Practice-Based Research Networks: Building the Infrastructure of Primary Care Research

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Family practice and primary care are rapidly achieving prominence as the foundation of a rapidly changing health care system, driven not by systematic reform but by the rapid advance of managed care. The knowledge base to support primary care practice, however, lags far behind after decades of neglect in the headlong rush toward overspecialization. The success of biomedical research in the United States in the last 50 years is due in large part to the network of tertiary care hospitals, where the specialized care of highly selected patients supports broad programs of teaching and research. There are no comparable laboratories, however, for research on the important content areas of primary care. The emergence and success of practice-based research networks over the past decade provide an important infrastructure for careful study of the health and health care phenomena that comprise primary care. Practice-based research networks have made a great deal of progress in methods development and have begun to contribute important information to the primary care knowledge base. They continue, however, to be underfunded and underdeveloped, existing on large infusions of volunteerism by the participating physicians.

The study recently completed by the Institute of Medicine's Committee on the Future of Primary Care will play a critical role in promoting widespread appreciation of the gap in the scientific base necessary to support primary care practice, the need for research in primary care, and the complementary relationship of this body of research and the more traditional biomedical research that has been so well funded.

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In the wake of a failed attempt to reform the health care system, powerful market forces are rapidly expanding primary medical care as the foundation of the United States health care system. The role of the primary care physician in the initial and continuing response to the problems people bring for medical attention has captured the imagination of organized delivery systems in rural, urban, underserved, and overserved areas and is now widely recognized to be the foundation of the health care system. Unfortunately, the majority of illnesses that people experience and for which they seek care remain inadequately characterized and poorly understood.[1,2] The growing awareness of the importance of primary care provides an unequaled opportunity to make a compelling case for the development of a scientific base for primary care practice.

A Scientific Base for Primary Care

The knowledge base that currently exists to support primary care practice simply is not adequate for the challenges faced by family physicians. In the primary care setting, patients present with multiple problems: some are diseases, others are illnesses that may become diseases, and many are neither, yet all are important and can measurably decrease function and quality of life. In all instances, patients experience their problems in the context of their occupation or unemployment, their family and social structure, and the joys and sorrows, successes and

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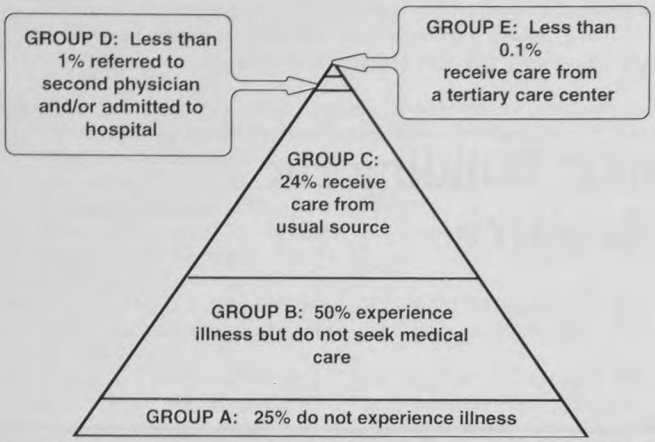

Figure. The "ecology" of health care, first articulated by White et al.[3] Most medical research is conducted at tertiary care institutions, where only 0.1% of patients receive care. Hence, little is known about the problems seen in primary care.

failures, triumphs and setbacks, and the camaraderie and isolation they perceive in their lives. In providing effective care, the primary care physician must balance the use of drugs, education, procedures, community services, reassurance, diet, exercise, counseling, and watchful waiting. The primary care physician must be able to listen actively, communicate effectively, and balance what is possible with the patient's expectation of care, often among a number of competing problems and patient concerns. If primary care is to respond effectively to the problems people bring to it, and to be practiced on a sound foundation of science, the current scope of research in medicine and health care must be broadened. Specifically, it should complement the rich products of biomedical research and provide the full body of knowledge necessary to respond to the health care needs of Americans.

Over the last 50 years, the United States has invested heavily in biomedical research and has built the largest and most productive research program in the world. This investment has contributed many advances in understanding disease mechanisms, and has placed the United States as the leader in advancing knowledge about disease. The products of biomedical research have improved medical practice, but alone are not adequate to guide the practice of primary care. The knowledge base required for primary care practice is more than the mere sum of the subspecialty knowledge bases: further knowledge is needed to inform care for many of the problems patients bring to the health care system.

The limitations in applying biomedical research to primary care practice derive to a large extent from the profound effects of the selection bias inherent in referral practices in the health care system. Several studies[3,4] have demonstrated the "ecology of medical care" and outlined the relationships, which are shown in the Figure. In a given community, approximately 25% of individuals (group A) do not experience an illness during a given month, while another 50% do (group B) but do not seek medical care. Approximately 24% (group C) seek and receive all their care for that episode of illness from their usual source of care, while less than 1% (group D) are referred to a second physician or admitted to a hospital, and less than 0.1% (group E) receive care from a tertiary care center. Yet most medical research in the United States focuses attention and resources on the 0.1% of the population at the top of the pyramid, with an assumption that the resulting knowledge is useful, not only in the practice of tertiary care but in the primary care of people in the community as well.

Knowledge from this 0.1% is useful, but not as much so as commonly believed. Biomedical research has been reductionist, tending to restrict the range of issues under study in several important ways.[1] First, biomedical research isolates single diseases or disease processes. Much research is designed to further understand the biomolecular mechanisms, diagnoses, and treatments of specific diseases. This often requires that the disease be studied in its fully developed form and in patients who do not have other diseases that would confound the study. In many cases, it requires as the focus of study a specific organ, tissue, cell, or intracellular process.

Second, disease is studied in highly selected patients. To focus on a specific disease mechanism or treatment effect, most medical research carefully restricts the characteristics of the patients under study. Studies often emphasize white male patients in their middle years with fully developed disease, without other comorbidity, and in whom compliance can be carefully controlled.

Third, most medical research is designed to evaluate single interventions. Although many clinical trials compare several interventions, they are rarely combined in a single arm of the trial in ways that are actually used in primary care.

Fourth, biomedical research tends to prefer "hard" outcomes, such as death or change in measurable physical indicators. Relatively little attention is devoted to key personal consequences of effective primary care, such as relief of suffering, a sense of having been understood, and the preservation or restoration of function. Furthermore, the strong focus on disease mechanisms of biomedical research often purposefully excludes the effects of the patient's physical and psychosocial environments, the powerful effects of the physician-patient relationship, and the multiple effects of system factors inherent in the organization and financing of health care services. Thus, much of our medical research has focused on a restricted realm

of investigation and thereby has constrained the usefulness of results for the primary care setting.

Practice-Based Research Networks as Laboratories for Primary Care

Our national success in basic biomedical research is due in no small part to a network of over 200 major tertiary care centers, where specialty care, teaching, and research are conducted. These institutions provide the infrastructure for our biomedical research enterprise, providing access to patients and their disease and the technology necessary to describe the diseases that are the focus of the research mission of these institutions. Studying the relevant phenomena of primary care, however, is a logistical challenge. There are no comparable institutions to study the unselected populations and problems that present to the primary care physician.

Conducting research to support the practice of primary care will require a new strategy that successfully unites practice and research in new ways and addresses three immediate challenges. First, we must gain access to the relevant health and health care phenomena of primary care. These include the undifferentiated illnesses that emerge from the community, the patients with these illnesses who present for care, and the settings in which primary care is provided. Second, we must identify and frame the practice-relevant research questions of greatest importance to the work of primary care physicians. This will undoubtedly require a foundation of descriptive knowledge that does not yet exist. Third, we must develop the capacity for conducting research that integrates the wisdom and experience of practicing clinicians with a rigorous and multi-method research approach that answers practice-relevant research questions.

One of the most exciting recent innovations in research in primary care is the development of practice-based research networks that serve as laboratories for the study of health and health care events in the real-world practice settings that characterize primary care. Most of the practice-based research networks also foster a close collaboration among practicing physicians in framing and defining the practice-relevant research questions and in gathering a multidisciplinary research team that brings scientific rigor to the research.

Practice-based research networks have been in existence in other developed countries for a number of years, with substantial governmental support and significant roles in research and disease surveillance. In the United States, practice-based research networks appeared in family medicine as early as the mid-1970s. The early networks included the Michigan Research Network, the Dartmouth Primary Care Cooperative Information Project (COOP), Minnesota Academy of Family Practice Research Panel, Wisconsin Research Network (WReN), and the Ambulatory Sentinel Practice Network (ASPN). More recently, the Pediatric Research in Office Settings (PROs) network has been formed with substantial support from the American Academy of Pediatrics. A recent report[5] counts a total of 28 primary care research networks in North America, of which the majority consist predominantly or entirely of family physicians.

The networks have evolved in different ways and now represent a healthy diversity in several important design features. Most of the networks exist within the organizational structure of professional organizations, although a few exist within academic departments, and others are independent organizations. Strategies for obtaining core funding, the details of which reflect their organizational affiliations, present a major challenge to virtually all the networks. Networks at varying levels of development have established strategies for identifying and seeking funding for their research. Although all networks value the input of their practicing clinicians, the stark realities of funding for primary care research often require innovation and compromise. Details of data collection within the participating practices vary by individual study, but networks have begun to amass a substantial body of experience on methods for collecting, transferring, and managing data, and for ensuring data integrity.

Although specific design features vary, the central characteristics of practice-based research networks remain remarkably constant and include four features. Networks capture health and health care events that characterize primary care in community-based patient populations. They provide access to the practice experience and care provided by full-time primary care clinicians. They focus activities on practice-relevant research questions, use appropriate, multi-method research design, and generally avoid having research methods define the research question. Finally, all networks strive for the systematic involvement of network clinicians in defining the research questions, participating in the study design, and interpreting study results.

Over the past decade, practice-based research networks have matured and are now producing high-quality research on a broad range of clinical and health services topics. The depth of network research is illustrated by the April 1994 theme issue of *The Journal of Family Practice*, which was devoted entirely to work by practice-based research networks. This issue featured original research from eight different US networks, and included topics as diverse as diabetes management, carpal tunnel syndrome,

screening for cervical cancer, and psychosocial problems in primary care.[6–13]

Support for Practice-Based Research Networks

Despite a great deal of success in producing quality research, all research networks share the serious challenge of sustaining an infrastructure capable of recruiting and retaining participating practices, supporting the network, and generating fundable research proposals. Although there is considerable variation in the status of current networks' infrastructural support, all rely heavily on volunteerism for central staff support, the cooperation of participating practices, and investigators who are willing to invest time and energy in pursuing research of interest to their practices.

Estimating true costs of maintaining a network is difficult for most networks, since the financial experience incorporates large infusions of volunteerism and the need to conduct credible research on shoestring budgets. Estimates of infrastructure costs range from $50,000 per year (assuming volunteer directors and researchers) to as high as $500,000 annually for national networks with full-time staffs. Infrastructure costs include such activities as recruiting and retaining participating practices, maintaining current data on participating practices and clinicians, developing strategies for formally and systematically incorporating the wisdom and experience of participating clinicians in the network research agenda, and recruiting appropriate research expertise to produce fundable research proposals.

Conclusions

Practice-based research networks have been shown to be feasible and functional as laboratories for the study of the common and important primary care problems experienced by people in the community. Despite the absence of systematic support for their growth and maturation, this important innovation in primary care research has produced an impressive body of research and now offers unbounded opportunities to further develop the knowledge base of primary care. With cutbacks projected for federal support for primary care research, however, there is great danger of losing the progress that has been made in developing and sustaining practice-based research networks. To sustain momentum at this juncture, several critical pieces must fall into place.

Through its study of the future of primary care, the Institute of Medicine will play a critical role in promoting widespread appreciation of the gap in the science base necessary to support primary care practice, the need for research in primary care, and the complementary relationship of this body of research and the more traditional biomedical research that has been so well funded. The final report of the Institute's study will be published this year.[14]

The federal research agencies must eventually step forward and allocate a reasonable portion of the annual federal investment in health research to support primary care research. Although the research will necessarily include less sensational conditions, it will nonetheless provide information that will benefit most Americans within a relatively short time frame. The predictably slow pace of such a change in public policy requires interim support from private foundations to sustain current progress until more balanced federal support for research is achieved.

In the meantime, the active practice-based research networks must seek new avenues of funding from the health care industry. Although the need to maintain research integrity and an arm's-length relationship has never been more acute, there are areas of potential overlap in the research agendas of primary care physicians and players in the health care marketplace. The unique perspective and opportunities for research on real-world problems that practice-based research networks offer can be very attractive to the health care industry. They are perhaps even more marketable than to the federal research agencies in the short run. For example, there are substantial areas of research in primary care that would seek to describe and improve outcomes for common conditions in which primary care physicians and managed care organizations share a common interest.

Above all, the practice-based research networks must continue to advance their shared knowledge of practice-based research methods, working on shoestring budgets, if necessary. Networks must collaborate by sharing experiences and developing strategies for the unique research methods inherent in network research. Continued success of practice-based research networks will contribute significantly to the development of a knowledge base to guide primary care clinicians in providing care for most of the problems most people experience most of the time.

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