The Case of Elizabeth Bouvia

Starvation, Suicide, or Problem Patient?

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In the summer of 1983, Elizabeth Bouvia, a 26-year-old woman physically incapacitated by cerebral palsy, checked into Riverside (Calif) General Hospital, saying that she wanted to starve to death. More than seven months later, she changed her decision. In a motel room in Tijuana, Mexico, Bouvia renounced her wish to die and ate solid food. This case attracted the interest of physicians, disabled individuals, and the public at large. Dramatic charges and countercharges were widely publicized.

We shall discuss several issues. First, was Bouvia exercising the competent patient's right to make decisions about her medical care or was she demanding that her physicians assist in her suicide? Second, what role should external interests, such as those of handicapped individuals, medical professionals, or society at large, have in medical decisions for patients like Bouvia? Third, is refusing food and water different from declining other care? Finally, how can physicians care for "problem" patients who make demands that appear unreasonable?

THE CASE OF ELIZABETH BOUVIA

Despite severe cerebral palsy, Bouvia moved out of a long-term care institution at the age of 18 years and completed a degree in social work. In 1982, she married and entered a master's program. Frustrated by her continued reliance on others, however, she left school and separated from her husband.

On Sept 3, 1983, Bouvia was voluntarily admitted to the psychiatric ward at Riverside General Hospital. She wanted to die. "Death is letting go of all burdens," she said. "It is being able to be free of my physical disability and mental struggle to live." Bouvia refused all food except liquids. She was not acutely ill, but she had painful arthritis and was almost quadriplegic. She could eat a normal diet when fed by someone else and could operate an electrically powered wheelchair with her right hand. She asserted that she was unable to take her own life and wanted the hospital to provide pain relief and hygiene while she starved to death.

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Bouvia's story became public in early October. The American Civil Liberties Union (ACLU) decided to represent her. It petitioned the Superior Court to prohibit feeding Bouvia against her will. The case escalated into a public debate. Disabled individuals held vigils at the hospital to convince her to change her mind. Bouvia's estranged husband hitchhiked to Riverside from Iowa, retained lawyers, and asked to be named her legal guardian. He charged the ACLU with using his wife as a "guinea pig." She filed for divorce. Columnist Jack Anderson's offer to raise funds for Bouvia's medical treatment was rebuffed. Richard Nixon sent a letter encouraging Bouvia to "keep fighting." A meeting with President Ronald Reagan was discussed. Two neurosurgeons offered free surgery to help her gain the use of her arms. A convicted felon volunteered to shoot her.

Attorneys for Riverside County said Bouvia wanted hospital staff to assist in a suicide. They claimed Bouvia was depressed and had attempted suicide four times before. Other testimony contradicted these charges. The chief of psychiatry at Riverside said publicly that he would forcibly feed Bouvia if necessary, even in defiance of a court order. He was convinced she would change her mind about dying. "The court cannot order me to be a murderer nor to conspire with my staff and employees to murder Elizabeth," he said.

On Dec 16, Superior Court Judge John H. Hews rejected Bouvia's request.[1] He ruled that Bouvia was mentally competent and not depressed. He said that four considerations justified overriding her wishes. First, although Bouvia was severely handicapped, she was not terminally ill. Second, she did not have "the right to end her life with the assistance of society." This would be suicide, not a natural death through starvation. Third, Bouvia's request violated the rights of other patients in the hospital and other people with chronic disabling diseases. Fourth, it undermined the ethical integrity of the medical profession.

When Bouvia then refused the liquid protein meals that had sustained her, Judge Hews authorized involuntary feeding. After Bouvia bit open her intravenous tubing, she was physically restrained and tube feedings were initiated. Her lawyers said Bouvia was being "battered" and "tortured." Hospital officials wanted to discharge Bouvia. Bouvia, however, refused any placement that would not let her starve to death. The state Supreme Court twice declined to review the case. An appeals court refused Bouvia's request to bar the hospital from discharging her.

The public rhetoric escalated. The associate chief of medicine said that Bouvia had demoralized the staff with her "diabolical" demands and that media coverage encouraged her to continue her fight.

On Feb 6, 1984, Judge Hews made permanent his order allowing forced feeding. Bouvia reiterated her refusal to eat. The standoff continued until April 7, when Bouvia unexpectedly checked herself out of the hospital. The hospital bill for the 217 days, excluding physicians' fees, was more than $56,000, paid by Riverside County and by the state of California.

Bouvia went to the Hospital del Mar at Playas de Tijuana, Mexico, known for amygdalin (Laetrile) treatments for cancer. She believed the staff would help her die. Her new physicians, however, became convinced that she wanted to live. Two weeks later, Bouvia left the hospital, hired nurses, and moved to a motel. Three days later, with friends, a reporter, and an intern from Hospital del Mar at her side, she gave up her plan to starve herself to death and took solid food. Bouvia said that she wanted treatment, including surgery to reduce muscle spasms.

As of August 1985, Bouvia's location and plans were not known. Her case was complicated further by the revelation that the newspaper reporter who covered the case most closely had a contract with Bouvia for book, television, and movie rights to her story.

COMPETENT PATIENT'S RIGHT TO DETERMINE MEDICAL CARE

Competent, informed patients have the right to refuse medical care, even when their refusal contradicts medical advice or might shorten their life.[2] This ethical principle has been supported by court decisions on such diverse treatments as blood transfusions for Jehovah's Witnesses and amputations for patients with gangrene. However, Bouvia's plan not to take food and water in the hospital involved more than a refusal of treatment. She wanted care while she died of malnutrition and dehydration. Her physicians considered this request to be assisting in a suicide or direct killing. Such assistance was morally and professionally unacceptable to them.[3]

The Bouvia decision supports the ethical principle that neither physicians nor patients may impose their wishes on the other.[2,4] Patients may decline treatment that physicians recommend. Physicians, however, cannot be required to provide care they consider medically unindicated or ethically inappropriate.

What considerations might justify not following a patient's wishes? The patient may be incompetent, uninformed, or coerced. Physicians might consider delaying a final decision while they try to correct conditions that impair competency, provide information, or eliminate any perceived coercion. Overriding a competent patient's informed decision is not justified. Attorneys for Riverside County argued that a patient who refuses nutrition eventually becomes incompetent and thus a candidate for involuntary feeding, because of the state's compelling interest in the preservation of life. Judge Hews, however, rejected these justifications for overriding Bouvia's wishes.

What difference does it make that Bouvia eventually changed her decision? Some might believe in retrospect that a paternalistic approach that discounted her stated wishes was justified. Retrospective judgments are fraught with difficulties, however, because they are based on information unavailable to the patient or caregivers at the time of the original decision. Bouvia had undergone a careful evaluation that excluded psychiatric illness and incompetence. Her change of mind could not have been forecast at the time of her initial decision. During her hospitalization, she had many opportunities to change her mind. Under these circumstances, the physician is not responsible for protecting a patient from the consequences of a competent decision.

It is legitimate to ask whether Bouvia had a medical problem at all and whether the hospital was the appropriate social institution to care for her problems. The physician's traditional roles are those of healer and student of disease. But the physician is not responsible if symptoms of a chronic illness cannot be cured or if a long-standing handicap cannot be reversed, nor is the physician responsible for solving the psychological, social, or economic problems caused by the patient's chronic disease. The physician's duties are to listen sympathetically, offer counseling and support, and provide appropriate referrals to community organizations, patient support groups, social workers, or psychologists.

Ironically, if Bouvia had carried out her plan outside of the hospital without assistance or had agreed to be discharged, her physicians and the courts would have had no reason to interfere. In Brian Clark's play, *Whose Life Is It Anyway?*[5] the quadriplegic sculptor who wants to die must sue to be discharged from the hospital, where he is being held against his will, so that he can carry out his plan. A judge eventually orders the hospital to discharge him. For seven months, this alternative was unacceptable to Bouvia.

ROLE OF EXTERNAL INTERESTS IN CLINICAL DECISIONS

In clinical decisions, the wishes of the patient take priority over the interests of others. In the Bouvia case, several claims were made about the importance of external interests. Bouvia's refusal of care involuntarily involved her physicians and the hospital staff. They considered her a disabled but otherwise healthy woman with a nonterminal condition who asked that they assist in her suicide. Her physicians felt that aiding with pain medicines while she starved was morally wrong, risked legal liability, and contradicted their duties to cure illness and respect the sanctity of life. Judge Hews agreed.

Similarly, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research has argued that, in rare cases, limiting self-determination for an individual patient may be an acceptable cost of "securing the general protection of human life."[6] In the Bouvia case, while the patient's self-determination and comfort were important, society's interest in maintaining a strong legal protection of life took precedence.

Caregivers also argued that acceding to Bouvia's plan would violate their consciences. A decision based on conscience involves more than personal discomfort or predilections. A violation of conscience must not only result in unpleasant feelings such as guilt or shame, but also a fundamental loss of integrity. Conscience involves deliberation based on moral principles.[7] People should be willing to justify appeals to conscience in public debate. The physicians' decisions in the Bouvia case met these criteria.

Third parties allegedly harmed by Bouvia's starvation plan included other patients in the hospital and handicapped individuals in general. Agreeing to her plan was seen as compromising the care of other patients. If Bouvia were allowed to refuse nutrition and therefore die, other patients might get worse treatment or believe that they would receive inferior treatment. However, little empiric evidence was offered to support these assertions about the detrimental consequences of her actions.

Indeed, concerns about adverse consequences could have been addressed directly. In the hospital, physicians and

administrators could have talked to other patients and staff about the issues and their responses, while respecting Bouvia's privacy. Such discussions occur commonly, for example, after a suicide on a psychiatric ward. Moreover, in public statements, physicians might have expressed sympathy for her plight and a commitment to provide high-quality, compassionate care.

In a sense, Bouvia was being chastised as a poor role model for other patients or handicapped individuals, although she was under no obligation to be a role model. More positive role models for patients and the handicapped are needed, but this need did not justify overriding Bouvia's wishes.

DIFFERENCE BETWEEN FOOD AND WATER AND OTHER CARE

While the Bouvia case was decided on the issue of suicide, not feeding, much public and medical reaction to the Bouvia case focused on the feeding issue. Food and water are sometimes considered basic and humane care that must always be given, because they symbolize love and concern for the helpless.[8] Not feeding a dependent person seems cruel, but so did restraining Bouvia after she bit open her intravenous tube.

Feeding can be analyzed, like other interventions, by considering the risks and benefits of treatment and the patient's wishes.[8-11] This concept of evaluating the benefits and burdens of providing food and water has been given judicial recognition by the California Court of Appeals in the Herbert case[12] and by the New Jersey Supreme Court in the Conroy case.[13]

It is difficult to draw analogies from the Conroy or the Herbert cases to the Bouvia case because the situations were so different. Clarence Herbert was an irreversibly comatose patient for whom intravenous fluids and mechanical ventilation were discontinued. The California court ruled that "A treatment course which is only minimally painful or intrusive may nonetheless be considered disproportionate to the potential benefits if the prognosis is virtually hopeless for any significant improvement in condition."[12]

Claire Conroy was an 84-year-old nursing home resident with severe dementia who was unable to speak, bedridden, and incontinent. She had contractions, several decubitus ulcers, and a gangrenous left leg. The New Jersey Supreme Court permitted under certain circumstances the withholding of life-sustaining treatments, including food and water, from incompetent nursing home residents who would die within a year. Despite these decisions, the criteria for withholding food and water from patients, whether competent or incompetent, comatose or awake, remain controversial. Some have advocated "a slow and conservative approach" to preserve the commitment of physicians and society to compassionate care and the preservation of life.[11]

This approach of weighing benefits and burdens is useful in analyzing the Bouvia case. Tube feeding can be complicated by aspiration, discomfort, and the need for restraints. Parenteral hyperalimentation can be complicated by sepsis, pneumothorax, and metabolic disturbances. Different people will weigh the benefits and risks of feeding differently, just as they might accept or reject hemodialysis or blood transfusions. The preferences and values of the patient should usually prevail.

In essence, Bouvia told her caregivers that the burdens of eating outweighed the benefits. Her caregivers viewed the situation differently. The benefits of providing food and water seemed apparent. Bouvia was not terminally ill and had a long life expectancy. More importantly, her refusal of nutrition also involved the participation in her killing by others. Judge Hews said that Bouvia's "self-starvation with the assistance of society" would constitute suicide. He said that it was appropriate to force food on her to save her life. These latter considerations, not the emotional desire to provide food and water to a patient unable to provide them herself, were decisive in his ruling.

Can a handicapped individual incapable of feeding herself die a natural death through starvation, as, for example, a patient with end-stage renal disease might die a natural death through uremia? The Bouvia case raised but did not resolve this issue. There has never been a requirement that patients must be terminally ill before they can refuse treatment, although limitations on treatment occur most commonly when patients are gravely ill or moribund. Bouvia was no more nor less terminally ill than a stable patient with renal failure. But a "natural death through starvation" should not require the participation of others.

MANAGING THE DISRUPTIVE PATIENT

While the Bouvia case is an unusual example of a patient's desire to determine medical care, it is a typical example of how a "problem" or "demanding" patient can disrupt hospital routines. From the start, Bouvia and her physicians were adversaries, not therapeutic allies. She was an unsolicited patient who made unusual demands at a county hospital and made her case public.

Bouvia's physicians did not have the option of withdrawing from her case. They were frustrated in their efforts to discharge her. Under the glare of publicity, hostility and a confrontational approach to Bouvia and her lawyers seemed to develop. Nurses took notes on her visitors and her telephone calls, which later were used as evidence against Bouvia in court. These actions probably reinforced Bouvia's perception that the hospital was opposing her, rather than helping her. Public pronouncements and personal attacks may also have escalated the confrontation.

Physicians often care for demanding, angry, or hostile patients who challenge the caregiver's authority and self-confidence.[14] These patients may, for example, demand pain medicines that the physicians feel are not medically indicated. Such patients have been termed "hateful" because they evoke such strong negative reactions from caregivers.[15,16] Physicians should recognize the negative emotional reactions that the patients evoke in themselves and other caregivers, work through these reactions, and not let them interfere with care. How caregivers feel about the patient is much less important than how they behave toward the patient.[15]

Caring for such patients requires building a partnership between physician and patient and a willingness by both parties to negotiate. To provide effective care, the physician must listen to the patient, show empathy, and elicit the patient's beliefs about illness and expectations for care.[17] Spending time listening uncritically to the patient helps to establish a therapeutic physician-patient relationship and may allow shared and realistic goals to be set. If the patient's requests contradict good medical practice or ethical guidelines, physicians need to define their limits with sympathy and clarity.

In this unusual and time-consuming case, these principles may have been overlooked. While Bouvia's caregivers may have wished to ventilate their emotions in private, in public they might have deescalated the situation by minimizing media statements and emphasizing areas of agreement with their patient. In discussions with her, they might have stressed their empathy for the limitations imposed by her severe handicaps. Because caring for "problem" pa-

tients is so difficult, other authors have called for improved training for physicians in communications skills.[18] For example, in a case like this a physician might say, "It must be terribly frustrating to want to do something and not be able to carry it out yourself, and then have others decline to help you. I wish we could do what you want, but we simply can't." A caregiver who needs to set limits on a patient's demands might emphasize the goals of relieving his or her pain and providing emotional support. For example, a physician might say, "We can't help you starve to death, as you request. But we can work with you to relieve your pain and your frustration."

Bouvia's physical limitations made it especially difficult to give her a sense of partnership in her care. But these limitations did not preclude giving her responsibility and control over the details of the hospital routine, such as the timing of blood tests, medicines, and toilet care. Enhancing a patient's sense of control may lead to greater agreement with the physician's recommendations.[19]

Withdrawal from the case by physician or patient is sometimes an alternative to caring for problem patients. No other hospital, however, would accept Bouvia as a patient. Discussion of this option may have increased the level of hostility. Instead of threatening to discharge Bouvia, her caregivers might have simply stated that they would care for her as necessary. Because caring for such a patient may be very stressful, it might have been helpful to change caregivers periodically.

CONCLUSION

The Bouvia case became controversial because of the strong emotions evoked by a severely handicapped patient's refusal to eat. The publicity diverted attention from important implications of the case. First, although competent patients have a right to refuse medical care, they do not have the right to ask caregivers to assist in a suicide or participate in a direct killing. Second, providing nutrition is a therapeutic intervention whose indications, benefits, and risks must be weighed. Third, Bouvia was an example of a "problem" patient, who does not conform to the norms of usual patient behavior. Although such patients frustrate caregivers, it is important to try to establish a constructive physician-patient relationship. Physicians who remember these aspects of the Bouvia case, not just the headlines, may learn important lessons for managing other difficult cases.

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