

## *Informed Demand for "Non-Beneficial"*

### *Medical Treatment*

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An 85-year-old woman was taken from a nursing home to Hennepin County Medical Center on January 1, 1990, for emergency treatment of dyspnea from chronic bronchiectasis. The patient, Mrs. Helga Wanglie, required emergency intubation and was placed on a respirator. She occasionally acknowledged discomfort and recognized her family but could not communicate clearly. In May, after attempts to wean her from the respirator failed, she was discharged to a chronic care hospital. One week later, her heart stopped during a weaning attempt; she was resuscitated and taken to another hospital for intensive care. She remained unconscious, and a physician suggested that it would be appropriate to consider withdrawing life support. In response, the family transferred her back to the medical center on May 31. Two weeks later, physicians concluded that she was in a persistent vegetative state as a result of severe anoxic encephalopathy. She was maintained on a respirator, with repeated courses of antibiotics, frequent airway suctioning, tube feedings, an air flotation bed, and biochemical monitoring.

In June and July of 1990, physicians suggested that life-sustaining treatment be withdrawn since it was not benefiting the patient. Her husband, daughter, and son insisted on continued treatment. They stated their view that physicians

should not play God, that the patient would not be better off dead, that removing life support showed moral decay in our civilization, and that a miracle could occur. Her husband told a physician that his wife had never stated her preferences concerning life-sustaining treatment. He believed that the cardiac arrest would not have occurred if she had not been transferred from Hennepin County Medical Center in May. The family reluctantly accepted a do-not-resuscitate order based on the improbability of Mrs. Wanglie's surviving a cardiac arrest. In June, an ethics committee consultant recommended continued counseling for the family. The family declined counseling, including the counsel of their own pastor, and in late July asked that the respirator not be discussed again. In August, nurses expressed their consensus that continued life support did not seem appropriate, and I, as the newly appointed ethics consultant, counseled them.

In October 1990, a new attending physician consulted with specialists and confirmed the permanence of the patient's cerebral and pulmonary conditions. He concluded that she was at the end of her life and that the respirator was "non-beneficial," in that it could not heal her lungs, palliate her suffering, or enable this unconscious and permanently respirator-dependent woman to experience the benefit of the life afforded by respirator support. Because the respirator could prolong life, it was not characterized as "futile."<sup>1</sup> In November, the physician, with my concurrence, told the family that he was not willing to continue to prescribe the respirator. The husband, an attorney, rejected proposals to transfer the patient to another facility or to seek a court order mandating this unusual treatment. The hospital told the family that it would ask a court to decide whether members of its staff were obliged to continue treatment. A second conference two weeks later, after the family had hired an attorney, confirmed these positions, and the husband asserted that the patient

had consistently said she wanted respirator support for such a condition.

In December, the medical director and hospital administrator asked the Hennepin County Board of Commissioners (the medical center's board of directors) to allow the hospital to go to court to resolve the dispute. In January, the county board gave permission by a 4-to-3 vote. Neither the hospital nor the county had a financial interest in terminating treatment. Medicare largely financed the \$200,000 for the first hospitalization at Hennepin County; a private insurer would pay the \$500,000 bill for the second. From February through May of 1991, the family and its attorney unsuccessfully searched for another health care facility that would admit Mrs. Wanglie. Facilities with empty beds cited her poor potential for rehabilitation.

The hospital chose a two-step legal procedure, first asking for the appointment of an independent conservator to decide whether the respirator was beneficial to the patient and second, if the conservator found it was not, for a second hearing on whether it was obliged to provide the respirator. The husband crossfiled, requesting to be appointed conservator. After a hearing in late May, the trial court on July 1, 1991, appointed the husband, as best able to represent the patient's interests. It noted that no request to stop treatment had been made and declined to speculate on the legality of such an order.<sup>2</sup> The hospital said that it would continue to provide the respirator in the light of continuing uncertainty about its legal obligation to provide it. Three days later, despite aggressive care, the patient died of multi-system organ failure resulting from septicemia. The family declined an autopsy and stated that the patient had received excellent care.

### Discussion

This sad story illustrates the problem of what to do when a family demands medical treatment that the attending physician concludes cannot

benefit the patient. Only 600 elderly people are treated with respirators for more than six months in the United States each year.<sup>3</sup> Presumably, most of these people are actually or potentially conscious. It is common practice to discontinue the use of a respirator before death when it can no longer benefit a patient.<sup>4,5</sup>

We do not know Mrs. Wanglie's treatment preferences. A large majority of elderly people prefer not to receive prolonged respirator support for irreversible unconsciousness.<sup>6</sup> Studies show that an older person's designated family proxy overestimates that person's preference for life-sustaining treatment in a hypothetical coma.<sup>7-9</sup> The implications of this research for clinical decision making have not been cogently analyzed.

A patient's request for a treatment does not necessarily oblige a provider or the health care system. Patients may not demand that physicians injure them (for example, by mutilation), or provide plausible but inappropriate therapies (for example, amphetamines for weight reduction), or therapies that have no value (such as laetrile for cancer). Physicians are not obliged to violate their personal moral views on medical care so long as patients' rights are served. Minnesota's Living Will law says that physicians are "legally bound to act consistently within my wishes within limits of reasonable medical practice" in acting on requests and refusals of treatment.<sup>10</sup> Minnesota's Bill of Patients' Rights says that patients "have the right to appropriate medical . . . care based on individual needs . . . [which is] limited where the service is not reimbursable."<sup>11</sup> Mrs. Wanglie also had aortic insufficiency. Had this condition worsened, a surgeon's refusal to perform a life-prolonging valve replacement as medically inappropriate would hardly occasion public controversy. As the *Minneapolis Star Tribune* said in an editorial on the eve of the trial,

The hospital's plea is born of realism, not hubris. . . . It advances the claim that physi-

cians should not be slaves to technology—any more than patients should be its prisoners. They should be free to deliver, and act on, an honest and time-honored message: "Sorry, there's nothing more we can do."<sup>12</sup>

Disputes between physicians and patients about treatment plans are often handled by transferring patients to the care of other providers. In this case, every provider contacted by the hospital or the family refused to treat this patient with a respirator. These refusals occurred before and after this case became a matter of public controversy and despite the availability of third-party reimbursement. We believe they represent a medical consensus that respirator support is inappropriate in such a case.

The handling of this case is compatible with current practices regarding informed consent, respect for patients' autonomy, and the right to health care. Doctors should inform patients of all medically reasonable treatments, even those available from other providers. Patients can refuse any prescribed treatment or choose among any medical alternatives that physicians are willing to prescribe. Respect for autonomy does not empower patients to oblige physicians to prescribe treatments in ways that are fruitless or inappropriate. Previous "right to die" cases address the different situation of a patient's right to choose to be free of a prescribed therapy. This case is more about the nature of the patient's entitlement to treatment than about the patient's choice in using that entitlement.

The proposal that this family's preference for this unusual and costly treatment, which is commonly regarded as inappropriate, establishes a right to such treatment is ironic, given that preference does not create a right to other needed, efficacious, and widely desired treatments in the United States. We could not afford a universal health care system based on patients' demands. Such a system would irrationally allocate health care to socially powerful people with strong pref-

erences for immediate treatment to the disadvantage of those with less power or less immediate needs.

After the conclusion was reached that the respirator was not benefiting the patient, the decision to seek a review of the duty to provide it was based on an ethic of "stewardship." Even though the insurer played no part in this case, physicians' discretion to prescribe requires responsible handling of requests for inappropriate treatment. Physicians exercise this stewardship by counseling against or denying such treatment or by submitting such requests to external review. This stewardship is not aimed at protecting the assets of insurance companies but rests on fairness to people who have pooled their resources to insure their collective access to appropriate health care. Several citizens complained to Hennepin County Medical Center that Mrs. Wanglie was receiving expensive treatment paid for by people who had not consented to underwrite a level of medical care whose appropriateness was defined by family demands.

Procedures for addressing this kind of dispute are at an early stage of development. Though the American Medical Association<sup>13</sup> and the Society of Critical Care Medicine<sup>14</sup> also support some decisions to withhold requested treatment, the medical center's reasoning most closely follows the guidelines of the American Thoracic Society.<sup>15</sup> The statements of these professional organizations do not clarify when or how a physician may legally withdraw or withhold demanded life-sustaining treatments. The request for a conservator to review the medical conclusion before considering the medical obligation was often misconstrued as implying that the husband was incompetent or ill motivated. The medical center intended to emphasize the desirability of an independent review of its medical conclusion before its obligation to provide the respirator was reviewed by the court. I believe that the grieving husband was simply mistaken about whether the respirator was benefiting his wife. A direct re-

quest to remove the respirator seems to center procedural oversight on the soundness of the medical decision making rather than on the nature of the patient's need. Clearly, the gravity of these decisions merits openness, due process, and meticulous accountability. The relative merits of various procedures need further study.

Ultimately, procedures for addressing requests for futile, marginally effective, or inappropriate therapies require a statutory framework, case law, professional standards, a social consensus, and the exercise of professional responsibility. Appropriate ends for medicine are defined by public and professional consensus. Laws can, and do, say that patients may choose only among medically appropriate options, but legislatures are ill suited to define medical appropriateness. Similarly, health-facility policies on this issue will be difficult to design and will focus on due process rather than on specific clinical situations. Public or private payers will ration according to cost and overall efficacy, a rationing that will become more onerous as therapies are misapplied in individual cases. I believe there is a social consensus that intensive care for a person as "overmastered" by disease as this woman was is inappropriate.

Each case must be evaluated individually. In this case, the husband's request seemed entirely inconsistent with what medical care could do for his wife, the standards of the community, and his fair share of resources that many people pooled for their collective medical care. This case is about limits to what can be achieved at the end of life.

### Notes

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