
Suffering, Cure, and Palliation — Bioethics in an Era of Diverse Idioms

by Douglas McNair

Traditionally, the bioethics movement has focused on issues concerning individual vulnerability, autonomy, and justice. Now, however, social suffering, which involves the vulnerability of groups of people, also merits the attention of bioethicists and healthcare workers to promote cross-cultural discourse and fairness in an increasingly interdependent world. The bioethics movement is essential to improving the sociology of disease and suffering and to developing an approach to population health that can enhance the care and respect of all people and broaden our sense of moral community.

This essay considers end-stage heart failure as a condition that illustrates the plight of vulnerable individuals and vulnerable social groups. My thesis is that unless we understand suffering, physicians cannot fulfill their duty to individual patients, and society cannot fulfill its duty to its constituent groups.

Two decades ago, Eric Cassell (1982) described the paradox that continues to confront us:

Medicine's traditional concern primarily for the body and for physical disease is well-known, as are the widespread effects of the mind-body dichotomy on medical theory and practice. I believe that this dichotomy itself is a source of the paradoxical situation in which doctors cause suffering in their care of the sick.

This paradox becomes progressively more dramatic as technological advances continue, in medicine and surgery and other clinical disciplines. Suffering, although distinct from pain is related to it and to the distress of physical symptoms (Donnelly 1996, Chapman and Gavrin 1993, Lynn and Harrold 1999). Suffering therefore includes pain but is a much broader reality. Cassell described suffering as an experience of "disintegration" — aspects of life and self or future fall away as the illness creates a different self, new relationships, and a new future or no future at all. This description is especially applicable in the case of chronic diseases, an aging population, and social fragmentation and exceptionalism (Casarett 1999, Casarett and Lantos 1998). To

understand this disintegration, we must know each patient and comprehend his or her vulnerability. Unless physicians understand suffering, they cannot fulfill their duty to individual patients; they may even cause harm by denying suffering that is not amenable to intervention with drugs, biotechnology, or medical devices — or by foreclosing on technology-based alternatives with which they are inadequately familiar or to which they are unable to obtain access for their patients. Further, unless society as a whole understands suffering, society cannot fulfill its duty to the various populations that comprise it. Our notion of suffering is affected, however, by changes in demographics and technology and an increasing awareness of the finitude of our resources. As a result, bioethics has a progressively wider, and more important role to play than it had in the past.

On the Brink between Therapies: End-Stage Heart Failure

There was John, the Mayor of the [IV] Pole People, who had been waiting longest in the Heart Failure/Transplant intensive care unit, four months, with increasing anger. . . . The wait is a roller-coaster ride: many go from melancholy to anger and back (C. Fox 1999).

Suffering, according to Cassell, includes a variety of sensations including anxiety, cognitive and perceptual changes, anger, and existential anguish. It disenfranchises and isolates those who are suffering from the social groups and communities in which they previously participated, and it creates "virtual communities" comprised of patients and caregivers who comprehend the specific context of the suffering. Increasingly, experiences of this sort emerge on the "brink" between one technology-intensive therapy and another. End-stage heart failure patients on the transplant waiting list and transplant-ineligible patients are in this situation when the effectiveness of high-dose medications to strengthen the heart (i.e., inotropes) begin to fail and the medicines' disintegrative cognitive and psychiatric side-effects begin to intrude on patients' experience of self and future. (See, e.g., Lehman 1998; Jones 1995; Gibbs, Addington-Hall, and Gibbs 1998; Rose and Stevenson 1998; Pritzker 1999; Cohn, Goldstein, and Greenberg 1998; Malik et al. 1999; and Petrucci et al. 1999.)

Alternative technological "destination" therapies (Holman et al. 1997, DeRosa et al. 1997), including implantable ventricular assist devices and permanent mechanical replacement heart devices, have the potential to eliminate this medication-related "nowhere to go" suffering, but many clinicians tend to temporize on the brink of such a decision, on the brink between medicine and surgery. Regardless of which choice they offer, many of these desperately sick patients will die. The ethical implications of temporizing at the "outer limits" of inotrope, thyroxine, and other medications' effectiveness have not been examined by the bioethics community.

From a traditional bioethics perspective, the principle of double effect states that if measures taken to relieve physical or mental suffering cause the death of a patient, they are morally and legally acceptable provided that the doctor's intention is to relieve distress, not to kill the patient. Double effect is an accepted principle without which the practice of medicine would be impossible, and the help it offers healthcare providers is representative of views

that have emerged from the bioethics movement.

Recent discussions of the principle of double effect have included focus on the care of terminally ill cardiac patients and the outpatient use of intravenous medications, like milrinone, which strengthen the heart's contraction. (See, e.g., Lehman 1998; Jones 1995; Gibbs, Addington-Hall, and Gibbs 1998; Rose and Stevenson 1998; Pritzker 1999; Cohn, Goldstein, and Greenberg 1998; Malik et al. 1999; Petrucci et al. 1999; and Fox 1999.) Regrettably, this discussion gives the false impression that using such medications is a high risk strategy. If correctly used, milrinone and similar medications are quite safe, and their use is justified: survival and quality of life benefits outweigh the risk of serious adverse effects such as sudden death. Indeed, clinical experience suggests that patients whose heart failure is relieved live longer than they would have had they continued to be debilitated and demoralized by unremitting heart failure. However, because of the neuropsychiatric side-effects of these powerful medicines, these patients frequently require sedation, morphine, and other medications to reduce anxiety and make them comfortable.

Most people accept that greater risk is acceptable in more extreme circumstances. It is axiomatic, however, that one should always use the effective measure that carries the least risk to life. Thus, although it may occasionally be necessary (and acceptable) to sedate a patient or to use powerful medicines to compel a recalcitrant failing heart to contract more forcefully — or, alternatively, to proceed with a ventricular assist device or heart replacement — it remains unacceptable (and unnecessary) to cause death deliberately.

It is sometimes stated that the principle of double effect is hypocritical — a mere smokescreen for orchestrating the patient's dying (Cook et al. 1999). In the context of managing severe heart failure, such views stem from failure to appreciate that double effect is a universal principle and the misguided belief that IV inotropes and concurrently administered medications may materially foreshorten the life of a dying heart failure patient or disrespect the values of the patient.

The example of end-stage heart failure is emblematic of vulnerable populations whose sufferings are, or may be, undervalued and underserved, because their specific illness and its context (e.g., their age, and social class) are inadequately understood and therefore accorded a low priority. Given the growing interplay between drug-based and medical device-based therapies in life-threatening diseases, we think it increasingly important to understand and mitigate the suffering associated with contextualized illness — contexts that include the cognitive changes, anxiety, and agitation that develop under modern medical management.

Responding to Change: We Need “Integrative” Clinical Approaches

On the one hand, the physician’s failure to acknowledge and recognize suffering can cause or perpetuate needless suffering. On the other hand, reflecting on suffering does not automatically provide answers to the difficult ethical issues and choices that pervade healthcare. Such reflection does focus, however, on interdependence, the essence of empathic care and on the personal dimension that is at the heart of individual human good.

Technology and the scientific method are necessary but insufficient parts of diagnosis and treatment. Medical science seeks certainty and control. By contrast, the essence of suffering is uncertainty and vulnerability; suffering is about finding personal meaning in the circumstances of loss, illness, limitation, dependency, and death. Despite significant advances in diagnosis and treatment, people still expect doctors to “care,” that is, to respond to their suffering. Regarding “brinks,” we believe McWhinney (1986) is correct:

Physicians’ personalities and their perceptions of themselves enter deeply into clinical method. Changing the tool, therefore, requires changing the person. If we are on the brink of a transformation of clinical method, we are also on the brink of a change in the way physicians think and feel.

(See also, Epstein, Quill, and McWhinney 1999).

This change is good if it entails rethinking the

meaning of medicine as an art and science. Unless we reject the notion that medicine is concerned only with what can be measured, we will never take the full measure of suffering and the vulnerabilities that dispose people toward suffering. In the future, the bioethics movement must recognize and elucidate the importance and ethics of integrative methods (Dalen 1999) in the care of individuals, such as end-stage heart failure patients, whose vulnerability stems in part from a marginalized social status.

Responding to Change: We Need an Approach to Social Suffering

Suffering, in short, is not a raw datum, a natural phenomenon we can identify and measure, but a social status that we extend or withhold depending largely on whether the sufferer falls within our moral community (Morris 1996).

Traditionally, the bioethics movement only intermittently addressed social and political and public health factors. However, the term social suffering describes both collective and individual human suffering associated with life conditions shaped by powerful social forces and is therefore within the province of bioethics. Unlike physical suffering or mental illness, social suffering is largely unmeasured, undocumented. New measures, such as disability adjusted life years (DALYs), designed to track the global distribution of morbidity in economic and individualistic terms, only barely represent the more general concept of suffering as a social experience and neglect most of what is at stake for people globally (Desjarlais et al. 1995). Today social suffering merits the attention of bioethicists and healthcare workers to facilitate cross-cultural discourse and peaceful development in an increasingly interdependent world (Morris 1996, Desjarlais et al. 1995, Kleinman 1999).

Social suffering has evolved from the state of ignorance, vulnerability to disease and famine, and terror associated with oppression in medieval times to the diverse forms of suffering associated with progress since the Enlightenment (Desjarlais et al. 1995). In recent times, demands for respecting human dignity have progressively reduced suffering under oppressive rulers and industrialism. Fruits of the bioethics movement,

including the Declaration of Helsinki, the Belmont Report, and the Patient Self-Determination Act, have helped to reduce human suffering in the late twentieth century. But unprecedented population growth, ethnic and gender conflict, and global economic trends make millions vulnerable to exploitation, poverty, disease, and genocide. Social suffering is more extensive now than in the past as a result of economic, cultural, and military influences (Desjarlais et al. 1995, Kleinman 1999), Link 1996, and Hobsbawn 1994).

A recent volume of writings expands our understanding of social suffering at the personal level and in the context of moral and political communities (Morris 1996). Anthropologists describe how the media use images portraying and often trivializing the suffering of distant peoples to propagate local political rhetoric. In some cases, the media arouse public emotions that shape perceptions of human problems and policy development for commercial or political purposes. In other cases, the media choose to ignore some types of suffering—a choice that may be erosive of community and the principles of ethical society. The bioethics movement may in the future help inform media ethics and reduce these risks.

Changes and New “Plateaus”: End-Stage Heart Failure

The comparatively predictable final course of cancer—with its one-to-two-month phase of progressive decline at the end of life—is well suited to the hospice model of care. But for individuals dying of diseases other than cancer [such as congestive heart failure], access to hospice has been limited, in part because they rarely manifest a discrete phase of inexorable decline at the end of life. . . . The sickest patients are not necessarily the ones who die first. If a high degree of predictive accuracy is demanded by those who interpret the 6-month prognostic requirement for hospice enrollment, few patients who die of these diseases will be eligible for hospice care [under current Medicare regulations](E. Fox et al. 1999).

The importance of congestive heart failure is

underscored by its prevalence and its prognosis. For example, more than 4.7 million people in the United States have congestive heart failure, and once failure develops, the six-year mortality rate approaches 80 percent in men and 65 percent in women (Kannel 1989). Heart failure is predominantly an illness of older people and, as our population ages, the incidence of heart failure and its mortality rate will continue to increase.

Many who are involved with end-of-life care recommend expanding access to hospice care for persons with severe heart failure. However, to be eligible for hospice under current administrative policies in the United States, these patients must generally have a prognosis for survival of less than six months. The six-month mortality for patients with severe heart failure is poor—upwards of 25 percent (www.AmericanHeart.org)—higher than some terminal-phase cancers. But while cancer patients often have relatively good quality of life until a period of deterioration several months before death, patients with end-stage heart failure tend to suffer on a “plateau” of continuous poor health for a varying number of months with episodes of exacerbation and partial recovery. Approximately half of these patients die suddenly, of cardiac arrest or severe abnormal heart rhythms, stroke or embolus, or other hard to predict events.

In a recent report that included 1,312 heart failure patients studied by the SUPPORT investigators, there were 302 deaths within six months following discharge from the hospital (E. Fox et al. 1999). Fully 40 percent of the heart failure patients in the study expressed a preference to receive palliative care, and 32 percent did use some form of home health services. However, access to palliative care was difficult under current rules, and fewer than 1 percent (8 out of 1,312) of end-stage heart failure patients obtained hospice care. In this instance, the policies and politics of care reimbursement and service capacity create vulnerability and differing degrees of social suffering. They establish virtual social classes based on diagnosis and restrict access to hospice services, providing resources on an exceptional basis to some patients whose illnesses have greater predictability (like cancer)

and withholding those resources from other patients whose conditions progress in less uniform or predictable ways. In other words, the rhetoric and power of cancer have to date prevailed over the rhetoric and power of heart failure and other diseases, and an inequitable distribution of social suffering is the result.

Conclusion

Our modern world is broadly and deeply distressing (Morris 1996 and Hobsbawn 1994). People in privileged countries tend to be inadequately aware of the suffering of millions and react only intermittently to media coverage. There are few sustained attempts to understand or mitigate the ethnic, racial, religious, health, or political causes of such misery. When indifference to individual and social suffering occurs in the United States and other developed nations, we must ask what it tells us about our humanity. Moreover, the bioethics movement must ask what can be done, now, when ecological degradation, population growth, cultural conflict, the emergence of new infectious diseases and the rebounding of older ones, and widening economic disparities threaten all people.

After the century just past which saw so much progress but also much devastating cruelty, we have now the opportunity to better understand and empathize with others (Kleinman 1999, Smart 1995, and Teeple 1995). New challenges for bioethicists, healthcare and pastoral workers, anthropologists and other scientists, and scholars in the humanities call for collaborative efforts across diverse societies to enhance our understanding of, and ability to diminish, social suffering.

What relevance do these considerations have to healthcare workers' and bioethicists' immediate areas of responsibility? The answer lies in recognizing that while the bioethics movement has in the past done much to advance the dignity and respect for persons who are in some way "in" the health system, improving the health of populations in ethically defensible ways will in the future require social, economic, political, and cultural change (Desjarlais et al. 1995, Kleinman 1999, Link 1996, and Murray and Lopez 1996). We are challenged

today to broaden our understanding of vulnerability, disease, and suffering. Healthcare systems need the influence of bioethics to become more effective in improving the sociology of disease and suffering and to develop an approach to population health that can enhance the care and respect of all people and extend the scope of what we recognize as our moral community. (Hartley 1993; Ricketts, Johnson-Webb, and Taylor 1998; Ricketts 1999; Levin and Schiller 1998; Mainous and Kohrs 1995; Moss 1999; Roberts 1999; Roberts, Bataglia and Epstein 1999; Sullivan and Brems 1997; Fullilove et al. 1998; Silver Babitz and Magill 1990; Schreiber and Zielinski 1997; and Casarett 1999)

References

- <<http://www.americanheart.org/chf/understanding/diagnosing.htm#class>>.
- Casarett, D. 1999. "Looking beyond Vulnerability: The Ethics and Science of Research involving Dying Patients." *Journal of Pain and Symptom Management* 18(2): 144-145.
- Casarett, D. J., and J. D. Lantos. 1998. "Have We Treated AIDS Too Well? Rationing and the Future of AIDS Exceptionalism." *Annals of Internal Medicine* 128(9): 756-759.
- Cassell, E. J. 1982. "The Nature of Suffering and the Goals of Medicine." *NEJM* 306(11): 639-645.
- Chapman, C. R., and J. Gavrin. 1993. "Suffering and Its Relationship to Pain." *Journal of Palliative Care* 9(2): 5-13.
- Cohn, J. N., S. O. Goldstein, and B. H. Greenberg. 1998. "Dose-dependent Increase in Mortality with Vesnarinone among Patients with Severe Heart Failure." *NEJM* 339:1810-1816.
- Cook, D. J., M. Giacomini, N. Johnson, and D. Willms. 1999. "Life Support in the Intensive Care Unit: A Qualitative Investigation of Technological Purposes. Canadian Critical Care Trials Group." *Canadian Medical Association Journal* 161(9):1109-1113.
- Dalen, J. E. 1999. "Is Integrative Medicine the Medicine of the Future? A Debate between Arnold S. Relman, MD, and Andrew Weil, MD." *Archives of Internal Medicine* 159(18): 2122-2126.
- DeRosa, J. J., M. Argenziano, B. C. Sun, K. Reemtsma, M. C. Oz, and E. A. Rose. 1997. "Implantable Left Ventricular Assist Devices: An Evolving Long-term Cardiac Replacement Therapy." *Annals of Surgery* 226(4): 461-468.
- Desjarlais, R., L. Eisenberg, B. Good, and A. Kleinman, editors. 1995. *World Mental Health: Problems and Priorities in Low Income Countries*. New York: Oxford University Press.

- Donnelly, W. J. 1996. "Taking Suffering Seriously: A New Role for the Medical Case History." *Academic Medicine* 71(7): 730-737.
- Epstein, R. M., T. E. Quill, and I. R. McWhinney. 1999. "Somatization Reconsidered: Incorporating the Patient's Experience of Illness." *Archives of Internal Medicine* 159(3): 215-222.
- Farmer, P. 1999. "Pathologies of Power: Rethinking Health and Human Rights." *American Journal of Public Health* 89(10): 1486-1496.
- Fox, C. 1999. "Heartless." *Life* November: 124-138.
- Fox, E., K. Landrum-McNiff, Z. Zhong, N. V. Dawson, A. W. Wu, and J. Lynn. 1999. "Evaluation of Prognostic Criteria for Determining Hospice Eligibility in Patients with Advanced Lung, Heart, or Liver Disease." *JAMA* 282(17):1638-1645.
- Fullilove, M. T., V. Heon, W. Jimenez, C. Parsons, L. L. Green, and R. E. Fullilove. 1998. "Injury and Anomie: Effects of Violence on an Inner-City Community." *American Journal of Public Health* 88(6): 924-927.
- Gibbs, L. M., J. Addington-Hall, and J. S. R. Gibbs. 1998. "Dying from Heart Failure." *British Medical Journal* 317(7164): 961-962.
- Hartley, D. 1993. "Commentary: Population-Based Health Care for Communities." *Journal of Health Politics, Policy, and Law* 18(2):755-761. <<http://www.muskie.usm.maine.edu/research/ruralheal/papers.html>>.
- Hobsbawn, E. 1994. *The Age of Extremes*. New York: Pantheon Books.
- Holman, W. L., R. C. Bourge, R. D. Spruell, C. P. Murrach, D. C. McGiffin, and J. K. Kirklin. 1997. "Ventricular Assist Devices as a Bridge to Cardiac Transplantation: A Prelude to Destination Therapy." *Annals of Surgery* 225(6): 695-704.
- Jones, S. 1995. "Palliative Care in Terminal Cardiac Failure." *British Medical Journal* 310(6982): 805.
- Kannel, W. B. 1989. "Epidemiological Aspects of Heart Failure." *Cardiology Clinic* 7:1-9.
- Kleinman, A. 1999. "Social Violence: Research Questions on Local Experiences and Global Responses." *Archives of General Psychiatry* 56(11): 978-979.
- Lehman, R. 1998. "Terminal Care of Heart Failure." *Lancet* 253(9137): 1394.
- Levin, B. W., and N. G. Schiller. 1998. "Social Class and Medical Decisionmaking: A Neglected Topic in Bioethics." *Cambridge Quarterly of Healthcare Ethics* 7(1): 41-56.
- Link, B. G. 1996. "Understanding Sociodemographic Differences in Health — the Role of Fundamental Social Causes." *American Journal of Public Health* 86(4): 471-472.
- Lynn, J., and J. Harrold. 1999. *Handbook for Mortals: Guidance for People Facing Serious Illness*. New York: Oxford University Press.
- Mainous, A. G., and F. P. Kohrs. 1995. "A Comparison of Health Status between Rural and Urban Adults." *Journal of Community Health* 20(5): 423-431.
- Malik, F. S., M. R. Mehra, P. A. Uber, M. H. Park, R. L. Scott, and C. H. Van Meter. 1999. "Intravenous Thyroid Hormone in Heart Failure with Cardiogenic Shock." *Journal of Cardiac Failure* 5(1): 31-7.
- McWhinney, I. R. 1986. "Are We on the Brink of a Major Transformation of Clinical Method?" *Canadian Medical Association Journal* 135(8): 873-878.
- Morris, David. 1996. "Social Suffering." *Daedalus* 125(1).
- Moss, A. H. 1999. "The Application of the Task Force Report in Rural and Frontier Settings." *Journal of Clinical Ethics* 10(1): 42-48.
- Murray, C. J. L., and A. D. Lopez, eds. 1996. *The Global Burden of Disease*. Cambridge: Harvard University Press.
- Petrucci, R. D. Kushon, R. Inkles, J. Fitzpatrick, C. Twomey, and L. Samuels. 1999. "Cardiac Ventricular Support: Considerations for Psychiatry." *Psychosomatics* 40(4): 298-303.
- Pritzker, M. R. 1999. "Chronic Heart Failure and Quality of Life." *NEJM* 340(19):1511
- Ricketts, T. C., ed. 1999. *Rural Health in the United States*. New York: Oxford University Press.
- Ricketts, T. C., K. D. Johnson-Webb, and P. Taylor. 1998. *Definitions of Rural: A Handbook for Health Policy Makers and Researchers*. University of North Carolina — Chapel Hill, Office of Rural Health Policy. <http://www.shepscenter.unc.edu/research_programs/Rural_Program/ruralit.pdf>.
- Roberts, L. W. 1999. "Health Care Dilemmas in Small Communities." *Hastings Center Report* 29(4): 28-37.
- Roberts, L. W., J. Battaglia, and R. S. Epstein. 1999. "Frontier Ethics: Mental Health Care Needs and Ethical Dilemmas in Rural Communities." *Psychiatric Services* 50(4): 497-503.
- Rose, E. A., and L. W. Stevenson, editors. 1998. *Management of End-Stage Heart Failure*. Philadelphia: Lippincott.
- Schreiber, S., and T. Zielinski. 1997. "The Meaning of Ambulatory Care Sensitive Admissions: Urban and Rural Perspectives." *Journal of Rural Health* 13(4): 276-284.
- Silver, M. P., M. E. Babitz, and M. K. Magill. 1997. "Ambulatory Care Sensitive Hospitalization Rates in the Aged Medicare Population in Utah, 1990 to 1994: A Rural-Urban Comparison." *Journal of Rural Health* 13(4): 285-294.
- Smart, N. 1995. *World Views: Cross Cultural Explorations of Human Beliefs*. 2nd ed. Englewood Cliffs, NJ: Prentice Hall.
- Sullivan, A., and C. Brems. 1997. "The Psychological Repercussions of the Sociocultural Oppression of Alaska Native Peoples." *Genet Soc Gen Psychol Monogr* 123(4): 411-440.
- Teepel, G. 1995. *Globalisation and the Decline of Social Reform*. Toronto: Garamond Press.