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azine treatments for Mrs. Hier because of the reasonable expectation that this would improve the quality of her existence (and, indeed, might even lead her to reverse her unwillingness to be fed).

The possibility that failing to feed a patient will increase the patient's suffering must be considered—just as we must consider that the failure to employ a respirator may lead to an agonizing death for certain patients, though it is acceptable for others. Remembering that the word "care" is related to "lament," we should evaluate each individual's need for solicitude and comfort, without assigning an overriding symbolic role to feeding. Society must protect debilitated people, who are often old and make "uninteresting" patients, from the risk of neglect or abandonment by their guardians and caregivers. But, as the courts have also recognized, we should not be insensitive to either the real or the symbolic harm that is done when patients without prospect of recovery or of human interaction are held on the cusp of death by feeding tubes.

Those who make and implement policy in this area face the difficult task of balancing the dictates of autonomy (which would often oppose feeding) with the impulse to paternalism (which would lead to feeding even resisting patients), all in the framework of community (which embodies our commitment to caring for each other). Perhaps, if we are fortunate, they will succeed in thinking boldly, clearing away the cobwebs of old confusions, while also cautiously evaluating each precious life that depends for its continuation upon their judgment.

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Life as a Work of Art

by ERIC J. CASSELL

In American medicine the principles that patients must consent to their care and that they have a right to refuse treatment have become firmly established over the past fifteen years. Underlying these principles are the right to self-determination and respect for autonomy. The changes in medical practice that followed acceptance of these ideas have occurred during a period in American society that stressed a *personalized* radical individualism. More than the political individualism of our heritage, and beyond the individualism of effort Americans cherish, radical individualism stresses characteristics arising from the interior of the person. I have a right to "be myself" and "do my own thing." Previously equality was stressed; now differences are more central.

Not surprisingly, during this same period medicine has shifted from a near-exclusive focus on disease toward a primary concern with the sick person. Indeed, I have argued elsewhere that the function of medicine is to help persons maintain or regain autonomy, which is inevitably damaged by serious illness, and which cannot be maintained without the help of a physician (or other caregiver).[1] In these last decades, then, the vocabulary of the moral—of right and wrong—has been added to the vocabulary of scientific medicine—of fact and content. Without question, the publicly acknowledged joining of a moral dimension to medical practice has greatly enriched medicine.

However, neither of the two kinds of understandings—the scientific or the moral (at least in their present form)—provide adequate guidance in instances where a person under medical care refuses to eat. Consider the story of Elizabeth Bouvia. A twenty-six-year-old woman disabled since birth by cerebral palsy, but not otherwise ill, Bouvia admitted herself to a psychiatric hospital. There she refused nutrition and declared her desire to die, apparently because she found her life of total physical dependency unbearable. A more common situation might be that of an old woman who has suffered a series of strokes and can neither care for herself nor leave the hospital. Finding the inevitability of long-term custodial care intolerable, she refused further food. These persons no longer wish to live in their present state (which will not improve) but there is no disease that will soon kill them. Because they cannot otherwise act on their own, they refuse nutrition in order to die.

It is very important to emphasize that *there is no theoretical difference between the refusal to eat and the refusal of any other treatment*. That no disease is present

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that will soon kill the patient does not morally differentiate these cases.[2]

Ugliness and its Absence

There are other ways of looking at the problem, however, where there are definite differences between a patient with terminal illness who refuses further treatment and a person like Elizabeth Bouvia who turns away all nutrition. A new patient enters an impersonal setting and requests that he or she not be fed no matter what happens. If, against their own wishes, the staff accede to the patient's desire, every day will present them with unpleasantness. While the patient starves to death over a four-to-six-week period, the bed must be made; the patient must be bathed and kept clean; bed sores may require treatment. The staff cannot hinder the patient's death: that would be assault. The staff cannot help the patient to a speedier death: that would be murder. In a setting whose moral basis is compassion and benevolence, patient and medical staff are in conflict—a conflict that will become more uncomfortable every day.

The word "ugly" seems to me the best way to describe such tests of the right to self-determination. The physicians (and probably most other caregivers) remain, each in their own eyes, responsible for the patient. Other staff will feel it the physician's job to resolve the problem. The social system that comprises the hospital will be conflicted and feel responsible (word will get around about the case within a few days; everyone will have an opinion). Thus, whether the staff are correct or not in feeling themselves responsible for the (to them) avoidable death of this patient, if they cooperate and let the patient starve, the scene becomes exceedingly ugly.

If the situation becomes a test of the institution's rights (institutions, too, have rights, as the court affirmed in the case of Bouvia), ugliness also ensues. Perhaps the doctors will order the patient force-fed. How many times will they put down a feeding tube and replace it when the patient pulls it out? How many days or weeks will the patient's hands be restrained to prevent the tube from being removed? Because of the demoralizing effect of such behavior on the nurses and attendants, and the brutalizing effect on the patient, the hospital may evict the person. If such patients could live on their own, they would not require the institution's assistance in order to starve. Starvation is not painful; hunger disappears within a few days and weakness is the only symptom (so long as water is taken; persistent thirst is very uncomfortable). Such persons cannot live outside an institution because they cannot take care of their basic needs. What will happen when they are evicted or returned, solitary beings, to the domicile from whence they came? The idea of evicting the patient is also ugly.

Some believe it is morally correct that Elizabeth Bouvia be allowed to starve while within the care of the institution. For others, it is morally correct that Bouvia be force-fed or evicted. Both understandings of what is morally correct result in ugliness. Let me emphasize that the issue of starvation (or not starvation) is not the major cause of difficulties in considering this case. Another script is possible. A patient well known to a physician suffers a disabling stroke, inevitably requiring transfer to a nursing home. She wishes to die and decides not to eat. She tells everyone how unhappy she is that her lack of appetite causes her to return every food tray untouched. The doctor does not put down a feeding tube nor force food in some other fashion. It is obvious that the patient is doing the best that she can. In fact, the patient will not refuse nutrition with intent to die unless there is (usually tacit) agreement between doctor and patient (or unless such agreement comes into being as the circumstances evolve). Ultimately the patient dies and the cause of death will probably be listed as stroke, not voluntary starvation to avoid transfer to a nursing home.

In this situation death may be sad or even tragic, but it is not ugly. This circumstance exemplifies more than the principle of self-determination, although the patient's autonomy is exercised. It demonstrates the ability of two people to forge a bond to meet the needs of both. Doctor and patient transcend the boundaries of self to find a basis for action to reach an agreed-upon goal. Not only must doctor and patient agree on the reasonableness of the patient's desire to die rather than go to a nursing home. They must also respect the institution's need to nourish a social climate that does not permit a patient to commit suicide with the assistance of medical caregivers, and that does not concur in a deceit. Most often such agreement takes place without overt discussion.

What does the ugliness of the Bouvia case and the absence of ugliness in the second case I outlined point to? These last fifteen years have made it clear that to focus exclusively on medical science and technology in the care of the sick is to miss the reason for medicine. Similarly, these cases suggest that to focus on the ethical as the narrow pursuit of rights, autonomy, or self-determination misses the reason for ethics.

The Narrow Pursuit of Autonomy

Autonomy is an odd concept. It is a goal toward which people strive, which never actually exists. No one is, or can be, truly autonomous—especially in the absolutist sense in which the word is often employed. Certainly not Elizabeth Bouvia, who wishes to die *because* she is so dependent on others and claims her right to receive the assistance of others in her death on the *basis of autonomy*. The concept of autonomy is the product of the cultural imagination of the last three hundred years. Part of the notion of the individual as an entity distinct and independent from other individuals when, in fact, no such separate individual exists.

A confusion exists, as Alfred North Whitehead has pointed out, between the importance of honoring individual values, and seeing individuals as separate entities. Such a confusion is not surprising, because the notion of the individual, as we know it, came into being during the same era when science was seeing the world as constituted of objects separate in time and space. Both imaginary notions, separate objects and separate individuals, have been extremely productive in our history; the former in the development of science and technology, and the latter in the rise of democracy and modern individualism. But each has distinct limitations as a basis for considering certain problems.

Note, for example, the artificial world that is generally constructed in order to consider ethical issues such as the refusal of nutrition. The case of Elizabeth Bouvia is presented as though it were an event, a *thing* that happened, rather than a *process* that unfolded. As an event in ethics (or law) the situation may be viewed as the conflict of an individual (as a holder of rights) with an institution—the hospital or medicine. These institutions are frequently portrayed as obstacles to the exercise of the individual's rights, in contradistinction to the institutions as socially warranted exemplars of compassion and benevolence.

Further, the actors in the event are regarded as basically separate from one another, their necessary connection and relationship are not recognized. The degree of abstraction required to frame this problem in purely ethical terms should make it clear that moral values may distort reality unless they are seen in the service of something larger than themselves. One does not have to remain within the medical-scientific or the moral framework to consider such cases; other types of values might be utilized. For example, economic values are all too often employed in medicine these days with effects that are not always salutary.

The Role of Aesthetics

Earlier I used the word "ugly" to characterize the outcome of Elizabeth Bouvia's refusal of nutrition. In so doing I was suggesting another dimension, the aesthetic, that might help order the complex values in such cases. I do not speak of aesthetics in the narrow sense pertaining to the established arts, but instead to an understanding of the beautiful or harmonious, or conversely, the ugly or chaotic. The relations of people with each other and their connections to other objects, events, or relationships can be examined, and even judged, from an aesthetic point of view. Many of us use the language of aesthetics in our day-to-day evaluation of things that at first glance do not seem to fall within the domain of the aesthetic. Mathematicians or scientists apply the term "beautiful" to equations, and scientists speak about an "elegant" experiment.

Charles Hartshorne has spoken of life as a work of art. We must remember that just as a work of art can be beautiful, it can also be garish, flat, uninspired, chaotic, or even ugly. Within an aesthetic framework of reference, autonomy is not important in itself, but rather for its function in the self-creation of a person, of a lived life. From the same perspective the passage of time can be portrayed in more human terms. Remember, when considered as a frozen moment in time (of any size), or as though there were no time, ethical issues as a clash of competing rights makes sense. But a frozen moment of time is an abstraction. Rather, these events unfold over time. In this "real-time" concatenation of moments autonomy achieves the human dimension of self-legislation.

One is always in a process of becoming; every second, every minute, hour, and day. The person one is becoming is constituted from: what one was (a moment ago); the circumstances of the moment—the presence of other people, the setting, the presence of disease—almost everything going on in one's internal and external world; one's inherent aim, interest, or purpose at the moment (the process is not random). It is here, in the moment-by-moment choices that determine the person, that autonomy has true meaning. Choice is the essence of the process. I do not mean to imply that at every moment people are actively and consciously thinking about what their aims are; we know that is not true.

But what *is* true is that at every moment people think some things are more important than other things, like some things more than others, select some action (no matter how minute) in preference to another. While many, perhaps most choices are made below consciousness, or without full awareness, most people if asked could explain why they did what they did. They could explain at some length, if pushed, why their choice makes sense: in terms of previous choices, in terms of the way they live their lives and of the kind of person they like to think themselves to be. That the explanations may be incorrect is not so important as the fact that the explanations, choices, and actions will *all* be consonant.

We must look at life's choices in a minute-by-minute, hour-by-hour, and day-by-day time scale to understand how sickness, medical care, and hospitals fit in, and how an aesthetic viewpoint can help us. Obviously, most people do not believe that sickness, disability, or death fit in at all with their purposes. However, illness, infirmity, and impending death are facts of fate—they are among the things that happen to people. Because of this, they are part of the circumstances of the moment from which persons constitute themselves. It requires effort to make choices in the milieu of sickness that are in harmony with the being one was in the moments before illness. Much must be denied, and fragments, precious and little, must be seized upon to remain within the rhythm of the earlier lived life. It is in these circumstances where choices that reflect independence and freedom of choice—autonomy—are most difficult.

Clearly, autonomous choices have a greater chance of prevailing with the aid of others rather than in conflict with them. The staff, too, are continuing to become themselves in these same moments, and the patient is part of the environment from which they are self-created, from which they must weave their own patterns of existence. Indeed, social groups, or institutions like hospitals, also have their patterns and textures of internal interactions and growth. (The use of words like "pattern," "texture," or even "harmony" are somewhat misleading because they suggest a repetitiveness in becoming, which is not the case. It is better to visualize a tapestry or think of a concerto to which each thread or note may be different from the preceding, but contribute positively or negatively to the beauty of the whole.)

A Wider Set of Values

Let us go back to the refusal of nutrition to summarize my argument. When cases where food is refused are seen predominantly as a clash of conflicting rights or a testing ground for patient autonomy, ugliness follows. Such outcomes testify to the limits of autonomy as an overriding principle and to the view of the individual as a discrete, separate, and isolated entity from which the principle arises. These cases point to the need to move beyond the constraints of merely medical-scientific values, even when, as in the past fifteen years, they have been enriched by the manifest addition of moral values. What is necessary is a wider set of values in which medicine serves the purposes of sick persons. In that larger framework, concepts like autonomy serve a more useful function by promoting an understanding of the place each person has in creating the texture and design of his or her own life. In the absence of an appreciation and consideration for the patterns and purposes of others, the strict, narrow exercise of ethical values is like random chords on the piano, or a life without a purpose.

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