The Case of Helga Wanglie:
A New Kind of "Right to Die" Case

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Helga Wanglie, an 86-year-old Minneapolis woman, died of sepsis on July 4 after being in a persistent vegetative state for over a year. She was the focus of an extremely important controversy over the right to die that culminated in a court decision just three days before her death.[1] The controversy pitted her husband and children, who wanted her life maintained on a respirator, against doctors at the Hennepin County Medical Center, who wanted her removed from the respirator because they regarded the treatment as inappropriate. The judge decided in favor of Mr. Wanglie, and Helga Wanglie died still supported by the respirator.

The Wanglie case differed in a crucial way from earlier right-to-die cases, beginning with the case of Karen Quinlan 16 years ago. In the earlier cases, the families wished to withhold life-sustaining treatment and the institutions had misgivings. Here it was the reverse; the family wanted to continue life-sustaining treatment, not to stop it, and the institution argued for the right to die. Mr. Wanglie believed that life should be maintained as long as possible, no matter what the circumstances, and he asserted that his wife shared this belief.

In one sense, the court's opinion in the Wanglie case would seem to be at odds with most of the earlier opinions in that it resulted in continued treatment of a patient in a persistent vegetative state. In another sense, however, the opinion was quite consistent, because it affirmed the right of the family to make decisions about life-sustaining treatment when the patient was no longer able to do so. By granting guardianship of Mrs. Wanglie to her husband, the judge indicated that the most important consideration was who made the decision, not what the decision was. I believe that this was wise; any other decision by the court would have been inimical to patient autonomy and would have undermined the consensus on the right to die that has been carefully crafted since the Quinlan case.

What are the elements of that consensus and how should they be applied to the Wanglie case and others like it? There is general agreement that competent adults may refuse any recommended medical care. This right, based on principles of self-determination, has repeatedly been buttressed by the courts. When patients are no longer mentally competent, families are to act in accordance with what the patient would wish (a principle known as substituted judgment).[2–4] Disputes have arisen, however, when the patient had not, while competent, clearly expressed his or her preferences. This was the situation in the Wanglie case, as it was thought to be in the Cruzan case.[5]

To avoid these disputes, there is a growing movement to encourage all adults to prepare a document that would provide guidance, if necessary, for their families and doctors.[6] Such documents include living wills, durable powers of attorney, and other instruments that have been specially devised for the purpose. Congress recently mandated that as of December 1991, all health care facilities must provide an opportunity for patients to prepare such a document on admission.

We are still left with the problem of deciding for those who have nevertheless provided no guidance, including those who were unable to do so, such as children or profoundly retarded adults. In these cases as well, families usually make decisions on behalf of the patient, but since the patient's wishes are unknown, the consensus holds that the family's decision must be consistent with the patient's best interests.[2–4] A decision consistent with best interests is usually defined as a choice that reasonable adults might make if faced with the problem. This is a vague but useful standard that, by definition, restricts the range of permissible decisions. It can, however, allow for more than one possible choice. For example, the decision to withdraw the respirator from Karen Quinlan was thought by the New Jersey Supreme Court to be consistent with her best interests, but her father was given the latitude to decide either way.[7]

The well-publicized legal disputes involving the right to die—such as the Quinlan case, the Brophy case in Massachusetts,[8] and the Cruzan case in Missouri—have reached the courts either because the institution believed it improper to withhold life-sustaining treatment at the family's request or because the institution wanted legal immunity before doing so. Until the Wanglie case, there was only one well-publicized case of the reverse situation—that is, of a family wishing to persist in treatment over the objections of the institution. This was the poignant case of Baby L, described last year in the *Journal.*[9] The case involved a two-year-old child, profoundly retarded and completely immobile, who required repeated cardiopulmonary resuscitation for survival. Baby L's mother insisted that this be done as often as necessary, despite the fact that there was no hope of recovery. Representatives of the hospital challenged her decision in court on the grounds that the continued treatment caused great suffering to the child and thus violated its best interests. Before the court reached a decision, however, the mother transferred the child to a hospital that agreed to continue the treatment, and the case became legally moot.

Unlike the case of Baby L, the Wanglie case did not involve a course that would cause the patient great suffering. Because she was in a persistent vegetative state, Mrs. Wanglie was incapable of suffering. Therefore, a compelling case could not be made that her best interests were being violated by continued use of the respirator. Instead, representatives of the institution invoked Mrs. Wanglie's best interests to make a weaker case: that the use of the respirator failed to serve Mrs. Wanglie's best interests and should therefore not be continued. It was suggested that a victory for Mr. Wanglie would mean that patients or their families could demand whatever treatment they wished, regardless of its efficacy. Many commentators also emphasized the enormous expense of maintaining a patient on life support when those resources are needed to care for people who would clearly benefit. In the previous essay, Steven H. Miles, M.D., the ethics committee consultant at the Hennepin County Medical Center who was the petitioner in the Wanglie case, presents the arguments of the institution.[10] They are strong arguments that deserve to be examined, but I believe that they are on balance not persuasive.

It is generally agreed, as Miles points out, that patients or their surrogates do not have the right to demand any medical treatment they choose.[11,12] For example, a patient cannot insist that his doctor give him penicillin for a head cold. Patients' rights on this score are limited to refusing treatment or to choosing among effective ones. In the case of Helga Wanglie, the institution saw the respirator as "non-beneficial" because it would not restore her to consciousness. In the family's view, however, merely maintaining life was a worthy goal, and the respirator was not only effective toward that end, but essential.

Public opinion polls indicate that most people would not want their lives maintained in a persistent vegetative state. Many consider life in this state to be an indignity, and care givers often find caring for such patients demoralizing. It is important, however, to acknowledge that not everyone agrees with this view and it is a highly personal issue. For the decision to rest with the family is the most sensitive and workable approach, and it is the generally accepted one. Furthermore, a system in which life-sustaining treatment is discontinued over the objections of those who love the patient, on a case-by-case basis, would be callous. It can be argued on medical grounds that the definition of brain death should be legally extended to include a persistent vegetative state, but unless that is done universally we have no principled basis on which to override a family's decision in this kind of case. It is dismaying, of course, that resources are spent sustaining the lives of patients who will never be sentient, but we as a society would be on the slipperiest of slopes if we permitted ourselves to withdraw life support from a patient simply because it would save money.

Since the Quinlan case it has gradually been accepted that the particular decision is less important than a clear understanding of who should make it, and the Wanglie case underscores this approach. When self-determination is impossible or an unambiguous proxy decision is unavailable, the consensus is that the family should make the decision. To be meaningful, this approach requires that we be willing to accept decisions with which we disagree. Only if a decision appears to violate the best interests of a patient who left no guidance or could provide none, as in the case of Baby L, should it be challenged by the institution. Thus, the sources of decisions about refusing medical treatment are, in order of precedence, the patient, the patient's prior directives or designated proxy, and the patient's family. Decisions from each of these sources should reflect the following standards, respectively: immediate self-determination, self-determination exercised earlier, and the best interests of the patient. Institutions lie outside this hierarchy of decision making and should intervene by going to court only if they believe a decision violates these standards. Although I am sympathetic with the view of the doctors at the Hennepin County Medical Center, I agree with the court that they were wrong to try to impose it on the Wanglie family.

Notes

1. In re Helga Wanglie, Fourth Judicial District (Dist. Ct., Probate Ct. Div.) PX-91-283. Minnesota, Hennepin County.
2. Society for the Right to Die. The physician and the hopelessly ill patient: legal, medical and ethical guidelines. New York: Society for the Right to Die, 1985.
3. Guidelines on the termination of life-sustaining treatment and the care of the dying: a report by the Hastings Center. Briarcliff Manor, N.Y.: Hastings Center, 1987.
4. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Deciding to forego life-sustaining treatment: a report on the ethical, medical, and legal issues in treatment decisions. Washington, D.C.: Government Printing Office, 1983.
5. Cruzan v. Harmon, 760 S.W.2d 408 (1988).
6. Annas, G.J. The health care proxy and the living will. N Engl J Med 1991; 324:1210–3.
7. In re Quinlan, 70 NJ 10, 355 A.2d 647 (1976).
8. Brophy v. New England Sinai Hospital, Inc., (Mass. Probate County Ct., Oct. 21, Nov. 29, 1985) 85E0009-G1.
9. Paris, J.J., Crone, R.K., Reardon F. Physicians' refusal of requested treatment: the case of Baby L. N Engl J Med 1990; 322:1012–5.
10. Miles, S.H. Informed demand for "non-beneficial" medical treatment. N Engl J Med 1991; 325:512–5.
11. Brett, A.S., McCullough, L.B. When patients request specific interventions: defining the limits of the physician's obligation. N Engl J Med 1986; 315:1347–51.
12. Blackhall, L.J. Must we always use CPR? N Engl J Med 1987; 317:1281–5.