

# Patient-Linked Databases: Implications for a Nursing Outcomes Research Agenda

Marcia Orsolits Stevic, RN, PhD

---

---

This paper will discuss the state of the art of current large, patient-linked databases, their inclusion of nursing care data elements, and their potential for supporting outcomes research efforts. Health care organizations and hospitals in particular have not become paper-less sites of sophisticated automation. Large national databases are not yet available for tracking trends in clinical outcomes over time. Institution specific financial and clinical databases seldom speak to each other. The attitudes and fears of health care professionals are some of the key factors in the lack of computerization and database development. Nurses and physicians may have separated practice from documentation and in fact, resent the increasing focus on their written words by payors, regulators and accreditors.

In spite of the major strides made by selected organizations and individuals, the health care industry is still embarrassingly behind in information technology development. Initial patient-linked databases were designed to track claims data and monitor reimbursement. Three (3) major types of systems exist today: Medicare's Claims Files, various "registries", and the evolving Uniform Clinical Data Set designed by HCFA. None of these data bases includes sufficient specific data elements upon which to systematically measure the outcomes of nursing care. We must help health care professionals appreciate and master information before we can expect them to develop the data sets required to support the complexities of clinical decision making, organizational operations and the learning process.

This is perhaps one of the most challenging issues for the profession of nursing. Information technology will be a major focus of health care's future. Nursing decision making and interventions/actions will comprise a substantial portion of critical facts and assumptions that will be required to measure/understand the outcomes of patient care and which processes contribute to these outcomes.

The very exciting opportunity here is the chance for Nursing to rally around the aspects of care that have been targeted at the policy level as the core indicators of the quality of our care and which also happen to represent the core definition of our practice. Patient/family education and functional independence are the heart of nursing care.

It is recommended that we consider HCFA's set of Generic Quality Screens currently used by the Medicare Peer Review system and the basis framework for the UCDS. We have a significant opportunity to work in collaboration with the major efforts under way to develop measures of effectiveness and outcomes of patient care.

## INTRODUCTION

The hopes, dreams and promises of 1970s and 1980s to automate patient care documentation have not come true. Health care organizations and hospitals in particular have not become paper-less sites of sophisticated automation. Large databases are not yet available

for tracking trends in clinical outcomes over time. Institution specific financial and clinical databases seldom speak to each other. Why not?

The attitudes and fears of health care professionals are the key factors in the lack of computerization and database development. Nurses and physicians have separated practice from documentation and in fact, resent the increasing focus on their written words by payors, regulators and accreditors. What would a day on a hospital unit be like if physicians, residents, nurses, respiratory therapists, physical therapists and social workers were required to base their daily interventions for patients on only the written results of the previous care giver? MAYHEM?! Come to think of it - it's obvious we don't base our clinical decisions on documented progress,.... and most patients would say they were never asked what had occurred and how they felt as a result. Then how do professionals make health care decisions? Based on some floating textbook picture of a plan of care... their own patterns of successful/not behaviors/interventions? Certainly not yet on pre-defined protocols/guidelines. We must help health care professionals appreciate and master information before we can expect them to develop the data sets required to support the complexities of clinical decision making, organizational operations and the learning process. One place this has occurred to some extent is in research (Eddy, 1990).

The explosion of health care information hardware and software flooded the market in the 1970s and 1980s. However, health care professions initially played a very minor role and the technological skill and expertise came from a wide variety of industries; banking, manufacturing. In health care, there is a very strong pattern of increasing specialization, new roles and diversification which has fragmented the attention of health care

professionals. Therefore the majority of work in automation and database development has been led by major vendors and the regulatory/reimbursement bodies.

At first, it was thought that mortality data would be a helpful outcome in identifying the "good" and the "bad" health care organizations and services. It soon became evident that deaths occur relatively infrequently, but complications and traumas can be problematic and substantial. (Blumberg, 1989; Chassin, 1989). A clinical database of these morbidity outcomes has not yet been designed.

Next, it seemed the characteristics of the physician and/or hospital could help us select a "good" one. Board certification, volume rates, liability records, staffing ratios and for profit status have all been compiled. These measures too have proven less useful than expected.

Both mortality and characteristics data are available in large national databases, for example the American Hospital Association's annual survey, and the Health Care Financing Administration's (HCFA) Medical Claims files. These can be merged with cost/charge data for fairly comprehensive analyses. However, this information is not readily available to nor entirely understandable to the average provider or researcher. (Shortell, 1988).

The next wave of evaluative data will need to be developed around a predictive, probability model. "If you see doctor X for Y procedure at Z hospital, your chances of dying (walking again, having a repeat, etc...) may be B percent. Data collection must be highly focused, systematic and scientifically rigorous to provide predictive information. There is now a beginning awareness of the role of nurses, social workers and other health care workers in the probability of a good outcome. However, we only have some guesses and empirical hints here, but we

do not yet have the breadth and depth of patient provider and specific data to even begin to answer these questions for non-physician providers. (Berwick, 1989).

### State of the Art

Initial patient-linked databases were designed to track claims data and monitor reimbursement. Three (3) major systems exist today: Medicare's Claims Files, various "registries", and the evolving Uniform Clinical Data Set designed by HCFA. The Medicare Claims files include several versions designed to support inpatient, outpatient and combined analyses of beneficiary utilization of resources, services charged and services reimbursed. The most recent version has been designed to support research efforts in the area of health care financing, resides within a HCFA bureau, and is accessible to providers and researchers. This file is named the National Claims History File and offers a systematic means of examining the patterns of health care service utilization. None of the claims files contain specific clinical data. For example, you can determine the number of lab tests a patient or group of patients may have received without any clue as to the appropriateness of the tests or the actions taken by providers based on the test results. Many researchers have attempted to "adapt" claims files data to quality indicators with varying success. A comprehensive discussion of the key issues, limitations and opportunities can be found in a recent publication by John Weiner of Johns Hopkins University. (Weiner et al, 1990.)

The various clinical registries have evolved among several medical disciplines in an effort to track patients involved in new and experimental treatments. By and large, these databases focus on the demographic and administrative data required to "find" patients/cases over time. Clinical data are then obtained and stored in ongoing, paper-based medical records. One can not usually

gather any meaningful measure of quality of care from these registries. At times, patient compliance and/or follow up and continuity of care can be inferred from registry data.

The most promising database of clinical information is HCFA's Uniform Clinical Data Sets (UCDS). UCDS evolved from several years of experience by the Peer Review Organizations (PROs) with generic quality review screens. Consistent data elements had been identified from the vast number of cases reviewed for substandard care. Those data elements have been programmed with algorithms to flag cases for intensive physician review. The system is new and controversial. Programming and developmental problems currently result in extremely lengthy data abstraction time. The algorithms are as yet undocumented and unavailable for reliability or validity testing. As HCFA refines the UCDS and these problems can be resolved, the potential for understanding the quality of care among the Medicare population will be greatly enhanced. Several research efforts are also underway to apply the UCDS to non-Medicare cases and to investigate its potential as an internal quality management tool for hospitals. The Peer Review Systems (Ohio PRO) and the Medical College of Wisconsin are two projects in these areas. To date, the UCDS includes several data elements that may be useful to measure nursing care quality: functional status, patient education and specialty referrals.

In spite of the major strides made by selected organizations and individuals, the health care industry is still embarrassingly behind in information technology development. While this is certainly not earth-shaking or life-threatening news, a crisis is eminent as society's need for information about the costs, accessibility, and quality of its health care services rises rapidly.

Health care providers are often characterized as “doers” vs. “thinkers.” The recent Medicare’s RVU system threatens to invert the hierarchy of “valued” health care services by increasing reimbursement for cognitive care over technological/invasive care. This is a good example of society’s need to better understand those abstract aspects of care that cannot be readily checked off a list, that require a flow of meaningful information over time, and that seem to have a substantial influence on patient outcomes. By and large, many of these aspects are nursing care.

What is “quality” health care? Let’s consider the recent definition from the Institute of Medicine (IOM):

“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.” (Donaldson et al, 1991).

This definition is quite consistent with the World Health Organization’s (WHO) definition of health:

“...a state of complete physical, mental and social well-being, and not just the absence of disease or infirmity.”

This broader view of health beyond disease, morbidity and mortality, and the IOM’s definition of quality of care are necessary to the successful provision of useful information for society. We now must broaden our internal evaluation of health care quality beyond death rates and clinical complications. In this context, the patients’ ability to function and their satisfaction with care become major measures of the effectiveness of the health care we

provide. If we are to measure our success in this way, what role will information technology play and how will nursing be represented?

This is perhaps one of the most challenging issues for the profession of nursing. Information technology will be a major focus of health care’s future. Nursing decision making and interventions/actions will comprise a substantial portion of critical facts and assumptions that will be required to measure/understand the outcomes of patient care and which processes contribute to these outcomes.

The recent policy thrust to measure medical effectiveness represents a major expansion of our focus on and definition of health care. It’s time to stop and take an inventory of where we are today with various diagnoses, treatments and procedures. Have we applied all the knowledge we have gained through the basic sciences and clinical research over the past 25 years? Why do health care services and costs vary so much across the country, and indeed, across one city? Why do patient outcomes vary for similar treatments/procedures? Can we do better for our society? Better applications of professional knowledge? Better matches of patient preferences and treatments? Better outcomes at less cost? (Donkin, 1989; Faltermayer, 1988).

To its credit, the new Agency for Health Care Policy and Research (AHCPR) implements the “expanded” definition of medical care to include the scope of services provided by a variety of health care professionals. A nursing advisory group was charged with identifying conditions where, nursing care was a major component. Nursing leaders have played a key role in the development of three initial practice guidelines to support quality measurement: pain management, continence care and skin care. These are all areas that have been

recognized as substantially influenced by nursing care management. There is a growing awareness, at the U.S. policy level, that nursing care makes a difference in cost, length of stay, disability incurred, and quality of care delivered.

### Strategies for Success

So, what is the challenge? Now we need to convince ourselves - our nursing organizations, our bedside nurses and yes, - most importantly - our future professionals that nursing care makes a difference. We need to broaden our definition of value to society and take the necessary risks to develop measures of our success that coincide with patients' and society's expectations of us. The initial guidelines reflect some measures of nursing care quality that we can build upon. We must prepare ourselves and those in the future, to develop further measure and to maintain the leadership in identifying key areas of nursing contribution, before they are defined for us.

The very exciting opportunity here is the chance for Nursing to rally around the aspects of care that have been targeted at the policy level as the core indicators of the quality of our care and which also happen to represent the core definition of our practice. Patient/family education and functional independence are the heart of nursing care. Often these are the things that make the real difference in the quality and the outcomes of care.

What to do until the database arrives? Take two aspirin and call the bureau of health statistics in a few years? Purchase the Medicare Claims (MEDPAR) file and "extrapolate"? Pull up the Tumor Registry and guess who received nursing interventions? Or better still: cre-

ate one ourselves? Yes, but how, when and who should be involved? And most importantly, what is the question to be answered by a nursing care database?

What are the potential questions for our "large database"? What is nursing's contribution to the effectiveness of patient care? Does nursing care make a difference? Which outcomes are we mainly responsible for? How can we systematically measure the quality of nursing care? Which data will need to be patient and nurse specific?

It is recommended that we consider the set of Generic Quality Screens currently used by the USA Medicare system. Six, straight-forward screens flag potential quality problems. These include: adequacy of discharge planning, medical stability at discharge, nosocomial infection, hospital incurred incidents, unexpected death, unplanned return to surgery.

More importantly, there are several nursing studies which could provide the beginning framework for such a database - including, but not limited to the Nursing Minimum Data Set (NMDS) (Werly and Long, 1988). Many studies have begun to go in this same direction, but severe limitations exist in the lack of large, standardized tests of data, the elements and/or tools and their relative acceptance within nursing practice.

### Summary

We have a significant opportunity to work in collaboration with the major efforts under way to develop measures of effectiveness and outcomes of patient care. We cannot afford to be or appear to be separatists. Differentiating nursing from medical contributions to various outcomes is useful only to understand the compo-

nents and articulate the mysterious. Success in improving outcomes can only come from blending the information back into integrated care delivery and shared responsibilities.

To believe that the whole is greater than the sum of the parts is to temporarily and at times artificially pull apart the components to better understand each one, the details of timing and precision, while basing actions/reactions on the powerful sum.

### References

Berwick, DM. Sounding Board. Continuous Improvement as an Ideal in Health Care. New England Journal of Medicine 320:53-56, 1989.

Blumberg, MS. Comments on HCFA hospital death rate statistical outliers. Health Services Research 21:715-39, 1987.

Brinkley, J. U.S. Releasing Lists of Hospitals with Abnormal Mortality Rates. The New York Times March 12, 1986, pp. A1, A22.

Chassin, MR, Park, RE, Lohr, KN, et al. Differences among Hospitals in Medicare Mortality. Health Services Research 24:1-31, 1989.

Donaldson, MS, Harris-Wehling, J, Lohr, KN. Medicare: New Directions in Quality Assurance. Washington, D.C.: National Academy Press, 1991.

Donkin, R. "Medicine's Search for 'What Works': What it Means to Employers," Business and Health, 7 (5):18-25, May 1989.

Eddy, D.

"The Challenge," JAMA 263 (2):287-290, January 12, 1990.

Eddy, D.

"Anatomy of a Decision," JAMA 263 (3):441-443, January 19, 1990.

Ellwood, PM. "Shattuck Lecture—Outcomes Management: A Technology of Patient Experience," The New England Journal of Medicine, 318 (23):1549-1556, June 9, 1988.

Faltermayer, E. "Medical Care's Next Revolution," Fortune, 126-133, October 10, 1988.

Knaus, WA, Draper, EA, Wagner DP, Zimmerman, JE. An evaluation of outcome from intensive care in major medical centers. Annals of Internal Medicine, 104:410-18, 1986.

Lohr, KN and Mock, GA (eds). "Advances in the Assessment of Health Status," Medical Care, 27 (Suppl.):1-20, March 1989.

McLaghlin, CG, Normolle, DP, Wolfe, RA, McMahon, LF, Griffith, JR. Small-area variation in hospital discharge rates. Do socioeconomic variables matter? Medical Care 27:507-21, 1989.

Nash, DB, "Medical Purchasing Guidelines for the Business Community: How to Ask the Questions and Get the Answers," QRB, Vol. 16(3):98-100, March, 1990.

Shortell, S and Hughes, E. The Effects of Regulation, Competition, and Ownership on Mortality Rates Among Hospital Inpatients. New England Journal of Medicine 318:1100-1107, 1988.

Stewart, AL, Greenfield, S, Hays, RD, Wells, K, Rogers, WH, Berry, SD, McGlynn, EA and Ware, JE. "Functional Status and Well-Being of Patients with Chronic Conditions: Results the Medical Outcomes Study," JAMA, 262 (7):907-913, August 18, 1989.

Weiner, JP, Pour, NR, Steinwachs, DM and Dent, G. "Applying Insurance Claims Data to Assess Quality of Care: A Compilation of Potential Indicators," QRB, Vol. 16:242-438, December, 1990.

Werly, HH, and Lang, NM, Identification of the Nursing Minimum Data Set, New York: Springer Publishing, 1988.