Fourth Annual Nicholas J. Pisacano Lecture

The Doctor, the Patient, and the Home: Returning to Our Roots

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I feel honored to be giving the Pisacano Lecture. I met Dr. Pisacano only once, but I have a vivid recollection of that meeting. It was in 1964, when I was a young general practitioner and a Nuffield traveling fellowship gave me and my family the opportunity of spending 6 months in the United States. I was interested in the development of general practice as an academic discipline, and among the places I visited was the new medical school at Lexington, Ky, where Dr. Pisacano was a member of the Department of Medicine. Dr. Edmund Pellegrino—the first Pisacano lecturer—was the professor of medicine. They were exciting days. The foundations of academic family medicine were being laid, and Dr. Pisacano was one of its pioneers. With his devotion to the art of medicine, I feel sure he would have approved of my topic: the care of patients in the home.

When family physicians of my generation entered practice, attending patients in their homes was an important aspect of our work. Part of each working day was devoted to home visits. In the 1950s it was a necessity. Where I practiced, many families did not have cars or telephones. There were epidemics of measles, mumps, and influenza. Chronically sick patients were cared for largely at home, and there was no expectation that dying patients would be admitted to the hospital. About one half of the deaths in my practice were at home.

Home visits were a necessity, but it was one we tried to keep under control. In a rural practice, a single visit to a distant village could wreck one's working day. Patients were accepted in the practice only if they lived within its geographic limits. It was understood that only those requesting visits by 10:00 AM would be guaranteed visits on that day, except for cases of urgency. In this way we did our best to allocate our time between office, home, and hospital. It was not the most efficient use of our time, and it was sometimes a chore, but in many ways it enriched our lives.

It is difficult to express in words the difference between knowing patients by their visits to the office and knowing them as a visitor to their homes. The home is where a family's values are expressed. It is in the home that people can be themselves. The history of the family—its story, its joys and sorrows, its memories and aspirations—are there on the walls. What one can learn in the home is often of real practical value. For this reason assessment in the home is different from assessment in the office or the hospital. Instead of asking about activities of daily living, we see patients in their own bedroom, bathroom, and kitchen, climbing their own stairs, and so on. When we review the medications, we can assemble them all—including those from the bathroom cabinet—by the bedside or on the kitchen table. We can sense for ourselves either the peace or the tension in the home. We can meet with the family on their own ground, where they are most likely to express their feelings. In the home the patient can be in control of his or her own care, and this can be a powerful influence on healing.

The word ecology is derived from the Greek word *oikos*, meaning home, so ecology is the study of living things in their environmental home. A family physician who works in the home is a practicing ecologist, which is why I prefer the term home visit to house call. A family creates a home

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out of a house, and it is the home that we enter as visitors. Knowing patients in their homes is not only an enrichment of our knowledge, it can also be a deeply affecting experience. Some of my most poignant experiences in medicine have been in the home, many of them in caring for dying patients and their families.

For many reasons home care and home visits by physicians declined steeply after the 1950s. The information systems and medical technologies of the 1960s and 1970s favored concentration of patients in hospitals. Radiology, pathology, intravenous therapies, and monitoring techniques required cumbersome equipment. Even in the 1950s, although mobile x-ray and electrocardiogram (ECG) units were available, and blood could easily be taken for the laboratory, information could not be rapidly transmitted over a distance. With paper as the medium, it made sense to concentrate a seriously ill patient's record in one place—the hospital. Hospital beds were plentiful. Many physicians came to believe that the hospital was the only place to treat the sick patient. This belief was expressed by two sayings that were often heard at the time: "If a patient's too sick to come to the office, he's sick enough to be in hospital," and "You can't practice good medicine out of a little black bag." I never thought that either was true.

During the 1980s, the trends began to change, driven by economic and social forces and by new medical and information technologies. Hospital length of stay was much reduced, partly a result of the drive for efficiency and partly a result of new surgical techniques and changing approaches to rehabilitation. The hospice movement made it possible for more patients to die at home. The new technologies favor dispersal of patients rather than concentration. Point-of-care information systems can monitor patients in the home and transmit the data to a distant nursing station. Nurses and physicians can enter and access data to or from an integrated patient record through a laptop or hand-held computer or through a computer in the patient's home. Interactive video enables patients, caregivers, physicians, and nurses to see and talk to each other across a distance. New portable technologies include subcutaneous infusion pumps for insulin or opioids; intravenous pumps for antibiotics, chemotherapy, and parenteral nutrition; tools for self-monitoring blood glucose and blood pressure; bedside blood biochemistry; pulse oximetry; and respirometry and respiratory support. Intravenous therapy is the fastest growing sector of home care.

Table 1. Characteristics of Patients Receiving Care From Home Health Agencies and Hospices in 1992.

Characteristics	Home Health Agencies	Hospices
Daily census of patients (no.)*	1,237,100	47,200
Mean age (years)	70	71
Most frequent first-listed admission diagnosis		
Heart disease (%)	12	10
Diabetes mellitus (%)	8	
Arthropathies (%)	6	
Cancer (%)	6	65
Cerebrovascular disease (%)	6	
Average duration of service (days)	94	60
Died while receiving care (%)	8	91

Data from the National Center For Health Statistics 1992 survey of home-health agencies and hospices. MMWR.[1]
*Estimated number of patients receiving care on any one day.

Advanced technologies, however, do not account for most admissions to home care. The first National Home and Hospice Care Survey, conducted by the National Center for Health Statistics in 1992,[1] reported that the most frequent first-listed admission diagnoses in home care patients were heart disease, diabetes mellitus, arthropathies, malignant neoplasms, cerebrovascular disease, essential hypertension, and fractures. These accounted for 46 percent of all first-listed diagnoses (Table 1). The average patient age was 70 years, and 75 percent were aged 65 years or older. The most common service provided was skilled nursing (80 percent). Sixty-five percent of hospice patients were admitted with a diagnosis of malignant neoplasms, and 10 percent with a diagnosis of heart disease. Eighty-seven percent of hospice patients received care at home, and 91 percent died while receiving hospice care. The average age was 71 years, and 77 percent were older than 65 years. As with home care patients, the most common service provided was skilled nursing (86 percent). Most of home care is conventional clinical medicine and nursing, not

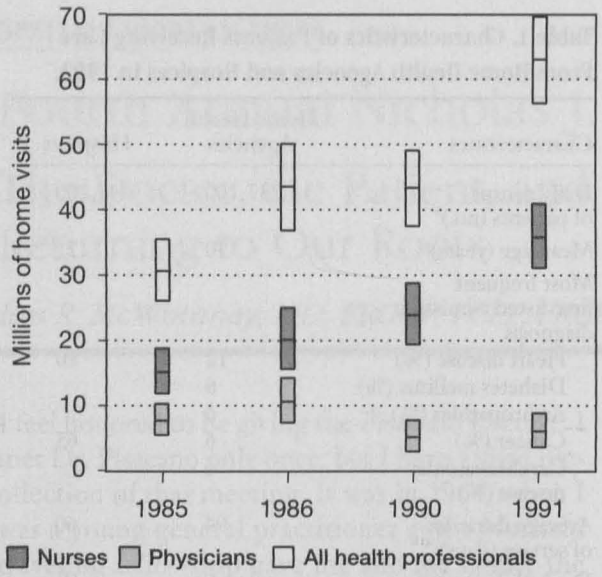

Figure 1. Home visits by health professionals, 1985-1991.

From the National Health Interview Survey.[2-5] Boxes show mean and 95% confidence intervals.

Note: Analysis of visits by nurses and physicians carried out in the Centre for Studies in Family Medicine on data supplied by the National Center for Health Statistics.

advanced technology. Although conventional, it is not straightforward. In the elderly, multiple morbidity is common, and clinical care is often complex and challenging. Many home care patients are, in fact, the patients we used to visit every day in hospital.

Home health care is the fastest growing segment of the health care system. Home visits by nurses have greatly increased since 1988, but visits by physicians have not increased at all. The US National Health Interview Survey (NHIS)[2,3] records home visits by health care professionals, enabling us to follow the trend year by year. The National Center for Health Statistics does not break down visits by health discipline, but we obtained the tapes from the National Center for Health Statistics and carried out a more detailed analysis at the Centre for Studies in Family Medicine. Analysis of the NHIS data for the years 1985, 1986, 1990, and 1991 shows a doubling of home visits by health care professionals from 31 million in 1985 to 63.6 million in 1991 (Figure 1). Visits by nurses increased from 15.4 million to 36.5 million. Home visits by physicians were not significantly different at 8 million in 1985 and 6.7 million in 1991. So this big increase in home care has taken place without any change in the practice of physicians. A national questionnaire survey of physicians in 1991 showed similar results. Family physicians made an average of only 21.2 home visits per year and 35 percent did not make any.[6]

The Consequences

If we continue on this course, I believe there will be serious consequences for our patients, their families, and ourselves. By distancing ourselves from our homebound patients and their families, we withdraw our support at a time when they are most vulnerable and in need of it. Caring for a relative with serious illness at home can be a devastating experience. Families come to expect that we will be there for them. Too often we either break the relationship or become a distant voice on the telephone or an occasional visitor. Patients and families who are abandoned in this way often have a sense of betrayal. We have defined our discipline in terms of relationships, and continuity of care is one of its cornerstones. How can we hold our heads up in the world when we fail to honor this commitment?

By distancing ourselves from homebound sick patients, we also forfeit the respect of our colleagues in nursing. They rely on us for our support, our clinical skills, and our knowledge of patients and their families. In difficult cases I think they welcome our leadership. If we are not available to them, patients are too often transported to an emergency department and returned home after an assessment that could easily have been done in the home. In the worst cases, dying patients are taken by their anguished, unsupported families to an emergency department, when all they need is the comfort and reassurance of the physician's presence.

I am concerned, too, for the consequences to ourselves. Our role in hospitals is changing from that of attending physician to that of providing collaborative, supportive care. Even that care might not be remunerated by some paying agencies. If we withdraw also from home care, what will happen to our clinical skills in the management of seriously ill patients? I suspect our skills will decline, and we will lose the self-confidence we need to take our place as a leading member of the home care team. Much of what we do in the office can be done by others. If we lose the clinical skills that define us as physicians, what will become of us?

Some Fallacies About Home Care

Some believe that home care can be given quite adequately by nurses, without major involvement by physicians. It is true that nursing has responded very well to the challenge of home care. Home nursing has a long tradition on which to build. Nurses are effective coordinators, administrators, and managers. Many nurses have mastered the new technologies, developing special skills in such fields as intravenous therapy, ostomy care, palliative care, and care of the aged. Nurses are accustomed to working as team members. It is said, however, that nurse practitioners with skills in clinical assessment will be able to replace physicians in most cases, which I believe to be a fallacy. Physicians spend at least 5 years learning clinical skills in clinical clerkships and residency training. For nurses to become equally skilled would require major changes to the nursing curriculum. Eventually, I suspect that nurse practitioners would be redefined as physicians, as was the case when apothecaries, filling an increasingly medical role in 19th century Britain, were redefined as medical practitioners.

It is not in anybody's interest for nurses to replace physicians in this way. The value of teamwork lies in the differences between the professions. Nursing and medicine have different skills and different values. When these are integrated, the result is an increment of care, a level of care that is different from the sum of nursing and medicine. We have so much to learn from each other if only we can work together. This effort should not become a struggle for control. It is very appropriate for nursing to play the leading role in home care, but there is also a need for collaborative medical leadership, and I believe leadership would be warmly welcomed by nursing professionals.

The revolution in communication technology leads some to believe that the physician's presence in the home will seldom be necessary. We can talk to the patient and the patient's caregivers through interactive television. The camera can show us the patient's facial expression, movements, skin, mouth. We will soon be able to palpate a patient electronically without being present. We can transmit the heart and lung sounds and download the ECG tracing, laboratory results, and mobile imaging reports from our computer. Why would we need to visit? Already such systems are reducing nursing visits, especially in rural areas. That they enable us to use our resources more efficiently is all to the good, but to think that they can replace our physical presence in the home is a fallacy.

What price will we pay for practicing medicine without touching our patients? The physical examination is more than a search for clinical data: it is one way we express our care and respect for the patient's body. Touch reaches out to the loneliness and isolation of the sick. Gentle touch—stroking or hand-holding—calms and soothes the anxious and troubled mind. Touch can reach us emotionally in a way our other senses cannot. When we are affected emotionally, we say we are touched. We describe a person who is sensitive to feelings as tactful. Touch can break through a person's defenses, leading to new levels of insight and integration. For the aged, touch has a special meaning. Eyesight will fade, the hearing can fail, but feeling remains. In those who are aged and lonely, there is often a deep yearning to be touched. "... In every branch of the practice of medicine, touching should be considered an indispensable part of the doctor's art."[7]

Visiting the home is not a purely utilitarian act. There is a deep symbolism in the home visit. A home visit is an act of humility. It says, "I care enough about you to leave my power base in my office or the hospital and come to see you on your own ground." The symbolism is especially strong in the care of the dying. What will happen to us if we no longer attend our patients when they are dying, one of the defining experiences of our profession? I sometimes hear colleagues say, "I go if it's necessary" or "I go if they call." We forget that anguished caregivers often find it impossible to articulate their needs. Often what they need is simply our presence, but how do they say that? That people sometimes find it safer to express feelings on the Internet than face-to-face might seem to reduce the need for physical presence. I draw the opposite conclusion. To me, it is not so much an indication of the superiority of the wired world as a tribute to the power of presence. "There is," writes Sven Birkerts,[8]

> ... a tremendous difference between communication in the instrumental sense and communion in the affective, soul-oriented sense. Somewhere we have gotten hold of the idea that the more all-embracing we can make our communications net-

> works, the closer we will be to that connection we long for deep down. For change us as they will, our technologies have not yet eradicated that flame of a desire—not merely to be in touch, but to be, at least figuratively, embraced, known and valued not abstractly but in presence. We seem to believe that our instruments can get us there, but they can't. Their great power is all in the service of division and acceleration. They work in—and create—an unreal time that has nothing to do with the deep time in which we thrive: the time of history, tradition, ritual, art, and true communion.

The long-term effects of new technologies give us many surprises. The sewing machine, heralded as the liberator of women, became an instrument for their exploitation in the sweatshops of our cities.[9] We have no way of predicting the long-term effects of communication technology. As we reap the benefits of the new technologies, we would be wise to keep to some of our old ways, not set ourselves adrift on uncharted waters.

Alternative Models

There are those who doubt that family physicians can handle both office and domiciliary practice, as they have in the past. A new primary care medical specialty is proposed, devoted entirely to home care. If we, ourselves, do nothing to fill the need, I expect that such will come to pass, but I cannot believe that it will be good. We define family medicine in terms of relationships, and continuity in the patient-doctor relationship is one of our core values. How can we justify breaking our long-term relationships with patients whenever, in sickness or old age, they become housebound?

There are those also who envision home care being provided by nurse practitioners, with the backup of hospital-based specialists. If family physicians, general internists, and pediatricians do not meet the need for home care, this could become the dominant model. I doubt whether it would work well. Hospital-based specialists' patients are usually dispersed over a wide area, making it difficult for practitioners to make home visits. Patients can be transported to the hospital when they need medical assessment, but I cannot believe that this standard of care will continue to be acceptable. Moreover, more than one half the patients receiving home care are older than 65 years. In this age-group, co-morbidity is common, and it makes sense for the attending physician to be a generalist. In most cases, the appropriate role for the specialist is that of consultant rather than primary care physician.

What We Need to Do

We have a long tradition of home care in family medicine, and it is still kept alive by those family physicians who understand its importance, but that is not enough. I believe the time has come for our discipline as a whole to reaffirm its commitment to home care. Of course, we cannot put the clock back to the 1950s, nor would we wish to. The world has moved on. Even the question, "Do you make house calls?" has little meaning now. Making one or two home visits a month is neither here nor there. The question is, "Can you work as a member of an integrated team caring for your patients at home?"

What are the implications for us? First, it means being proactive rather than reactive in home care. A reactive physician does nothing except by request. Home visits are made only on request; drugs are ordered at the nurse's request; telephone calls are returned but not initiated. A proactive physician does an assessment in the home, develops a plan of management with the nurse, schedules regular visits, initiates telephone calls. Being proactive means being available for unexpected problems and emergencies, either in person or through a deputy who can provide the same level of service. It means being clinically competent and up-to-date with new home care technologies and conversant with community resources and how to deploy them. I think we will also need to give thought to the geographic distribution of our practices. Limiting our practice to a neighborhood could have other benefits, strengthening our link with the community and making us ecologists in yet another sense.

These conditions are hard, and although many of these services are not well remunerated, the best way of getting the attention of paying agencies is to do the job well. Some aspects will be difficult for individual physicians to accomplish by acting alone. We are dealing with new institutions, and we will need to relate to them through new organizations of physicians at the local level, just as we relate to hospitals through the organized medical staff. It is through such organizations that we can maintain standards of care, com-

municate with management, provide in-service education, arrange on-call rotas, and deal with geographic dispersal of patients. Many models are available for study and are often referred to as hospitals in the home or extramural hospitals.[10,11]

This approach is a big challenge for our academic departments and residency programs. Can we provide a learning environment in which residents can acquire the skills of home care and experience the joy of this aspect of practice? Can we provide leadership in research and development in this rapidly growing and changing field? I think it is of the utmost importance that we do.

Gordon Doig analyzed data from the National Health Interview Survey, Lynn Dunikowski did the literature search and traced sources of information, and Leslie Meredith prepared Figure 1.

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