

Testimony for the IL Senate Special Committee on Medicaid Reform
December 21, 2010

Anne Scheetz, MD, FACP
2417 West Medill Avenue, Chicago IL 60647
773-486-6276

Speaking for Physicians for a National Health Program, IL Chapter

Board certification:

Board Certified in Internal Medicine with Added Qualifications in Geriatric
Medicine

Professional society memberships (for identification purposes only):

American Academy of Home Care Physicians
American College of Physicians
American Geriatrics Society

Additional membership (for identification purpose only):

Chicago End of Life Care Coalition

Hospital staff memberships:

St. Joseph Hospital, Chicago: LOA from August 31, 2010
Mercy Hospital, Chicago, Emerita

Thank you for this opportunity to testify.

My name is Anne Scheetz. I am a physician with more than thirty years experience providing primary care in the city of Chicago and nearby suburbs. Until my retirement at the end of August, 2010, I specialized for nearly twenty years in the care of the frail elderly. Throughout my thirty years of practice, I made house calls to people who had great difficulty leaving home to receive medical care, and for the last ten years had a solo private practice dedicated to house calls exclusively.

I believe myself to be one of the most experienced house call physicians in the country. However, other physicians in Chicago and the suburbs, and throughout the country, make house calls.

Speaking of just the last ten years, almost all of my patients were elderly. All of my few younger patients and about one-third of the elderly ones were dually eligible for Medicare and Medicaid. Because it is the only reliable payer for physician home visits, in my private practice I accepted only patients who had regular Medicare as their primary insurance. During a previous period, when I was employed by Mercy Hospital in Chicago, I made house calls to patients from the hospital's clinic regardless of their insurance; some of these patients received their insurance through managed care companies. I have seen the policies and decisions of managed care companies, as well as health insurance companies in general, cause morbidity, disability, and death. I have included with my written testimony a copy of a letter I wrote in 1995, published in the Journal of the American Geriatrics Society, describing one such case.

It is my belief that by shifting the location of primary care to the homes of patients who had great difficulty going out, I (in common with other home care

practitioners) saved Medicare and Medicaid many thousands of dollars, as well as improving both medical care and quality of life. Like other house call physicians and nurse practitioners, I did this despite a number of obstacles. Medicaid rarely paid me. Medicare regulations do not allow house call physicians and nurse practitioners to receive payment for travel time or reimbursement for any travel expenses; this constitutes a disincentive to make visits on an as-needed basis as compared to grouping visits to one geographic area. Patients who are unable to leave home are necessarily sicker on average than people who are able to leave home, and therefore require a great deal of time.

To illustrate the needs of people living at home, and the possibilities as well as the problems of caring for them, I will briefly describe some of my own patients, with some details changed in order to protect their privacy.

In my private practice, because I was paid by regular Medicare, I was able to visit patients solely on the basis of medical necessity, without requesting pre-approval. One twenty year old dually eligible patient with mental retardation, and behavioral problems and a seizure disorder controlled well with a single drug, needed visits, for the most part, only once every six months. However, when she became irritable and passed blood in her urine, I made an urgent visit and then more frequent visits

until the problem was fully resolved. Because this patient became agitated to the point of violence when her family took her out on the street, care outside of the home could easily have resulted in injury to the patient, administration of additional drugs with the risk of side effects, psychiatric hospitalization, and a cascade of other complications.

On the other hand, in the case of a terminally ill patient whose family refused hospice, I visited daily for five days and remained in telephone contact with the family, until she died at home; again, no pre-approval was needed. Without these daily physician visits to deal with medical issues and help the family work through the patient's dying process in their own way, the family would certainly have called an ambulance and had the patient taken to the hospital.

Whenever possible, I made urgent and emergent visits when patients or families called to report symptoms that required physician assessment, even though this increased my unreimbursed practice costs. When I was unable to schedule such a visit, the patient would have to go to the emergency room, or decide to endure the problem until I could come.

Many of these very sick patients did, nonetheless, have to go to the hospital at some point. Because all of them had regular Medicare, they were able, if stable enough, to go to the hospitals where they were known, where their records were available, and where they could see their regular doctors. This both increased the quality of their care, and likely saved money. Also, because they had regular Medicare, patients were able to preserve relationships with specialists whose care was so essential that it made overcoming the difficulties of going out desirable. For example, a patient who was bed-bound as a result of severe autoimmune disease was able to see her rheumatologist, traveling by ambulance, once or twice a year for monitoring of her illness and her medications beyond what I could do. Between those visits, I provided all of her medical care, including ordering blood tests through a company that sends technicians to the home, and keeping the rheumatologist updated about her condition.

Some patients had unusual disorders such as muscular dystrophy or myasthenia gravis that had been worked up at one of Chicago's major medical centers. Again, provided the patients and families considered the difficulty of leaving home to be worth the benefit received, patients were able to maintain follow up with experts in their diseases without seeking pre-approval.

Some patients developed new and complex problems that required creative approaches because of the patients' underlying frailty. In those cases, again because the patients had regular Medicare, I was able to consider any and every practitioner and institution as a possible source of help, without needing to seek preauthorization for anything. I cannot emphasize how important this is to good care. These difficult cases included, among many others, a woman with severely limited mobility because of a spinal condition who began to pass stool from her vagina; a man who needed a procedure for kidney stones who also had a propensity to serious bleeding; and a man with dementia, heart disease, and prostate cancer whose wife also suffered from dementia. Such cases are extremely intricate; patients may be miserable and yet the usual interventions may carry the risk of death. Often every possible course of action entails serious risks and requires the cooperation of many people. Such cases require the primary physician to seek out multiple expert opinions and to hold multiple emotional discussions with the patient and family before they can make an informed choice about a course of action. For the physician, these problems are both time-consuming and stressful. The difficulties are compounded immeasurably if, on top of the intellectual and emotional demands of dealing with the medical and social aspects of the problem, the physician must try to explain the problem and plan to an insurance company bureaucrat who is incapable of understanding and whose job it

is to avoid spending any of the managed care company's money on actual care.

Furthermore, the imposition of a third party between the physician on the one hand and the patient and family on the other undermines trust in the physician's judgment.

In caring for these complex patients I was able to order consultations, hospitalization, home wound care, home nursing and therapy, x-rays, laboratory tests, and hospice care according to medical necessity and the patient's values with, except for medications, very rare requirements for pre-approval. I could in good faith inform patients and families who were concerned about financial incentives that I received no financial rewards either for ordering or for not ordering any service. Also, the time and effort involved for me in ordering services was not excessive and did not constitute a barrier; while in the case of HMO's, physician time and effort to get approval for necessary services are significant barriers. The lack of financial and other incentives was especially important when I discussed end-of-life issues, as I did with all patients and families who were willing; and most especially this was important when the end of life was actually in sight, when patients and families came face to face with mortality. In the best of circumstances decision-making at these times involves complex warring emotions of hope, denial, grief, anger, and acceptance. It is difficult and sometimes

impossible for the discussions and decision-making to go on when the physician has, or the patient and family perceive the physician to have, a personal stake in the outcome. In my practice, the majority of patients who died died at home.

When it comes to decision-making under difficult circumstances, it is also important that the physician involved is one chosen by the patient and family, someone with whom they feel comfortable and by whom they feel understood. For all of my patients, I was the physician they had chosen; often I had been recommended by a previous trusted physician. If we did not get along, they were free to turn elsewhere, and some did. When we had to deal together with difficult issues, we could do so with mutual trust.

The one area of my private practice in which medical necessity was not the determining factor was medications, since Medicare Part D places insurance companies between patients and doctors. One patient died of a bleeding ulcer after being unable to afford the co-payment for her ulcer medicine. Another patient was placed at risk of serious eye injury from shingles when his Part D company delayed approval of the standard medication. In some cases, the Part D company's representative lied to family members, in one case telling the family that they wanted to approve a requested medication, but could not because I had failed to

complete the necessary forms correctly. In at least one case, my relationship with a patient's family was so damaged by problems with the Part D company that it could not continue.

To sum up, good medical care for sick, frail people requires that decisions be made on the basis of medical necessity and patient and family values without interference by third parties who stand to make or lose money. Good medical care requires trust among patient, family, and physician, which means that patients must be able to choose their doctors and know that the doctors are not being penalized or rewarded by insurance companies. Good care requires that all resources of the health care system be available for possible use in difficult cases.

I cannot help but be aware that the experience of patients, their families, and the health care practitioners who care for them will not be the determining factors in decisions about the future of Medicaid. I ask that all of us remember that in the majority of cases of medical bankruptcy the patient is insured when she or he gets sick; and also that there is no law of nature that makes non-preventable illnesses cheaper than preventable ones. No matter how well we live, all of us will die, and before we die Medicaid may well be part of the future of some currently secure person in this room, or of someone dear to one of us.

At the end of August of this year, I left the practice of clinical medicine to become a full-time volunteer working for single-payer national health insurance. The US spends far more money per person annually than any other country in the world for health care, and yet we are the only industrialized country that segregates its poor into a program like Medicaid. While you deliberate on how to balance the budget of this rich state in this rich country at the risk of the lives and the health of the poor and the disabled, I ask that you also work to bring us into the modern civilized world of one health care system for everybody. Such a system will be less expensive and more efficient, as well as far more just. In Illinois we have the opportunity to do this by supporting HB 311, of which I hope all of you will become co-sponsors.

Attachment: Scheetz, A. Access to Hospice Care. J Am Geriatr Soc 1995; 43:1174.

###

LETTERS TO THE EDITOR

ACCESS TO HOSPICE CARE

To the Editor: Hanrahan and Luchins¹ found that inability to predict survival was a barrier to provision of hospice care for demented patients. Managed care plans may bar access to hospice care even when the medical complications of dementia clearly limit life expectancy.

An 81-year-old male with long-standing dementia was referred to our physician housecall program because of increasing difficulty leaving home. He did not walk and was completely dependent in activities of daily living. He had a neurogenic bladder with indwelling suprapubic cystostomy tube and had been treated as an outpatient for urinary tract infection. The patient had required a colostomy for intractable constipation and had symptomatic degenerative joint disease. He had no other life-threatening illnesses. Six weeks later, during an upper respiratory infection, examination showed lower extremity spasticity, dysphagia, weight loss, and pain on being moved. His serum albumin was 3.3 g/dL. The patient's family reported poor pain control, sleep disturbances, and verbal and physical aggression. The patient had signed a durable power of attorney for health care, naming his "beloved son" and his daughter-in-law, who had been caring for him, as surrogate decision-makers. They declined feeding tube placement and wished to provide palliative care at home for the remainder of the patient's life.

For editorial comment see p 1170

A referral was made to hospice. The agency retained by the patient's insurance plan to certify hospice benefits refused to authorize payment on the grounds that the patient did not have a terminal illness. Three physicians, including an internist and an oncologist, upheld the denial following appeals by the family and the attending physician. Finally, a gerontologist reversed the denial, and 18 days after the original referral, approval for hospice was given. The patient was admitted to hospice 4 days later and died at home 3 days after that.

The principal lesson of this case is that the referring physician must insist on speaking to a reviewer who is experienced in the care of end-stage dementia. Nonetheless, reviewing agencies, if they perceive that it is in their interests to do so, may place barriers in the way of hospice care. Through the heroic efforts of his family, and with the help of a visiting nurse who had no hospice training, as well as frequent physician contact, this patient remained at home despite suboptimal care. By withholding approval for hospice until the last few days of life, the certifying agency saved money for the insurance carrier at the cost of avoidable suffering to the patient and the family.

*Anne Scheetz
Mercy Hospital
Chicago, IL*

REFERENCE

1. Hanrahan P, Luchins DJ. Access to hospice programs in end-stage dementia: A national survey of hospice programs. *J Am Geriatr Soc* 1995;43:56-59.