

Hope and Hopelessness at the End of Life

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Efforts to improve end-of-life care have been hindered by widespread delays in discussing and initiating this care. The dynamics of hope and hopelessness may be crucial in these delays. The author reviews recent literature concerning hope and hopelessness at the end of life. Modern dying is more prolonged and more shaped by human choice than ever before. Therefore, hope and hopelessness play a more active role in the dying process. Hopelessness is not a simple product of prognosis, but is shaped by state and trait psychological factors. Hope at the end of life can come in various forms: for cure, for survival, for comfort, for dignity, for intimacy, or for salvation. Hopelessness at the end of life is therefore not simply the absence of hope, but attachment to a form of hope that is lost. The concept of anticipatory grief may help us interpret hope and hopelessness at the end of life. Improving end-of-life care will require looking beyond prognosis and preferences to understand the dynamics of hope and hopelessness. To be successful at diversifying hope at the end of life, we must foster the trusting interpersonal environment where this is possible. (Am J Geriatr Psychiatry 2003; 11:393-405)

"Death is not what it used to be. For most of human history, medicine could do little to prevent or cure illness or extend life, and living to an old age required considerable good fortune. Dying—like being born—was generally considered a family, communal, and religious event, not a medical one."¹

When does someone begin to die? What should a dying patient hope for? We have acquired the capacity to control or shape many aspects of the dying process. Dying is now as much a matter of human decision as of impersonal fate or divine providence. So we now anticipate dying with new responsibilities and new anxieties. In this article, I will focus on the dynamics of hope and hopelessness during the dying process. During a difficult time, we find a reason for

living in the hope for something better. By hope, I mean a person's positive orientation toward his or her personal future. John Locke described hope as "that pleasure in the mind, which every one finds in himself upon the thought of a profitable future enjoyment of a thing, which is apt to delight him."² Unfortunately, some people are unable to imagine any future enjoyment and thereby suffer from hopelessness. I will argue that this interplay between hope and hopelessness at the end of life is more important and more complex than is usually appreciated. In medicine, hope is often reduced to the issue of prognosis or chance for survival. In psychiatry, hopelessness is often reduced to a symptom of major depression. Yet hope and hopelessness at the end of life are not simply medical or psychiatric problems. They encompass nearly all that human culture and spirituality have to offer.

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Hope and Hopelessness

Most of us will die later and slower than our ancestors did. Until this century, mortality rates after infancy were similar through the lifespan. But modern medical care has done very well at rescuing patients from acute disease. Now deaths are concentrated in old age. Life expectancy was less than 50 years in 1900. By 1995, American women could expect to live 79 years and American men almost 73 years.³ These older Americans now die with a substantial burden of chronic disease. Over 75% of them will live past 65, but they will likely suffer from cancer, stroke, heart disease, obstructive lung disease, or dementia during their last year of life; 80% now die in hospitals or long-term care facilities.⁴ At the time of death, 75% are non-ambulatory, 33% are incontinent, and 40% are cognitively impaired.⁵ There is a great deal of fear around modern dying, with euthanasia and physician-assisted suicide as popular now as they ever have been.⁶

Dying in the Hospital

We have not yet figured out how to effectively address these fears and significantly improve the dying process in the hospital. It appears that disseminating the best information available about medical prognoses and patient preferences does not substantially improve the quality of dying. Using these strategies, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) was unable to improve five targeted end-of-life outcomes: 1) the presence and timing of Do-Not-Resuscitate (DNR) orders; 2) patient-doctor communication; 3) doctors' knowledge of patients' care preferences; 4) number of ICU days before death; or 5) the amount of pain.⁷ Mathematical prognostic models utilizing objective clinical data were developed in SUPPORT that improved slightly on established prognostic models and physicians' survival estimates,⁸ but this information did not change physician behaviors with individual patients. The recognition that the patient was dying and the transition to palliative care still occurred very late in the course of ICU care.

SUPPORT documents the fact that that physicians and surrogates are often unaware of seriously ill patients' preferences. The care provided to patients is often not consistent with their preferences and is often associated with factors other than preferences or prognoses. Furthermore, SUPPORT documented the

finding that there was no evidence that increasing the rates of documentation of advance directives results in care that is more consistent with patients' preferences.⁹ Although the intervention to support patient preference did not change care, it does not appear that patient preferences were ignored by physicians in the SUPPORT study. In-depth interviews with patients, physicians, and the nurses responsible for the intervention revealed that physicians were not unilaterally disregarding advance directives. Rather, physicians and family came very late to seeing these critically ill patients as "absolutely, hopelessly ill" and therefore came to implement the advance directives very late in the course of treatment.¹⁰ The judgment that a patient is "dying" thus appears to be a critical element in end-of-life care. SUPPORT suggests that effectively addressing this issue will require looking beyond improving the information available about prognoses and preferences.

Since their creation in the 1950s and 1960s, it has been widely understood that "the ICU (intensive care unit) and its technologies have the obligation to preserve life whenever possible, regardless of human and economic costs."¹¹ As we have come to question this obligation in recent years, it has been difficult to scale back this "rule of rescue" in the intensive care unit. DNR orders have become the most widely utilized tool by which intensive care is limited. During the 1980s, DNR orders came to be written more frequently and sooner in the course of an ICU stay.¹² Indeed, a national survey in 1995 revealed that 74% of (non-brain-dead) ICU patients received less than full life support at the time of death. But there was a wide variation among hospitals in end-of-life care. The percent of ICU deaths preceded by a DNR order varied between 0% and 83%.¹³ Other "critical events" in end-of-life care in the ICU include withdrawal of electronic monitoring. But there is persistent disagreement about whether non-monitored patients belong in the ICU. To not know how far a patient is away from death goes against the culture of the ICU. Clear consensus has not yet been achieved on when and how to hold back the life-saving "muscle" of the ICU.

The concept of futility appears to offer a means to rationalize end-of-life care in the ICU. According to a widely used definition, a medical intervention can be deemed futile if it has less than 1% chance of success. It is argued that physicians do not need to offer

futile interventions to their patients.¹⁴ Unfortunately, clear futility is quite rare. Patients undergoing bone marrow transplantation who develop respiratory failure with hepatic or renal failure, for example, have no chance of survival.¹⁵ But, for most clinical situations, published data are not adequate for the determination of futility. Even for interventions where the data clearly support a determination of futility, such as tube feedings in patients with severe dementia¹⁶ or terminally ill¹⁷ patients, it can be difficult to put an end to practices with intuitive appeal. Misunderstandings about quantitative and qualitative futility appear to be widespread among medical residents.¹⁸ Estimates of the economic impact of futility-based decisions in the SUPPORT sample indicate that the cost savings would be quite small. Futility, therefore, does not now offer the unambiguous signpost for end-of-life care in the hospital that some have hoped it would provide.

Overestimation of prognosis by critically ill patients and their families is common and is associated with preferring more life-sustaining treatments—which may be inappropriate or injurious.¹⁹ But bringing all parties to an accurate and realistic estimate of prognosis may not answer as many problems as first appears. Because of the personal beliefs and behaviors of the people involved, the highest-quality prognostic information available may not be adequate to ensure timely implementation of end-of-life care. As Timothy Quill has explained, “Patients, their families, and clinicians frequently collude to avoid mentioning death and dying, even when the patient’s suffering is severe and the prognosis is poor.”²⁰ Sometimes, ICU physicians will perform one final procedure, for example, dialysis, even though no one really believes it will work. This is done to prove to the family and colleagues that everything has been tried and to remove uncertainty from the decision that this patient is dying. These expensive procedures appear to be ordered to correct physiological abnormalities, but they may be serving a primarily psychological function. This suggests that we must look beyond biomedical prognostic information to understand social and psychological barriers to improving end-of-life care in the hospital.

Dying Outside the Hospital

It is anticipated that more deaths will occur outside the hospital than has been the case in the recent past.

Regrettably, the turn to end-of-life care is no better marked for patients outside the hospital. The best prognostic model for mortality for elderly patients after hospitalization has good predictive power (area under ROC curve = 0.79), with mortality ranging from 13% in the lowest-scoring group to 82% in highest-scoring group.²¹ But this still leaves considerable uncertainty regarding the fate of individual patients. Medicare began to cover hospice care in 1983. But the National Hospice Organization reported that by 1995, only 17% of deaths involved hospice care.²² Although Medicare will cover 6 months of hospice care, most patients are admitted quite late to hospice care. The median length of survival for patients in hospice has been reported to be 36 days.²³ The need to verify a prognosis of less than 6 months has been blamed for the infrequent and late referrals to hospice.

But there is evidence that fears of physicians and patients may also impede end-of-life discussions and hospice referrals. In a prospective study of AIDS patients and their clinicians, Curtis et al.²⁴ found that clinician barriers were more common and more strongly associated with the lack of end-of-life communication than patient barriers. Two specific clinician-identified barriers were associated with less communication: “the patient is not very sick yet” and “the patient is not yet ready to talk about end-of-life care.” After “too little time during appointments,” the most common clinician-identified barrier to end-of-life discussions was “I worry that discussing end-of-life care will take away my patient’s hope.” Clinicians often wait until death is in sight before discussing dying. Protecting patients’ hope appears to be a crucial motive for this delay.

Curtis et al. have also identified the aspects of physician skill at end-of-life care that patients with end-stage chronic obstructive pulmonary disease, cancer, or AIDS consider most important.²⁵ The physician skills most needed to appropriately initiate end-of-life care thus appear to be interpersonal and psychosocial rather than skills involved in mastery of biomedical prognostic models. The decision that a patient is dying will always be uncertain. Experts from Joanne Lynn to Timothy Quill have argued that waiting until death is certain to initiate end-of-life care is waiting too long. Yet there are looming fears for physicians, patients, and families that initiating or even discussing end-of-life care too early could de-

stroy hope or even hasten death.²⁶ Patients want physicians to both be honest and to protect hope.²⁷

Deciding to forgo life-prolonging care is a sentinel event in the care of critically ill patients. Hence, we must ask about the dynamics of hope in the tension between a longer life and a better death. What should we hope for at the end of our lives: for cure, for survival, for comfort, for dignity, for intimacy, or for salvation? What should clinicians hope to provide? As death approaches, which hopelessness is normal and which is pathological? The psychiatric literature has drawn a strong line between recognizing that death is imminent and desiring that death come sooner. But does this provide an adequate understanding of patients' daily fluctuation between fighting, accepting, and desiring death? Medicine has thought of hope at the end of life largely in terms of prognosis for survival. Psychiatry has thought of hope at the end of life largely in terms of hopelessness and suicide. Neither of these approaches is probably adequate.

Psychiatry has studied hopelessness much more thoroughly than hope. In order to review the psychiatric literature relevant to these issues, we will need to focus on hopelessness, rather than hope. We will examine hopelessness in five domains: 1) hopelessness in depression; 2) hopelessness in suicide; 3) hopelessness in quality of life; 4) hopelessness in disease-progression; and 5) hopelessness in religion and culture.

Hopelessness and Depression

There is much common ground between hopelessness and depression, both classically considered symptoms of melancholia. Now, hopelessness is widely recognized to be a cardinal symptom of major depression. Since Beck developed a scale to measure hopelessness, it has been noted to be closely related to depression severity.²⁸ As Susan Block has explained, this is also true at the end of life when the hopelessness is persistent and pervasive.²⁹ Episodic and focal hopelessness are much more common experiences of the dying and not as strongly linked with depression. In elderly persons, hopelessness may indeed be a more reliable indication of a depressive disorder than depressed mood.³⁰ But it is clear that poor prognosis and hopelessness are quite distinct among seriously medically ill patients. Cancer patients show a higher prevalence of depression than the general

population.³¹ But disease stage does not have a direct relationship to depression or hopelessness in cancer patients. The link between disease stage and psychological adjustment is mediated by coping style, with passive coping styles associated with more depression and hopelessness.³² This is consistent with data on depressed outpatients demonstrating that dysfunctional cognitions and poor problem-solving help predict hopelessness beyond depression severity.³³ It may be the natural tendency of seriously ill patients to overestimate their chances for survival. Clinicians report that patients who consistently underestimate their prognosis are almost always depressed.

Trait hopelessness associated with neuroticism stands in sharpest contrast to the transient hopelessness that often occurs in terminally ill patients.³⁴ Ira Byock argues that this transient hopelessness should be understood as a form of grief over losses associated with illness, because it generally occurs without the other components of depression. "While a person's sadness and depressed mood at the impending loss of all things and people in her life may be intense, it can usually be treated with non-medical supportive care and counseling. Clinical depression is not normal, and simple support will not suffice."³⁵ Below, we will consider the possibility that persistent hopelessness in dying persons can be understood as a complicated form of anticipatory grief.

Hopelessness and Suicide

Suicide can seem the only hope when all other hope is lost. Thus dying patients may, paradoxically, contemplate death as the only possible escape from dying. Aaron Beck has argued for years that hopelessness is the "key variable linking depression to suicidal behavior."³⁶ He has shown that hopelessness predicts eventual suicide for depressed psychiatric inpatients³⁷ and outpatients.³⁸ Among elderly patients, others have shown that hopelessness predicts suicidal ideation best in the presence of moderate or higher levels of depressive symptoms.³⁹ Furthermore, elderly patients who have attempted suicide tend to have higher levels of hopelessness even after successful treatment of depression.⁴⁰

However, factors beyond hopelessness must be considered if the links between depression and suicide are to be fully understood. Various "reasons for living" have been identified as protective against sui-

cidal acts for inpatients with major depression. These include: feelings of responsibility toward family, fear of social disapproval, moral objections to suicide, greater survival and coping skills, and a greater fear of suicide.⁴¹ On the other side of the balance, physical illness appears to be a risk factor for suicide throughout the lifespan. Even among teenagers, those with physical illness are more depressed and make more suicide attempts.⁴² In a national survey, the presence of a general medical condition predicted a 1.3 times increase in likelihood of suicidal ideation. Pulmonary diseases (asthma, bronchitis) were associated with a two-thirds increase in the odds of lifetime suicidal ideation. Cancer and asthma were each associated with a more than fourfold increase in the likelihood of a suicide attempt.⁴³ End-stage renal disease is also associated with increased risk of psychiatric disorders.⁴⁴ It is, again, important to note, however, that neither hopelessness nor suicidal ideation are directly related to disease severity or prognosis in a wide range of medical illnesses such as AIDS, amyotrophic lateral sclerosis (ALS), and cancer.⁴⁵

Suicide at the end of life. In recent years, researchers have been interested in whether desire for death at the end of life is similar to suicidal ideation at other times in life or whether it is a distinct clinical phenomenon. It is well known that the proportion of suicide attempts that result in death increase dramatically in old age.⁴⁶ In one study of 85-year-olds without dementia, 4% reported thinking that life was not worth living in the month before the interview; 4% had had death wishes, and nearly 1% had thought of taking their lives, although none had seriously considered doing so. Suicidal feelings were clearly associated with psychiatric disorders and with the use of anxiolytics.⁴⁶ Psychotic and substance abuse disorders become less significant in suicide with advancing age, leaving mood disorders as the clearly dominant psychiatric risk factor.⁴⁸ Depressed elderly men are at particularly high risk for completing suicide. Multiple studies have confirmed hopelessness as a strong predictor of suicidal ideation, suicide attempts, and completed suicide in elderly persons.⁴⁹

Minagawa et al.⁵⁰ studied psychiatric disorders in 109 terminally ill patients in a palliative care unit; 28% had delirium; 11%, dementia; 7%, adjustment disorders; 3%, amnesic disorders; 3%, major depression. Depression rates are clearly increased in can-

cer⁵¹ and AIDS patients⁵² who report significant levels of pain. Chochinov and colleagues have reported a number of studies with terminally ill patients. They found that those with a persistent desire to die have been reported to have higher rates of depression than those without a persistent desire.⁵³ But it is important to note that approximately 40% of those with this persistent desire to die did not meet depression criteria. They also found that hopelessness independently predicted suicidal ideation after they controlled for depression.⁵⁴ At the end of life, as earlier, hopelessness appears to be closer to the desire to die than is depression.

Hopelessness has also been shown to affect seriously ill patients' medical treatment decisions. Menon and colleagues⁵⁵ found that elderly medically ill veterans with high levels of hopelessness desired less life-saving treatment during their current illness. They were five times more likely to refuse CPR during the current hospitalization. Major depression alone did not significantly influence the desire for life-saving treatment. Emanuel and colleagues⁵⁶ asked 988 terminally ill patients about their interest in euthanasia or physician-assisted suicide (PAS) in standard hypothetical scenarios. Although 60% supported euthanasia or PAS in these situations, only 10% reported seriously considering these options for themselves. Those who felt appreciated, were over 65, or were African American were less likely to be personally interested. Those who had depressive symptoms, substantial care-giving needs, or pain were more likely to be personally interested. Depression was not related to general support for PAS, but those with depressive symptoms (on the Medical Outcomes Depression scale) were among the most likely to change their mind about PAS at follow-up 2 to 6 months later. Hopelessness was not specifically assessed.

Ganzini et al.⁵⁷ studied a group of 100 patients with ALS concerning their attitudes toward assisted suicide. Those patients who would consider assisted suicide were more likely to be men, had a higher level of education, were less likely to be religious, had higher scores for hopelessness, and rated their quality of life as lower compared with the patients who were opposed to assisted suicide. Wilson et al.⁵⁸ also found that the 12% of 70 advanced cancer patients interviewed who had an immediate interest in PAS had higher ratings on depression, anhedonia, hopelessness

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ness, and the desire to die than those who did not have this immediate interest. These studies are consistent in showing greater rates of depression and/or hopelessness in those who are currently interested in PAS. These studies do not clarify the source of this hopelessness or its reversibility. Clinical reviews of the psychodynamics of the request to die, which consider hopelessness in greater detail, have not included empirical testing.⁵⁹

One recent advance in studying end-of-life care is examination of a broader set of outcomes than suicidal ideation or interest in assisted suicide. Breitbart and colleagues⁶⁰ assessed hopelessness and depression in their study of 92 terminally ill cancer patients. They found that hopelessness added to depression's power to predict high scores on the Schedule of Attitudes toward Hastened Death.⁶¹ This scale looks at attitudes ranging from active suicidal ideation to treatment refusal to passive resignation in the course of illness. Harvey Chochinov⁶² has studied determinants of the will to live in 168 terminally ill patients. Will-to-live was assessed twice daily on a visual-analog scale. Will-to-live generally changed less than 10% on any given day, although on some days it changed as much as 35%. Through the course of the hospitalization, anxiety, then depression, was most strongly associated with will-to-live. This shifted around the last day or so, when physical symptoms, especially dyspnea, became most predictive. A broader set of outcomes at the end of life is thus providing a richer sense of the antecedents and consequences of hopelessness, but much detail needs to be added to this picture.

Assessment of hopelessness and depression at the end of life are really only important if we can do something to reverse them. In a recent study of physicians whose patients had requested assisted suicide, 90% reported psychological issues as relevant, and 70% reported that almost all their patients had an antidepressant trial; but only 30% had consulted a psychiatrist, and only 10% found it helpful.⁶³ Unfortunately, because of problems of recruitment and randomization of terminally ill patients into depression-treatment studies, we do not have controlled data about depression treatment to draw upon.⁶⁴ Both antidepressants and psychostimulants have been reported as effective for depression treatment in case series. Some of these case series report a decrease in the desire for death among treated patients.⁶⁵ Some

psychotherapies, such as life review, have been reported successful at reducing hopelessness and depression in frail elderly nursing home residents.⁶⁶ There are thus grounds for optimism that at least some forms of hopelessness at the end of life might be treatable, but the extent and nature of these treatment effects remain to be defined.

Hopelessness and Quality of Life

Traditionally, hopelessness has been considered a psychological reaction to one's health state, rather than a part of the health state itself. But as our understanding of health broadens to include health-related quality of life, we may need to consider hopelessness as a component of health itself.⁶⁷ Hopelessness has recently been incorporated into quality-of-life measures outside of psychiatry.⁶⁸ Hopelessness has also been assessed as a component of the existential distress accompanying dying.⁶⁹ These studies are part of a general trend to incorporate patients' perspectives into our understanding of health.⁷⁰

We are beginning to understand what other components of patients' health state are most closely related to hopelessness. Hopelessness appears to be strongly related to suffering in patients with ALS, though the causal direction of this relation is not clear.⁷¹ Prospective data do suggest that hopelessness in ALS is not related to time since diagnosis, degree of disability, or illness progression during the period of observation.⁴⁵ Once again, hopelessness does not appear to be directly driven by objective disease severity. Hopelessness decreased for HIV patients receiving combination antiretroviral treatment, but this improvement was not related to individual medical improvement of markers of HIV illness progression. Those classified as improved on HIV disease-severity measures were no more likely than those who remained unimproved to report a significant decline in measures of distress and hopelessness.⁷² Hopelessness thus appears to be an important component of health for those with life-threatening illness. To address it effectively, we need to look to clinical interventions beyond those that modify objective disease severity.

Hopelessness and Disease-Progression

There is a growing but still controversial body of evidence that suggests hopelessness may promote

disease severity and mortality. The evidence for a disease-effect of hopelessness is strongest in cardiovascular disease. Hopelessness has been prospectively linked with cardiac mortality in coronary disease patients⁷³ and in the general population.⁷⁴ Objective measures of carotid atherosclerosis also show greater progression in men with higher levels of hopelessness.⁷⁵ Some studies have shown increased mortality in hopeless cancer patients, especially in those with breast cancer.⁷⁶ But these findings are less well replicated than those in heart disease. Hopelessness has been shown in some studies to predict mortality in hospitalized patients⁷⁷ and in older adults generally.⁷⁸ New evidence suggests that strained caregivers of elderly disabled spouses also have higher mortality rates.⁷⁹

The evidence that hopelessness promotes disease progression, although not conclusive, must be considered a counterbalance to the poorly supported, but accepted view that disease progression itself promotes hopelessness. Hopelessness is not a simple product of prognosis, but may itself shape prognosis. However, there are no controlled studies at this time demonstrating that hopelessness in terminally ill patients hastens non-suicide death.

Hopelessness and Religion

Religion played an important role in end-of-life care before medicine had anything to offer dying patients. It continues to be an important way to give meaning to the dying process for many patients.⁸⁰ Many had assumed that religious individuals would have less fear of dying than others, but the literature has not supported this hypothesis.⁸¹ Recent literature suggests, however, that religious belief, but not religious practice, may protect against hopelessness at the end of life.⁸² Koenig and colleagues⁸³ similarly found that "intrinsic religiosity," but not religious attendance, predicted a shorter time to depression remission in medically ill older patients. But they have also shown that religious activity may decrease mortality in older adults, especially women.⁸⁴ Whether this effect is specific to religious activity, as opposed to other organized social activity, is not known.

Even if religious belief or practice is conclusively shown to promote survival, this is not its intention. In contrast to medicine, religion does not construe hope primarily as "hope for survival." Accepting the

inevitability of death, religion provides other forms of hope: hope for an afterlife, hope for salvation, hope for nirvana. Medicine cannot provide these other forms of hope, and perhaps it never has pretended to. But in its power to prolong survival, it helps us forget that there are other goods to hope for. We want medicine to be our bulwark against death, to do the work that all of culture used to do. We have been called to the "war on cancer." We are reminded that an AIDS cure "is possible only through research." Even the counterculture New Age literature is full of the importance of will, visualization, and "the fighting spirit" in the struggle for survival.

Medicine is our hope in the war on death. We hope that better pain control at the end of life will relieve our fear of death. In a national sample of VA patients, families, and care providers, freedom from pain was ranked most important and dying at home least important among nine major attributes of end-of-life care.⁸⁵ We moderns continually substitute medical supports for dying patients for the myriad non-medical supports for the dying we have used throughout history. "Technology becomes a global approach to achieving the goals of care. . . . At issue is the intensity of care overall, more than the merits or demerits of specific interventions."⁸⁶ Patients may continue toxic therapies against long odds because they have been presented with no meaningful alternative ways to have hope.

THE VARIETIES OF HOPE AT THE END OF LIFE

Medicine and psychiatry both operate with a one-dimensional understanding of hope at the end of life, which must be overcome if we are to provide more humane dying for our patients. Medicine thinks of hope as prognosis. If hope for survival is gone, then hope loses institutional support in medicine. Hospice and palliative care provide competing perspectives, but are still out-powered and under-funded. Psychiatry approaches hope in terms of its absence, hopelessness. Hopelessness is understood in terms of its association with depression and points toward a need for treatment of depression.

Hopelessness in dying persons might also be understood as a form of anticipatory grief. Anticipatory

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grief was first described as a psychological reaction to "potential death" by Lindemann in 1944.⁸⁷ It was later recast as a "reaction to inevitable death" by Clayton and colleagues.⁸⁸ Although the concept of anticipatory grief is controversial, some studies have suggested that grief symptoms in bereaved spouses are more intense before the death than after.⁸⁹ There is evidence that the grieving process for family members of dying patients begins with end-of-life discussions.⁹⁰ These discussions may be delayed to avoid this "anticipatory grief."⁹¹ Well-known symptoms of complicated grief, such as disbelief about the death and refusing to accept the reality of the death, may be clinically important before the death. Threatened with loss, many individuals will intensify, rather than forsake, attachment behaviors.⁹² If grief is not allowed and acknowledged, care decisions may be distorted by the attempt to salvage some form of hope. A completed bereavement process is marked by the emergence of new forms of hope, whereas a complicated bereavement is marked by continued hopelessness.⁹³ New treatments for complicated grief, such as Traumatic Grief Treatment, are currently being tested.⁹⁴

Previous studies have demonstrated an association between complicated grief and suicidal ideation in bereaved elderly persons.⁹⁵ In one study, 29 of 70 bereaved spouses (41%) met proposed criteria for complicated grief, but only 6 of these 29 (21%) met criteria for major depression.⁹⁶ However, complicated grief was much more common in those with a lifetime history of major depression. Grief processes may therefore supplement depression as a way to understand hopelessness in the dying patient and her family. The course of spousal bereavement appears to be strongly shaped by the presence or absence of strain during the caregiving phase.⁹⁷ How to promote some completion of anticipatory grief is a paradoxical, but probably essential, question for end-of-life care. Attempts have been made to facilitate anticipatory grief for the parents of dying children, but results have been mixed.⁹⁸ The concepts of anticipatory and complicated grief have not yet been tested in dying patients. Yet it is clear that the rich diversity of hope and hopelessness at the end of life is lost in the stark opposition currently offered to us between hope for life and desire for death.

There are many varieties of hope possible at the end of life: for cure, for survival, for comfort, for dig-

nity, for intimacy, for salvation. We think of hopelessness as the absence of hope. But if we remember the wide range of hope possible, another understanding emerges: Hopelessness is not the absence of hope, but an attachment to a form of hope that is lost. If we are tied to a hope for survival that is "sinking into the deep blue sea," we will be unable to see the other forms of hope floating before us. This possible diversity of hope suggests that the challenge at the end of life is not so much protecting or restoring hope as diversifying and redirecting hope. But there are institutional, cultural, and psychological barriers to accomplishing this.

Institutional barriers. To qualify for Medicare hospice benefit, patients must currently have a life expectancy of less than 6 months and forswear life-prolonging treatment. Much has been written about how this requires more prognostic precision than is possible and results in hospice stays of weeks, rather than months.¹ It also imposes a daunting psychological barrier for patients, who often feel as if they are choosing between the possibility of life and a certain death. A Faustian bargain for a toxic therapy with little chance of prolonged life can seem reasonable and even noble compared to certain annihilation. Many have argued that we must move beyond the forced choice between curative and palliative care that is caused by the uncertainties of prognosis. Joanne Lynn, for example, has stated, "Good care at the end of life will have to include long-term care for the very sick, since no method can target only those patients who are to die soon."⁹⁹ The uncertainties of prognosis are even greater in diseases like obstructive lung disease and congestive heart failure than in the case of cancer, around which hospice has been organized.¹⁰⁰ Equally important to these arguments based on the uncertainties of prognosis are arguments based on dynamics of hope. If we force patients to relinquish hope for survival before they begin hoping for solace, they will often refuse.

Cultural barriers. Although nursing homes are an increasingly important site for terminal care, our deep ambivalence about nursing home placement for ourselves and our loved ones make good terminal care in this setting difficult to define and pursue. By 1993, 20% of deaths occurred in nursing homes, with future increases likely. Yet only 1% of the nursing

home population enrolls in hospice care. This has been attributed to quality standards and reimbursement policies that favor high-technology restorative care over labor-intensive palliative care.¹⁰¹ But there are also complicated psychological processes about support and abandonment operating in the nursing home that may make acceptance of dying difficult.¹⁰²

Supportive relationships are crucial for the dying patient. Surveys repeatedly identify "being a burden to others" as one of the most prominent fears about dying.¹⁰³ And yet, "dying alone" is also a prominent fear. Although nursing home placement can arise from disrupted family relations, it can also lead to loss of continuity with care-providers as well as further family disruptions.¹⁰⁴ The increasing age and debility of the dying make return to care of the dying within the family unlikely and nursing homes seem inevitable. But increasing the compatibility of family support and nursing home support may be one way to improve the environment for dying. There are also possible alternatives for supported care outside of long-term care institutions. The On Lok model of care for frail elderly patients developed in San Francisco's Chinatown may be one alternative. This model provides for health and supportive services during the day, allowing elderly patients to return to their homes at night.¹⁰⁵ This kind of service might allow some who now die in nursing homes to die at home.

Psychological barriers. The reason these programs that preserve the relationships of the dying are important—and relevant to this article—is that it seems that only within the context of these relationships can hope be diversified. Trusting relationships are the domain within which the expansion of hope is possible because this is where it is safe to grieve. Steven Miles has succinctly stated, "When switching from cure to comfort, redirecting hope requires reasserting connections to family, friends, religion . . . thereby one dies *in community*." He goes on to explain, "A dying *person* is different from a dying *patient*. The former is defined in terms of his or her own values and relationships. The latter is defined by the role of being under medical care."¹⁰⁶ Patients can tolerably be treated as malfunctioning bodies in the ICU as long as there is a possibility of returning to fully functioning personhood. When dying is accepted and that possibility is lost, families need their ill member to be respected as a person in the present. Spiritual and

familial rituals can help with this transition. "These (sacred end-of-life) ceremonies can transform the patient back into a person *before* the treatment is removed."¹⁰⁶ To prolong survival, we've turned dying people into patients, and that is part of the problem. To improve dying, we do not need them to just be better patients experiencing improved symptom control. We need them to be something more than patients. Family and friends are a crucial part of this process. Families and friends are strangers in the ICU and even in the nursing home, but they should not be strangers to the dying patient. This is for the benefit of the family as well as the dying patient. "In personal deaths, values and community enable intergenerational cultural work and education to occur. A dying patient shows a family how to die."¹⁰⁶

Throughout life, health and survival are merely the means to other ends. They allow us to work, to love, and to play. At the end of life, it can seem that survival is the point of life, perhaps the only point. If hope for survival is lost, then all of life's value is lost. Re-connecting with significant others offers the possibility that we can reinvigorate other purposes in life and rediscover other forms of hope. No one has written more compellingly about this possibility at the end of life than Ira Byock. He makes it clear that the question about whether enough effort at *cure* was provided for the dying patient is always also a question about whether we have provided enough *care* for our dying loved one. "Did we do the right thing? Did we make the right decisions? Did we give up too soon or hang on too long? Was there anything else we should have done? Did we seize every opportunity, take every action for a loving, peaceful end?"³⁵ Byock works at showing that his hospice patients still matter to others, and still have a role in the community, even if only as a recipient of care. "but in allowing yourself to be cared for, and being a willing recipient of care, you're contributing in a remarkable, valuable way to the community." He is a strong advocate of "the five things of relationship completion" from the hospice tradition. The five things to say to significant others before you die are: "I forgive you;" "Forgive me;" "Thank you;" "I love you;" and "Goodbye."³⁵ These efforts at relationship closure are reported to facilitate the dying process, but have not been yet subjected to controlled studies.

Fear of death and fear of dying are universal and unavoidable perils on the path to palliative care.

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Emotions around these issues are huge and difficult for clinicians to manage. We need to provide better support for physicians making the difficult decision that a patient is dying. Physicians are still rewarded by peers for saving lives, but not for saving patients from protracted dying. Discussions about dying are often delayed by unspoken agreement between patient, family, and provider. Initiating end-of-life discussions requires considerable skill. Timothy Quill makes some useful suggestions that allow the issue of dying to be opened without taking away hope. "Asking 'What would be left undone if you were to die sooner rather than later?' gives a message that time may be short."²⁰ "How do you think about balancing quality of life with length of life in terms of your treatment?" may allow patients to begin to place survival in context. Even after patients have moved into the hospice or palliative-care setting, it may help to bring their attention to existential issues. Ira Byock has suggested, "What are the most important things for you in whatever time you have left?" and, from the British hospice tradition, "How are you within yourself?" These questions encourage patients to find meaning in dying by redirecting their quest for hope.

CONCLUSION: DYING WITH OUR PATIENTS

All our lives, we resist the thought that we are dying. Few of us know how to go on hoping when we are dying. Fear of dying is a normal, perhaps essential, human experience. It can be magnified or distorted in psychologically vulnerable individuals.¹⁰⁷ By virtue of selecting medicine as a profession and being socialized for the job of saving lives, physicians may be especially unaware of their own fears of dying.¹⁰⁸ Psychiatrists receive more training than other physicians about how their personal feelings may affect patient care, but this does not usually include feelings about dying. Caring for dying patients challenges us to share the experience of dying with our patients.¹⁰⁹

If we allow ourselves to be affected by dying patients, we will be transformed by the experience. This requires relinquishing control over the clinical process in ways that are novel for many physicians.

I have tried to demonstrate that the dynamics of hope and hopelessness are central to our improving the care of dying in our society. Discussions of dying are often delayed in order to protect hope. Patients and families hope to avoid death, and physicians hope to avoid failure. Discussions of dying are conducted in a context of uncertainty and overwhelming emotions. This is because grief for patient, family, and provider generally begins with these discussions. Hopelessness may well be the most crucial factor in persistent patient desires to hasten death. It, too, may be a symptom of complicated grief associated with the dying process. Most, but not all, of this hopelessness appears to be associated with major depression. Other sources of hopelessness are poorly defined and inadequately addressed in our current care of the dying.

Medicine is now moving beyond improving prognosis to provide comfort, but it also must not impede the redirection of hope beyond medical institutions. Psychiatrists treating patients at the end of life need to look beyond competence evaluations and depression treatment to help patients expand the repertoire of hope available to them.¹¹⁰ We know a few things that we can do to help diversify hope for dying patients: palliative care that reduces symptoms, to allow for lucidity and relationship; bringing family and friends into intensive care and nursing home settings; patient life-review by writing biographies and dictating stories; and fostering reconciliation with friends, family, and community. But there should be many more items on this list.

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