

HAP Takes its Show on the Road

by Debra Hornstra, M.A.

Last summer, the Sarah Lawrence Health Advocacy Program sent four distinguished faculty members to the Chicago suburb of Oak Brook, Illinois, to present a series of seminars to patient advocates from Veterans Administration hospitals around the country. The VA is the nation's largest integrated health-care system, with about 200,000 staff working in 172 hospitals, 376 ambulatory care clinics, 132 nursing homes, and hundreds of other facilities. The VA system is also the country's largest provider of graduate medical education and one of its largest research organizations.

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The vastness of the VA system is reflected in its census. In fiscal year 95/96, the last year for which data is available, VA hospitals admitted over 800,000 patients. On an average day, the system filled almost 75,000 beds, including about 11,500 in psychiatric units and some 33,500 beds in nursing homes. If this doesn't sound busy enough, consider that more than 29 million outpatient visits were also recorded. More than \$27 billion in federal funds was spent to finance these activities.

Veterans are entitled to medical care in compensation for their service to country. But despite that entitlement and the generally high regard in which veterans are held, the VA system is not immune to economic pressures now forcing change upon all hospitals nationwide. Staff cutbacks and widespread departmental reorganization demand creativity and new thinking, much of that provided by Kenneth W. Kizer, MD, MPH. Kizer has been the VA's Under Secretary for Health since 1994 and

functions as the CEO of the Veterans Health Administration and chief architect of the VA's reengineering efforts. Part of his new thinking concerns the role of the VA's patient representatives, now called patient advocates in reflection of their growing influence within the institutions where they work.

Rose Gates, the VA's National Director for Patient Advocates, was the VA's point person for the seminars, which constituted the first formal in-service training ever held for the VA's patient advocates. A nurse who also holds a master's degree in education, Gates first became familiar with the Sarah Lawrence Health Advocacy program through a patient representative at the Philadelphia Veteran's Administration hospital who had earned her master's degree at SLC.

"I was very impressed with her skills," says Gates, "so I asked her who I should contact to learn more about the program, and I got a meeting with (Health Advocacy Program Director) Joan Marks and took a couple of patient representatives with me." Gates says the meeting "far exceeded" her expectations and soon she and Marks were busy developing the seminar series.

Four HAP instructors were invited to participate, each presenting a different aspect of the program. The challenge to Alice Herb, Terry Mizrahi, Marvin Frankel and Michael Fabrikant was to take their semester-long courses and synthesize them into just a few hours. Each admits to some pre-seminar jitters, but the overwhelmingly positive evaluations they received are a testament to their professionalism and preparedness.

"It started off as high anxiety because of the way it was formatted," says Alice Herb, who taught the bioethics component. "But fear is a great motivator. We tried very hard." Accustomed to facing small groups of students at Sarah Lawrence, the faculty also had to rework their presentations for groups of 30 that were characterized by enormous differences in age, educational attainment and career experience.

Gates' goals were clear, as is her satisfaction with the seminars as

they were realized. "I wanted to develop a solid baseline of patient advocacy skills, and I feel like that was accomplished." Indeed, almost all of the VA's 200-plus patient advocates took part in the Sarah Lawrence seminars, and they were extremely grateful for the opportunity. After sitting in on all the sessions, Gates herself came away thinking "the content was important and exceptional, but it was also the personalities of the faculty, and their significance as role models, that I saw as crucial. I had never experienced a faculty as dedicated to a project as was this one."

The enthusiasm was mutual. "This was a group of students who were substantially engaged across the board," says Michael Fabrikant, who taught evaluation and assessment of advocacy initiatives. "I was also very impressed with the leadership, especially Rose Gates and (Education Coordinator) Joan Murray. They met with us every day and gave us positive, constructive feedback, usually right on the money."

"The advocates were most interested in improving their clinical and political skills," says Terry Mizrahi, who taught the morning sessions, entitled *A Framework for Health Advocacy: Models of Advocacy Practice*. "We tried to give them a conceptual and theoretical framework for their work: definitions, processes, and strategies."

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Mizrahi says the initially forbidding condensed nature of the seminars was ultimately successful because it forced the instructors to be creative in structure and format, not just content. "This was not an attempt to teach in six hours what you normally teach in thirty," Mizrahi makes clear. "What we found is that these students wanted more off-site credentialing. We satiated some of their thirst for informa-

tion, but we also whetted their appetite for more.”

Marvin Frankel, who teaches *The Nature of Illness and Caring* to SLC’s HAP students, led the seminar on *Multiple Perspectives On Talking with the Seriously Ill and Dying Patient*, which emphasized the social construction of illness and death. He found it a challenge to address himself to such a diverse group. “It was very hard to speak to all 30 of them at the same time, there was such an extraordinary variability in participants.”

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Frankel found that much of his material was new to the VA students, including a segment on the nature of anxiety and a two-hour workshop on developing empathy. “Many of the students could not believe that empathy has anything to do with efficacy. In the role plays, they were shocked at how bad they were at it, and some couldn’t bear the difficulties they were having.”

Frankel’s experience underscores Rose Gates’ concern that the VA’s patient advocates need a lot more training than they currently get. Michael Fabrikant found that most had never really considered reporting a tool of their trade. “Very few of them had ever thought about using data as an advocacy tool, as a strategy. We were trying to enable people to rethink how and why they develop reports,” explains Fabrikant. “The structure of a report will either engage people, or it will disengage them.”

Alice Herb found the students had done quite a bit of thinking about ethical issues, however. “Their instincts regarding what was fair and equitable were excellent. Their whole orientation was: how can we make things better for the patient?” Herb presented five cases for discussion each day, all drawn from real-life incidents that had given the students trouble. The cases covered such topics as patient autonomy, informed consent, advance directives, ethics committees, and confidentiality. The

segment on advanced directives was accompanied by a film on the subject produced by Herb while at Montefiore Medical Center in the Bronx.

Terry Mizrahi was particularly impressed by the students’ level of commitment to their work. “They feel a deep sense of responsibility toward their patients. It’s a commitment based on a compensatory model, i.e. you served your country, now we will take care of your medical problems.” This promise is threatened by budgetary constraints that began during the Reagan administration, and the attendant increased scrutiny of patients’ demands. “The result,” notes Mizrahi, “is that the VA’s long-standing patient-centered orientation is now up against an anti-bureaucratic, anti-organizational mood.”

“The number of veterans is not expanding, and the patient population is getting older,” Mizrahi continues. “Resources are shrinking and patients are being pushed into other systems. The VA advocates want to be much better at internal advocacy and they need to be much better at coordinating their activities and offering referrals and joint services.”

Chronic illness is another area in which the advocates need more education. “In the past 30 years,” says Marvin Frankel, “the medical profession has created a whole new class of people who are chronically ill. Chronic illness requires a quality of care that humans have never before had to provide.” Citing the modern tendency to be embarrassed by illness, Frankel says the key question becomes “Under what conditions do people seek emotional support?” The answer bears directly on the patient advocate who must increasingly assist those whose illnesses will not be cured.

Rose Gates, who says she made “friends for life” through the seminars, hopes for continued association with the SLC Health Advocacy Program. “We are really trying to be progressive,” she explains, giving Kenneth Kizer “a lot of credit” for encouraging efforts like hers. “Right now we are identifying and getting ready to train mentors, two for each of the VA’s regional networks. We’re working with the National Education Center in Minneapolis to develop additional curriculum, and we aim to have more classes with Sarah Lawrence, perhaps next for our supervisors. My dream is to provide ongoing education for all the VA’s patient advocates.”



*Left to right seated: Rose Gates, Michael Fabricant and Joan Murray.
Standing left to right: Sandra Braunschweig, Alice Herb, Terry Mizrahi and Marvin Frankel.*