

# Virtual Mentor

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## Case in Health Law

### *Bouvia v Superior Court: Quality of Life Matters*

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#### Introduction

Elizabeth Bouvia was a mentally competent, young, quadriplegic woman who suffered from cerebral palsy, leaving her completely bedridden and dependent on others to perform all her activities of daily living. Despite having a college degree, she was financially unable to support herself, did not have a stable living situation, and relied on public assistance for all aspects of her care. In 1983, at age 26, she expressed a desire to end her life [1]. Ms Bouvia then attempted to accomplish this by self-starvation in a California public hospital, an act which was widely publicized in the media.

A California court denied Ms Bouvia judicial assistance to starve herself to death and issued a court order allowing the hospital to commence force-feeding her by inserting a nasogastric tube [2]. After several unsuccessful attempts to find a publicly funded apartment with visiting nurses to provide care, Ms Bouvia once again became a patient in a public hospital, and in 1986 she was eventually transferred to High Desert Hospital (HDH), another public facility. When Ms Bouvia could no longer be spoon-fed without nausea and vomiting HDH inserted a nasogastric tube against her will to avert potential starvation. The medical staff acted against Ms Bouvia's wishes because of her life-threatening condition, her previous efforts to starve herself, and her prognosis which indicated she could survive an additional 15 to 20 years with adequate nutrition [3]. Her caregivers believed that the state's interests in preserving life compelled such an action.

Ms Bouvia sued the hospital and its staff, seeking a court order from the Superior Court of Los Angeles County, to have the nasogastric tube removed and to stop all medical measures to which she did not consent.

#### Disposition

The trial court denied Ms Bouvia's request, stating that her prognosis justified the state's interest in preserving her life. The court said that to rule otherwise would be tantamount to aiding and abetting suicide, since Ms Bouvia's motive for refusing treatment was to die. Ms Bouvia immediately appealed the trial court decision.

The appellate court acknowledged that a competent adult has the right, in the exercise of control over his or her own body, to determine whether and to what extent to submit to medical treatment [4]. A competent patient also has a basic and fundamental right to refuse any medical treatment, even if it may save or prolong his or her life [5].

Although the questions of refusing and withdrawing treatment are often considered in the context of terminal prognoses (which Ms Bouvia did not have), the right nevertheless exists under both the state and federal constitutions and is not limited to “terminal” patients [7].

Physicians may establish the medical diagnoses and prognoses of patients, but the competent patient is entitled to make the ultimate decision about what care will be rendered, with the “patients interests and desires...the key ingredients of the decision-making process” [7].

The court further recognized that a patient’s right to self-determination regarding medical treatment is based upon the patient’s being mentally competent and able to understand the consequences of withdrawal or refusal of care. The court noted that Ms Bouvia was mentally competent, understood the risks involved in refusing nasogastric tube feeding, and, hence, any objections to her refusal of the feeding could not be based on those grounds.

The hospital staff argued that the interests of the state should prevail over the rights of the patient to refuse treatment. Traditionally, viable state interests include: (1) preserving life, (2) preventing suicide, (3) protecting innocent third parties, and (4) maintaining the ethical standards of the medical profession, including supporting the right of physicians to effectively render necessary and appropriate medical services.

The court decided that these interests, although valid, were insufficient to overcome Ms Bouvia’s right to refuse medical treatment. The appellate court concluded that the trial court had erred in deciding that, just because Ms Bouvia could live an additional 15 to 20 years with sufficient feeding, the state’s interest in preserving her life for that period prevailed over her individual right to autonomy. The appellate court emphasized that the trial court’s focus on the potential additional *years* of life available to Ms Bouvia without considering her *quality* of life during those years had been erroneous. Indeed, quality is an equal, if not more significant, consideration to be weighed by the court.

The appellate court noted on this basis, that it is not the policy of the state to preserve every life. In this case, if treated against her wishes, Ms Bouvia would have to endure 15 to 20 years of a severely diminished quality of life. The court stated that “[i]n Ms Bouvia’s view, her quality of life has been diminished to the point of hopelessness, uselessness, unenjoyability, and frustration. She, as the patient, lying helplessly in bed, unable to care for herself, may consider her existence meaningless” [8]. Since it is “patient’s interests and desires [that] are the key ingredients of the decision-making process,” the court concluded the decision to forgo medical treatment belonged solely to Ms Bouvia [9]. As an important component to her perception of a high quality of life, Ms Bouvia had the right to live out the remainder of her life in dignity and peace as she herself defined it.

The appellate court also addressed the issue of suicide, holding that Ms Bouvia’s decision to exercise her right to refuse treatment and accept the consequences of that

refusal was not equivalent to an election to commit suicide with the hospital staff aiding and abetting this act [10]. The appellate court ruled that no assessment of the “motive” behind Ms Bouvia’s decision should be performed, and the trial court had been wrong to do so. The appellate court noted that Ms Bouvia could exercise her right to refuse medical treatment regardless of her motive, and no criminal or civil liability would attach to caregivers when honoring a competent, informed patient’s refusal of medical services [11]. However, the court stated that the hospital and staff were free to provide the care to which Ms Bouvia consented, such as alleviation of her pain.

In sum, the appeals court reversed the trial court’s determination and held that Ms Bouvia had the right to have the nasogastric tube removed because: (1) she had a fundamental right to refuse medical treatment; (2) her rights superseded the state’s interests; (3) quality of life was a valid and essential consideration; and (4) fulfilling the patient’s desire to refuse treatment was not equivalent to assisting the patient in committing suicide. After the appellate court’s ruling, the feeding tube was removed and Ms Bouvia was eventually discharged from the facility. In the months that followed, Ms Bouvia continued to lose weight and suffer increasing discomfort from arthritis and other ailments [12]. She then entered a private convalescent hospital, agreeing not to attempt starvation [12].

As a postscript to the case, Ms Bouvia’s attorney and personal confidant, Richard Scott, who led the high-profile fight to give Ms Bouvia the right to refuse treatment, committed suicide 6 years after the decision. Ms Bouvia indicated then that she still wanted to die, but, after receiving pain control for secondary diagnoses, the process of starvation proved too physically painful to carry out. Although she considers herself a “reluctant survivor” and living the life she dreaded, she is still alive today [19].

### **Commentary**

The 2 medical ethics principles of respect for autonomy and beneficence inevitably conflict at some point. The principle of respect for autonomy directs that a patient’s wishes should be honored, including those regarding the nature and extent of his or her health care, while beneficence binds the physician to provide care that promotes the patient’s well-being, including the relief of suffering and the preservation of life [13]. As long as the patient’s wishes are reasonably established, courts usually follow the principle of autonomy when conflict occurs. As seen here, the appeals court upheld Ms Bouvia’s right to make her own medical decisions by requiring the hospital and staff to respect her desire to refuse nutritional treatment while continuing the pain control to which she had consented.

The *AMA Code of Medical Ethics* Opinion 2.20 addresses this conflict between respect for autonomy and beneficence:

The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the preferences of the patient should prevail. The principle of patient autonomy requires that physicians respect the

decision to forego life-sustaining treatment of a patient who possesses decision-making capacity [14].

Hence, the ethical focus in such a conflict should always be on a competent patient's preferences as expressions of his or her autonomy. This means that physicians must understand the wishes and desires of the patient, particularly when it comes to implementing advance directives or the use of health care proxies [15]. The *AMA Code of Medical Ethics* further indicates that quality of life is of specific concern in ethical decision making. Opinion 2.17 states that:

[i]n the making of decisions for the treatment of...persons who are severely disabled by injury or illness, the primary consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society. Quality of life, as defined by the patient's interests and values, is a factor to be considered in determining what is best for the individual [16].

The opinion goes on to state that quality of life can be considered "when deciding about life-sustaining treatment" [16]. Again, this standard highlights the need for physicians to have excellent communication and relationships with patients so they can understand their interests and values about quality of life in order to carry out the patient's wishes most effectively.

Although Opinion 2.17 stipulates that quality of life should be "a" factor to be considered, it should, in fact, be the *overriding* factor of concern to clinicians. As the court stated about Ms Bouvia, "[s]he herself is imprisoned and must lie physically helpless subject to the ignominy, embarrassment, humiliation, and dehumanizing aspects created by her helplessness" [17]. Only Ms Bouvia could understand what such a prospect meant to her quality of life, and only through her decisions and communications with her caregivers could she express that understanding. As the court stated, it is not, and should not, be the policy of any care provider, "[t]hat all and every life must be preserved against the will of the sufferer" [18]. Unfortunately, although acting in good faith, Ms Bouvia's caregivers were attempting to do just that.

Finally, it should be emphasized that quality-of-life considerations and withdrawal of treatment do not, in themselves, constitute physician-assisted suicide or voluntary active euthanasia. A patient's right to refuse or to withdraw from medical treatment, even at the risk of causing his or her own death, is not only constitutionally protected on the state and federal level, but is ethically distinct from active and knowing efforts to end life. Patients who refuse or discontinue life-sustaining treatment are not committing suicide, but dying—or accepting death—caused by the underlying disease. Hence, physicians who honor their patients' wishes to forego life-sustaining treatment are not assisting in their patients' deaths.

Overall, the patient's own wishes and best interests must always be considered when deciding on any treatment. It is imperative that this assessment be made when patients refuse treatment. In these situations, assessment must include a strong deferral to the patient's perspective regarding his or her quality of life. This is simply another

expression of patient advocacy and respect for patient autonomy. Through high quality, continuous communication, and trust between the patient and the physician, the expression of the patient's wishes—and the best interests of the patient—can occur both in treatment and treatment refusal situations.

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