Avoiding the mismeasurement of medicine and improving care

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Résumé

DANS CE NUMÉRO, ANDRÉ LALONDE ET ELIZABETH TAYLOR, de l'Institut canadien d'information sur la santé (ICIS), décrivent les nouvelles terminologies normalisées pour la collecte de statistiques sur les soins de santé (page 1561). Les données normalisées procurent des avantages aux patients, aux médecins et aux directeurs de services de soins de santé, mais pour tirer profit de ces avantages, nous devons pouvoir comprendre comment recueillir des données pertinentes pour les soins à apporter aux patients sans entraver l'activité des médecins, et en assurer la confidentialité en dehors du bureau et de l'établissement de soins de santé. Les dossiers médicaux électroniques, malgré les difficultés que présente leur mise en oeuvre et les problèmes prévisibles mais non insolubles que présentent les normes de l'ICIS, semblent promettre un meilleur échange d'information et une meilleur collecte de données. Des meilleures données pertinentes sur le plan clinique aideront à atténuer le problème des erreurs de mesure dans le système de soins de santé et, par conséquent, à améliorer les soins prodigués.

The taxonomy of medicine is a dry, obscure and esoteric subject usually reserved for people with a peculiar obsessive–compulsive bent — like me. Nonetheless, it is important. In this issue (page 1561) André Lalonde and Elizabeth Taylor outline the new terminology standards of the Canadian Institute for Health Information (CIHI) for collecting health care data in Canada, both information about inpatient morbidity, mortality and procedures and — more important, as care devolves to communities — primary care statistics. In a nutshell, the CIHI has declared that the 10th revision of the *International Statistical Classification of Diseases and Related Health Problems* (ICD-10)[1] will be the standard for recording morbidity and mortality and that the new Canadian Classification of Health Interventions (CCI) will be the standard for recording processes of care, excluding the prescribing of pharmaceuticals. The authors describe how the decisions were made, the advantages of the new systems and a little bit about how they work. Consequently, starting in 1999, as the provinces adopt them, these standards will be applied in the "front sheets" we all see in hospital discharge documents, as well as to provincial billing statistics.

Why are these changes important to physicians? The health care system needs data to guide its management and expenditures, and recording standardized data in hospitals and office practice is the only way we have to measure the performance of the system. Imperfect as they may be, these data are the meters and gauges by which health care managers, both in government and in the private sector, discover how to provide health care more cost effectively. Until now, the accuracy and reliability of these data, especially for primary care, have been questionable. The tools now in use have mismeasured the medical profession, particularly in office-based practice. The existing problem will be compounded acutely as more traditional hospital care is performed in the home and in family physicians' offices. Recording the "billing diagnosis" leads to highly inaccurate perceptions of the reality of care given outside hospitals. This is partly because the billing diagnosis is irrelevant to the care given and partly because the current terminologies themselves are unsuited to clinical care. In addition, there is an increasing body of evidence to suggest that the reliability of hospital "front sheet" diagnoses is also poor. Nonetheless, these are the only statistics we have, and

health care managers will continue to use them for lack of anything better. Fortunately, the CIHI is bringing some standardization to the chaos.

Use of controlled terminologies

The notion of using a controlled terminology for diagnoses is not foreign. Psychiatrists have been using the DSM system (*Diagnostic and Statistical Manual of Mental Disorders*[2]) for years. There are few practising psychiatrists who have no knowledge of DSM-IV, yet I doubt that many practising family physicians or internists have more than a passing knowledge of the International Classification of Primary Care (ICPC)[3] and ICD-10. In the Netherlands the use of ICPC has yielded astonishingly good longitudinal data about general practice.[4] Why is it that psychiatrists have accepted a standardized terminology wholeheartedly (and this acceptance has made the psychiatric profession stronger scientifically), whereas other specialists in Canada, including family physicians, have a dismal record of using standardized recording instruments? The answer to this question is, I believe, related to the fact that the general medical terminologies available so far have not had a clinical orientation and have not been very "doctor friendly." They yield no practical return to the practitioner in the way that the DSM system does. Furthermore, students and residents are not given any formal training in the reasons for or tools of standardized data collection.

Terminology standards are essential for obtaining statistics longitudinally so that we can look at both the epidemiology of disease in general practice and disease trends in individual patients. The new world that opens up is that of the ability to understand what happens to individuals and groups, beginning with the reason for the visit and continuing on to the process of care, to problem labelling and, ultimately, to the outcomes of care.

Beyond standards to electronic information systems

Standards are a necessary first step but alone are not enough to accurately represent the care given in the health care system. A standard terminology is just a catalogue, a tool to ensure that we all use the same terms. To accurately depict care, we need mechanisms for recording data, based on these standard terminologies, that are reliable and that accurately reflect what happens to patients. Therefore, the methods we use to collect data, both for use in hospitals and physicians' offices and for statistical reporting, must meet certain criteria. The data must be personal, yet anonymous. The methods of data collection must conform with care-provider needs at the point of

service, and the resultant data must reflect the actual process of care. Only data relevant to care should be gathered, not data demanded by third parties.

Having data that meet these criteria would not only be advantageous to health care managers but would also benefit patients and physicians in practice. For example, electronic medical records (EMRs) use standardized data to help the physician practise better medicine. It is only by means of standard terms that EMRs can generate prompts, alerts and reminders, which have been shown to be effective in helping the physician cope with the information overload associated with complex cases.[5]

"Episode-oriented epidemiology" is a term used to describe the kinds of care given outside hospitals.[6] Hospital episodes are discrete — the patient enters the hospital, is treated and leaves one way or another. But as care devolves to communities and as more of a continuum of care develops from hospitals to the various levels of home- and office-based community care, episodes of care become longitudinal and intertwined. Coronary artery disease may be one episode with many encounters, both in the hospital and in the office. In contrast, a urinary tract infection may be one episode with a single encounter. We will need to track our patients and their concurrent problem episodes through the health care system. We will also need to aggregate data from individuals, without compromising the patients' anonymity, to understand trends and outcomes in the population. A properly designed EMR system with the ability to chain encounters into episodes and the ability to maintain the anonymity and confidentiality of standardized collected data will be a necessary tool to abet the process.

Implementing an EMR system, especially in office-based practice, is beset with many problems, particularly related to physician data entry, confidentiality, reliability and cost.[7,8] Yet EMRs may be just the tool we need to improve the flow of patient care information in the more integrated health care system of the near future. In the new health care continuum, I believe that continuity of care will be best achieved by each person having a personal physician who knows the patient, as well as his or her "context," and by continuity of information in electronic systems that use terminology standards, so that we all "speak the same language."

Predictable problems

What are the foreseeable problems with the CIHI's choices? ICD-10 is a classification. It is therefore a system of grouping clinical entities. It contains nonspecific terms such as "J98.8 — Other specified respiratory disorders," and does not have codes for certain rare or highly specific entities, so the choice of a term for an individual patient

may not be obvious. It lacks terms for many common symptoms, and there is occasional confusion between symptoms and diagnoses.

So far, it seems that the CIHI has focused mainly on the hospital sector — where the transition to the new terminologies and conversion of older data will be difficult enough — and little on community care. The problems of standardized data collection are magnified in physicians' offices, since physicians do not have the support structures of hospital medical records departments and will find it impractical to use "help lines" and training materials in the course of a busy clinic. Lalonde and Taylor point out that ICD-10 is accompanied by an interpretation volume, but that will make it cumbersome to use at the point of care and virtually impossible to use in office practice. Therefore, each specialty also needs a more complete and specific clinical terminology (a nomenclature) germane to that specialty. For family practice the World Organization of Family Doctors has recommended a combination of ICPC and ICD-10. At our institution we have created an expanded clinical terminology mapped to these 2 classifications for use in primary care EMRs.[9] It is important to allow different specialties to use different clinical terminologies, as long as they all map back to ICD-10. For example, DSM-IV is completely mapped to ICD-10 and can continue to serve the psychiatric profession, at the same time allowing standardized data collection for the CIHI.

In contrast to the ICD-10, the new CCI developed by the CIHI is a terminology to list and classify all nonpharmaceutical interventions in the system. A Canadian version of a terminology of this type has not previously existed. CCI differs from ICD-10 in that it classifies interventions using terms that are specific and clinically relevant. There will likely be no need for a clinical nomenclature at the "front end," as there is with ICD-10. Computer search algorithms should make term selection fast and accurate. Because it is new and still under development, the CCI will require evaluation for validity and reliability.

One area not addressed by Lalonde and Taylor is the issue of reporting standards for laboratory tests; another is pharmaceuticals. If information in the health care system is to be integrated, declared standards for both of these areas are needed.

Conclusion

The paper by Lalonde and Taylor is a starting point for physicians to understand better how their activities are measured and a chance for them to see the possibility of improved patient care through better information flow. By understanding the mechanisms of standardized data collection, physicians have an opportunity to participate in "getting it right." We still need to research ways to improve the reliability and validity of data recording. We also need training in medical schools and residency programs about the rationales and tools for standardized data collection. Better information from practice benefits us all — patients, physicians and health care managers.

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