

# The Gazette

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## Hopkins And State Team Up On Bioethics

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A quiet but stunning bomb dropped on the health care community in November 1995. That's when the SUPPORT Study, a Robert Wood Johnson Foundation \$28 million multicenter study, found that in hospitals across the nation, despite the world's best medical care, the critically ill were not receiving the care they wanted and needed. Worse, the study disclosed that interventions aimed at improving the care of the dying, implemented in phase two of the study, had no effect as physicians continued to ignore advance directives, living wills and patient wishes.

The ripple effect from that study has led to a unique partnership between the Hopkins Bioethics Institute and the Maryland Attorney General's Office to find ways to improve the dying process for Marylanders.

"This partnership, funded by a grant from the Robert Wood Johnson Foundation, brings together the Bioethics Institute and the policy expertise of the state Attorney General's Office," says Ruth Gaare, academic program director of the Hopkins Bioethics Institute, founded in 1995 as a university-wide center focused on the moral dimensions of health care and policy. "Together we will gather as much information as possible on all factors that influence patient care at the end of life. This will include data from hospitals that promote good care as well as information from physicians, patients, their families and social workers. With this data, we hope to craft creative new policies and law."

In forming the partnership, Maryland Attorney General J. Joseph Curran Jr. cited the value of both the scholarship and commitment from the Bioethics Institute.

"We look forward to establishing a model for assessing the impact of the law on this crucial area of health care and devising reforms that will bring real benefits to patients and their loved ones," Curran said.

"Improved pain management is a central focus to the project," Gaare says. "Even people who are otherwise getting the best in medical care sometimes die in serious pain. This is ironic because there is so much in the medical literature now about pain management."

Jack Schwartz, of the State Attorney General's Office, will work closely with Gaare and the Bioethics Institute to understand what--if any--laws and regulations impede physicians from prescribing medications that effectively manage severe pain.

"One factor in patient suffering is under-medication," Schwartz says. "We want to understand how legal reforms might support those trying to provide excellent palliative care, the kind of care to improve quality of remaining life rather than heroic care aimed at extending life against great odds. Palliative care is the kind of care necessary at the end of life, when measures to cure become inappropriate. That's what the project is about."

Gaare pointed to a recent case in which a five-year-old child with a terminal brain tumor was sent home from the hospital with orders for an oral pain medication. When his condition worsened, the physician on-call was reluctant to increase his pain medications.

"According to the child's parents, he suffered horribly," Gaare recounts.

Gaare adds that the SUPPORT Study tapped into a problem not previously empirically documented. "One of our missions is to bring together people with various perspectives, including patients and their families, nurses, doctors, hospice groups and health care regulators, to understand why some physicians and other health care providers feel there is no problem when empirical evidence says there is a problem."

Schwartz and Gaare suspect that physicians, who may be worried about legal ramifications if their medication patterns go "beyond the norm," may not prescribe pain medications at the levels that would be truly effective for dying patients. Doctors may fear being "marked" in ways that may trigger regulatory scrutiny of their practices. "If this is a case of the law impeding comfort, then the laws need to change," Schwartz says.

"We hear countless anecdotes about people suffering needlessly at the end of life because of the way the law works," says Schwartz, who, along with Gaare, has served as an adviser to many hospital ethics boards. "If people are suffering because of how the law works, that's unacceptable, and we'll do whatever necessary to change that."

Gaare emphasizes that the bioethics and legal partnership is not after a legal quick fix. "The Bioethics Institute is bringing empirical research and an analytic framework to the Attorney General's project," she emphasizes.

Gaare is quick to point out that past legislation introducing living wills and other advance directives--the kind that the SUPPORT Study found were more often than not ignored--meant well and were fine in theory, but in practice were ineffective. "The time is over for well-meaning, thoughtless legislation," Gaare says. "The key is finding good ideas based on empirical research. We thought the advanced directive was a good idea. It was well-intentioned, but has proven ineffective. We are creating a forum to bring people together to look at questions about a physician's ability to use the most effective pain medications possible as well as look into how state policies and regulations affect the dying."

In their quest for information, Gaare and Schwartz will interview the families of patients who have recently died in area hospitals. They will be asked to describe the dying process and offer their opinions about palliative care and end-of-life decision making. Also, by forming an advisory board from a wide range of constituencies, Gaare and Schwartz hope to draft recommendations that will ultimately improve the care of the dying in Maryland.

"Medical treatment at the end of life should involve the patient, the family and the health care team," Gaare stresses. "Laws should operate in the background to assure that a patient's values are respected. We're trying to make sure that laws do not get in the way of good care. In spite of well-meaning medical care, and well-intentioned legal interventions, we still do not have a dependable system that assures, measures and addresses pain or ensures compassionate care at the end of life."