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Preface

Quality health care requires quality patient data

The problems with the underlying information basis of the health care system have been under discussion and under review for a number of years, but have not yet been solved. The papers selected for the 2003 Yearbook of Medical Informatics should add to the discussion and hopefully lead to some solution.

According to the Institute of Medicine of the National Academy of Sciences in Washington, D.C., few issues are more central to the ongoing debate on health care in the United States than quality of care. [1]

In 1990, the Institute of Medicine developed a definition which is still widely accepted today: "Quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge." [2]

Numerous quality of care studies were done using ICD-9-CM coded data. In a study of complication occurrence in medical inpatients by Geraci et al. [3], it was found that "ICD-9-CM codes in administrative data were poor measures of in-hospital complication occurrence in our study population".

A more recent similar report by McCarthy et al. [4] within the Complications Screening Program is equally critical of the ICD-9-CM codes. In their conclusions, the authors state: "These findings highlight concerns about the clinical validity of using ICD-9-CM codes for quality monitoring."

Most studies to evaluate quality of care in recent years that relied on ICD-9-CM coded data have found this statistical international classification inadequate. Furthermore, the ICD-9-CM coding problems were carried over into the diagnosis-related groupings (DRGs). When the reimbursement of hospitals by Medicare under the prospective-payment system began, the first requirement was that the system be based on the patient's diagnoses at discharge. These were then aggregated into DRGs and these were used for hospital payment following the relative weight of the DRG multiplied by a standard amount adjusted for certain hospital-specific factors.

Although the DRGs have nothing to do with quality, these studies serve to demonstrate further the inadequacy of the ICD-9-CM. One such study on Medicare Prospective Payment by MacMahon and Smits [5] reviewed the ICD-9-CM and its deficiencies. They conclude that the goal of the DRGs was to segregate distinct patient types in terms of use of hospital

resources and the goal of the Medicare prospective payment system was to provide hospitals with an incentive to be efficient in the treatment of clinically distinct types of patients. Both of these goals are severely compromised by the lack of specificity of the ICD-9-CM which serves as the foundation of DRGs and the prospective payment system. They also suggest that if the system cannot be revised to allow necessary clinical distinctions among patients, then a new coding system should be developed.

In 1996, with the Health Insurance Portability and Accountability Act (HIPAA), the U.S. Congress transformed the National Committee on Vital and Health Statistics (NCVHS) into the nation's primary external advisory group for health information policy. By October 1998, this committee had prepared a concept paper [6] to assure a health dimension for the national information infrastructure.

This comprehensive report has a section on tasks for the health information infrastructure. It deals with population-based data, computer-based health records, knowledge management and decision support and telemedicine. Following this discussion, there is a section on standards and measures. A paragraph deserves quoting:

"A high priority is the development of standards and nomenclature for capturing the state of knowledge in medicine and health care. Standards of terminology must be developed, maintained, and made accessible at minimal cost to users. These forms of standardization are critical to the linkages and comparisons needed to assess both the quality of care and the health status of the population.

The Unified Medical Language System of the National Library of Medicine is a good start for this process, but it is not sufficiently *encompassing. Clinical records need to reflect primarily clinical realities and not focus on financial and billing procedures and terms. Care will be most easily delivered in a cost-effective and high quality manner if the language used for care delivery and a variety of management purposes most accurately reflects medical conditions and treatments."*

The NCVHS was and still is the guardian of the ICDs needed for health statistics, yet, it has finally realized as a high priority that nomenclature and standards of terminology are critical to assess quality of care and the health status of the population. There is of course no mention that such a standardized nomenclature, which is now a sine qua non for their informatics base, was presented to Doctor Theodore Cooper, Assistant Secretary for Health at Health Education, and Welfare on June 9, 1976 in Washington. His staff attending the meeting rejected the concept on the grounds that the ICD was adequate for their needs. The time for a nomenclature of medicine had not yet arrived.

By October, 1998 when the concept paper was presented, a multiaxial nomenclature for the medical record existed but was not mentioned, however the Unified Medical Language System of the National Library of Medicine was mentioned as a good start, but not sufficiently encompassing.

In spite of the predominant use of statistical classifications by government agencies, it has now become a high priority that, to assure quality care, a standard nomenclature be developed to capture medical data where it is generated at the patient's bedside or during an encounter in a clinic or doctor's office. Many research papers have demonstrated that statistical classifications were not intended or designed to measure the quality of care given to individual patients because of their lack of granularity and specificity.

If one returns to the 1998 report by the National Roundtable on Health Care Quality [1] there are interesting comments in the last paragraph.

"The burden of harm conveyed by the collective impact of all of our health care quality problems is staggering."
"Meeting this challenge demands a readiness to think in radically new ways about how to deliver health care services and how to assess and improve their quality. Our present efforts resemble a team of engineers trying to break the sound barrier by tinkering with a Model T Ford. We need a new vehicle. The only unacceptable alternative is not to change."

Over the last 25 years, the focus of the governments and medical associations has been to expand the ICD using different extensions to gather better statistics and to develop from the ICD the Diagnosis-Related Groups (DRGs) to reimburse hospitals. The American Medical Association developed a series of editions of the Current Procedural Terminology (CPT) to pay for physician services. There was no plan to develop a nomenclature for the basic clinical information of a specific patient that could be used to assess the quality of care given. In that environment it was taken for granted that quality care was being given, until patients and consumer groups began seriously questioning the system. Now there is a crisis.

The delivery of health care can always be improved by informatics, but the quality of health care cannot be improved unless there is an underlying basis of a standardized multilingual medical terminology to specify the data.

Such a standard exists, but it has yet to be recognized by government

agencies and is far from being implemented. In 1993, Marion Ball, then President of IMIA, wrote the Foreword to SNOMED International [7]. Here are a few quotes:

"SNOMED International offers a predefined structured vocabulary, only a few years ago considered an unobtainable goal."

"A comprehensive nomenclature, it can serve as the clinical nucleus for a Composite Clinical Data Dictionary (C^2D^2) and provide the infrastructure for computerizing the patient record."

"As we work towards global health through informatics, standard nomenclature will give us the foundation – the infrastructure – upon which our future health care delivery system will rest. The work contained in these volumes will take us well into the 21st century and lead the way to information when, where, and how (W^2H) we need it. I recommend it to you."

After 1993, there were numerous papers treating the subject of standard nomenclature and some official bodies stated their position.

In a 1997 position paper by the Board of Directors of the American Medical Informatics Association [8], it was stated that a national health information strategy should focus on a series of objectives one of which was standards development.

"The potential of computer and communications technologies cannot be realized for health care unless a universal language or vocabulary is developed, kept updated and made accessible at minimal cost."

If it is now recognized that a standard nomenclature reflecting primarily the clinical realities is essential for the delivery of quality care, this same standardized terminology will soon be recognized as essential to the proponents of evidence-based medicine. In a recent white paper (2001) on Clinical Decision Support Systems for the Practice of Evidence-based Medicine [9], the authors propose five central areas of activity, the first being the "capture of both literature-based and practice-based research evidence into machine-interpretable formats suitable for CDSS use."

Although many scientists and scientific societies have now recognized the need for the specificity of a nomenclature for health care, official government agencies have been reluctant to sanction its development. One exception is the National Health Service of the United Kingdom which acquired the Read Codes which were designed for the primary care physician and his practice.

In the United States, nomenclature development began in 1965 with the publication of the Systematized Nomenclature of Pathology (SNOP) by the College of American Pathologists (CAP). The basic multi-axial structure was widely accepted and SNOP was translated into multiple modern languages. The success of this approach was the impetus that led to its extension to all of medicine and the publication of several editions of the Systematized Nomenclature of Medicine.

By 1998, the CAP, with a new team of physicians, nurses and knowledge base experts began developing SNOMED into a reference terminology for the computerized health care record. In 1999, the CAP formed a strategic alliance with the U.K. National Health Service to merge SNOMED with the Clinical Terms derived from the Read Codes into a single English language master edition called SNOMED-CT.

To all those government agencies and scientific associations who have repeatedly stated the need for a nomenclature as a basis for the delivery of quality health care, they should now realize that one has existed for a number of years and that it has now been refined into a computer-compatible health care reference terminology. This terminology is the foundation of the pyramid of documentation (Figure 1) in the health care setting, where over 90% of the data gathered is patient-related.
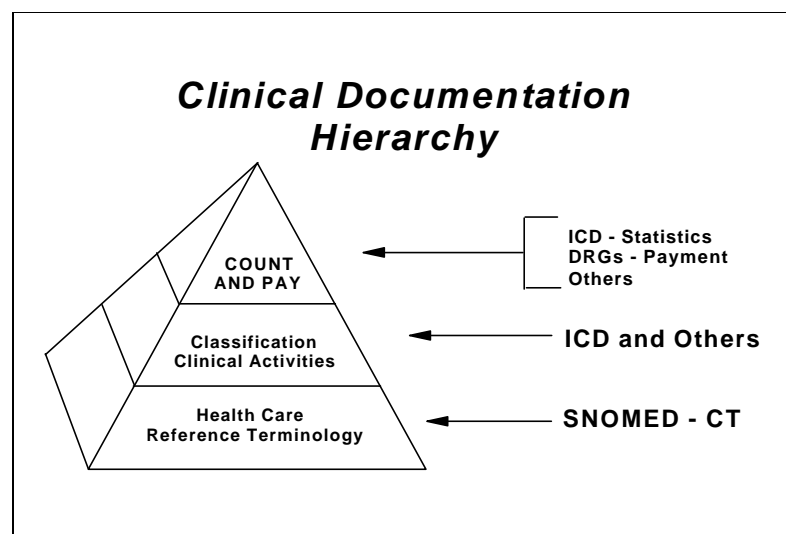

Fig. 1. The pyramidal representation of clinical documentation shows the nomenclature base provided by a controlled clinical terminology. All administrative activities and classifications are derived from solid patient information.

In summary, the computer-capture of coded specific patient information will provide the quality data needed for the delivery of quality health care. Hopefully, the papers gathered in this 2003 Yearbook will further discuss the role of informatics in our collective search for quality health care.

References

1. Chassin, MR, Galvin RW and the National Roundtable on Health Care Quality. The Urgent Need to Improve Health Care Quality. JAMA 1998 280(11).

2. Lohr KN, ed. Medicare: A Strategy for Quality Assurance. Washington, DC. National Academy Press 1990.

3. Geraci JM, Ashton CM, Kuykendall DH, Johnson ML, Wu L. International Classification of Diseases, 9th Revision, Clinical Modification Codes in Discharge Abstracts are Poor Measures of Complication Occurrence in Medical Inpatients. Med Care 1997;35:589-602.

4. McCarthy EP, Iezzoni LI, Davis RB, Heather Palmer RH, Cahalane M, Hamel MB, Mukamal K, Phillips RS, Davies DT. Does Clinical Evidence Support ICD-9-CM Diagnosis Coding of Complications? Medicare Care 2000;38:868-876.

5. McMahon LF, Smits HL. Can Medicare Prospective Payment Survive the ICD-9-CM Disease Classification System? Annuals of Internal Medicine 1986;104:562-566.

6. National Committee on Vital and Health Statistics. Assuring a Health Dimension for the National Information Infrastructure. Presented to the US Department of Health and Human Services Data Council, 1998 Oct 14.

7. Côté RA, Rothwell DJ, Palotay JL, Beckett RS, Brochu L. The Systematized Nomenclature of Human and Veterinary Medicine – SNOMED International. College of American Pathologists. Northfield, Illinois 1993 April.

8. Board of Directors of AMIA. Position Paper: A Proposal to Improve Quality, Increase Efficiency, and Expand Access in the US Health Care System. JAMA 1997;4:340-341.

9. Sim I, Gorman P, Greenes RA, Haynes RB, Kaplan B, Lehmann H, Tang PC. Clinical Decision Support Systems for the Practice of Evidence-based Medicine. JAMA 2001;8:527-534.

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