Advocacy in Medicine: A Look Back and a Look Ahead

Katherine S. Lobach
Professor Emerita of Pediatrics
Albert Einstein College of Medicine
Bronx, New York 10461

It is a common and reasonable belief that many of the future leaders in medicine will be found among the students who are elected to Alpha Omega Alpha (AOA). When it comes to leadership in medicine, the young have heroes they admire, and those who are older revel in the progress of their protégés. But not everyone in medicine can or wants to be a leader – not even the AOAs. We have the recent example of two Einstein alumni in which the AOA wife stayed home and practiced medicine and the non-AOA husband went on to a different kind of non-medical leadership as the governor of Vermont, and for a period, aspired to lead the US.

But even if leadership per se is not for everyone, there is one attribute of leadership that every physician should develop: the attribute of being an advocate. Indeed, advocacy is such an intrinsic element of medicine that it could be called a professional imperative. Hardly a day goes by in which the conscientious practitioner does not advocate for the needs of a patient. Hardly a week or month goes by in which physicians are not moved as individuals or through their professional societies or organizations to speak out on issues that concern them.

The literature on advocacy distinguishes between "case" advocacy and "class" advocacy. Case advocacy is defined as addressing the needs of the individual and family, while class advocacy aims to change, develop, or improve systems, institutions, or social factors that affect health. This commentary will address the topic of class advocacy, offering perspectives from both the past and the future.

First, a few general thoughts about class advocacy in medicine will be drawn from a look back at efforts. I have observed or participated in from years past. The word "effort" is used advisedly, because effective advocacy does require work. Alternatively, the term "struggles" applies, because if there were no opposition, there would often be no call for advocacy. Second for your consideration will be a look ahead to some issues that concern them.

The choice of an advocacy cause is usually personal and idiosyncratic. That is to say, that unless they are policy wonks or directors of the Center for Disease Control, most people looking for a cause would not usually consult a compendium of health goals and objectives as, for examples, Healthy People 2010, the ten-year program issues by the United States Department of Health and Human Services listing the 467 objectives in 28 focus areas (U.S. Department of Health and Human Services, 2000). In reality, most people's advocacy choices originate form their own immediate concerns or from matters which touch their lives. That is not to say that such advocacy is necessarily or always self-interested; often, it is not. But it certainly does arise, especially in medicine, from the context or environment in which we are functioning. For example, I have been labeled a child advocate, but before I started to advocate for children I was first a pediatrician, and it is quite possible that if I had not been a pediatrician, I would have become some other kind of advocate.

Presumably, your day to day experiences will be the most fertile source of causes for your advocacy. I observed a dramatic example of that phenomenon one summer in the early 1970's when a stream of toddlers were admitted to the pediatric ward at Jacobi Hospital with injuries from falling out of high windows. After about the fifth admission, with one or two children dead on arrival, the chief resident at the time decided enough was enough. With support from his chairman, he called the newspapers and contacted the city Department of Health. Window falls soon became a cause celebre, and over the next two years, research was conducted, the city health code was amended to require installation of window guards in multifamily dwellings, and the public was educated in a campaign called "kids can't fly."

Over the next 16 years, annual window falls deceased from 150 to 35 and deaths from 25 to 5; by 2002, only three falls were reported (Personal communication).

There are times when an advocacy battle must be fought on several fronts. That was certainly true when it came to the promotion of breastfeeding. This was a case where the involvement of the media and a partnership with a city agency helped the advocacy to succeed. The opposition, of course, was from landlords.

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cow's milk formula for infants was steadily starting to replace human milk, beginning at birth. There were various societal reasons for this change, but the availability and marketing of commercial infant formula played a major role. When commercial formula was first devised, it was used mainly for feeding premature infants. Even after it began to be used for feeding healthy full term infants, for many years it was only dispensed with a doctor's prescription. But eventually, as we know, it was marketed and sold directly to parents and families.

The decline of breast-feeding was a matter of concern to some women, some nutritionists, and a few health professionals, but on the whole, pediatricians were mostly indifferent. The American Academy of Pediatrics (AAP) gave little more than lip service to the value of breast-feeding. After all, formula was safe and convenient, and while the evidence for the superiority of breast milk was suggestive, it was not conclusive. Doctors and nurses no longer learned how to help mothers successfully manage breast-feeding. Hospital nurseries were supplied with formula gratis, and were given sample packs to distribute to mothers at discharge. The federally funded “Special Supplemental Nutrition Program for Women Infants Children” known as “WIC,” which was established in 1972, provided formula to low-income mothers without making any serious attempt to encourage them to breast-feed.

How and where could we begin to promote breast-feeding, and why make the effort? Why was easy: women, including professionals like myself, had wanted to breast-feed and found little help. Nevertheless we persevered and gained an experience that was important and satisfying. We wanted other women to have the same opportunity for this experience. We also felt justified in believing that further study would more firmly establish the superiority of human milk for infant nutrition, as indeed it has (AAP, 2004).

Although the movement to revive and promote breast-feeding involved many groups, for the pediatricians that participated, our first thought was to turn to our own professional society, the AAP. Usually we expect our professional societies to be the advocates on our behalf and the home for our own advocacy, but in this situation, we had to advocate to the AAP; that meant writing letters, submitting resolutions, and calling meetings. To their credit, the AAP leadership responded. Over time, a task force was established, policies were updated, and ultimately, there developed an entire section of the AAP devoted to breast-feeding.

Reeducation of health professional also had to be a major component of this effort, both locally and at national meetings. To do that, we called in the few available experts, developed our own expertise, and went out on the grand rounds and lecture circuit.

Modifying the way hospital nurseries operated was perhaps the most difficult part of this effort. Ultimately, it was the effort of mothers and their pediatricians that many hospitals instituted rooming in, feeding on demand, and no supplementation with formula. Formula samples were no longer distributed at discharge, and at least some hospitals stopped accepting free supplies of formula for their nurseries.

Today, almost two-thirds of women initiate breast-feeding in the hospital. At six months, 32.5% are still nursing their babies (AAP, 2004). The goals set in the plan for Healthy People 2010 are for 75% to initiate breast-feeding in hospitals and for 50% to continue for at least 6 months. Clearly, the work is unfinished, and one of the several lessons to be learned is that the advocates‘ work is never done!

Turning to contemporary problems in health care, I would identify three overarching issues that ought to be at the forefront of advocacy efforts today and in the future. These are mental health care, racial and ethnic disparities in health and health care, and health care financing and the plight of the uninsured.

Mental health care in the US is ripe for transformation. Seven percent of adults in this country suffer from serious mental illness in any given year, and perhaps nine percent of children will have a serious emotional disturbance. There is now sufficient knowledge exhibiting effective treatment of mental illnesses that the goal of recovery, rather than just the management of symp-
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...with the acceptance of a long-term disability, is realistic. Yet, in the words of the President's Commission on Mental Health, which issued its report last July, "mental health services and supports...remain fragmented, disconnected, and often inadequate ...today's system is a patchwork relic – the result of disjointed reforms and policies" (New Freedom Commission on Mental Health, 2003). There are other obstacles to mental health care as well, for example, the social stigma that surrounds mental illness and the unfair limitations on mental health benefits in private health insurance – incidentally, about 57% of mental health care is publicly funded.

The Commission report offers a series of recommendations for addressing these problems, ranging from calling for a "national campaign to reduce the stigma of seeking care" to "screening for mental disorders in primary health care across the life span" to "creating state comprehensive mental health plans." Many of these recommendations will require a change in policy, thus acting as an excellent initiation point for advocacy. Perhaps the most compelling recommendation is the call to "address mental health with the same urgency as physical health.” Surely that is a summons to the entire filed of medicine, regardless of specialty.

In the annals of advocacy, the civil rights movement was arguable the greatest achievement of the twentieth century. Yet even in that arena, much still remains to be done, not least of which is the remedying of the racial and ethnic disparities in health and health care.

Several years ago the Surgeon General issued a call to action on these disparities, and since then much has been learned about their nature. For instance, an extensive national survey by the Commonwealth Fund in 2001 showed that members of minorities were more likely to lack health insurance or a regular source of care than the majority population. Minorities often reported communication problems with their physicians, such as not being listened to, not fully understanding their doctor, or having questions but not asking. They received less preventive care such as colon cancer screening or counseling for smoking cessation, and less monitoring of chronic conditions such as hypertension, diabetes, and heart disease (Collins et al., 2002).

The Commonwealth Fund made a number of recommendations, including: public financing of interpreter services, training for clinicians in communicating and interacting effectively with patients from different cultures, and more attention to preventive care. But, in their words, “…most fundamental to ensuring quality medical care for minority Americans is the availability of affordable, comprehensive health insurance” (Collins et al., 2002).

However, the issues of the inadequacy of mental health services, lack of access for minorities, as well as a host of other current concerns all stem from the health insurance problem, or more accurately, the health care financing problem.

It is public knowledge that 45 million of our population are uninsured, that we spend more per capita for health care than any other industrial nation with less satisfaction and poorer health statistics, and that the system as is costs far more to administer and can still be a nightmare to navigate. Although many problems exist in this system, there are a few points that deserve particular attention.

First of all, the presence of large numbers of uninsured people is not just their problem; rather, it has an effect on all of us who are insured. A recently issued report of the Institute of Medicine called A Shared Destiny: Community Effects of Uninsurance outlines a number of ways that communities may suffer when they have high rates of uninsured people (The Institute of Medicine, 2003):

1. Local emergency rooms will be over-used, since that is where uninsured people go when they need care, and that leads to diminished emergency room access for everyone, including those with insurance.

2. Special hospital services, such as burn and trauma units, neonatal intensive care, and psychiatric emergency care cannot generate enough revenue to be developed or to continue operating in a community that has large numbers of uninsured.

3. Uncompensated care for hospital admissions of uninsured people must be cross-subsidized by higher per diem charges to the insurance carriers, those who are insured, and/or by increased taxes.

4. When there are fewer people available to pay for care from physicians and hospitals, there will be fewer doctors practicing in a community and fewer hospital beds. This absence creates a loss to the overall economy of an area.

5. When local health departments are called upon to provide personal health care to the uninsured, they must divert resources away from population based care, such as the control of infectious diseases that may affect the entire community.

With a list like this, surely no one could disagree that we all have a stake in confronting the problem of the uninsured.
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The problems for physicians created by our complex system of financing health care are apparent as well. They include exasperation with the excessive bureaucracy of the payment system; struggles with the calls for productivity and concerns about inadequate reimbursement; dismay at the predomination of physician independence and exercise of clinical judgment; and frustration with the inability to arrange needed procedures, consultations, and drugs for the uninsured.

So what is to be done?

Last August, the Journal of the American Medical Association (JAMA) published a proposal by the Physician’s Working Group for single-payer national health insurance (Physicians’ Working Group, 2003). To date, over 11,000 physicians and medical students have endorsed the proposal. It builds on the concept that health care is a human right, and it posits several fundamental principles: health coverage should be universal, comprehensive, and both affordable and cost-efficient.

One useful way of describing this program is to call it “Medicare for all,” at least Medicare as it was before the passage of the rather peculiar Medicare Modernization Act of 2003. Like Medicare, national health insurance would be federally financed, have automatic enrollment, uniform benefits and coverage, and low overhead and administrative costs. Certainly Medicare is not perfect, but I am not aware of anyone over 65 who wants it to undergo any fundamental changes except to improve its benefits.

During the course of this past election year many of those running for office were presented a variety of proposals. These proposals ought to be measured against the principles mentioned: will coverage be universal? Will it be comprehensive? Will it be affordable and cost-efficient? This is certainly an area in dire need of advocacy, and an appropriate starting point for budding medical student advocacy.

In conclusion, the words of the character Malvolio Shakespeare’s in “Twelfth Night” are relevant: “Some are born great, some achieve greatness, and some have greatness thrust upon them.” To paraphrase, some are born advocates, some achieve advocacy, and some have advocacy thrust upon them. In one sense, we are all born to advocate, even if its only for our next feeding, but actually only a few of us are born with the drive that will propel us into the forefront of class advocacy. Nevertheless, if we make a commitment, search for allies, and take action, almost all of us can achieve the role of advocate, and even those who may be reluctant or indifferent will not find it easy in our profession to avoid having advocacy thrust upon them, whatever the nature of the cause might be.

Perhaps you have found your cause already, or perhaps your cause it still waiting to find you. Either way, remember that an advocate is defined as “one who is summoned.” When the summons comes to you, I hope you will welcome it, join ranks with those who have gone before you, and help prepare the way for those who will follow after you.

NOTE

Based on a lecture at the induction of the Alpha Omega Alpha Society, May 6, 2004.

REFERENCES


Personal communication. Window Falls Prevention Program, New York City Department of Health.

