

Potential of Practice-Based Research Networks: Experiences from ASPN

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During the past 20 years, the feasibility of practice-based research in networks has been established in the United States. The initial work of these networks has revealed the need for a better understanding of family practice and the rest of primary care in order to address the challenges facing our health care system. This paper explores the nature, potential, and limitations of

practice-based research networks based on the results of a dozen studies conducted by the Ambulatory Sentinel Practice Network (ASPN).

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There has been an unfortunate misunderstanding about family practice and the rest of primary care, sometimes called in the aggregate "general medical practice." This misunderstanding usually goes unstated, and is one of those largely unexamined assumptions that paralyze us and keep us from moving on until we recognize them. Simply stated, we believe and behave as if the medical specialty knowledge base is of great use in general medical practice. This is the assumption that leads to medical school curricula and continuing medical education programs through which specialists explain to students and generalists what to do when confronted with their specialty's problems. It is this assumption that also leads us to think that the way to improve general medical practice is to summarize the existing knowledge bases into guidelines, and views the principal problem for general medicine as one of dissemination. It is this assumption that allows us to see the local practicing physician as a problem instead of a resource and a solution and it is this assumption that allows us to avoid confronting the need for research in family medicine and the rest of primary

care. All of us who practice know that the specialty knowledge base *is* of use, but it is *overrated* in terms of how useful it is in practice.

While changes in reimbursement curriculum, and physician supply policies are all necessary, they are insufficient to correct our health care system gone awry. They must be accompanied by progressive thinking about the nature of health and disease and specifically about a not-yet-achieved union between science and general medical practice. We need more, not less, science in frontline practice, and we need to consider other ways of knowing if we are to achieve the task of medicine, ie, solving our patients' problems.

It is this unmet need to understand and improve general medical practice that has inspired the resurrection of practice-based research and the establishment of networks, such as the Ambulatory Sentinel Practice Network (ASPN),¹ the Pediatric Research in Office Settings (PROS) network,² the Dartmouth Primary Care Cooperative Information Project (The COOP),³ the Wisconsin Research Network (WReN),⁴ the International Primary Care Network (IPCN),⁵ and others.⁶ The need for a better understanding of general medicine and the potential to improve practice while containing or reducing health care costs are evident in the initial work of practice-based research networks. Some of the results from the Ambulatory Sentinel Practice Network exemplify the nature, potential, and limitations of such networks.

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A Description of ASPN

The Ambulatory Sentinel Practice Network of North America is the oldest national practice-based primary care research network, with collaborating practices in the United States and Canada. It was created in 1978 to study problems as they present in the primary care setting and to increase the knowledge base regarding the practice of primary care medicine. At the end of 1993, ASPN consisted of 72 practices in 32 states and 4 Canadian provinces and had conducted 29 studies. These practices are composed of 343 clinicians who provide care for approximately 350,000 patients, representing approximately 800,000 visits per year. There is a rural predominance in ASPN. Most of the practices are community-based, with a primary mission of serving their patients. Most of the ASPN clinicians are family physicians, but the network includes and involves internists, pediatricians, nurse practitioners, and physician assistants as well. These clinicians meet annually and communicate via newsletters and other meetings to determine the network's direction and activities. Efforts are under way to increase the network practices to 125, with a recruitment emphasis on practices that serve racial and ethnic minority populations as well as those in relatively underrepresented regions of the United States and Canada.

In addition to data collection for specific research projects (eg, surveys, blood specimens), ASPN routinely collects and maintains data in four areas of network operations. First, all ASPN practices annually submit a report, which describes their active patient population, defined as patients seen by an ASPN practice during the previous 2 years. The current age and sex distribution for all ASPN practices combined has been compared with that of the US population, and no significant differences have been found for any category. Second, on a quarterly basis, ASPN collects data that update the characteristics of the practices and individual clinicians in ASPN. This permits not only accurate description of the network and its practitioners but also relevant trends over time. Third, since 1991, ASPN has replicated the National Ambulatory Medical Care Survey (NAMCS) in all practices and instituted a policy that requires NAMCS in all practices joining the network. Finally, ASPN practices report data on specific topics on a "weekly return card." This mechanism provides two types of denominator information: portion of the week during which the practice was available to its patients, and the total number of encounters during the week. At any given time, the "weekly return card" also provides current data on two or more specific topics that are under study by the network.

Examples of Practice-Based Investigations from ASPN

Headache

ASPN began its research in 1982 with three simultaneous surveys, using the weekly return card as the data collection instrument. One of the first studies was a description of visits in which headache was discussed. One hundred twenty clinicians in 38 practices in the United States and Canada reported 4940 visits involving 3847 patients.⁷ From these patients, 1331 individuals with new headache were identified and organized for a separate analysis.⁸

This simple survey confirmed that many people saw their doctor for headaches (1.5% of visits in ASPN), approximately half of these headaches were new, and half were judged by the clinician as severe or disabling for the patient. The greatest burden of headache involved people aged 15 to 44 years. For more than 70% of headache patients, the clinician had only one opportunity to evaluate the problem and did so with few investigations. Only 1 in 20 of these patients was referred. Approximately half of the patient visits for important headaches led to a diagnosis of something other than tension or migraine headache, and 1 in 8 did not fit into any specific diagnostic category. Two thirds of patients received advice and three fourths received medication. Almost half of the patients who visited a second time presented a different combination of symptoms that were likely to be diagnosed as more than one type of headache. More than three fourths of patients presenting with a new headache were managed without any diagnostic tests, and only 2% had a computed tomography (CT) scan at first visit. This observed use of CT scans contrasted with the contemporaneous recommendations of the National Institutes of Health (NIH) consensus panel. When applied to the entire US population, an estimated \$2 billion worth of additional CT scans would be required per annum to meet these NIH recommendations.

Recognizing the lack of useful information to guide family doctors in their use of CT scans to evaluate patients with headache, ASPN clinicians decided to examine how family doctors use CT scans to detect serious intracranial disorders.^{9,10} Fifty-eight practices conducted two concurrent descriptive surveys. One began with the decision to evaluate patients with a headache with a CT scan ($n = 339$ scans), and the other started with patients with a new diagnosis of intracranial tumor ($n = 25$), subarachnoid hemorrhage ($n = 17$), or subdural hematoma ($n = 8$). These investigations confirmed that approximately half of the patients with subarachnoid hemorrhage (SAH) or tumor complained of headache,

and only one third had other symptoms or signs suggesting a neurological problem. Because ASPN clinicians were concerned about possible diagnostic delays, ASPN focused on some 250,000 patients and 400,000 potential patient-years of observation to learn that at least four patients with brain tumors had a diagnostic delay of 1 month or more and at least three patients with SAH had a delay of longer than 2 days from first headache visit to CT scan. Interestingly, two of the three patients with SAH had a delay in diagnosis because of false-negative CT scans. An unexpected observation for patients undergoing a CT scan was that one in six scans was interpreted as having an abnormal radiographic finding. Most of these findings were of questionable clinical significance, resulting in unnecessary concern for both family doctors and their patients.

When considered together, these descriptive surveys suggest that the routine use of CT scans for initial investigation of many patients with headache, instead of the selective approach used in ASPN, would increase health care costs and could lead to adverse effects with little additional benefit.

Spontaneous Abortion

Forty-nine practices in 18 states and 4 provinces conducted an observational study with subsequent chart audit of usual care for 171 miscarriages.¹¹ This simple descriptive study showed that 40% of miscarriages were managed entirely in the office setting or at home, and, in contrast to recommendations for management at the time of the study, in standard texts, only half were managed with dilation and curettage (D&C). One woman in eight had a subsequent D&C after initial management. These were women for whom an initial decision to avoid D&C proved untenable. The decision to perform D&C centered on a clinical judgment about bleeding and pain. Controlling for gestational age, there were no differences in complications at follow-up between women treated with and without D&C. Apparently, family doctors can selectively manage women who miscarry and achieve similar results with or without D&C. Perhaps the most important information resulting from this study was the finding that the greatest morbidity associated with miscarriage recognized by clinicians was not infection or hemorrhage, but psychological distress. We still know relatively little about the psychological impact of this frequently occurring loss.

Pelvic Inflammatory Disease

Thirty-eight practices in 16 states and 2 Canadian provinces conducted an observational study of the usual pri-

mary care of women thought to have pelvic inflammatory disease (PID).¹² This study focused on 384 first visits for PID and confirmed that the clinical picture of what is called PID in family practice is less severe than that reported in most published series, with fewer women having fever, masses, and extensive tenderness. Forty-three percent of these women met contemporaneous recommendations for hospitalization, but only 9% were admitted. Some observers might interpret this lack of hospitalization as mismanagement that could be a factor in the infertility epidemic. However, contemporaneous National Ambulatory Medical Care Survey (NAMCS) data revealed that the admission rate observed in ASPN for women who were perhaps less ill was slightly higher than the rate reported for obstetricians and gynecologists included in the NAMCS. This study revealed again the enormous financial implications of adhering strictly to guidelines for practice: bridging the gap between practice and guidelines would cost the US health care system about \$1.2 billion per annum. To date, there are no adequate guidelines for the management of PID in the general medical setting.

Chest Pain

One hundred nine clinicians in 37 practices located in 18 states and 3 Canadian provinces reported their usual care of 832 nonhospitalized patients with chest pain.¹³ This sample of patients confirmed that chest pain remains a complex problem of adults and is a common problem for the family doctor in the office. Only 4% of the patients with chest pain were seen in the emergency room, 7% were referred, and 7% were admitted to hospital. Almost two thirds of all diagnoses were accounted for by three categories: angina, nonarticular chest-wall pain, and pain presumed to be of gastrointestinal origin. As would be expected, diagnoses differed significantly by age, sex, and race.

This exploratory study found several promising areas for further investigation, including a previously unreported high frequency of costochondritis in black women, the disproportionate use of electrocardiograms (ECGs) in the evaluation of patients thought to have psychosomatic pain or pain of gastrointestinal origin, and considerable clinician uncertainty in the management of patients with chest pain thought to be of gastrointestinal origin. Regardless of diagnosis, there was approximately twice the level of consultation, hospitalization, and ECG-ordering when the clinicians reported a tentative diagnosis. Particularly notable was a discordance between ASPN clinicians' perceptions of their own and their patients' level of concern in 43% of patients. When the clinicians believed their own level of concern differed

from that of their patients, patients were perceived to be more concerned than the clinician 80% of the time, and in the remainder, the clinician was more worried, usually about angina or myocardial infarction. It is unknown how this perception of discordance affects the management of chest pain in general medical practice.

Otitis Media

Several national practice-based research networks united to study usual care of otitis media by family doctors in Australia, Belgium, Great Britain, Israel, the Netherlands, New Zealand, Canada, Switzerland, and the United States.¹⁴ Participating clinicians reported up to 15 consecutive patients with presumed otitis media. This descriptive study involved 3224 patients and indicated that the proportion of patients prescribed antibiotics varied greatly among the countries, from 32% in the Netherlands to 98% in Australia, New Zealand, and the United States. The duration of typical antibiotic use also varied by country from 5 to 10 days. With an 84% follow-up rate and only limited survey data as an outcome measurement at 2 months, outcome was not associated with diagnostic certainty, and patients not given antibiotics reported a higher rate of recovery than those who received them. Changing the duration of antibiotic (ampicillin) treatment from 10 to 5 days in the United States would reduce national health care expenditures by an estimated \$50 million per annum.

This study also examined day care as a risk factor in otitis media.¹⁵ A history of recurrent acute otitis media, poor hearing, and tonsillectomy or adenoidectomy all occurred more frequently in children aged 2 to 5 years who were in day care, compared with those cared for at home. Day care children with clinical presentations not different from those of other children were brought to their physicians more promptly after the onset of symptoms and received more referrals to otolaryngologists at the time of the initial visit for acute otitis media. Day care seems to pose a significant risk for otitis media and its adverse consequences, and it may have more impact on otitis media than our medical treatment.

Approximately 15% of the patients with otitis media in this international study were adults, allowing the first report of acute otitis media outcomes comparing adults and children.¹⁶ The spectrum of tympanic membrane findings was similar in adults and children, but in adulthood, almost 60% of otitis media patients were women. Adults were more likely to present with ear pain, sore throat, discharge from the ear, and a history of tonsillectomy and adenoidectomy than were children, and adults sought medical help more quickly, with more than 95% receiving treatment within a day of symptom occurrence.

Increasing age was associated with decreasing frequency of recovery from acute otitis media 2 months later, especially in patients aged 25 years and older. Previous episodes appeared more predictive of poor outcome for adults than for children. Adults receiving oral antibiotics at the initial visit had lower rates of recovery than those not receiving antibiotics, and neither antibiotic type, duration, nor interaction of type and duration were significantly related to outcome. Individual patient characteristics, such as past history, were better predictors of outcome than therapy.

Human Immunodeficiency Virus

Using the practices' age and sex data and the results of a telephone survey of 65 practices in urban and rural settings, ASPN learned that at the end of 1987, the acquired immunodeficiency syndrome (AIDS) was at least as prevalent in the primary care practices of ASPN as would be expected using national estimates for the population at-large.¹⁷ All recognized cases had at least one risk factor, and patients with human immunodeficiency virus (HIV) infection were reported by both urban and rural practices.

ASPN subsequently collaborated with the Centers for Disease Control and Prevention in an investigation designed to estimate the seroprevalence of HIV-1 infection in individuals seeking medical care in 44 ASPN practices and for whom blood was drawn for clinical purposes as part of usual care. This blinded, anonymous study, which linked selected epidemiological information to the results of blood tests for HIV-1 antibody, included as of December 1990, 9076 blood specimens. Limited to persons aged 15 to 49 years and adjusted for practice population and sample size, the rate was 2.3 per 1000 from June 1989 through December 1990.¹⁸ This result was similar and consistent with other surveillance data from hospitals, job corps entrants, military applicants, first-time blood donors, and mothers of live infants. Of 25 individuals positive for HIV, 10 were not recognized as HIV-positive by the clinician and 8 were not known by their clinician to be at risk for HIV. Stated differently, 1 in 1000 ASPN patients was infected without recognition, and furthermore, family doctors were usually unaware that the patients had any risk factors for AIDS.

Cough

Curiosity among ASPN clinicians about how acute bronchitis is diagnosed in primary care led to a study in which 47 practices prospectively reported usual care of 1398 children up to 14 years of age with a cough, using the

weekly return method of data collection.¹⁹ Most of the children in this study were not seriously ill, and less than 1% were hospitalized. Three fourths of these children had been coughing for a week or less, and most were diagnosed as having bronchitis, viral upper respiratory tract infection, otitis media, or asthma. However, in the stated opinion of ASPN clinicians, the parent expected the child to receive an antibiotic in 215 of these children. In these instances, parental expectation for an antibiotic prescription doubled the likelihood of a diagnosis of bronchitis and was surpassed only by the physical finding of rales in its influence on that diagnosis. On the other hand, parental expectation of treatment with an antibiotic reduced the probability of a diagnosis of viral upper respiratory tract infection. These effects persisted when the influence of other variables was controlled for by logistic regression. It appears that parental expectation must be considered as another potential determinant of diagnostic and prescribing patterns in general medical practice.

Carpal Tunnel Syndrome

ASPN collaborated with the National Institute of Occupational Safety and Health to conduct a cohort study describing how patients thought to have carpal tunnel syndrome (CTS) present to primary care clinicians, and how they are initially evaluated and managed. Clinicians in 74 practices in 30 states and 3 Canadian provinces reported on 552 patients, with data collected using the weekly return method, visit check lists, and patient questionnaires.²⁰ Most CTS cases occurred among women, many of whom were homemakers and thus would not have been identified as having an occupationally related condition. The highest incidence of CTS was among rural practices. However, in this survey, patients with CTS were more likely to be technical sales and administrative workers than operators and laborers, possibly reflecting the use of computers in the workplace.

While 6% of patients experienced significant occupational difficulties during a 4-month follow-up, in most instances this condition was successfully managed by ASPN clinicians. They did so without much initial testing or referral, using readily available, relatively inexpensive interventions. Treatment was generally conservative, consisting of splints and nonsteroidal anti-inflammatory drugs. More than 90% of these patients were managed without a change in employment status. This study exemplified aspects of the special selection biases of general medical practice and again focused attention on classification biases that could lead to overtreatment of what may be a self-limited condition.

Some Advantages and Limitations of Practice-Based Networks

Results such as these reveal a dynamic interaction among doctors, patients, and illness, and suggest that there is much to be learned through careful examination of the problems people bring to their family doctors and of what happens with these problems with and without treatment. It is difficult to imagine how these problems and their management can be identified and investigated independent of the practice setting. Of course, there are both advantages and limitations to practice-based research, specifically in networks.

Among the advantages of practice-based research networks, three stand out. The first is access to phenomena often neglected by researchers but of great importance to many people. With attention to the special selection and observer biases of general medical practice, investigation of these phenomena enhances the opportunity to generalize results to practice. The second is raw power. It is possible to enroll a few hundred patients in any given week in an investigation that might span a career in a single practice. The third is an efficiency analogous to that inherent in a reusable space shuttle. The same network can conduct multiple studies about various questions, sequentially or concurrently.

These three advantages coalesce and produce a synergism that results in a merging of the practicing and academic communities. This synergism links questions from practice to answers from practice that are applicable in practice—a scenario in which the practicing clinician emerges as a solution rather than a problem.

One of the major concerns about research based in practice settings is the completeness and accuracy of reporting. While there is no definitive, permanent response to data quality, experience to date is encouraging. For example, during the first 5 years of operation, 90% to 100% of eligible practices participated in the studies conducted in ASPN. The poorest participation level was a 3-month period in 1985 when only 86% of the total possible weekly reports from practices were received. The most complete reporting rate was 98% for a quarter in 1987. For practices that commit to a study, 92% to 95% reporting has been typical.

The accuracy of practice reporting was assessed using data from ASPN's miscarriage study.²¹ Two individuals in each practice audited the information for each reported patient, comparing the study data with that of the medical record. The overall error rate was 4.5%, for a total of 106 errors out of a possible 2361. Seventy percent of these errors came from 5 of the 34 participating practices, and 66% of the records were error free. An unexpected finding of this audit was that 24% of the

miscarriages were not reported in the medical record. One question this raised pertains to the medical record as a gold standard in practice-based research. It is possible that the eyewitness report of clinicians at the time of a critical clinical event, such as miscarriage, should be the standard for the medical record.

During the developmental years of practice-based research networks, questions of generalizability have been considered as another key methodological issue. While the networks themselves are an approach to improving the general applicability of knowledge to practice, they are inherently unusual. Perhaps results from networks such as ASPN are not representative of "usual" practice and, therefore, are of questionable value in assessing or influencing the full scope of practice. There are many ways to characterize practice, clinicians, and patients, and, of course, there are various methods available to adjust data and analyze results.

Random surveys are another means of assessing how a research network compares with "usual" practice. ASPN replicated one such survey, the National Ambulatory Medical Care Survey, to compare patients and practices in ASPN with those of general and family practices included in NAMCS.²² This survey revealed substantial similarities between the patients and practices of the family physicians in ASPN and those of the general practitioners and family physicians in the United States. Similarities included the distribution of patients by age and sex and the proportions of patients covered by Medicare and Medicaid. The populations served by both groups were almost entirely self-referred, established patients. Patients seen by both ASPN and NAMCS physicians had broad and diverse reasons for consulting a doctor, and the most frequent reasons for visits were remarkably similar. The frequency and distribution of diagnoses were also similar, with only a few differences among the top 20.

ASPN and NAMCS family physicians were also alike in the services they provided for patients. Both groups of physicians provided similar therapeutic and diagnostic services, and both used more diagnostic tests for female than for male patients. Medications were used with similar frequencies. Dispositions were virtually identical, including referral rates, hospitalizations, and expectations of follow-up care. The average face-to-face time spent with patients as reported by ASPN and NAMCS physicians was the same. There were, of course, some differences. For instance, ASPN practices delivered more preventive services and pregnancy care, and recognized more psychological problems.

Overall, these comparisons indicate that ASPN represents a relevant laboratory in which to pursue the description of practice and investigate various questions

about contemporary general medical practice in the United States. This conclusion probably applies to other networks as well.

Conclusions

For general medical practice to meet the expectations of medicine and society, it must be able to receive and organize the full spectrum of problems people bring to physicians and to respond definitively to most of the problems most of the people have most of the time. The old assumption that the knowledge base for specialty medicine is appropriate and sufficient for general medical practice is wrong. There is much to be discovered in general medical practice about the maintenance and promotion of health, origins of illness, prediction of clinical significance, recognition and treatment of problems, relief of the incurable, and interactions among people, their environment, and time.

Practice-based research networks are now known to be a feasible approach to gaining access to the relevant phenomena of general medical practice, and their work so far has begun to stake out a territory that merits exploration, definition, and development. This frontier of medicine represents the intellectual challenge of general medicine and specifically invites present and future family doctors to accept the challenge of discovery that will revitalize general medical practice. The new knowledge that comes from practice-based research will not find application to only a few with fully developed or perhaps unusual disease. It will benefit virtually everyone.

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