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Health-related quality-of-life data should be regarded as a vital sign

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Abstract

Objectives: The health care system systematically collects data on risk factors, processes of care, and the amount and type of services provided; in short, it mainly measures inputs. The system only sporadically collects data on the health status and health-related quality of life (HRQL) of those served. What does the system actually produce? It produces quality-adjusted survival; yet, there is little systematic effort to collect such outcome−output data.

Study Design and Setting: Systematic routine use of HRQL instruments to assess the health of all patients is one step toward filling this void.

Results: Assessing the HRQL on all patients provides the information needed to create a report card on the system. Furthermore, the routine use in the context of chronic care management has the potential to improve patient−clinician communication, provider and patient satisfaction, shared decision making, and health outcomes.

Conclusion: Over five decades of methodological development have provided a rich array of HRQL instruments. A plethora of technologies facilitate the collection, transmission, and storing of information. What is needed is training to assist patients and providers in the meaning and use of such information and the will to use it to improve performance, accountability, and patient care. Administrative support is also necessary. © 2013 Elsevier Inc. All rights reserved.

Keywords: Health outcomes; Health-related quality of life; Quality-adjusted survival; Health status; Chronic-care management; Satisfaction

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1. Introduction

In 2009, health care expenditures in the United States accounted for 17.4% of Gross Domestic Product, much higher than the average of 9.5% for the 34 Organization for Economic Co-operation and Development (OECD) member countries (http://www.oecd.org/). What does the United States get for those expenditures? This important and basic question is very difficult to answer. More fundamentally, what is the output of the health care and public health systems? I suggest that what these systems produce is quality-adjusted survival, a theme to which I will return in the following.

2. A thought experiment

Imagine an interview with Paul S. Otellini, President and Chief Executive Officer of Intel. “What did your company produce last year?” “We produced “n” Intel® Xeon® processors, and so forth.” Now, imagine interviewing Mary Brainerd, President and Chief Executive Officer of HealthPartners in Minnesota, a well-respected health maintenance organization. Ms. Brainerd would be able to report in impressive detail on the amount of health care services delivered by HealthPartners but would be unable to quantify output. This result is not unique to HealthPartners; the same could be said for virtually any health care delivery organization in the United States and other OECD countries.

3. What is routinely measured?

The system routinely records data on health care inputs, processes of care, and risk factors [1]. Some of the most comprehensive electronic medical record systems are found in the US Department of Veterans Affairs medical care system [2] and US health maintenance organizations, both organization-specific systems [3] and consortia [4,5]. These systems are probably “as good as it gets.” The information in such systems illustrates what is routinely available, typically including sociodemographic characteristics of patients/members, diagnoses, height, weight, hospitalizations, visits to the emergency departments, ambulatory care visits,

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Conflict of interest: It should be noted that D.F. has a proprietary interest in Health Utilities Incorporated, Dundas, Ontario, Canada. HUInc. distributes copyrighted Health Utilities Index (HUI) materials and provides methodological advice on the use of HUI.

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What is new?

Key findings

- The routine use of a wide variety of measures of health-related quality of life (HRQL) is necessary to enhance the effectiveness and efficiency of the health care system.

What this adds to what was known?

- The health care system produces quality-adjusted survival. The routine use of preference-based measures is essential for estimating the output of the system.

What is the implication, and what should change now?

- HRQL measures should be an integral component of chronic care management and being routinely used to monitor the performance of the health care system. Patients and clinicians will need to be trained to exploit this powerful source of information, and administrators will need to support those activities.

utilization of other health care services, prescription medications, procedures, laboratory and pathology results, chart notes, and vital signs. Yet, even in these rich data systems, except for mortality, there is typically very little information on outcomes.

There are, however, important exceptions to the generalization that the system mainly records data on health care inputs. Particular clinical units scattered throughout the system routinely assess certain aspects of health status. For instance, many pain clinics routinely assess pain and symptoms of depression. A number of registries include both generic and targeted measures of health status, as do many clinical trials. The inclusion of these measures in registries and trials has added valuable information on the burden of various diseases and health problems and the effectiveness of interventions in improving health outcomes. Some units such as the Spine Center at Dartmouth-Hitchcock include comprehensive serial assessments of health status using multiple instruments [6]. In addition, in response to regulatory requirements, health status (mainly focusing on risk factors) is routinely assessed for certain groups such as US Medicare special needs patients. Furthermore, starting in April 2009, the National Health Service in England began to use health-related quality-of-life (HRQL) measures systematically in a top–down quality improvement program with initial implementation in elective surgery [7].

There are parallels in population health surveys. In the United States, the Behavioral Risk Factor Surveillance System collects information on risk factors along with some measures of outcome including functional status, “cut down” days because of physical or mental health problems, and self-rated health (excellent, very good, good, fair, and poor).

4. How to transform these activities into a comprehensive effort?

More than five decades of methodological development have resulted in a rich array of generic, preference-based, and specific instruments to assess health status and HRQL [8,9]. We have the necessary tools for measuring outcomes, tools that typically are as reliable as standard clinical measures [10]. An extraordinary array of technologies for data collection have emerged to complement traditional paper and pencil and interviewer administration, including the Internet, mobile phones, tablets, lap top computers, and interactive voice recognition systems. Collecting and storing data are easier and cheaper than ever.

5. Rationale for assessing health status

Feinstein [11] suggested that “assessments of health status are important because improvements in symptoms, other clinical problems, and functional capacity are usually the main goals of patients in seeking clinical care.” Health status and HRQL measures offer a means for quantifying these outcomes, a measure of the output of the health care system [6,9].

6. The next steps?

For general surveillance, patients could receive annual birthday wishes with an invitation to complete a generic questionnaire and relevant targeted measures. In chronic care management, assessments could be linked to visits and ongoing surveillance. Parallel with these efforts, comprehensive generic measures could be added to all ongoing population health surveys, providing a linkage between health care delivery and population health survey data.

The routine use of measures of health status and HRQL in the health care delivery system would be a major change in organizational behavior, never an easy process. Patients and health plan members would have to be trained to complete questionnaires in a timely manner. Problems such as literacy, visual impairment, and cognitive limitations will have to be addressed. Yet, for the most part, these “barriers” have been successfully overcome in clinical trials and population health surveys. When patients believe that the information is important and that it will be used to improve their care, they are generally quite willing to complete questionnaires.