We all hear about the need for information on what kind of care is worth providing in terms of both costs and final results for the patient. Outcomes research is receiving much attention now because it is expected to fill this information gap. Occupational therapists, like other health care professionals, are in the midst of either contributing data to a large data bank that will be used to generate outcomes data or conducting outcomes research themselves. Outcomes research will play a major role in health care policy as well as in direct clinical decision making. But the health policy questions being asked make it apparent that outcomes data are not easily applied. The eagerness to use outcomes can outpace the availability of data and is raising many policy questions about how the data should be used. This article presents an overview of how outcomes data are being used in health policy making and the questions they raise.

Defined comprehensively, outcomes of care can include the usual mortality and morbidity outcomes as well as quality of life, physical functioning, and mental and emotional status. Outcomes can be complex in definition because treatment often affects patients along a time continuum, from the relatively short term to the very long term. Outcomes research links these short-term and long-term outcomes with the type of care that patients with a particular health condition receive. The purpose of outcomes research is to identify what works best for which patients (Guadagnoli & McNeil, 1994).

What makes outcomes research unique and distinguishes it from clinical trials is that outcomes research examines the effectiveness of treatment as it is administered under real-life circumstances, where patients as well as the treatment itself are likely to have some variances. For example, in real life, patients may not take medications exactly as scheduled or may not do exercises specifically as recommended, and a number of therapists can provide therapy. In contrast, clinical studies examine the potential benefit of a treatment under relatively ideal circumstances, with strict adherence to the treatment protocol and a tightly defined patient population.

Outcomes studies typically attempt to include a cross section of patients with a given health condition who receive either alternative treatment modalities or a single treatment modality. Patients who have the same health condition may differ from each other in ways that could have a bearing on the effectiveness of treatment, including gender, age, comorbidities, social background, and economic status.

The current level of interest in outcomes research is heightened by the possibility that it will provide a wealth
of information that can be used to settle long-standing, thorny problems in health care. Information on the outcomes of care could empower the patient and public to take greater responsibility in choosing among treatment options, providers, and health benefit plans. Outcomes data can also provide information on the cost-effectiveness of treatment options, which employers, managed care organizations (MCOs), and other health benefit plans can use in designing benefits and establishing reimbursement criteria. Finally, outcomes can provide information to physicians and other health care providers on the effectiveness of treatment, which then can affect professional consensus on the norms of care and be applied to professional guidelines. Eventually, outcomes information could explain, and perhaps justify, variations in practice. Where variations cannot be justified, outcomes information might facilitate changes in practice patterns. Thus, outcomes research has important policy implications and raises some difficult questions. However, as much as outcomes information could shed light on these difficult health care issues, it can also be misapplied as a quick fix for these issues.

Public and Patient Information

Until very recently, outcomes of care referred to broad clinical outcomes such as mortality, morbidity, and infection rates (Chassin, 1996). However, the outcomes data were generally used within hospitals and other health care institutions to improve the delivery of care and were not released to the public. An important departure from this usual use of outcomes data occurred in 1987 when the Health Care Financing Administration (HCFA) released to the public mortality rate data from hospitals around the country that provided care to Medicare beneficiaries. At the time, it was believed that the statistics would offer greater public accountability and begin to empower patients to make more informed decisions about where they received care (Roper, 1988).

Information is vital in helping the public make necessary choices, particularly while health care continues to be provided through the private, competitive market. Generally speaking, it is a reasonable use of outcomes information. The questions that became apparent as HCFA released the data and that continue to be asked are: What kinds of information are needed by the public? What outcomes should be reported to the public? In what format should reporting be done? The early efforts of HCFA illustrate the importance of these policy questions.

The HCFA data did not differentiate between hospitals that had a hospice unit and those that did not. Thus, some hospitals reported considerably higher mortality rates than others because they contained hospice units. The data were misleading because they were presented without explanation or stratification of the hospitals (Roper, 1988). Besides being misleading, such broad-brush reporting of data is not useful. The public needs more specific information.

Today, hospital mortality reports come from state data banks. States such as California, Pennsylvania, and New York regularly release mortality data to the public, and in some instances, the data are available for specific procedures, such as coronary artery bypass graft and other diseases that carry a high risk of mortality ("Experts Defend New York CABG Death Studies," 1996). Additionally, mortality data are now adjusted for severity risk or the severity of illness. Such adjustments take into consideration that some hospitals may have patients who are very ill or patients with comorbidities. When the mortality data are adjusted for severity, they provide a more comparable measure across hospitals (Iezzoni, 1996).

With the severity of illness controlled, the next question is whether the variances in mortality rates among hospitals are related to the processes of care. However, discovering the link between mortality and processes of care can be elusive. For example, the HCFA's Cooperative Cardiovascular Project studied the 30-day mortality rates of patients treated for heart attacks in hospitals. The researchers were unable to explain three quarters of the variation in mortality across hospitals; thus, they concluded that there is powerful evidence against using short-term survival data after heart attack to measure hospital quality of care ("Huge Study of HCFA Heart Study," 1996). Until the link between mortality and process of care is understood, it is difficult to attach meaning to mortality data or improve the process of care, and thus, the usefulness of outcomes data to the public or the patient is very limited.

Health Benefits Design

MCOs and other benefit plans are interested in using outcomes data as a marketing tool to demonstrate the quality of care that their plans provide for employers and prospective enrollees. Presently, however, MCOs and other benefit plans have very few outcomes data, and in lieu of these data, they typically report the percentage of their enrollees that receive various screenings and preventive services, such as mammograms, cholesterol screenings, and childhood immunizations. Each MCO chooses which screenings it reports and how it will collect and analyze the data. For example, all MCOs do not report on cholesterol screening; some might report on childhood immunizations, others might report on mammog.
raphy, and most report on a combination of these. In addition, the data are collected and analyzed differently from one plan to another. Because the reports are not comparable between MCOs, the enrollee does not really have useful information, and the reports are a long way from outcomes data.

The need for outcomes data to better inform benefit plan enrollees and purchasers is recognized throughout the health care industry and is being addressed. Several organizations are developing outcomes that are useful to the public and have some relevance to the actual performance of the health plan. The National Committee for Quality Assurance (NCQA), which is the major accrediting body for MCOs, will use clinical outcomes measures in its accreditation standards, HEDIS 3.0. The NCQA says that to date, most outcomes measures are not feasible and scientifically valid, but the committee will release a set of testing measures that benefit plans can volunteer to use (“NCQA: HEDIS 3.0 Still Short on Outcomes,” 1996).

Another group that is drafting outcomes measures is the Foundation for Accountability (FAccT). FAccT is an organization that grew out of the Jackson Hole Group1 and is committed to developing quality of care indicators that reflect outcomes as well as processes of care. FAccT includes purchasers of health care, consumer advocacy groups, and government agencies. The group will not have an accreditation function but will offer its measures to other bodies, such as the NCQA, to use for accreditation purposes (“Outcomes Top Priority in New FAccT Performance Measures,” 1995).

A major policy controversy is developing around the MCOs’ and other benefit plans’ intentions to use outcomes data as a basis for selecting and designing benefit plans, establishing reimbursement criteria, and developing provider networks. Assuming that outcomes data will be developed by or for payers, an especially sensitive policy concern is defining cost-effective care. It is not uncommon to read announcements from MCOs that the use of outcomes data has slashed the costs of care in treating a particular disease. These proclamations are often made with little regard to the validity, reliability, and scant availability of the outcomes data. But the hyperbole illustrates the eagerness of benefit plans and payers to use outcomes studies as a basis for cutting costs. The concern is that in their eagerness to apply outcomes data for cost cutting purposes, payers will reimburse only the least expensive alternative treatment, will be willing to use any outcomes study to justify doing so, and will use outcomes data selectively. The threat to the quality of care is looming.

Some MCOs prohibit physicians from telling the patient about suitable, alternative care that might be more expensive and is not covered by the plan. This part of the contract that the provider signs with the MCO is known as a “gag clause.” Legislative action against these clauses is building, and most professional associations have developed policy positions against gag clauses.

Other plans reimburse physicians or offer other financial inducements for achieving outcomes as defined by the plan (“Internists at Jackson Hole,” 1995). This is an ethically questionable use of outcomes and practice guidelines because it strongly pits the financial interests of the provider against the patient’s need for comprehensive, thorough, and timely diagnosis and treatment. The financial inducement generally supports providing the patient with the least expensive treatment alternative and minimal diagnostic testing and discourages referral for specialty care.

However, state legislatures are becoming aware of these issues and are beginning to regulate the managed care industry. In November 1996, the state of California will have voted on the largest set of regulations for managed care so far (Schodolski, 1996). These regulations would prohibit MCOs from offering physicians financial inducements to deny or delay care and would ban them from requiring that physicians not tell patients about alternative, and perhaps more expensive, treatments that the plan does not cover.

Quality Improvement

Another use of outcomes data is to improve direct care. As outcomes information becomes available, it is incorporated into practice guidelines. To this end, several professional associations have already begun to design outcomes studies. For example, the American Academy of Ophthalmology has established a National Eyecare Outcomes Network to track outcomes (“Eye Doctors Developing National Outcomes Network,” 1996). Likewise, hospitals are tracking outcomes. For example, Columbia/HCA Healthcare Corporation will create an institute for outcomes that uses data from its 340 hospitals nationwide (“Columbia/HCA Creating Outcomes Institute,” 1996). Occupational therapists also have contributed data to a large outcomes research and data project developed by Formations in Health Care, which has been purchased by

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1The Jackson Hole Group consists of nationally known health policy analysts who formulated a plan for managed competition that was incorporated into the Clinton Administration’s health care reform proposal, which since has been scuttled. The group meets informally in Jackson Hole, Wyoming; has a self-selected membership, no distinct leader, and no ties to other organizations; and continues to study and discuss health policy.
an Atlanta-based health information firm, Medirisk.

Physicians, occupational therapists, and other direct providers have been ethically bound to consider the interests of their individual patients; therefore, they generally believe that treatment must be tailored to meet the patient's needs. This belief represents one facet in the policy debate of whether patients should be limited to the least expensive, effective treatment; whether patients should have access to all effective treatment options; or whether such options should exist for those patients who can independently finance their care. Professional associations and other professional groups recognize the importance of understanding the outcomes of care. They also recognize the ramifications that outcomes data may have on physicians' authority to advise patients on treatment options and to tailor treatment to meet their patients' individual needs.

All developers of practice guidelines concur that outcomes of care should be incorporated into their guidelines as outcomes data become available. Because outcomes data can carry great weight and because practice guidelines increasingly guide clinical decision making, physicians and other health care providers want to be certain that the guidelines are based on valid outcomes data that are relevant to everyday practice. The need to have valid data has led providers to initiate their own outcomes studies to address the questions about what works and for which patients.

Conclusion

Outcomes information will be used by the public and patients, by payers, and by providers. Each group has its own specific interest in the outcomes information, and the interests of each raise policy questions that will have to be addressed. Ideally and in the long run, outcomes research can be expected to clarify the effectiveness as well as the cost-effectiveness of health care. In so doing, it may also highlight the ethical issues that underlie policy decisions.

However, outcomes research is still relatively new; its methods and applications are in the process of being developed and tried. Because outcomes research is expected to answer many questions and means different things to different persons, it is possible to misunderstand and misinterpret outcomes data. Outcomes studies must be designed to fill its specific purpose, data must be valid and reliable with the specific purpose in mind, and information must be applied wisely.

References


