A Commentary—Putting Autonomy in Its Place
Developing Effective Guidelines

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Once again, as illustrated in the provocative article by Theresa S. Drought and Barbara A. Koenig (2002), social science research shows its importance for ethics. They have done what should have been done long ago, putting autonomy in its place once and for all. If there have always been richer perspectives available on end-of-life care than the principle of autonomy, for well over two decades it has had a dominant, even overwhelming, position. It has been the characteristic point of departure for considering the rights of patients, the duty of physicians, and the shaping of clinical practice for terminal care (Wanzer et al., 1984). Of course, it has long been recognized that the principle of autonomy cannot be applied to children, the mentally incompetent, and the comatose patient. Even so, the practices and rules favored for those patients have had the shadow power of autonomy hanging over them: What might they want if they were free to choose, or what did they say they wanted in the past if they later became unable to express their wishes, and so on. The principle of autonomy has seemed inescapable even when not directly applicable.

Drs. Drought and Koenig have succinctly listed the main cultural and historical reasons why autonomy came to have such an important place in earlier years. Even now, it is hardly to be dispensed with; it is an important principle. But it is not the only principle, or value, to be brought to the bedside of the dying patient. It is especially important, moreover, that one particular interpretation of autonomy be excised from our moral reckoning: autonomy as the foundation of human dignity. The value of a human life should never be confused with the right or capacity to make choices, to direct our own lives, or to be free as citizens and persons.

For political and legal purposes, autonomy is an important right, and surely a central American value. But the possibility of political freedom, or the psychological capacity to make self-determining choices, is very much an accident of political systems, our physical condition, and our individual psychological makeup. Whatever value we attribute to human life, however we choose to characterize human dignity, it must remain free of such contingencies. It must be something that cannot be taken from us even if we are political prisoners, or live in repressive societies, or if we lack the capacity for one reason or another to fully direct our own lives.

I stress this point because of a suspicion that autonomy has gained much of its power as an ideal from the conflation of choice and dignity, as if good care cannot possibly be provided, and the patient’s dignity respected, unless autonomy is accepted and, most important, exercised. What Drought and Koenig make clear is how misleading such a conflation can be. The evidence they present shows that by no means do all competent patients want to make their own end-of-life decisions; that in many, if not most, cases there are in fact no decisions to be made, and that how they live their last days may be more important to them than how they die. I would add one more implication of their study: The up-to-date physician who thinks the most important priority in the care of patients is to respect their autonomy may be missing the point, the wrong model of caring in our minds.

If we think of the present reigning model of care as one centered on the principle of autonomy, of patient choice, then what might constitute a better model? By a “better model,” I mean one that would by no means aim to jettison the value of autonomy but would include it, along with other values of no less importance. And then how might we move from there to the fashioning of guidelines for end-of-life care?

We might go at that task in four stages. First, the elements of a full picture of what “care” entails would be necessary, encompassing the main actors and influences in patient care. The second would be to identify the needs that patients have and that should be honored. The third would be to characterize the process that might best be undertaken to develop effective guidelines, and the fourth would be to specify the key elements of such guidelines. I make no pretense here to develop a full model to serve as an alternative to the autonomy model. But I do hope to say enough to suggest a plausible direction, worth further development.
Elements of the Care Situation

A full model of caring should encompass more than the patient alone (Callahan, 2001). The needs of the patient will inevitably be influenced by the needs of others:

- the needs of physicians and other caretakers
- the needs of family and friends
- the need of institutions and their ingrained habits of operation

Although it would make no sense to talk about the needs of technology, it can be said to have its demands and shaping powers, and they must also be taken into account.

The patient is, so to speak, surrounded by people, institutions, and technologies—each of which can have an influence on what the patient needs, or thinks he/she needs, and on how those needs are met (or not met). If we are social animals, as Aristotle noted long ago, we cannot, as persons, be fully understood apart from the other persons—and the power and tools they wield. Of course, the needs of patients and others can be symbiotic, because it is possible for patient needs to influence the needs of others.

The Needs of Patients

Once it is understood that the patient is part of a social network of needs and institutions, the patient can then be seen within a context, without which it will not be possible to grasp the difficulty of satisfying his or her needs. How the full circle of needs is managed—that of patients and those around them together—is likely to be the key to meeting the needs of the patient (or so my model has it).

When patient needs are considered, the most common tendency is to think of emotional needs: How the patient emotionally copes with his situation. "Caring" is often thought of as responding to such needs, which is why it has often, too often, been associated with a patient’s affect, and not much more than that. But that picture does not do justice to the full human makeup, of which emotions are only a part. Nor can we get a good sense of a person by thinking of guidelines. I take it that the purpose of ethical guidelines is ordinarily—and desirably—not that of imposing; even if the principles they need to be successful.

To categorize these needs is no more than to say that human beings are rational creatures, feeling subjects, social animals, and beings who choose and live by certain values. Is any one of these categories in principle more important for human life than any other? It is hard to see how that could be so, if only because it is difficult to imagine a human life that could be satisfying or satisfactory if any one of the needs was systematically ignored or minimized—as would almost surely happen if one of the needs is taken always to be overriding. This is not to say that, for us as individuals, some of the needs may be more dominant or insistent than others, or that their force will vary depending on particular situations in life. But, it is to say that we all have that range of needs, and the permanent failure to have one or more met when possible will significantly deprive a person of important help in living out the end of life as well as possible. No less important, if one or more of the needs is thought always to be the most important for everyone, then we open the way to a misunderstanding of individuals and their needs.

Now, if that is so, then it is possible to understand how serious a mistake it is to assume that a person’s values—a desire for autonomy, for instance—must invariably outrank all other needs. Or, that a person’s capacity to reason through to certain decisions expresses the most important need. For some people, as Drs. Drought and Koenig show, that may well be true—but that is something to be discovered in the care of patients, not automatically assumed. When a desire to make personal decisions is discovered, it should be respected. But when it is not discerned, then the alternative needs that are uncovered should be honored. Autonomy is thus put in its place, one of importance if expressive of a patient’s deepest needs, but to be put aside in favor of a response to other, more pressing needs. Autonomy is to be respected, not imposed; and it is not everyone’s need.

The Making of Guidelines

There is nothing automatically valuable about guidelines for end-of-life care. If not well formulated, they can cause confusion and possibly even harm. If not well promulgated, they may not do the good they could do. If not well reviewed from time to time, they may become fossils from another era. If not well developed, they may not elicit the interest and commitment they need to be successful.

I will look only at that last point, the development of guidelines. I take it that the purpose of ethical guidelines is ordinarily—and desirably—not that of fixing hard and fast rules, even if the principles they enunciate are meant to be taken with full seriousness.
Their aim is, instead, to guide: To move caretakers in a particular direction, to enunciate the moral values and principles at stake in end-of-life care, and to call attention to the needs of patients, those needs that must be acknowledged if proper care is to be provided.

It is the process of developing guidelines that is almost as important as their contents. For guidelines to be well formulated and taken seriously, it is vital that their formulation should (a) come out of an effort to involve the entire relevant community in their formulation, however long and difficult that process may be; and (b) that the contents win the active agreement of those who will be affected by them. A community-wide debate should take place (whatever the relevant community may be), a debate undertaken with the expectation that there may be serious disagreements, that they should so far as possible be resolved, and that it is understood that, with experience and further thought, it may be necessary to revise them in the future.

The aim of such a process is that the guidelines be an expression of long and difficult thought, and on the part of everyone. The weight of that process, as its verbal expression of long and difficult thought, it may be necessary to revise them in the future. The aim of such a process is that the guidelines be an expression of long and difficult thought, and on the part of everyone. The weight of that process, as its verbal formulations, is what will give it bite and staying power.

The Content of Guidelines

It is not my place here to devise guidelines. I want only to see what some elements of guidelines might look like if my proposed categorization of needs proved attractive. Most extant guidelines consist of a number of various points that should be kept in mind by caretakers and made available to patients and their families as a touchstone of the care they should receive. That is a sensible way to formulate and present guidelines. Guidelines do not necessarily require prioritization to be effective, but some communities may want to attempt to do so.

Here is an attempt to articulate, in the form of a guideline, the points I made previously in categorizing human need:

Patients come to critical moments in their health, including the threat of death, with a variety of needs: cognitive, emotional, relational, and valuational. It is vital to determine, from discussions with them and their families, just which needs are the most important. For some, it will be vital that they be allowed to make as many decisions as possible about their care; they want their autonomy respected. For others, their emotions, or their relationship with families and friends, or a desire to place their trust in their physician's discretion, may be more important. Every effort should be made to determine which needs are most important to patients, and their care should proceed accordingly.

A guideline of this kind is not likely, however, to have any effective impact unless the process for developing guidelines suggested previously was taken seriously. It will have to be understood what it means to speak of the “needs of patients,” not a self-evidently clear phrase. It will have to be debated fully and long enough so that everyone has a sense of what is being talked about—and everyone has had some significant guidance in learning how to discern patient needs. Many patients will be inarticulate even if otherwise competent. They may be unclear, or uncertain, or conflicted about their most important needs. Staff education and extended discussion will be imperative in working through such situations.

An obvious complication in such a process is that a patient may have, even after probing, no clear self-perception about her needs or simply remain confused and uncertain. Most of us, it might be recalled, do not have a great store of experience about the end of life. We experience it only once, and what we learn is not retroactive. We may know how others got through it all, so far as we could see. But that does not tell us what we should feel, how we should decide (if we want to), and what we should decide.

My analysis suggests some research possibilities. One of them would be an examination of guidelines in other areas of life, attempting (a) to determine which kind have been most effective, (b) what the process of putting them together encompassed, and (c) how they are reviewed and assessed once they are put into practice. Guidelines have been developed in the fields of business, social work, and journalism, for instance, some with much more success than others. Another research possibility would be to synthesize some of the vast literature on human needs, and then to see (more fully than I have done) through patient, family, and clinician interviews, just how the fact of a terminal illness intensifies, or changes, or suppresses one or more of those feelings. We no doubt as human beings bring our past life to the bed of our dying, but what happens to the way we have construed the world and our life in those final moments?

References

