifying stroke risk factors, evaluating the effect of stroke treatment in a real-world setting, and for determining predictors of stroke outcomes. A hospital-based stroke registry might also be useful for monitoring and improving the quality of stroke care[1].

The Taiwan Stroke Registry (TSR), launched in August 2006, is the largest nationwide stroke registry that Taiwan has ever had. More than 100,000 stroke patients had been registered by 2014, and the registry is still growing[2]. Recently, new and enthusiastic generations of researchers from a few hospitals have been increasingly devoted to disseminating knowledge by analyzing individual hospital-specific stroke data that share the common data elements of the TSR, and they have synthesized scientific evidence important for clinical practice[3,4]. Research that uses the data of other hospital-based stroke registry systems, such as the Taipei Veterans General Hospital Stroke Registry, are also emerging. For example, in the current issue of Acta Neurologica Taiwanica, the authors report predictors of one-year poor functional outcomes in patients with posterior circulation ischemic stroke caused by arterial dissection. This work, in addition to another work by Chung[5,6] et al, highlights the importance of detecting arterial dissection in patients with a posterior circulation stroke, and of developing a treatment strategy for them.

The successful experience of the Taipei Veterans General Hospital Stroke Registry[6] might have several implications for stroke researchers in Taiwan who want to set up their own stroke registry:

1. It is important to prospectively register the data of every consecutively admitted stroke patient. When stroke patients are admitted to non-neurology wards, the data usually does not get entered into the stroke registry, which will diminish the registry's representativeness.

2. There should be a standardized investigation protocol for each hospitalized stroke patients. For example, high-resolution or standard brain magnetic resonance image and angiography to determine stroke etiology, as shown by Chung et al[6].

3. A well-coordinated stroke team with several specialists should be in place to regularly review, ideally, every 1-2 weeks the clinical and image data of newly registered stroke patients. Regular expert review is an important strategy for ensuring the completeness and validity of a stroke registry.

It is very expensive to maintain a good stroke registry, and there is always a trade-off on the amount of data to be captured on a case report form; i.e., the more items there are on the form, the more difficult and time consuming it will be to complete the registration of each patient. However, collecting data related to the

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quality improvement and accreditation of stroke care (e.g. guideline adherence and timeliness of thrombolysis) is essential, because it directly helps routine patient care and will more easily attract financial support from hospital administrators. Selecting an appropriate amount of essential items as the common data elements and adding special items for specific study projects, e.g., the results of detailed transcranial Doppler examinations of posterior circulation, as in Chung[6] et al, may be a reasonable solution. The linkage of a stroke registry and the National Health Insurance Research Database has been proved feasible[7-10] and might save time for patient follow-up.

In the era of publish or perish, it is understandable that some researchers who claim to "own" certain stroke registry data might be reluctant to release those data to other "outsider" researchers. However, they should be reminded that, because of limited time, personnel, and specialized training, it is very possible that just a small group of people might not be able to explore exhaustively all potentials of the registry data. Stakeholders should set up a transparent and efficient mechanism for all interested researchers and clinicians, especially for younger ones, to propose their research questions and find their answers in the registry data.

Finally, and most importantly, we should keep in mind that behind each case entry in the stroke registry is a human being who suffered tremendously. It is only fitting, therefore, that we should leave behind our pride, prejudice, and indifference to collaborate and to share knowledge and data in order to improve clinical practice and to reduce the suffering of future stroke patients.

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