
Community Guidelines for End-of-Life Care: Incremental Change or Significant Reform?

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Advance directives and outcomes research are two widely used but insufficient tools for improving end-of-life care. The Colorado Collective for Medical Decisions strongly supports their use, but only as supplemented by the development of clinical care guidelines capable of dealing with both futile and marginally effective health care situations.

Although end-of-life care in America is probably more satisfactory today than it was thirty years ago, most professionals and lay persons agree that there is still ample room for improvement. The Colorado Collective for Medical Decisions (CCMD), a consortium of professionals and lay persons working together to develop guidelines for appropriate end-of-life care, is an experiment to see if guidelines can lead to better end-of-life care.

Why Guidelines?

The benefit of clinical guidelines in health care has been modest at best. Why, then, would we look to guidelines to help improve end-of-life care? The answer is that guidelines (if properly understood) can be useful tools.

Let us start with the underlying problem: too often, care at the end of life is inadequate. The goal in health care is to provide *compassionate* care, but present solutions only “nibble” at the problem. A comprehensive, multifaceted approach is needed.

In the last couple of decades, two techniques have received considerable attention: advance directives and outcomes research. Lofty expectations for these approaches can be summarized as follows: If we did a better job discussing advance directives, most patients would voluntarily forego inappropriate, aggressive care at the end of life; and if we could predict outcomes more accurately, we could determine what interven-

tions are futile (or very unlikely to succeed), and discourage patients and their families from these interventions.

Unfortunately, no matter how thoroughly we discuss advance directives, and no matter how accurate our outcomes research becomes, fundamental problems remain. Despite their theoretic value, advance directives have limited value in clinical practice (Tonelli 1996; Teno et al. 1997). There are many reasons for this, including relatively low utilization rates and the proliferation of “boilerplate” forms that contain few, if any, personalized instructions. An additional factor, one not adequately considered in the medical literature, is the likelihood that implementation of advance directives reflects the biases of clinicians more than it does the autonomous choices of patients and their families.

CCMD strongly supports the use of advance directives. Most clinicians working with CCMD spend considerable time discussing preferences with patients and patients’ family members. However, we don’t believe that advance directives, as currently used, will significantly improve end-of-life care.

On the second front, as helpful as outcomes research has been, it has limited usefulness. One drawback to outcomes research is that it tends to focus on physiologic variables and phenomena that are relatively easy to measure. The best prognostic scoring systems, for example, do not mea-

sure the tremendous psychological, social, and economic impact that a serious illness can have on surviving family members. Another drawback is that outcomes research provides little or no help in a situation in which a family is pinning its hopes (or its denial) on a "miraculous" recovery by their loved one. No matter how accurate and comprehensive prognostic scoring systems become, they will have little impact in decision making for individuals who fervently wait for a miracle. Consider, for example, a prognostic scoring system that predicts that a patient with multi-organ failure has a two percent, with confidence intervals of one percent, chance of surviving intensive

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care. Assume that more sophisticated outcomes research, based on a much larger data set, concludes that the same patient actually has a one percent chance of surviving with confidence intervals of 0.25 percent. Will the more accurate information matter to the mother who is hoping that a miracle will save her extremely premature baby? Probably not.

Outcomes research is indeed useful. CCMD's guidelines are based largely on well established outcomes research. However, we anticipate that the debate over the next decade will not be influenced as much by more accurate outcomes research as it will be by cultural values, religious viewpoints, and economic shifts.

As important as advance directives and outcomes research are, they will not, by themselves, take us much farther down the road to improved

end-of-life care. New approaches are necessary. The CCMD consortium members believe that community guidelines represent a new approach that can lead to better end-of-life care. Guidelines that reflect the values of the community have the potential to

- enhance patient autonomy
- give the community a stronger voice in the allocation of resources
- provide reassurance to families that a course of care is in the patient's best interest and is supported by their peers
- encourage providers and institutions to pursue courses of care they believe to be right and just, not simply courses they believe to be legally safe.

A More Global View

CCMD is asking professionals and lay people throughout Colorado to consider five domains in the development of community guidelines. Following is an outline of these domains, accompanied by a summary statement of CCMD's message to professionals and the public:

1. Ethics — We must balance the welfare, interests, and needs of the community with the needs of the individual, understanding that ethics are not necessarily determined by "majority rule."
2. Religion — We should respect diversity, accept mortality, and recognize the rich traditions of weighing the benefits and burdens of medical interventions.
3. Law — We should permit patients, families, and medical providers to create solutions instead of threats of litigation and defensive medicine.
4. Stewardship — We should use resources responsibly so we can maximize benefits for present needs *and* future generations.
5. Aging — We should acknowledge that aging and mortality are shared by us all.

The Guidelines

The following guidelines were crafted by several subcommittees of CCMD. They are the result of four years of interaction between professionals and interested lay persons. All the guidelines have undergone multiple revisions. Most were initially more detailed than the final guidelines shown here. Realizing that the guidelines are simply guidelines, and not commandments or absolute rules, CCMD has opted for simplicity so that professionals and lay persons can use these guidelines without detailed explanations. Although CCMD may make further revisions, we anticipate general acceptance of the following:

CCMD's Adult Guidelines

Appropriate End-of-Life Care

- Medical care for a person approaching the end of life should focus on comfort care, including control of pain and meeting other personal needs.

Comfort Care

- Each hospital and nursing home should provide comfort care.
- Doctors and nurses should recognize the need for comfort care and encourage its timely use.

Shared Decision Making

- Hospitals and nursing homes should encourage nurses, social workers, and chaplains to discuss appropriate end-of-life care with doctors, patients, families, and friends.

Cardiopulmonary Resuscitation

- CPR should not be performed when the person has indicated that CPR is not desired.
- CPR should not be continued when there has been no favorable response after thirty minutes of CPR (except in cases of hypothermia).
- CPR should not be performed when recovery is known to be extremely unlikely.

Permanent Vegetative State

- People in a permanent vegetative state

should receive comfort care instead of life-sustaining interventions.

End-Stage Dementia

- People with end-stage dementia should receive comfort care instead of life-sustaining interventions.

Tube-Feeding

- Long-term tube-feeding should not be used for people in a permanent vegetative state or with end-stage dementia.

Dialysis

- Long-term dialysis should only be used for people who can cooperate with treatments.
- Short-term dialysis should not be used for people who have a negligible chance of survival.
- Long-term dialysis should not be used for people in a permanent vegetative state or with end-stage dementia.

CCMD's Neonatal Guidelines

Low Birth Weight/Early Gestational Age Newborns

- Infants who are likely to survive should be given all appropriate medical interventions even if they have mental or physical limitations.
- Infants who are extremely unlikely to survive infancy due to extreme prematurity should receive comfort care instead of aggressive life-sustaining interventions.

Newborns with Lethal Birth Conditions

- Infants who are extremely unlikely to survive infancy due to a lethal birth defect should receive comfort care instead of aggressive, life-sustaining interventions.

Comfort Care of Dying Infants

- Infants for whom survival offers only a short lifetime filled with significant suffering should receive comfort care instead of aggressive life-sustaining interventions.

Shared Decision Making

- When the outcome of aggressive medical care for an infant is uncertain, the family should be provided with comprehensive information about outcomes.
- When the outcome of aggressive medical care for an infant is uncertain, decisions about life-sustaining interventions should be made jointly by the family and the medical care team.

To date, we have surveyed over 6,000 professionals and lay persons throughout the state and heard their impressions of the guidelines. Preliminary results indicate that there is strong support for many of the guidelines, but only moderate support for a few of them. Although overall agreement (between 70% and 80%) is high, we don't believe we can consider this feedback a consensus. From the beginning, we emphasized that we would not promote strict institutional policies unless a clear consensus were to emerge. We now must decide how to use the guidelines when there is not a definite consensus, but only a strong majority in their favor.

The Next Steps

Several important steps are necessary before we can expect the guidelines to have much effect on end-of-life care for citizens of Colorado. First, the guidelines will need further revision if Colorado is to speak with one voice. Some groups, for example, have major reservations about the guideline on tube-feeding. Most of these groups have religious affiliations. If the guidelines are to represent the perspectives of diverse cultures and religions in the state, further compromises will be necessary. However, we don't expect the final set of guidelines to be significantly different than the ones outlined above.

Second, we plan to ask that institutions (for example, hospitals, extended-care facilities, and home-care agencies) incorporate the guidelines in their mission statements. Institutional support will be essential for effective use of the guidelines, particularly the guideline on shared decision making. Our hope is that institutions will promote the guidelines more effectively than they have promoted the Patient Self-Determination Act.

Third, we will ask institutions to adopt policies that encourage collaborative use of the guidelines. Nurses, social workers, and chaplains will be encouraged to play a more active role in the discussion of advance directives and guidelines. Shared decision making is one of our fundamental principles. Thus far, CCMD has developed two policies that compliment the guidelines: a policy for long-term care facilities and a policy for acute-care institutions.

We will ask every long-term care facility to adopt a policy requiring that selected staff members are knowledgeable about

- guiding patients and family members through decisions about end-of-life care
- outcomes of CPR and other life-sustaining interventions
- the benefit of time-limited trials, particularly for feeding tubes

- advance directives.

We will ask all hospitals to adopt a policy that will allow any health care provider or family member to initiate an "appropriateness review" of interventions. The "appropriateness review" team will consist of at least six professionals (two physicians, two nurses, a social worker or case manager, and, when indicated, a chaplain) who will share their perceptions of the appropriateness of aggressive interventions for a particular patient. The unit supervisor (or designee) will coordinate this process, which might be considered a "rapid response ethics consultation."

Compared to most ethics committee review procedures, however, CCMD's proposed hospital policy is different because the reviewing clinicians will be those who are directly involved with the patient and/or the patient's family. If this process does not lead to resolution, the case then will be referred to the ethics committee.

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Fourth, CCMD will develop tools to help professionals counsel patients and their families about end-of-life care. We believe professionals should be more prescriptive than just neutral, when discussing options for end-of-life care. In most cases, this approach will actually enhance patient autonomy (Quill and Brody 1996).

The Role of Guidelines in Clarifying Values

The futility debate has been a debate about values and extreme measures. We are learning the

importance of addressing less extreme, but nevertheless inappropriate, measures. Importantly, it is *not* a debate about money alone. CCMD never has maintained that the reduction of futile or inappropriate intensive care would save significant amounts of money (Murphy 1997). We do believe, however, that stepping back from futile or inappropriate care will help our society learn how to step back from many different kinds of marginally effective health care.

We see futile care as the tip of the iceberg. It is the vast chunk of ice under the surface, representing marginally effective care across the clinical spectrum, that can do the most damage. We contend that successful navigation around the tip of the iceberg is necessary to assure that the icebergs don't destroy the vessels.

Continuing this metaphor, we suggest that successful navigation involves setting limits on marginally effective health care so that all citizens may benefit from comprehensive health care plans. Our bias is that some sacrifice will be necessary to develop a just health care system in which all citizens are insured for at least a basic minimum level of health care services. The sacrifices will require a significant cultural shift (Murphy 1997). We believe the futile or inappropriate care debate is an area in which our society can reach acceptable compromises.

During the last four years, we had hoped that the managed-care revolution would help the public and professionals make responsible trade-offs. Our experience in Colorado suggests that managed-care companies will *not* be able to provide leadership in encouraging more responsible stewardship. Their fear of public backlash is simply too great. There is pervasive public suspicion that any savings from managed-care limits would go to lining the pockets of administrators and stockholders, not to providing more comprehensive primary care to underserved populations.

How do we overcome this mistrust? First, communities must learn how to set priorities in health care.

Second, payors must feel confident that these priorities reflect the values and preferences of the public they serve. For example, managed care organizations are much more likely to respect a set of priorities that has arisen from a grassroots movement and does not just reflect preferences of special interest groups.

Third, the priorities must be set in closed systems. There must be grounds to believe that limited coverage in some areas (for example, inappropriate intensive care) results in expanded coverage in other areas (e.g., expanded medication benefits). Finally, members of communities must have a way of obtaining health care interventions that are considered inappropriate by the rest of the community. Our experience in Colorado suggests that the public *will* accept limits, as long as individuals can purchase additional procedures (either out of pocket or through church funds) that are not covered because of the priorities set by the community.

Conclusion

There are no shortcuts or easy answers, nor is there a "recipe" for organizations to follow in promoting guidelines for improved end-of-life care. However noble it sounds to engage "the community" in discussion, we have learned that there is no single accessible "community." Instead, there are numerous communities and interest groups, who have little practice and few vehicles for dialogue or interaction. We have found it necessary

to build bridges before we can cross them.

Another important "environmental impact factor" affecting our guidelines has been the managed-care evolution, that has changed the climate of doctor-patient relationships and sent clouds of suspicion about mercenary motives or power struggles scuttling across horizons.

Yet another hurdle is the "consumer movement" in medical care. Fueled by inflated expectations (and budgets), patients and providers recoil at the very concept of limited resources. Somehow it seems "un-American" to consume less.

Charting a course toward improved end-of-life care involves these and many other "iceberg" issues of great complexity. CCMD remains committed to developing and using guidelines as tools and starting points for decision making. Weathered but still optimistic, we face the challenges ahead.

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