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The Social Origins of Dignity in Medical Care at the End of Life

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How do social forces constrain or foster dignity at the end of an individual's life? Such a question rightly concerns individual patients, their families, and decision-makers beyond the circle of immediately affected people. A society in which people die in an undignified fashion must surely be concerned with this state of affairs. And a key measure of the credibility of any health-care system is surely the respect and dignity it accords to its most vulnerable patients, those who are dying.

Unfortunately, numerous studies in the US document that many patients die prolonged and painful deaths, receiving unwanted, invasive, and impersonal care in the process. Surely this is undignified however dignity is defined. What is more, this type of care is not consistent with the care people themselves desire. Table 1 illustrates the discrepancy between people's desires regarding their terminal care,[1] and the outcomes that are actually observed. This is a sorry report card indeed. The gap between the care that is desired and the care that is provided is substantial and, at least in most cases, needless. For example, 40–70% of Americans die in pain, yet effective treatment for pain is widely available.

This discrepancy threatens patient dignity in at least two ways. First, it is undignified in itself to die in pain or otherwise endure a bad death. Second, it is undignified to give patients a kind of care at the end of life that is inconsistent with their wishes. In a comprehensive, grounds-up study of how Americans define a 'good death,' involving the identification and assessment of 44 relevant attributes, one study found that patients identify a heterogeneous set of objectives, as shown in Table 2.[2] The items on this list are noteworthy for their explicit statement of the importance of dignity, for their emphasis on metaphysical concerns near the end of life, and for their emphasis on specifically social aspects of good death—all of which are key elements of dignity.

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[1] K.E. Steinhauser et al., 'Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers,' *Journal of the American Medical Association*, 284 (2000), pp.2476–2482.

[2] Ibid.

Table 1 The contrast between ideal, desired deaths, and reality (K.E. Steinhauser, N.A. Christakis, E.C. Clipp, M. McNeilly, L. McIntyre, and J.A. Tulsky, 'Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers,' *JAMA*, 284 (2000), pp.2476–2482.)

Attribute	% of patients agreeing 'very important'	% of Americans achieving objective
Be free of pain	93	30–50
Not be a burden to family	89	45
Have a doctor who listens	95	30–45
Die at home	70	15
Know what to expect	96	15

Table 2 Patient-identified attributes of a good death (K.E. Steinhauser, N.A. Christakis, E.C. Clipp, M. McNeilly, L. McIntyre, and J.A. Tulsky, 'Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers,' *JAMA*, 284 (2000), pp.2476–2482.)

Attribute	% of patients agreeing 'very important'
Be kept clean	99
Name a decision-maker[*]	98
Have a nurse one likes[*]	97
Know what to expect	96
Have someone who will listen[*]	95
Maintain one's dignity	95
Trust/like one's physician[*]	94
Have finances in order	94
Be free of pain	93
Be mentally aware	92
Say goodbye to important people[*]	90
Be at peace with God	89
Not burden family[*]	89
Resolve unfinished business	86
Share time with close friends[*]	85
Believe family is prepared[*]	85
Feel prepared to die	84
Presence of family[*]	81
Not burden society[*]	81
Not die alone[*]	75

[*] These attributes of a good death, deemed by patients to be very important, all contain explicitly or implicitly social elements.

Unfortunately, not only do physicians appear to be ill-equipped to provide the kind of care that patients desire, but also, they often do not even realize that such features are important to patients. For example, while the great majority of patients identify important aspects of a good death as including being mentally aware, being

at peace with God, retaining the ability to help others, and not burdening family or society, only roughly half of physicians are aware that such features are important to patients at the end of life.

Though the two are not necessarily the same thing, a good death is clearly related to a dignified death. One empirically derived conceptual model of dignity in dying patients, based on interviews with terminally ill people, is worth examining in this regard since the items identified in this model as being part of dignity are closely related to attributes of a good death. This work highlighted three aspects of dignified care at the end of life: (1) bodily concerns (such as cognitive acuity, functional capacity, physical and psychological distress); (2) 'dignity practices' (such as the ability to help others, being hopeful, maintaining a sense of normalcy), and (3) social features (such as not burdening others, being concerned about the aftermath of one's death, and having social support).[3] Interestingly—and worrisomely—many of these items are also the ones that patients think are important aspects of a good death but doctors relatively less so. This itself may help to explain why so many sick people find modern medical care undignified.

Most generally, the lack of dignity in care at the end of life appears to arise from a more widespread misdirection of the efforts of the health-care system in the care of seriously ill patients. Psychiatrist Leon Eisenberg drew a classic distinction between 'disease' and 'illness,' wherein the former is the biological expression and the latter is the 'lived experience' of disease, including its social and moral aspects.[4] When doctors treat disease and not illness, they contribute to a decrement in the patient's dignity. Indeed, routinized forms of care that are increasingly prevalent in medicine, such as 'clinical practice guidelines,' while very advantageous in several ways, also run the risk of effacing the salience of the individual and his unique circumstances and hence, in treating a person like a mere object, compromising his dignity.

Dignity and Its Social Origins

The way the health-care system treats a vulnerable, terminally ill patient is thus instrumental to whether a patient ultimately has a dignified death. This is related to the classic argument, advanced by psychologist B.F. Skinner in *Beyond Freedom and Dignity*, that dignity is not an inherent attribute of individuals, originating within them, but rather is a product of their physical and social environment.[5] The circumstances surrounding the seriously ill should be objects of inquiry if we want to

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[3] H.M. Cochinov, T. Hack, S. McClement, L. Kristjanson, and M. Harlos, 'Dignity in the Terminally Ill: A Developing Empirical Model', *Social Science and Medicine*, 54 (2002), pp.433–443.

[4] L. Eisenberg, 'Disease and Illness: Distinctions Between Professional and Popular Ideas of Sickness', *Culture, Medicine, and Psychiatry*, 1 (1977), pp.9–23.

[5] B.F. Skinner, *Beyond Freedom and Dignity* (Indianapolis: Hackett Publishing, 2002 [1971]).
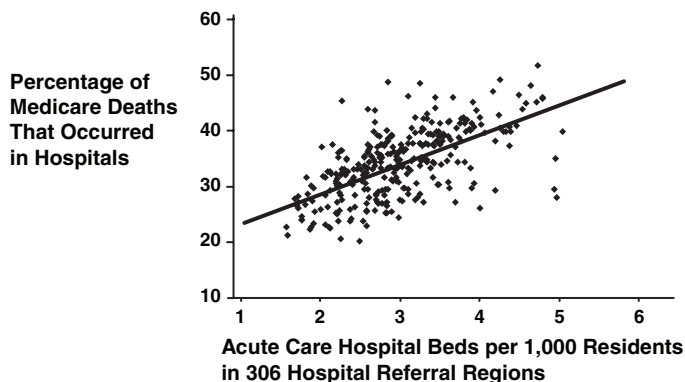
Fig. 1 Relationship between regional hospital bed supply and occurrence of death in institutions (Dartmouth Medical School, *The Dartmouth Atlas of Health Care*, 1998 (Chicago: American Hospital Association, 1998), http://www.dartmouthatlas.org/)

understand the dignity afforded by the health-care system and should be objects of our intervention if we want to enhance human dignity, especially at the end of life.

For example, much could be said of the importance of reforming medical institutions or medical procedures so that care at the end of life could become more dignified. Two external aspects of our care system that impinge on the ability of individuals to have a good death, a death in keeping with their preferences and comporting with their dignity, illustrate this point.

Figure 1 shows the association between the percent of deaths occurring in hospitals and the regional supply of hospital beds, based on data from the *Dartmouth Atlas of Health Care in the U.S.*[6] The data suggest that as much as 38% of the variation in whether death occurs in a hospital can be attributed to the local availability of hospital beds. That is, if you are a patient who wants to die at home and you happen to live in an area with lots of hospital beds, you are especially unlikely to have your wishes fulfilled, for reasons having nothing to do with your preferences. On the bright side, these results suggest that public policy (e.g. as it pertains to the placement of hospital beds) matters, and can affect what happens, both in the sense of increasing the likelihood of a particular outcome, and also in the sense of enabling people to realize their own objectives.

Figure 2 documents the substantial inability of physicians to formulate accurate prognoses. In this study, doctors made predictions about how long 505 of their patients would live. The objective was to quantify the magnitude and nature of the error in the prognoses physicians formulate (and not necessarily communicate). This study found that doctors overestimate survival by a factor of about five.[7] That

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[6] Dartmouth Medical School, *The Dartmouth Atlas of Health Care*, 1998 (Chicago: American Hospital Association, 1998).

[7] N.A. Christakis and E.B. Lamont, ''Extent and Determinants of Error in Doctors' Prognoses for Terminally Ill Patients: Prospective Cohort Study', *British Medical Journal*, 320 (2000), pp.469–473.
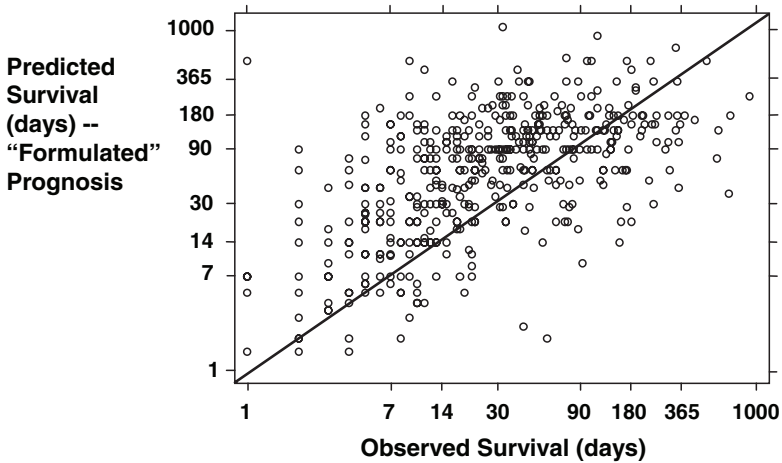
Fig. 2 Relationship of prognoses formulated by physicians and actual patient survival (N.A. Christakis and E.B. Lamont, 'Extent and Determinants of Error in Doctors' Prognoses for Terminally Ill Patients: Prospective Cohort Study,' *British Medical Journal*, 320 (2000), pp.469–473.)

is, for the typical patient in the last year of their life, the doctor thinks that they may have, say, six months to live, but actually they can expect to live only a month. This kind of prognostic mis-calibration can seriously undermine high-quality care near the end of life in various ways.[8] For example, another study found that patients' generally optimistic and incorrect prognostic estimates were associated with an aversion to palliative care. That is, patients' false understanding of their situation can interfere with their ability to realize the kind of end-of-life care they themselves also say they want.[9]

These two rather technical examples of how structural features of the medical system affect patient experience highlight not only the larger debate about internally held versus externally bestowed dignity, but they also raise the classic sociological concern of the 'collective constraints on individual opportunities,' or how individual experience is shaped by the social setting. Other examples with respect to the care of the terminally ill abound, such as how a lack of training in end-of-life care or in opioid use, or structural features affecting the availability of drugs used in end-of-life care, or rules governing access to hospice care, affect patient experience and patient dignity. If we are to increase dignity at the end of life, our efforts ought necessarily to be directed at the health-care system.

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[8] N.A. Christakis, *Death Foretold: Prophecy and Prognosis in Medical Care* (Chicago: University of Chicago Press, 1999).

[9] J. Weeks, et al., 'Relationship Between Cancer Patients' Predictions of Prognosis and Their Treatment Preferences,' *Journal of the American Medical Association*, 279 (1988), pp.1709–1714.

Death with Dignity and Euthanasia

Despite the recognition of the extent to which dignity depends on the environment surrounding an individual, dignity also appears related to traits within an individual. For example, dignity is typically felt to contain a notion of personal self-governance. Consequently, 'death with dignity' has become, sadly, a euphemism for certain kinds of physician-assisted suicide and euthanasia. Support for euthanasia is often driven not only by a desire to avoid what is seen as the 'torture' of patients by the health-care system, but also by arguments about a 'respect for persons' or a 'respect for a person's dignity'.

Indeed, modern modes of death and dying have become so problematic that euthanasia is achieving new legitimacy such that a 'death with dignity' movement emerged in the USA beginning in the 1990s. The most fundamental reason for this is that modern medicine—whatever else it does—often increases suffering when it prolongs life. Moreover, this increase in suffering takes place in a setting wherein patients see front-page newspaper headlines asserting that 'doctors are lax in easing pain' and that 'doctors admit ignoring dying patients wishes'. Patients appear to want not just the 'right to die', but also the right to be killed. People are dissatisfied with the technicalization, medicalization, professionalization, and institutionalization of death in modern American society. Euthanasia—in many ways paradoxically—is seen as standing in opposition to these developments.[10]

Hospitals are becoming increasingly viewed as singularly unsuited not only to a 'natural', but also to a painless and dignified death. The juxtaposition in a hospital of high technology, bureaucracy, and professionalization on the one hand and the most fundamental and unchanging of human experiences—such as birth, death, and pain—on the other hand, is increasingly viewed as inauspicious. Hospitals are coming to be construed as a necessary evil for the curable, but as an unnecessary evil for the incurable.

In fact, one of the assumptions underlying the increasing acceptability of euthanasia in American society is that dying is a private, individual, self-directed, and intimate event. Dying in modern contexts connotes a fear of losing control, which loss is antithetical to a core American value. The option to be killed is thus somehow seen as restoring dignity to a process that has become undignified.

This is disquieting. Whatever the policy, clinical, or ethical justifications for it, there is nothing dignified about euthanasia. The problem with euthanasia is that it eradicates the pain by eradicating the patient. It solves the problem by eliminating the victim. And it addresses what might rightly be seen as an external threat to human dignity by internalizing it within the suffering patient.

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[10] N.A. Christakis, 'Managing Death: The Growing Acceptance of Euthanasia in Contemporary American Society', in: R. P. Hamel and E.R. DuBose (eds.), *Must We Suffer Our Way to Death? Cultural and Theological Perspectives on Death by Choice* (Dallas, Texas: Southern Methodist University Press, 1996), pp.15–44.

Table 3 'Ideal Types' and the historical evolution of perceptions of death (T. Walter, *The Revival of Death* (London: Routledge, 1994), p. 48)

Context	Traditional	Modern	Neo-modern
Bodily context	Quick and frequent	Hidden	Prolonged
Social context	Community	Public/private	Private = public
Authority	Religion	Medicine	Self

This shift in the appeal of euthanasia can also be traced, in part, to the observation that a person is seen as dignified (and gets credit from others) when he does something that is volitional, that is neither motivated by biological impulses nor by the external threat or reward of others. We grant maximal dignity when there is no obvious reason for a behavior. Hence, we regard the acceptance of death—and some regard the euthanistic embrace of death—as especially dignified. 'We recognise a person's dignity or worth when we give him credit for what he has done. The amount we give is inversely proportional to the conspicuousness of the causes of his behavior.'[11] Indeed, we give the most credit when there are evident reasons for behaving differently.

But does dignity really arise in proportion to resisting some kind of temptation? And does dignity demand that doctors and patients practice euthanasia? When people fashion their own way of dying, *sui generis*, we nowadays accord them tremendous dignity. Is having a wholly individual or 'original' or self-imposed death what is dignified? Is complying with prevalent norms about a good death dignified? Or does dignity have altogether different origins?

This example of the dignity in accepting pain and suffering or, paradoxically, in rejecting these features at the end of life, and hurrying death on, highlight sociologist Tony Waters' observation that notions of a good death have changed across time, as illustrated in Table 3.[12] At present, death typically involves prolonged illness, occurs in a social context that melds the personal and the public, and invokes as an ultimate authority (one that properly exercising the most control over the process) the self. In 'neo-modern death,' the split between public and private domains is effaced when a private experience is publicly celebrated.

The Social Origins of Dignity at the End of Life

Something about dying alone, apart from others and hence socially disconnected, appears especially undignified—dying 'like an animal' in the parlance of many patients. This may be part of the origin of suspicions that hospital deaths are undignified because the deaths occur in an institutionalized and sequestered way, apart

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[11] B.F. Skinner, *Beyond Freedom and Dignity* (Indianapolis: Hackett Publishing, 2002 [1971]), p.58.

[12] T. Walter, *The Revival of Death* (London: Routledge, 1994).

from relevant others, or with inauthentic interactions with others—that is, not 'real' others, but instead with people inhabiting social *roles*, such as a 'doctor' or a 'nurse.' This may also explain why patients so often want to have truly personal interactions with their caregivers, as this in part helps restore their dignity. Earlier, we noted the salience in patients' perceptions of a good death of having a doctor who listens. Here is one physician's description of such an attempt by a patient at social connection:

> The last day I saw him in the emergency room, he was looking at me with those roving eyes and gasping for breath. I leaned over him and stroked his hair. He looked at me and said, 'how's that new house of yours?' I said, 'I'm not really moved in.' And he said, 'You make sure you decorate it nicely.' It was a very personal interchange. He was dying, and his last interaction with me was as a person, not as a doctor.[13]

Dignity for the patient here, in part, means being known as a person rather than as a diseased individual, and interacting with the doctor in a personal way.

There is, moreover, something dignified about making social connections even when one is about to lose all of them. And people seem to crave this. Here is one example of a family member's description:

> He got home, and they got him out of the ambulance. I remember him saying, "Oh, can I wait just a minute, to remember the sunshine." This for somebody who hadn't seen the sun in so long. It was almost like we had a party that evening. Everybody was there, and we sang songs. He died that night, at home, and everybody was there.[14]

Another patient explicitly makes the connection between dignity and social connections:

> [What gives my life dignity is] having a family. Having the little fellow that lives next door. That give me a lot of cheer. Well, it doesn't matter how bad things get. I always know that my family is there and I'm very lucky. Not everybody's family is supportive. But I know that they love me. Yeah, because I belong to somebody and they belong to me.[15]

This recognition that social connections are a key part of a dignified death is supported as well by the frequency with which items related to social connections make it onto the list of important attributes of a good death in Table 2. There are strong social components in patients' definition of a good death.

In short, a key way that dignity is 'social' is that people incorporate social elements into their perceptions of a good or dignified death. As we have seen, a second key respect in which dignity has social origins is the observation that institutional structures affect patient dignity. Finally, the social environment impinging

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[13] K. E. Steinhauser, E. C. Clipp, M. McNeilly, N.A. Christakis, L. McIntyre, and J.A. Tulsky, 'In Search of a Good Death: Observations of Patients, Families, and Providers', *Annals of Internal Medicine*, 132 (2000), pp.825–832.

[14] Ibid.

[15] H.M. Cochinov, T. Hack, S. McClement, L. Kristjanson, and M. Harlos, 'Dignity in the Terminally Ill: A Developing Empirical Model', pp.433–443.

Table 4 Additional features of idealized types of death (T. Walter, The Revival of Death, (London: Routledge, 1994), p. 48)

	Traditional	Modern	Neo-modern
L	Plague	Cancer/CD	Cancer/AIDS
Trajectory	Fast	Hidden	Prolonged
Life expectancy	40	70	80
Typical death	Child	Elderly	Elderly
Atypical death	Old (venerated)	Young (senseless)	Young(senseless)
Others seen dying	Frequently	Rarely	'Witnessing'
Authority	God	Medicine	Self
Know through	Clergy (male)	Doctors (male)	Counselors (female)
Good death	Conscious ready to meet God	Unconscious/sudden no bother to others	Aware/precious finish business

on dignity at the end of life is of substantial relevance for another reason: social factors contribute to the very definition of a dignified death and, consequently, perceptions may vary across social and cultural groups. There is a social construction of notions of dignity, a strictly social ontology.

Indignity originates in the treatment of one person by others. And, conversely and just as assuredly, dignity can depend upon the treatment of one person by others. While this is a general observation, it is especially relevant in end-of-life care. If we are serious about dignity, we should revise the way we care about the dying—not only for the sake of patients—but also for the sake of doctors; for it is undignified for the doctor, and for our society, to provide undignified care.