

Advocacy and Activism: Missing Pieces in the Quest to Improve End-of-life Care

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ABSTRACT

Increasing attention has focused on end-of-life care and has identified significant deficiencies in access and quality of care. When problems with quality or access to care have been identified for other diseases or conditions, the public has often responded vigorously. This paper describes two kinds of public action that have been effective in improving health care in other areas: advocacy and activism. However, a public response to improve end-of-life care has been muted. We discuss some of the reasons for this lack of response, and propose ways in which providers and funding agencies can work with patients and their families to improve end-of-life care.

INTRODUCTION

IT HAS BECOME APPARENT in recent years that end-of-life care in the United States suffers from serious deficiencies. Since the Institute of Medicine's influential report identified end-of-life care as a problem and a priority¹ numerous studies have added to a list of shortcomings in care for dying people in this country.²⁻⁴ These data paint a grim picture of care at life's end that is characterized by poor quality and inadequate access to valuable services.

When serious flaws have been found in other aspects of health care, the public response has often been swift, loud, and effective. One early example of a powerful public reaction occurred with the introduction of hemodialysis for treatment of end-stage renal disease. When the public realized that access to this potentially life-saving treatment was limited, the result was a

general outcry, intense lobbying, and federally funded access for all who needed it.^{5,6} Since then, the public has mobilized in support of acquired immune deficiency syndrome (AIDS) research and treatment, breast cancer research funding, and against so-called "drive-by deliveries" in obstetrics. In all of these areas, public action expanded access to desired services and research, and raised standards for care.

Given the prevalence and severity of the deficiencies in end-of-life care, it is somewhat surprising that there has not been a similar groundswell of public interest and action in this area as well. End-of-life care has near-universal significance because most people will die after a period of illness or disability, and therefore everyone stands to gain from improvements to the current system of care. Moreover, most people will become caregivers for dying family or friends. In both of these ways, everyone is a stake-

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holder who is likely to benefit from improvements in end-of-life care.

In this paper, we outline the ways in which public action would help to rapidly and substantively improve end-of-life care. We focus on two kinds of public action: advocacy to improve the care of oneself or a family member, and activism to improve care for a group. We discuss some of the opportunities for advocacy and activism in end-of-life care, and we outline some of the barriers that exist. We conclude by suggesting ways that health care providers can align themselves with constructive public action to achieve urgently needed improvements in access and quality of care.

CURRENT PROBLEMS WITH ACCESS AND QUALITY

Deficiencies in the current system of end-of-life care are severe and pervasive (Table 1). Broadly, these deficiencies can be described as problems with quality of care and problems with access to care. Problems with quality of care are numerous, and include an unacceptably high prevalence of pain and other symptoms^{3,4,7} and a paucity of social and emotional support services for dying patients and their families.⁸

Obstacles to access are equally troubling, and reflect system-wide problems with the way that end-of-life care is funded and delivered.⁹⁻¹¹ Chief among these is the "either-or" dichotomy that forces patients and their providers to choose between life-prolonging and palliative modes of care, when concurrent interventions of life-prolonging and palliative intention are often clinically indicated. This dichotomy is imposed and epitomized by the current hospice payment system that requires a prognosis of 6 months or less for eligibility. This criterion effectively restricts

access to those with a limited life expectancy. When combined with the threat of legal sanctions and stiff fines for incorrect prediction of survival, it creates a strong deterrent to timely referral.^{12,13} Overall, the result has been that patients may not have access to hospice until late in their illness.¹⁴

Despite these deficiencies in end-of-life care, public demands for improvement have been muted. For instance, there are no general movements or broad-based coalitions to improve end-of-life care as there are to improve care for diseases such as AIDS, breast cancer or Alzheimer's disease. End-of-life care also lacks public education programs to create informed consumers as there have been in obstetrics, and coalitions that lobby for increased funding as there are for AIDS and other diseases.

This is not to say that public involvement in end-of-life care has been entirely absent. The public has played a role in nonprofit organizations such as Choice In Dying and Americans for Better Care of the Dying, Partnership for Caring, and the Robert Wood Johnson Foundation's Last Acts campaign are attempting to build public support through public education and community initiatives.

Examples of activism include education programs for legislative staff and Washington, D.C.-based staff of professional health associations and Congressional policy briefings and testimony, meetings with regulators regarding issues of access, quality and costs of needed goods and services. A recent flurry of work at a regulatory level has occurred in response to the media attention and law enforcement efforts occasioned by deaths attributed to Oxycontin™ (Purdue Pharma, Stamford, CT). Leadership of the organizations mentioned and other nonprofit organizations have been working with the Drug Enforcement Agency regarding problems of drug diversion while emphasizing the need to ensure proper treatment of people in pain and the need to ensure availability of opioids to patients for whom they have been properly prescribed, particularly in underserved, poor neighborhoods. Consumer advocacy tools have been developed and are being disseminated to assist people with issues of access and quality of care. These include the Patients' Bill of Rights, legally valid user-friendly advance directive forms, answers to "frequently asked questions," pain scales (for various ages and abilities), symptom journals, tips for choosing hospitals, home health and hospice programs,

TABLE 1. CURRENT PROBLEMS WITH END-OF-LIFE CARE

1. Inadequate training for providers (e.g., training in attitudes, knowledge, and skills)
2. Failure to measure important indicators of quality care (e.g., pain management)
3. Organizational barriers to end-of-life care (e.g., poor continuity of care)
4. Financial/payment barriers (e.g., 6-month hospice requirement)
5. Legal barriers (e.g., triplicate prescriptions)
6. Inadequate research/evidence to guide practice

assisted living facilities and nursing homes, and tips for talking with doctors about symptoms and preference for care. All of these efforts are valuable, representing early attempts to build community interest and involvement. They are not outgrowths of public involvement as much as they are attempts to develop this involvement.

Perhaps the single clear exception to this pattern of public apathy and inaction has been in the movement to legalize physician-assisted suicide. This highly charged discussion has been the epitome of public involvement, with instructional websites, lobbying, and a proliferation of grassroots organizations. This issue has sparked the public imagination, and has motivated broad-based public action. However, this action is unlikely to result in substantial improvements in end-of-life care because it has been narrowly focused on rights of privacy and freedom from public restraints, not on improving care. Although the assisted suicide debate may be viewed as a response to deficiencies related to end-of-life care, it is an oblique response that has not fostered constructive changes in health care policy and practice.

Therefore, if public action is to be effective in improving end-of-life care, it must target existing deficiencies directly. Opportunities to do so exist at two levels. First, individuals can press for improved access to and quality of care for themselves and their family members. That is, they can be advocates for their “family” of relatives and close friends. Second, individuals can act in ways that collectively advance goals of expanded access to and quality of services. In doing so they become activists. Below we discuss advocacy and activism, and the opportunities and obstacles that exist for each.

INDIVIDUAL AND FAMILY ADVOCACY

Advocacy is essential to improving end-of-life care because involvement at this level can most directly affect providers' behavior. Patients and their families should expect—and be prepared to demand—that providers will elicit and respect preferences for end-of-life care, that they will manage pain and other symptoms effectively, and that they will follow patients throughout the course of their illness. In fact, limited evidence suggests that patients and their families can receive better end-of-life care if they are educated

and if their expectations for care are raised.¹⁵ Furthermore, if enough patients share these expectations, it is reasonable to expect a shift in the standards that clinicians set for themselves, and their expectations of the institutions and health plans with which they work.

In other areas of clinical practice, patients and their families have shown that advocacy can be remarkably successful in changing provider practices. One of the most impressive examples comes from the field of obstetrics. In a relatively short time, an educated consumer population, armed with new expectations, reshaped the way that medicine approaches pregnancy and childbirth. Prenatal and delivery care have been transformed from a physician-directed set of encounters to a collaborative process in which women and couples act in partnership with their physicians and increasingly, with midwives.¹⁶ Much of this progress was won by individuals who came to their providers as advocates, and clearly expressed their expectations for care.

Similar gains have been achieved by caregivers on behalf of others. For instance, parents of children with disabilities often become quite knowledgeable about their children's care and come to clinical encounters with demands for expertise from physicians. Similarly, the caregivers of patient with Alzheimer's disease may become advocates on behalf of parents or spouses affected.^{17,18}

The exhortation to become an advocate for one's own health care and the health care of loved ones is hardly new, and bookstores offer a comprehensive selection of self-help books devoted to an infinite array of health-related topics. Recently, the ranks of these publications have grown to include comprehensive guides to end-of-life care as well.¹⁹ However, a similar degree of advocacy may be difficult in the setting of end-of-life care because public expectations are remarkably low. Indeed, data suggest that patients and their families may be quite satisfied with care that fails to provide basic symptom relief.^{3,20,21} But when patients and families lack benchmarks of “a good death,” it may be very difficult for them to recognize deficiencies in their own care. Therefore, several complementary strategies will be required to encourage effective advocacy by patients and their families (Table 2).

First, accounts of “good deaths” are necessary to serve as benchmarks in order to raise expectations. These accounts can be disseminated to pa-

TABLE 2. OPPORTUNITIES TO INCREASE
ADVOCACY AND ACTIVISM

Advocacy
Stories of "good deaths" to raise expectations
Patient bills of rights
Standards for care widely available to potential patients
Measures of quality end-of-life care as "report cards"
Litigation in select cases
Activism
Enhance expectations for care in related areas (e.g., pain management)
Enlist disease-based voluntary health associations to:
Raise awareness
Enhance expectations of members
Gather data about members' experience and goals
Participate in coordinated political action

tients and their families through patient educational materials, and through the media. It is important to note that no single "good death" can serve as a template. Instead, ideas about what constitutes a good death are likely to be complex and diverse. Even if common themes inform perceptions of a good death, such as dignity, control, or a chance to help others,^{22,23} these qualities will be understood in different ways, and weighted differently by different people. Therefore, the accounts of good deaths that are disseminated should be diverse as well. A realistic goal is to disseminate a variety of diverse accounts, in which all patients can find examples of what a good death would be for them.

These accounts of a variety of good deaths can be used as the background for a well-crafted patients' "bill of rights" that can anchor demands for better end-of-life care. These demands need not create an antagonistic relationship between patient and physician. Indeed, these are not necessarily demands that patients should make of their physicians. Instead, these are expectations that patients and physicians should have of the health care system.

To encourage and support effective advocacy, standards for care should be made available in print and recorded media formats as well as on Internet websites of respected, nonprofit watchdog organizations and those standards should be applied to create "report cards" that are easily understandable and readily accessible. These standards can serve as guides to physicians and families who may be uncertain whether a patient is receiving optimal care.²⁴ Tools like these can also

exert pressure on the health care system if they help physicians, patients and their families to choose institutions and health plans based on their ability to facilitate excellent end-of-life care.

Patients and their families should also be aware of legal means for improving care.²⁵ Lawsuits can be an important force in improving end-of-life care because they effect change on a scale that would otherwise require the advocacy efforts of many individuals. In this respect, lawsuits can be considered as an important tool of both advocacy as well as activism (discussed below). In obstetrics, lawsuits pursued by patients with the support of physicians and medical professional associations proved to be a powerful force in curtailing 24-hour length of stays for deliveries. Of note, lawsuits have also been influential in establishing the right to refuse treatment.^{26,27} Many of the later cases have focused on refusing life-sustaining treatment near the end of life both by patients,^{28,29} and by others on patients' behalf.^{30,31}

This is a broad set of goals, and will require the dissemination of information that must be accurate, up-to-date, and consistent. A variety of agencies and institutions will have roles to play. Initially, however, public funding agencies and private foundations can be instrumental in developing basic resources to enable people to become informed consumers and effective advocates. Funding is needed for demonstration projects that promulgate standards for care, creation of patient bills of rights, and report cards and that disseminate diverse narratives of good deaths.

SOCIAL ACTIVISM

Advocacy by individuals can directly improve care for a patient. However, organized public participation, or activism, is required to alter institutional and professional policies, curricula and standards of care. The individuals who are involved in activism may be patients and their families. However, patient and family involvement is activism rather than advocacy if improving care for groups of patients, or systems of care is a goal.

Sometimes actions can have both advocacy and activism as concomitant goals. Although most lawsuits are intended to improve care for a single patient, or more often to redress wrongs that occurred in the course of that patient's care, they also have the potential to improve access and

quality of care for large groups. For instance, the media coverage of lawsuits that seek damages for inadequate pain and symptom management can focus local attention on end-of-life care. Specifically, these lawsuits can increase clinicians' and institutions' awareness of end-of-life care as a problem and a priority. Litigation can also exert pressure on hospitals and insurance carriers to raise standards for care. Although they should be used judiciously, there is a potentially important role for litigation as part of a broad campaign of public action.

Opportunities for activism are numerous. Indeed, much of the current crisis in end-of-life care is attributable to system flaws that must be addressed through organized public and consumer action and legislation.³² Carefully structured and vigorous public efforts will be required in a variety of specific arenas. For instance, there is general agreement that fundamental changes in hospice eligibility criteria are needed,^{9,10,33} as are global standards for reimbursement for end-of-life care,³⁴ and Medicare waivers for palliative care demonstrations.¹¹ Legal protection for physicians who prescribe high doses of opioids will also be essential to improving end-of-life care.³⁵ In addition, federal funds are needed for research to improve end-of-life care and new modes of reimbursement and financing that replace the dichotomous either-or model with a needs-based approach that foster a continuum of life-prolonging and palliative care. Public watchdog organizations would also provide a valuable service by monitoring quality and access to specialized end-of-life care.

In other health-related areas, activists have been remarkably successful in using consumer power and legislation to achieve similar goals. This lesson has been most vividly illustrated by the history of AIDS research and treatment. Coalitions of AIDS activists were able to accomplish far more than a single group could have. For instance, the creation of funding programs such as the Ryan White CARE Act was the product of a formidable collaboration between the gay community and the hemophilia community, and included both patients and their families. Activism directed at human immunodeficiency virus (HIV) drug testing and approval, on the other hand, called for aggressive tactics for which the gay community proved well-prepared.^{36,37} In a short time, community activism accomplished astonishing legislative changes in funding for HIV care

and pressured the Food and Drug Administration (FDA) to streamline the process of approval of potentially valuable medications.

Another example of successful activism can be found in the recent history of obstetrics. In addition to individual advocacy by patients described above, efforts to change the policies of health plans also included substantial political pressure that was brought to bear on managed care organizations.³⁸ In a number of states this resulted in unprecedented legislation mandating minimum postpartum stays.³⁹ Overall, these changes illustrate the power of educated and organized individuals acting together to effect social change.

Activism directed toward improving end-of-life care may prove more difficult to organize and advance. Patients and their families face at least four obstacles in becoming effective activists for better end-of-life care. First, the very nature of illness places caregivers and patients at high risk of symptoms and stress that disable them from taking vigorous action. Second, most patients are not part of a cohesive community that is accustomed to political action. Third, voluntary health organizations, which are natural nexuses for patient and family activism, may be reluctant to promote end-of-life care, feeling that acknowledging death may be counterproductive to raising money needed for research into life-prolonging treatments. Fourth, any efforts to generate activism will likely encounter cultural avoidance and denial of dying and death. We examine each of these obstacles, and potential constructive responses to them below.

The first obstacle is a paradox of sorts. Those patients who suffer the greatest burden of symptoms and inadequate care are the patients who have the most to gain by becoming activists. But they are also the least able to do so if they are burdened with severe symptoms. The same constraints trap the families of seriously ill and dying patients. These family members are often full-time caregivers and face demands on their psychological and physical health, their time, and their finances.⁴⁰⁻⁴² Studies of caregivers have revealed the often overwhelming responsibilities that families shoulder and the substantial burden of unmet needs many families suffer.^{8,43,44} For these reasons, patients with severe symptoms and caregivers who are heavily burdened have the most to gain by improving the health care system. However, they have the most difficulty doing so.

To overcome these obstacles and build a broad base of activism, it will be necessary to enhance people's expectations for pain and symptom management in a variety of different care settings. For instance, all patients should expect adequate pain and symptom management during routine surgery and in the outpatient clinic. In having such expectations, knowing what to ask for—and when to complain—each of these settings become places in which all patients can exert pressure on the health care system to be more responsive to their needs. Patients who know their rights and have the energy and capability to assert those rights can act as advocates to raise standards of care for themselves. By applying these same expectations to improve conditions and adherence to standards of care, they can also improve the care of others whose capacities for self-advocacy have been sapped by illness. Examples of efforts directed at institutional or system change that qualify as activism include, complaints to local hospital administration, a resident and family petition seeking to improve staffing during nights at a local nursing home, letters to the editor, formal complaints to state or federal regulatory authorities, or a law suit seeking damages arising from inadequate staffing or care. In addition, future caregivers can also become activists before they are burdened excessively. For instance, individuals can think now about the challenges that they will face when their parents age, and can support demonstration programs such as Medicaring,¹¹ or legislation to improve care in nursing homes.

Potential activists for end-of-life care face a second obstacle. A sense of a mission-driven community is a crucial catalyst for activism. The lack of a shared disease-specific experience may make it difficult for activists in end-of-life care to emulate strategies that proved successful in AIDS, end stage renal disease, Alzheimer's disease and breast cancer. Furthermore, it may be very difficult for patients and their families to think about, and to plan for, care around the time of death. All patients would benefit from improvements to end-of-life care, but this common purpose may not always be obvious, or easy to accept. Until there is general recognition that better end-of-life care should be a common goal, the strategies of AIDS patients or breast cancer survivors may be difficult to adopt. For activism to be successful in improving end-of-life care, it will be necessary to build a recognition of shared goals and an ac-

knowledgment that end-of-life care should be a priority.

An important strategy to achieve this goal will be to enlist the support of disease-based voluntary health associations such as the American Cancer Society, the Candlelighters Childhood Cancer Foundation, the Treatment Action Group for AIDS, the Susan G. Komen Foundation for breast cancer survivors, the National Cancer Survivorship Coalition, the National Family Caregivers Association, or the National Association of People with AIDS. These groups can be ideal starting points for building a broad-based collaborative program of social activism because they represent people affected by potentially life-limiting illness and because they have structures in place and lines of communication open. Moreover, these organizations are already active in professional and public policy arenas and many have memberships that are committed to public activism.

However, within this strategy lies the third obstacle to activism. Although voluntary health associations are essential to improving end-of-life care, they may be reluctant to take on this issue. Much of these associations' existing research and fund raising is built on hope for a cure, and attention to dying may be perceived as a dilution of focus. Worse, it may be viewed as an admission of defeat. Consequently, it is possible that voluntary health associations will see attention to end-of-life care as potentially damaging to their organizational image and fund development. To counter this concern and avoid unintended negative effects of collective action to improve end-of-life care, it will be necessary to create positive, hopeful messages that can be used to recruit voluntary health associations and their members. At least initially, these messages should emphasize goals that are less threatening, such as assistance for burdened caregivers, and better pain and symptom management.

To enlist the support of these associations, grant support from public agencies or private institutions will be essential. Support can encourage associations to act in three areas. First, funding can support these groups in gathering information through membership surveys and focus groups about members' needs and priorities. Second, funding can help disease-specific voluntary health associations and patient groups to raise awareness of end-of-life issues and expectations of care among their members through

education and Internet-based communication. Finally, funding can help disease groups to organize activist efforts in productive directions, such as letter-writing campaigns, media events or direct legislative lobbying.

The sense of denial and fear that characterize public reactions to discussions of death and dying is a fourth obstacle to social activism. This barrier is far more insidious and pervasive than those described above, and may prove to be far more resistant to change. An extensive literature on the communication of risk has demonstrated that public messages fail to generate public interest or alter behavior if the people do not perceive that they are at risk.^{45,46} This is true of virtually every public health risk and intervention that has been studied. Denial of death, and a reluctance to think about the implications of poor end-of-life care for oneself and one's family, may represent a significant impediment to generating effective activism.

Although not easily overcome, research on risk communication has identified key strategies that have proven useful in other settings.⁴⁷ Media may play a critical role in what is known as the social amplification of risk.⁴⁸ That is, the media can increase the likelihood that an event will have an impact on public opinion by highlighting certain aspects of that event, such as its involuntary or inescapable nature, its impact on identifiable individuals, or the inequitable distribution of its consequences. In other settings, these are features of events that have been termed "fright factors," and that have been used successfully to increase awareness about health hazards.⁴⁹

THE ROLE FOR CLINICIANS IN ADVOCACY AND ACTIVISM

Advocacy and activism need not be left to patients and families alone. Professional caregivers may initially react defensively to advocacy and activism as intrusions on their professional authority, but clinicians are stakeholders in the health care system and have an inherent interest in improving end-of-life care. In fact, professional organizations have been active in addressing acknowledged deficiencies through programs such as the American Medical Association's Educating Physicians in End of Life Care (EPEC) training, and physicians have an important role to play in activism generally.⁵⁰

Advocacy and activism should not be viewed as a struggle between patients and clinicians. Instead, effective advocacy is the result of a partnership among clinicians, patients, and their families. Effective social change is facilitated through collaborative action among stakeholder constituents.

Clinicians can take the lead in forging such an alliance because they retain the trust of patients and their families to a degree that even the most respected organizations cannot hope to match. This trust places clinicians in a unique position to serve as catalysts for both advocacy and activism. Most importantly, clinicians can contribute to change by adhering to standards of care that meet or exceed patients' and families' expectations. Clinicians' training and the health systems within which they work should enable them to promise patients that intolerable suffering will not mark their final days and that the care they receive will be consistent with their preferences. Clinicians can describe "good deaths" as points of reference, helping patients and their families imagine what is possible in the way of positive outcomes despite unwanted circumstances.^{23,51} Simultaneously, providers can engage in professional activities that raise expectations among colleagues. And, in leading by example, they can raise expectations within local institutions and health systems and professional communities. Health care providers can be active in this manner as individuals, as group practices and as members of professional associations that establish formal standards of care. Clinicians can also help patients and families to identify ways in which their goals were not met. Specifically, clinicians will know when an insurance company's refusal of a desired palliative treatment—perhaps an expensive parenteral antiemetic medication or hospital admission for pain management—or support service is unreasonable. They also know when a nursing home will not accept a patient for respite care or when a Medicare fiscal intermediary rejects certification of an additional Medical Hospice Benefit period, forcing a patient to be discharged from a hospice program on which the patient and family have relied for complex care needs. Examples of these sorts represent important failures of the current system of care at the end of life. They also represent potential points of leverage at which patients or their families can become advocates and activists for better end-of-life care.

Clinicians are well positioned to contribute raw material needed for activism by collecting stories. Both positive accounts of excellent end-of-life care and satisfying life closure and tragic stories of care gone awry and needless suffering are valuable. The history of activism in these and other areas has demonstrated that stories have the potential to motivate the public in ways that numbers cannot. Stories have the potential to change policy and practice in ways that statistics alone cannot. Indeed, what attracted the public's attention and support for the Ryan White AIDS CARE Act was not data regarding insurance coverage among HIV-infected people, but rather the story of a family that could not afford prohibitively expensive medications.⁵² Similarly, it was the story of a hemodialysis patient, told directly to Congress, which laid the foundation for the Medicare End Stage Renal Disease program.⁵ These precedents suggest that clinicians can also use the stories of real patients to motivate change in end-of-life care.

CONCLUSION

The strategies described here for advocacy and activism can be complementary and synergistic forces in improving end-of-life care. At one level, as advocates, patients, and families can have direct and immediate impact, driving change much more quickly than "top-down" regulation or professional certification and quality improvement efforts. This is particularly true if advocacy is fueled by achievable expectations, and facilitated by practical consumer tools, such as relevant patients' bill of rights and health care report cards.

But "top-down" professional and health systems initiatives are also essential, and their success or failure will ultimately shape the environment in which advocacy takes place. Advocacy can only be effective if patients and their families recognize inadequacies and if they have the information and tools needed to effect change. Large-scale public education initiatives, widely accessible and understandable quality indices, and clearly defined avenues for complaints and recourse are all needed. All of these will require significant commitments and energetic efforts directed at social change. These efforts will also require ongoing evaluation to assess their effectiveness in changing public perceptions, behavior or both.

Substantial, lasting improvements in end-of-life care will require a combination of advocacy and activism built on a foundation of data and stories. These efforts to expand access and improve the quality of valued services will require the commitment of individuals, clinicians, and disease groups and the support of funding agencies. Establishing this foundation will not be easy, in part because of the obstacles described above. However, as professionals, as members of families, and as individuals who will inevitably face life's end, we all have an important stake in making sure these goals are met and ample reasons to invest the time and energy required to achieve these critical goals.

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