

THE SURGE OF COMMUNITY INVOLVEMENT

Charging that medical care is too scarce or costly or both, and that hospitals stand aloof from their communities, lay groups from coast to coast are assaulting the traditional autonomy and authority of the medical profession and its institutions. Using tactics ranging from sit-ins to class action lawsuits, they are winning a bigger say - sometimes a dominant one - in the financing and delivery of health care.

The movement has sparked a wide range of reactions among physicians. Some, especially in academic medicine or on the staffs of public hospitals, welcome it, even link hands with it. But most established practitioners, while professing interest in what the "consumer" has to say, fear that if laymen muscle into positions of power they will be tempted to interpose in medical decisions. Some doctors have Orwellian visions of "commissars" telling them when, where, and how to practice. (In health matters these days, "consumer" is the popular term for laymen. Health care professionals themselves are "providers.")

So far, most of the agitation has been against hospitals. And none have been more besieged than those in poverty areas. A good example is Temple University's sprawling Health Sciences Center, located in the black Tioga and Nicetown communities of North Philadelphia. Ever since the residents formed the Citizens of Tioga-Nicetown, Inc., they have prodded the Temple center to "change its attitude." In 1966, the group fought and defeated (in the city council) Temple's plan to build a new teaching hospital. The CT-N charged that it was not consulted by the school and that the new facility would harm the community, according to Harold Jones, the association's full-time executive director.

Temple got the message. In 1970, school representatives sat down with a delegation from the association to work out a formal understanding of Temple's relationship to the community. After 18 months of weekly talks, the two sides last March put their signatures to what may be an unprecedented document in the history of American medical schools. By a binding contract, Temple agreed to:

Let the community take part in the interim and final planning of all future facilities;

Hire three \$6,500-a-year "community hospital representatives" to serve in the ER as instant ombudsmen for the patients;

Let community physicians call in department chairmen and arrange, if possible, for their patients to be admitted;

Offer all health center jobs to community residents first; if the community can turn up a qualified person within four days, he gets the post.

Survey the community's health care needs, then work with residents to fulfill the needs (already begun: prenatal, mental health, and sickle cell anemia services);

Pay up to \$15,000 over and above the fair market value for any house demolished for health center expansion, and pay the displaced home owner all moving costs; in addition, Temple shall not leave a house or property unused for more than six months. If the university owns a house for a longer period, it must then renovate and rent it, according to the agreement.

"It would be nice to report that Temple initiated these changes on its own, but everyone knows it was community pressure that did it," says a candid Temple spokesman. At least, he adds, there were never any ugly confrontations. Pathologist Paul Kotin, dean of the Health Sciences Center, called the agreement "amicable," and said the medical staff, though unrepresented in the talks, had not

complained about any of the terms. CT-N Executive Director Jones said Temple's days of being "paternalistic and patronizing" to the community were over. On the brighter side, he hopes a "new spirit of understanding has been created."

In Chicago, community organizations have been zeroing in on the perennially troubled, 2,100-bed Cook County Hospital. In 1970, several groups - backed by some staff doctors - picketed, prodded, and pressured the county's board of supervisors (a patronage-dispensing body of elected politicians) into relinquishing control of the then-crumbling hospital to a special nine-member governing commission that included a community representative and two MDs. But now community activists are struggling with the commission to get it to incorporate a citywide community advisory board that wants to do far more than advise. The board, formed by various neighborhood and health consumer groups, proposes that it be given money, staff, and office space to help select the county hospital personnel, monitor spending, hire "patient advocates," and identify and plan for community health needs.

Dr. James Wagner, assistant professor of preventive medicine and community health at the University of Illinois College of Medicine and a leader of the community advisory board, contends that Dr. James Haughton, executive director of the governing commission, initially agreed on the need for the board but then changed his mind. Dr. Wagner claims that Dr. Haughton wants more middle-class, "traditional, Rotary Club type" members on the board. A spokesman for the governing commission, however, replies that the only source of disagreement was over how much power the board would have.

Meanwhile, Dr. Haughton himself has assumed the role of patient advocate and blasted those members of the Cook County Hospital medical staff who, he says, want "to run their own little empires independent of everyone else. Patient care is primary, and teaching and research are secondary," points out Dr. Haughton, whose uneasy relationship with the staff erupted into an open split last November when he fired five physicians for threatening to "close and destroy" the hospital. The doctors are now appealing, but even that is bogged down in controversy.

In Boston, a citywide "consumers' health council" was formed two years ago, claiming to represent the metropolitan area's poor. Priscilla Rhodes, chairwoman of the group, reports that despite "very slow progress and lots of resistance from hospitals," the council has scored some points. It got three consumers named to the board of prestigious Peter Bent Brigham Hospital, and helped to block a proposed expansion of Boston's Faulkner Hospital.

The longest and perhaps bitterest struggle to achieve community influence in a hospital has been going on since 1969 in the south Bronx of New York City, home of 400,000 blacks and Puerto Ricans. The area's one hospital, Lincoln, has had various floors, clinics, and centers taken over and occupied by community residents ranging from Black Panthers to the clergy, often with the backing of house staff physicians. The community protestors have demanded and won such things as a complaint table in the emergency room, a methadone maintenance program, the expulsion of the chief of pediatrics, Dr. Arnold Einhorn (MWN Dec. 25, '70/Jan. 1, '71), and a number of outreach projects.

An increasingly common ghetto-community demand - one made by both the Philadelphia and Chicago groups - calls for hiring patient advocates. The poor contend they need sympathetic ombudsmen on hand to help them deal with censorious, supercilious, and noncommunicative physicians and nurses. And the Spanish-speaking communities want translators as well.

One of the country's first patient advocates, Celestine Cobb, was hired by Yale-New Haven Hospital in 1968 in response to community pressure. Mrs. Cobb, a former nurse, says most patients complain about physicians' reticence. "Doctors don't explain diagnoses or tests. They won't tell you what to expect before and after surgery. I've been trying to get across to them that patients want to be involved in their own treatments, to be informed. I've had some success."

At first, Mrs. Cobb recalls, the medical staff resented her "intrusions." Several physicians tried to get her fired, and she was "tucked into a cubbyhole, with no secretary and even limited phone privileges." But today, according to chief resident David Melchinger, "she's considered invaluable. We use her more than any other service. She attends our morning reports and we talk over particular issues of patient management. She tells us about social and family problems pertinent to each case. She may ask what to tell the family, or she'll ask us to explain things to them." And Mrs. Cobb now has an office and a secretary.

New Haven community groups have also prepared a pamphlet on patients' rights, another new twist in health consumerism that appears to be spreading. The pioneer pamphlet came out two years ago at the Dr. Martin Luther King Jr. Health Center, an affiliate of Montefiore Hospital and Medical Center in the Bronx. Written in simple English and Spanish, it was distributed initially to 11,000 families in the south Bronx. The author, Liery Wynn, now a patient advocate at the center, says he wrote the booklet "because of the hassles I had to go through three years ago when I was mugged and had half my head torn off. I was sent from one hospital to another and was pushed around like an animal. I wanted to do something to counteract the degradation of the patient in the waiting room." The resultant brochure includes such counsel as: "You have a right to be treated with respect, the patient has a right to consent to or refuse any treatment, and the patient has a right to see letters and to know about conferences about him and the results of such conferences." The booklet also spells out the procedure for filing a formal complaint and advises patients of their obligations to keep or cancel appointments, follow medical orders, and the like. Now several other New York hospitals publish, or soon will, patient-rights pamphlets similar to Wynn's.

Surprisingly, the move toward recognition of patients' rights got a big boost from the Joint Commission on Accreditation of Hospitals. Its revised standards, published in December 1970, include a preamble - now widely known as the patients' "bill of rights" - in response to consumer groups, the most vocal of which was the National Welfare Rights Organization. Dr. John D. Porterfield III, JCAH director, says the preamble shocked quite a few hospitals with its "forceful and explicit" statements, such as: "The patient has the right to communicate with those responsible for his care, and to receive from them adequate information concerning . . . his medical problem, the planned course of treatment, and the prognosis."

As consumers grow more conscious of their rights as patients, they are also becoming more aware that general health problems can be dealt with as legal problems. In courts across the land they are suing government agencies, hospitals, and medical organizations in cases whose outcomes could have far-ranging impact. For counsel, they draw largely upon a cadre of young Office of Economic Opportunity-funded attorneys, a surprising number of them women, at the University of Pennsylvania's Health Law Project in Philadelphia and at the National Health and Environmental Law Program in Los Angeles. For back-up, they often have the eager assistance of house staffers chafing at the decay of public hospitals.

In Washington, D.C., consumers are seeking to improve care for the poor through suits filed against a voluntary hospital (Cafritz Memorial) and the city government, which operates D.C. General Hospital. In the Cafritz case, they charge that the hospital gets Hill-Burton funds, yet fails to provide a "reasonable volume" of care to the medically indigent as required by the 1946 federal law.

The hospital tried unsuccessfully to get the suit thrown out of U.S. District Court. It argued that only HEW could enforce the Hill-Burton law. HEW, in fact, did move just last month to spell out what the ambiguous "reasonable volume" means. It ordered that the 6,300 facilities receiving Hill-Burton funds must provide free services at a level not less than 5% of their operating costs nor less than 25% of their net income, whichever is greater. The order, barring a court challenge, is scheduled to go into effect this month. It appears to strengthen the suitors in the Cafritz case, as well as those in the three other Hill-Burton cases now in litigation in Colorado, West Virginia, and Louisiana. A fifth case, in Florida, was settled in the plaintiffs' favor last November when the U.S. District Court ordered a Miami hospital to provide free or below-cost services equivalent to 11% of its gross revenue.

In the so-called quality of care suit against D.C. General, the claimants assert that the hospital has an obligation to provide a level of medical care equal to that at other hospitals in the community. The case is still in court, but the plaintiffs won a preliminary skirmish last summer when the bench granted them an injunction against the hospital, ordering it to keep at least three licensed MDs on duty at all times. The ruling followed the death of a patient who allegedly had to wait six hours before being examined by a physician.

Meanwhile, on the U.S. District Court docket in Washington, D.C., are two cases that could shake hospitals to their foundations. In one, five groups of elderly citizens from San Francisco and Washington, D.C., allege that Congress, in its Medicare laws, unconstitutionally relinquished public authority to a private body when it empowered the JCAH, in effect, to determine if a hospital can take part in the program. The law states that JCAH accreditation automatically entitles the hospital to participate. This, they charge, enables unsafe and unsanitary hospitals to get Medicare funds. As proof, they cite San Francisco General and D.C. General hospitals, both of which retain their accreditation despite extraordinary consumer and house staff efforts to prove to survey teams in 1970 and 1971 that neither met JCAH standards. (At San Francisco, challengers cited 286 alleged violations.) Defendants in the suit, scheduled for court argument next month, are HEW Secretary Elliot Richardson and the JCAH.

Health Law Project attorney Margaret Ewing, main counsel for the plaintiffs, theorizes that "legislative power is vested in the government and cannot be delegated to private groups like JCAH." She says the plaintiffs want HEW to write and enforce its own standards.

Dr. Porterfield defends JCAH standards as sufficiently strict and says that most consumer complaints are "patently off base. They want to identify a specific incident and bring us in as the FBI of hospitals. So if an orderly maltreats a patient, they come to us. Or again, their complaints are strictly quantitative - like a five-hour wait - and have nothing to do with quality. Patients forget that a hospital is by nature inconvenient."

Another suit, which might be considered a companion to the Hill-Burton cases, challenges the constitutionality of the Internal Revenue Service's 1969 reversal of a long-standing position that private hospitals, if they want to retain their tax-exempt status, must not deny services to those unable to pay. Marilyn Rose, the attorney in the case, claims that the IRS, in making the ruling, ignored the "historically accepted meaning of charitable: giving aid to the poor." She also contends that the IRS commissioner lacks the authority to execute the ruling. The case was scheduled for hearing late last month.

Some of the lawsuits are being waged by physicians themselves. In California, for example, 70 residents at Los Angeles County-USC Medical Center filed suit charging that overcrowding and understaffing compromised the quality of medicine they practiced. Attorney Alan F. Charles reports that out-of-court negotiations with the county gained an extra \$5 million for care of the indigent and other reforms. Meanwhile, physicians and nurses at Philadelphia General Hospital sued the city charging that a job freeze had reduced quality of care below acceptable levels.

While some doctors back consumer rights, laymen are joining established health care groups. The American Public Health Association has opened its membership to laymen and two years ago set up an action board that has subsequently aided both plaintiffs and lawyers in several suits against hospitals and government agencies. It provided data, for example, in the widely publicized Alabama mental health cases in which a federal court last month shattered judicial precedent by specifying in great detail the minimum standards for state mental hospitals.

Occasionally, MDs get so wrapped up in the consumer movement that they join its ranks full time - like the three physicians on New York City's Health Policy Advisory Committee, a research organization promoting a total restructuring of the health care system. And in Washington, Ralph Nader has lured Dr. Sidney Wolfe away from ten years of metabolic research at NIH to head up a health research group.

Dr. Wolfe and a handful of young colleagues are trying to keep track of how well the FDA and the Department of Labor use their congressional mandates to protect the health of consumers and workers. ("Terribly," says Dr. Wolfe.) This summer, they plan to investigate two Washington-area hospitals and compile detailed profiles of variables rarely measured - utilization of blood; the influence of drug company detail men, the rates of surgery, and the formulary of drugs. They're also translating relevant medical journal reports into plain English for local consumer groups.

Meanwhile, the established medical organizations have responded to the consumer tide by creating varied mechanisms for consumer input - the most favored being the advisory committee. Within the past four years the AMA, AHA, and JCAH have set up lay advisory groups. Despite their mile-long titles, though, none seems to have had much impact. The AMA's has only 12 members, the AHA's 15 (including two providers), and both meet only twice a year. JCAH's, added only after a confrontation with the National Welfare Rights Organization, totters for lack of funds, but does claim to have influenced new standards.

The organizations, however, receive considerable consumer input in other ways. Both the AMA and AHA have relatively new committees on the health care of the poor, and AMA has had a Council on Rural Health for decades. In addition, AHA last year created a Division of Consumer Health, and brought in a black civil

rights worker, Thomas Fuller, to head it. (One of his first undertakings was to hold a consumer conference at which about 60 outspoken laymen gave the AHA an earful.) Further, AHA has long-range plans to involve consumers at all levels of the organization, Fuller reports, and next month AHA will hold its first, Institute on Consumer Relations. As for the JCAH, its survey teams now hold public hearings for the presentation of grievances against the hospital up for inspection.

Advisory committees are also popular with the New York State Legislature. In 1968, it passed a controversial Ghetto Medicine Law that provided funds to 23 voluntary New York City hospitals to improve outpatient care. To qualify for the program, hospitals had to let boards dominated by community representatives monitor their spending of state funds. The following year, when the legislature acted to put the city's 18 municipal hospitals under a quasi-public Health and Hospitals Corporation (HHC) by 1970, it mandated that the hospitals set up advisory boards having at least 51% community representation.

According to Ana O. Dumois, director of the nonprofit Community Health Institute that provides back-up training for the ghetto medicine boards, such groups have run up against formidable hospital administration resistance to requests for information. One board - at St. Vincent's Hospital and Medical Center in Manhattan - even took its hospital to court to try to get more information. A spokesman for that advisory board says it wanted to see for itself why the hospital wound up short of funds for a 17-story addition when it had already purchased and cleared a site. The addition was to include two floors for ambulatory care.

A lawyer for St. Vincent's said the committee asked for more than it had a legal right to inspect, such as line-by-line details on salaries and equipment. He added that construction was postponed simply because bids were too high. At last report, a negotiated settlement between the two sides appeared in sight.

Despite what Mrs. Dumois calls the hospitals' "paranoid secrecy," the boards have had some impact, she says. They have been able to set up grievance mechanisms for patients, cut patient waiting time, keep clinics open longer, and spur administrative reforms.

Dr. Lowell E. Bellin, first deputy commissioner of the New York City health department, and two colleagues, have conducted a "nonpolemic" survey of the boards' first year of experience. Dr. Bellin reports that the boards have accelerated long-overdue reforms and turned out to be - along with the health department participation - a "nonexpendable ingredient" in the ambulatory care program. He adds that the trouble in dealing with "uninformed, inexperienced consumers was outweighed by the increased leverage that the health department won in negotiating standards of ambulatory care with the hospitals." He concluded that "whatever mutual suspicion and misunderstanding may have initially existed between hospital administrators and consumers are now being cleared up."

So far, only three of the city's 18 municipal hospitals have organized their boards, and the time runs out this summer. Their lack of zest for the task may have something to do with what befell Staten Island's Sea View Hospital and Home for the Elderly when its board was formed earlier this year: Most of the 150 staff physicians resigned. They were infuriated when they learned that the community board had allocated the medical staff only one of the 29 seats. Doctors rejoined the hospital staff only after the board agreed to expand to 37 members, including three physicians.

Still upset about the board's potential power, the medical staff has asked the HHC to spell out its specific authority in medical matters. "The potential for politics and corruption is enormous," laments internist Edward Robitzek, Sea View's director of medical services. "The board will be involved in budgets and priority-setting. What happens if we feel we need a \$30,000 EEG, but a board member has a brother-in-law in the asphalt business and we wind up with a parking lot instead?"

Dr. Donald C. Meyer, a dentist who heads the Doctors Association of the City of New York, which represents physicians on the HHC payroll, says of the boards, "There could be a real danger of patient care being influenced by people without adequate knowledge. Doctors don't mind consumers giving advice, but we don't want them telling us how to practice."

"Nonsense," comments surgeon Arthur C. Logan, a member of the HHC board of directors. "Consumers are not going to review medical care. They're just getting a voice in policy matters. Doctors have medical boards in the hospitals as their input mechanism, and it's time the consumers had a forum of their own." Dr. Logan reports HHC guidelines do say consumers will participate in setting priorities. "Doctors might say they need an organ transplant program, but the board could decide that a treatment program for drug addicts or alcoholics might be needed more." He also reports that the boards will have veto power over every new executive officer hired by their hospitals.

The New York City physicians' concern about lay interference is shared by physicians all over the country, according to Dr. John Burkhart, Knoxville, Tenn., FP, and a member of the AMA House of Delegates. "If consumers got control of health care facilities it would lower the quality of medical care and result in rules and regulations that would thwart the physician, creating barriers to his judgment that couldn't be overcome. I think most of my colleagues feel the same way about it." Adds AMA President Wesley Hall, "No sir, we don't want outsiders telling us how to run our business."

Yet a recent survey by the staff of Dr. Burkhart's own AMA Committee on Health Care of the Poor found little substantiation for such anxiety. The staff visited 30 community health programs around the country, including five run by community boards. "In no project," it reported, "were consumers telling providers how to deliver the technical aspects of medical care."

Consumer control has been in force for some time now at a few of the OEO's neighborhood health centers. The \$8-million, 27,000-enrollee center in the Watts section of Los Angeles, for example, has been run since January 1970 by a 25-member board that includes only two providers. According to Dr. E. Leon Cooper, OEO's associate director of health affairs, health center consumers "have demonstrated that they can govern better than clinicians. And physicians have learned not to fear it. They've discovered that the consumers have no intention of interfering in their technical practice."

Dr. David Spencer, an internist at a health center organized and run by the community of Toppenish, Wash., reports "no major problems for the medical staff. We were careful to define the areas of the governing board's purview. There has been no attempt to interfere on the technical side."

Dr. H. Jack Geiger, professor of community medicine at the State University of New York at Stony Brook, says physicians, even if they are committed to consumerism, have trouble getting used to it. "It's the way we're trained - to propose and dispose. We're taught we know best, that because we have responsibility

for human life our word goes on everything. Doctors have never had the experience of being held accountable to consumers."

Edward V. Sparer, director of Pennsylvania's Health Law Project, agrees. "There is a professional ideology that justifies nonaccountability," he says. "It's unhealthy. It strips people of their autonomy, leaving them as objects to be treated or ignored, instead of encouraging their development and independence."

Nearly everyone agrees, however, that physicians no longer fear consumer participation (as opposed to control). Just a few years ago, says Yale public health professor George Silver, "physicians were scared that wild men were going to take over. Consumer participation was a hot issue. Now the question is what part should the community play, not whether it should. Now the controversy is over control, not participation."

Dr. Burkhardt regards himself as an "enthusiastic backer" of consumer participation. So does Dr. Merlin DuVal, HEW Assistant Secretary for Health and Scientific Affairs. "We usually tap experts for advice," he says, "but now we're bringing in consumers. We've set up an advisory council to NIH, and there's a trend toward more consumer involvement in HEW departments. Consumers have the same goals as providers. We are being won over. There's no need to be frightened of them," the HEW official assures.

One federal mechanism for involving consumers is comprehensive health planning (CHP). Mandated by the Comprehensive Health Planning and Public Health Services Act of 1966 and subsequent congressional amendments, the act calls for organization of some 300 regional and state CHP councils by 1973. There were 172 at last count. Every one of them must have a consumer majority. (What constitutes a majority sometimes is a matter of dispute. APHA President Myron Wegman, president of the southeastern Michigan CHP, reports that when the council was being formed, physicians insisted that a majority meant 51%. The consumers said 60%. After a drawn-out struggle, everyone settled on 55%.)

The councils supposedly play a big role in setting state and local health care priorities and in putting a damper on all unnecessary hospital construction. But critics debunk most of them as powerless, and complain that their lay members are either political appointees or "token" consumers. The councils' one mandated role - reviewing all federal grants - is merely advisory.

But in a few states, including California and Arizona, legislatures have given the agencies teeth. Dr. David P. Michener, medical consultant to California's state CHP council, says it has turned down some hospital plans "but not enough. It's very hard for the council to resist pressure, and the pressure is great." The Phoenix agency, even before getting its regulatory power, boldly declared a moratorium on all hospital construction and, with one exception, made it stick.

In addition, some CHPs initiate their own health projects. The Phoenix agency, for instance, has a \$2.6-million OEO grant to set up three types of health delivery systems in five poverty areas. The Des Moines, Iowa, agency set up a drug treatment "contact and halfway house," and helped influence a private hospital to admit patients without regard to ability to pay.

The CHPs and the consumer movement in general have had their impact on hospitals and Blue Cross plans. An AHA spokesman reports a trend among metropolitan hospitals to recruit more community representatives as trustees -



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a move that counters the tradition of board domination by businessmen, lawyers, and health professionals. A few hospitals have even set up community advisory committees voluntarily.

Blue Cross boards, either through state legislation or their own initiative, are dropping providers in favor of consumer representatives. By July, 32 of the 74 plans will have a majority of public representatives. Some, like the Boston and Rhode Island plans, dropped providers altogether. In Philadelphia, subscribers now elect representatives, and the Richmond, Va., plan will start selecting board members on a geographic basis.

The consumer invasion of Blue Cross, which sometimes extends to Blue Shield plans, too, has also disturbed some physicians. In Oklahoma, where both plans recently realigned their boards in favor of laymen, the state medical association withdrew its endorsement of Blue Shield - which meant individual physicians would no longer endorse the plan to patients.

In justifying the unusual action, Tulsa radiologist Lucien M. Pascucci, president of the state medical association, said the Blue Shield board sometimes is faced with judgments on medical diagnoses, claims for treatment, and physicians' fees. "This means laymen will be passing on questions of quality of treatment. Doctors know more about the patient, and we are in the position to decide what is best for him. To deny us that interferes with basic concepts of American medicine. We can't function as good physicians with a commissar above us."

Looking ahead, the surge of consumer involvement in health care delivery shows no sign of abating. But it remains to be seen whether physicians and laymen together can provide higher-quality care for more patients than the medical community itself has provided up to now - and whether this can be done without compromising the doctor's authority as a physician.