

aortic-valve replacement. Patients with the highest intraoperative blood loss had the greatest preoperative decrease in von Willebrand factor multimers. In every case, the distribution of the multimers and the values for laboratory indexes of von Willebrand factor function became normal on the first postoperative day, a finding that is consistent with the 12-to-20-hour half-life of von Willebrand factor in vivo. Furthermore, the recurrence of aortic stenosis or a mismatch between patient and prosthesis was associated with the recurrence of abnormalities in von Willebrand factor. The authors conclude that acquired von Willebrand syndrome is common in aortic stenosis and may be associated with bleeding symptoms or increased operative blood loss and that the recurrence of the syndrome may indicate

persistent or recurrent valvular stenosis. It is possible that shear stress–induced cleavage of von Willebrand factor causes hemostatic defects in other conditions associated with turbulent, high-pressure blood flow. Recognition of this relation has implications for patient care. In general, acquired von Willebrand syndrome associated with cardiovascular lesions does not respond well to desmopressin or to the transfusion of clotting-factor concentrates and requires surgical correction of the flow abnormality.

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1. Heyde EC. Gastrointestinal bleeding in aortic stenosis. *N Engl J Med* 1958;259:196.

BEHIND THE RESEARCH

Death by Voluntary Dehydration — What the Caregivers Say

Sandra Jacobs

Researcher Linda Ganzini, M.D., says she was “stunned” after tallying the questionnaire results reported in this issue of the *Journal* (pages 359–365): Among the hospice nurses in Oregon who were surveyed, nearly twice as many had cared for patients who chose voluntary refusal of food and fluids to hasten death as had cared for patients who chose physician-assisted suicide. This study takes an initial step toward examining the experience of voluntary refusal of food and fluids for patients and their caregivers. The nurses’ descriptions of the deaths resulting from voluntary refusal of food and fluids accord with the few published anecdotes suggesting that voluntary dehydration is a surprisingly peaceful way to die. The common theme is that when elderly, terminally ill patients stop eating and drinking, they do not live much longer and the death is not gruesome. The primary complaint, dry mouth, can be treated with ice chips or swabbing. Yet the process of guiding patients through this option has remained uncomfortable — and largely unknown — for all but the few physicians and nurses who have witnessed such deaths.

“As a doctor, there’s nothing more central to what you’re trained to do than to support homeosta-

sis. When you decide to turn your back on that, your gut feeling is, ‘something awful will happen,’” said Peter Reagan, M.D., a family physician in Portland, Oregon. “When bad things don’t happen . . . when something awesome happens, it’s surprising and shocking.” Reagan recalls an elderly patient who, having been debilitated for years by severe arthritis pain, sought but did not qualify for physician-assisted suicide under Oregon’s Death with Dignity Act. Disappointed, she opted instead to cease consumption of food and fluids. Reagan watched, surprised, as his suffering patient became self-confident and seemingly happy. Her family gathered. For a week, they visited and reminisced. Then, without requesting any palliative care — even ice chips — her body rapidly failed, and she died.

“There was something a little uncomfortable about this for the hospice, for the family, and for me,” said Reagan. “We felt complicit.” As he and other physicians describe it, this “giving permission” may indeed be uncomfortable, but for Reagan it was preferable to turning away. “The most important thing is to stay involved, because that feels a lot better as a doctor. Saying ‘This is all I can do for your [disease]’ is not nearly as satisfying as saying,

‘What can I do for you and your family?’” That involvement, he said, may provoke an emotional response that “can be more uplifting than shattering. It’s very inspiring to see someone take that kind of charge of his or her life.”

Paul Bascom, M.D., director of the Palliative Medicine and Comfort Care Team at Oregon Health and Science University in Portland, described an elderly patient with diabetes who, when blindness threatened her ability to live independently, chose to stop taking insulin as well as to stop eating and drinking. She was admitted to an inpatient hospice. Her equanimity surprised Bascom and his colleagues. “She seemed delighted to be with us here,” he said. “I thought that after a week of this happy time here, she’d want to resume food and fluids.” She did not. “That was challenging to the staff, that she would make this decision and yet be this engaging person.” After about 10 days, her level of arousal decreased. She died without requesting sedation or other comfort care.

Few published accounts describe voluntary dehydration in younger patients, as a 43-year-old Utah woman with rapidly progressing amyotrophic lateral sclerosis learned. “Our friends who are doctors said, ‘It could be good; it could be terrible. I’ve never heard of it. Tell us about it,’” her husband recalls. Four months after her diagnosis in January 2001, she could not bathe or dress herself. Medication failed to relieve her pain at night. Twice, in May and June, she ceased eating and drinking with the intention of hastening her death. Both times she resumed eating and drinking on the third day. “Doing it too early is too hard — either because we’re hardwired for survival or for spiritual reasons,” her husband said. But he believes that having the option of voluntary refusal of food and fluids and having a supportive physician prevented his wife from taking her life by means of an overdose. And it relieved him of pressure to help her commit suicide if things became intolerable. “It gave my wife a lot more peace,” he said. In her final months, friends helped her prepare two full decades’ worth of birthday gifts and notes for her six-year-old daughter. That done, she began a third and final fast in late July. After two days, she ceased feeling hunger. Caregivers used a signaling list to learn what she wanted, such as having her mouth moistened from a spray bottle, or getting lorazepam or morphine drops for her back pain. She remained conscious into the second week. Her daughter, who avoided her dying mother by day, crawled into her bed at night. By day 13 of her fast, the woman began receiving a morphine infusion

through a pump and was soon unconscious. On day 16, she died.

“We remember the counterintuitive stories more than those that meet our expectations,” said Ganzini. “These are memorable stories, because we have the sense that [death by dehydration] will be quite gruesome.” Although most of the deaths described in her study were deemed to be of good quality, follow-up interviews with a subgroup of nurses revealed that, in some cases, there were problems and a poor-quality death. For example, an obese woman in her 40s who had multiple sclerosis lived for several weeks after her fast began and exuded an odor that made it difficult for the nursing staff to care for her. “Are there some patients for whom this might not be a good option — those who don’t have a malignant process or organ failure?” asks coauthor Theresa A. Harvath, R.N., Ph.D. “For them, it may take too long. There may be suffering that we don’t yet understand.”

“If [as a physician] you’re asked to ‘give permission,’ what will be the standard?” asks Bascom. “If someone is chronically ill and not expected to die soon, you have to make the ethical decision as to whether you will be a part of it, rather than intervene as you would in the case of a suicide attempt or a young person with anorexia. Once you’ve decided that, your role is to ensure comfort, remain involved, and monitor and treat symptoms as they develop.”

For the right candidates — patients who have received a thorough evaluation, are not deeply depressed, and are usually already receiving hospice care — “I believe wholeheartedly that it’s an easy procedure,” said J. Andrew Billings, M.D., founder and director of the Palliative Care Service at Massachusetts General Hospital in Boston. “But not enough is known about what it’s like for patients and families, so there must be good support in case things don’t go well.” Billings’s greatest concern is that people will embark on this course without good palliative care.

Ganzini, too, was so concerned that she hesitated to publish these data. “I was worried about thousands of elderly, depressed people going on hunger strikes,” she said. “And I’m worried that some physicians will too quickly offer this as an alternative when we don’t know enough about it.” Ultimately, her decision to publish her study was inspired by a nurse whose own brother ceased consuming food and fluids while his family took great pains to conceal his choice from hospice workers. “We have to get this out and talk about it,” Ganzini said, “because this is happening.”