

# Virtual Mentor

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## Clinical Case

### Media Attention to End-of-Life Cases

Commentaries by Ware G. Kuschner, MD, and John J. Paris, SJ, PhD

George Whitlock has lived in rural Georgia for all of his life, third in a family of 7 siblings. He started his own business building houses in his community. George is something of a legend for his kind manner and generosity—“pay us when you can” is a sentence frequently out of his mouth. A portly, balding man of 50, now he supervises more than works on the construction site and presides over his family of 2 daughters and his wife.

One day, George was walking on the frame of the second floor of a large house he was building for people from the city. As foreman Jim White tells it, “I turned around and George was gone.” Jim recalls a horrifying moment when he finally saw George lying prone 2 floors below. Jim sent someone for the doctor and tended to George until help arrived.

Dr Shirley Wolcott, an internist and longtime resident of the community, was the first to arrive, and an ambulance came soon after. She accompanied George to the hospital where tests showed that George had suffered a heart attack and subsequent head trauma from the fall with brain swelling due to an intracranial hemorrhage. George was taken by helicopter to a regional trauma center where he was stabilized and put on a ventilator. Later a feeding tube was inserted.

After a week went by, George’s family and Dr Wolcott requested a transfer to their community hospital, so they could be near to George and Dr Wolcott could monitor his recovery. Dr Wolcott initially assured them that once the swelling receded, George would recover consciousness, based on what she was told at the hospital by the neurologist who examined George’s brain scans.

As the weeks turned into months, however, Dr Wolcott became more and more convinced that George would not make the recovery she was hoping for and requested a second consult by another neurologist from the city hospital. After fully examining George, the neurologist found that the damage to his brain was more extensive than previously thought and told Dr Wolcott that George was in a persistent vegetative state (PVS) and unlikely to regain consciousness. Dr Wolcott broke the difficult news to George’s family and counseled them through the process of deciding how to proceed. They agreed with Dr Wolcott that if George wasn’t going to recover consciousness he wouldn’t want to be kept alive indefinitely, which he would view as being a burden to his family.

The Whitlock family were also members of an influential church community. They asked that the community pray for them and the difficult decision they were making to remove George's life support, a plea that provoked both sympathy and outrage among the large congregation. One member went so far as to contact local television stations about the case, resulting in national media attention. Another, an emergency physician, saw George on television and concluded that the consulting neurologist's findings had to be mistaken. He lobbied the media and the Whitlocks to get more specialists to examine George. The Whitlocks were left somewhere in the middle, relentlessly tugged by those who wanted them to let George go and those who thought this action was unethical at the least and possibly tantamount to murder.

Dr Wolcott was unwittingly caught in the public limelight, being asked whether she had advised the Whitlocks to "pull the plug."

### **Commentary 1**

by Ware G. Kuschner, MD

Let's begin by identifying the stakeholders and the other influential actors in this case. Their comments, actions, and beliefs drive the conflict that is pitting community against family and physician against physician. First, and above all, there is George. It bears emphasis that George's welfare and any of his previously expressed beliefs about life support in the setting of grave illness must remain central to any discussion about what constitutes appropriate medical care. Next, there are George's family and Dr Wolcott; the people in George's life who are now obligated to make medical decisions in concert for George, since he has lost decisional capacity. Finally, there is the community, or, more precisely, 2 communities. There is the intimate, face-to-face community in which George and his family live, which includes the members of their church. There is also the "community" of the general public created by media attention that has taken an interest in this case.

### **Central Tensions**

There are 2 central tensions in this case. First, there is conflict over who is speaking for George's best interest. Dr Wolcott and George's family have the legal authority to determine what constitutes appropriate medical care for George, and they have an ethical duty to abide by George's treatment preferences as expressed prior to his injury. They have developed a plan to withdraw life support that is predicated on: (1) the consulting neurologist's diagnosis of persistent vegetative state and the prognosis that George is not likely to regain consciousness, and (2) the family's understanding of George's treatment preferences. Tension has evolved because some members of the local faith community and general public have expressed strongly held beliefs that conflict with the family's and physician's plan. Members of the community have challenged both the premise for the decision to withdraw life support and the act itself, arguing that Dr Wolcott and the family are developing a plan that is based on incorrect information ("the neurologist's findings had to be mistaken") and that it is not ethical to withdraw life support.

A second central tension in this case is uncertainty about the physician's role in the public conflict. What are Dr Wolcott's obligations, if any, to become embroiled in the public debate about George and to attempt to defuse the conflict?

### **Dr Wolcott's Roles**

*Legal obligations.* Dr Wolcott's principal obligation is to George. She has a contractual obligation to provide standard medical care consistent with her patient's treatment preferences. Although George did not prepare an advance directive detailing his treatment preferences in the setting of grave illness, he did provide cues to his family and physician that if he were irreversibly gravely ill he would not want to be kept alive indefinitely. George did not appoint a durable power of attorney for health care before his injury; but he does have engaged family members who are empowered legally and ethically to act as his surrogates for medical decisions [1, 2]. In this setting, it is the responsibility of the patient's surrogates to make decisions, in concert with the treating physician, by the method of substituted judgment. The standard of substituted judgment dictates that the surrogate must act in accordance with the patient's known or likely preferences. The decisions need not be in agreement with either the proxy's personal preferences nor those of the physician. Dr Wolcott must abide by these treatment preferences, unless they are in conflict with her own values, in which case she would be obligated to assist the family in finding another physician for George [3, 4].

*Family-centered care.* Does Dr Wolcott have obligations beyond those to George? There are evolving expectations that the health care team should attend to the needs of the family in end-of-life care [4-6]. Principles of family-centered care include showing dignity and respect for patient and family, information sharing, family participation in case management, and collaborative decision making.

The family's announcement to the community of its decision to withdraw life support has created special tensions and conflict for the family. The principle of family-centered end-of-life care compels Dr Wolcott to provide the family with emotional support that should include displays of empathy for the criticism and ostracism the family may be experiencing and also for the ambivalence, guilt, and fear they may be feeling as a consequence of their decision.

Dr Wolcott should provide continuing assurance that the family's decision is what George would have wanted and, therefore, is ethically sound, as well as legal. Dr Wolcott should assure the family that she and they have done everything possible to bring comfort and dignity to George, including respecting his autonomy by adhering to all of his treatment preferences. Dr Wolcott's support of the family's emotional well-being will help the family find solace in their decisions and reach emotional closure when George dies.

*Addressing conflict in the community.* It should come as no surprise that members of both the local community and larger public have different opinions as to what constitutes ethical care of George or of any person in a persistent vegetative state. Dr Wolcott has several options in addressing conflict in the community. These include empowering

the family to educate critics of the basis for their decision to withdraw life support. Specifically, Dr Wolcott can advise the family to communicate: (1) The treatment preferences that George expressed prior to the injury, (2) the thoughtful deliberation that preceded the decision to withdraw life support, (3) the extended time period over which events have unfolded and (4) George's lack of progress over this period of time, and (5) the concurrent opinions of qualified physicians including a neurologist, who have examined George, that there can be no expectation of meaningful recovery as George would want.

With permission of George's family, Dr Wolcott could volunteer to speak to a church leader (eg, minister) about the care George has received and the basis for the plan to withdraw life support. She can communicate essential information to the church leader about George's status, prognosis, and wishes. This, in turn, may empower church leaders to address conflict within the faith community about the family's difficult decision. The church leader's moral authority within the church may facilitate "getting the message out" that George is being treated with dignity, respect, and in accordance with his wishes.

Finally, there is the larger community of the general public, including the television audience. If the family wishes to address this audience, Dr Wolcott may extend her support through a public announcement that reviews the challenges of the case and the decision-making rationale.

### **The Emergency Physician's Opinion and Behavior**

The emergency physician's judgment and motivations can be questioned. He has displayed prejudicial behavior, literally prejudging George's status based on the incomplete information of a television report, thereby undermining his credibility and moral standing in this case. Absent a professional or personal relationship with George that trumps that of other physicians or family members, he lacks both legal and ethical authority to make decisions about the next best course of care. His behavior has contributed to family tension, which is in conflict with the principles of family-centered care. Even if the emergency physician had special expertise in traumatic brain injury, the above mitigating factors constrain him from rendering a definitive conclusion about the quality of health care George is receiving.

Finally, physicians have an ethical obligation not to undermine the reputation and professional standing of another physician without cause. The emergency physician's public criticism of the neurologist's assessment is inconsistent with this precept.

Physician commentary on diagnosis, prognosis, and treatment of disorders should be limited to areas of expertise. Medical expertise is predicated on sufficient education, training, and experience in a medical discipline. Opinions about ethical matters and articulation of personal values and beliefs should be distinguished from commentary on the medical facts of a case. A physician is entitled to discuss an ethical matter outside of his or her specialty, provided a clear distinction is made between the ethical issue being discussed and the medical facts and opinions of a case.

## References

1. Annas GJ. The health care proxy and the living will. *N Engl J Med*. 1991;324:1210-1213.
2. Lang F, Quill T. Making decisions with families at the end of life. *Am Fam Physician*. 2004;70:719-723.
3. Ending the patient-physician relationship. American Medical Association, Office of the General Counsel. Available at: <http://www.ama-assn.org/ama/pub/category/4609.html>. Accessed September 27, 2005.
4. Snyder L, Leffler C for the Ethics and Human Rights Committee, American College of Physicians. Ethics manual, 5th ed. *Ann Intern Med*. 2005;142:560-582.
5. Truog, RD, Cist AFM, Brackett SE, et al. Recommendations for end-of-life care in the intensive care unit: The Ethics Committee of the Society of Critical Care Medicine. *Crit Care Med*. 2001;29:2332-2348.
6. Rabow MW, Hauser JM, Adams J. Supporting family caregivers at the end of life: "They don't know what they don't know." *JAMA*. 2004;291:483-491.

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## Commentary 2

by John J. Paris, SJ, PhD

The hypothetical Whitlock case raises several questions concerning the medical treatment for a patient in a persistent vegetative state. One of these issues—must such a patient undergo life-prolonging interventions—was first raised in the landmark 1973 case of Karen Ann Quinlan. There, the New Jersey Supreme Court ruled, "No external interest could compel Karen to endure the unendurable, only to vegetate a few measurable months with no realistic possibility of returning to any semblance of cognitive or sapient life" [1]. The court's rationale for its ruling was that the constitutional right to privacy was "broad enough to encompass a patient's decision to decline [unwanted] medical treatment" [1].

While a competent patient can readily exercise that right, the issue is more complex for the incompetent patient. In such cases, as the *Quinlan* court noted, the only practical way to prevent destruction of the right is to permit the patient's family to render their best judgment as to what the patient would want. If the choice would be to withdraw a life-prolonging intervention, that decision, the Court declared, "should be accepted by a society, the overwhelming majority of whose members would, we think, in similar circumstances, exercise such a choice in the same way for themselves or for those closest to them" [1].

Other jurisdictions have articulated variations on that standard. The Massachusetts Supreme Judicial Court in *Saikewicz* utilized "substituted judgment" to determine the

idiosyncratic values of an individual patient [2]. Under that rule the decision maker's task is, in the Court's words, "to don the mental mantle of the incompetent" to discern what the patient would choose if able to do so. New York and Missouri adopted the much more rigid requirement of "clear and convincing" evidence of what the once-competent person would want before authorizing the withdrawal of life-sustaining interventions [3]. That requirement necessarily precludes the withdrawal of medical interventions from minors, the never-competent and all of those who for whatever reasons have never formally articulated their preferences on the use of life-prolonging treatments [4].

### **Interventions or Basic Care?**

A second issue in George Whitlock's situation, one that roiled the nation in the recent Terri Schiavo case, is whether artificial nutrition and fluids are medical interventions to be evaluated like any other medical treatment, or basic care that may not be withheld or withdrawn so long as the patient is physically able to process nutritional support. For those who subscribe to the latter position, the removal of artificial nutrition and fluids is tantamount to "starving the patient to death." Such an action would be criminal negligence or deliberate homicide. The AMA's Council on Ethical and Judicial Affairs rejected that view in an Opinion issued in 1984 [5]. There the Council defined artificial nutrition and fluids as life-sustaining medical treatments, which are no different from other life-prolonging interventions such as mechanical ventilators or dialysis machines. Further, it held that it is not unethical to remove such interventions from patients who are terminally ill or who are in persistent vegetative conditions provided such a decision is made in accordance with the patient's values or "best interests."

That position was subsequently adopted by every state court of final jurisdiction that has ruled on the status of artificial nutrition and hydration. The legal issue was definitively resolved in the United States in the Supreme Court's 1990 *Cruzan* decision where the Court recognized that under our Constitution a person has "a constitutionally protected right to refuse even potentially life-prolonging artificial nutrition and fluids" [3]. Justices O'Connor and Brennan specifically cited the AMA's opinion for the proposition that artificial feeding cannot be distinguished from other forms of medical treatment.

### **No Breach of Duty**

With this legal and medical background we have the context for assessing the charges of "murder" in the Whitlock case. As the California Court of Appeals put it in *Barber v Superior Court*, a case in which 2 Los Angeles physicians were indicted for first-degree murder for, at the family's request, removing an intravenous feeding tube from a patient diagnosed as irreversibly unconscious: "The patient has no obligation to undergo the intervention, and therefore the physician no duty to provide it" [6]. Since there was no breach of duty by the physician in withdrawing the IV, there was no criminal act. What occurred rather, was the recognition by the family and physicians that there is no need to utilize medical interventions to prolong the life of a patient who is dying or one for whom there is no realistic expectation of return to a functioning, cognitive existence.

Another issue raised in the Whitlock case is the accuracy of the diagnosis of persistent vegetative state. Any diagnosis is, of course, subject to the standards within the profession for adequacy and accuracy. Those standards require a trained diagnostician making the assessment based on the evidence. That standard was met in this case.

Nothing would justify an uninvolved physician's making a diagnosis on a patient whom he has not examined and whose records he has not reviewed, nor for publicly challenging the findings of a well-qualified neurologist's "full examination." This is particularly true of the due diligence that would accompany a neurological examination done for a second opinion.

An outside physician, if asked by the patient's family, might advise that they ought to have the diagnosis "confirmed" by another well-qualified neurologist. If in the extreme case it appears to someone, including one licensed to practice medicine, that the treating doctor's actions are a violation of the law, the proper recourse, as the Florida State Supreme Court made clear in *In re Dubreuil*, is for that party to inform the local prosecutor [7]. To otherwise thrust oneself uninvited into a case is to be—in the description the New York Court of Appeals used to characterize the right-to-life attorney who brought the *Baby Jane Doe* case into the judicial system—an "interloper," ie, one with no relationship to the patient, no personal knowledge of the facts in the case, and no standing to challenge the family's decision [8].

Nor is there any ethical justification for an outside physician to speak to the media about an individual case other than to explain how a diagnosis is made for a particular condition and to educate the public as to what the literature says about such a diagnosis. This might be done, for example, if there were an interest in the medical condition of someone who was a prominent public figure. Illness itself, however, does not transform a patient into a public person subject to media scrutiny.

For the treating physician, Dr Shirley Wolcott, the patient's privacy rights, HIPAA regulations [9], and the physician's commitment to confidentiality with regard to what she has learned in her interactions with her patient preclude her making any public comments on the case —other than in the face of a "serious and imminent threat to the health and safety of a person or the public" —without the permission of the patient or the patient's proxy.

The license to practice medicine gives one the awesome responsibility of acting for the best interests of his or her patient. It does not transform the individual into society's Don Quixote. Physicians might well heed the words of Justice Benjamin Cardozo in *The Nature of the Judicial Process* where, writing on the role of a judge, Cardozo notes, "[The judge] is not to be a knight-errant, roaming at will in pursuit of his own idea of beauty or of goodness...He is not to yield to spasmodic sentiment, or to vague and unregulated benevolence" [10].

## References

1. *In the Matter of Karen Quinlan*, 70 NJ 10, 355 A2d 647 (1976).

2. *Superintendent of Belchertown State School v Saikewicz*, 373 Mass 728, 370 NE2d 417 (1977).
3. *In re Eichner*, 52 NY2d 363, 420 NE2d 64 (1981); *Cruzan v Director, Missouri Department of Health*, 497 US 261 (1990).
4. Paris J. The unfortunate legacy of Brother Fox: a diminishment of the rights of the dying patient. *N Engl J Med*. 1980;330:282-285.
5. American Medical Association. Opinion 2.20. Withholding or withdrawing life-sustaining medical treatment. *AMA Code of Medical Ethics*. Chicago: AMA; 2004:70-71. Available at: [http://www.ama-assn.org/apps/pf\\_new/pf\\_online?f\\_n=browse&doc=policyfiles/HnE/E-2.20.HTM&&s\\_t=&st\\_p=&nth=1&prev\\_pol=policyfiles/HnE/E-1.02.HTM&nxt\\_pol=policyfiles/HnE/E-2.01.HTM&](http://www.ama-assn.org/apps/pf_new/pf_online?f_n=browse&doc=policyfiles/HnE/E-2.20.HTM&&s_t=&st_p=&nth=1&prev_pol=policyfiles/HnE/E-1.02.HTM&nxt_pol=policyfiles/HnE/E-2.01.HTM&). Accessed October 26, 2005.
6. *Barber v Superior Court*, 147 Cal App3d 1006, 195 Cal Rptr 484 (1983).
7. *In re Matter of Patricia Dubreuil*, 629 So2d 819 (Fla 1993).
8. *Weber v Stony Brook Hospital*, 60 NY2d 208, 456 NE2d 1186 (1983).
9. Health Insurance Privacy and Portability Act of 1996. Pub L No 104-191 (1996).
10. Cardozo B. *The Nature of the Judicial Process*. New Haven, Conn: Yale University Press; 1921. Cited in: [*Application of the President and Directors of Georgetown College, Inc.* Burger W. (dissenting).] 331 F2d 1010, 1117 (1964).

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