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PHYSICIAN-ASSISTED SUICIDE: AN ANTHROPOLOGICAL PERSPECTIVE

*Cheryl Mwaria**

The current debate concerning physician-assisted suicide, and what has been called its twin, active voluntary euthanasia, is directed toward the public policy question of whether these should be legalized. Proponents of legalization focus on the rather narrow issues of autonomy and relief from suffering of the individual. Opponents base their arguments on the sanctity of life, concerns about a "slippery-slope," and the appropriate role of physicians.¹ The debate itself is conducted primarily by "experts" in social policy formation. Together, these factors severely constrain the nature and structure of this debate, precluding a discussion of wider social norms and ideals and the manner in which legalization will affect social relations.

In considering physician-assisted suicide, the real challenge lies in understanding the nature of culture itself. By definition, culture is learned behavior pertaining to norms for what is considered proper, moral, or even sane; as well as values, customs, beliefs and artifacts that comprise the knowledge and technology by which we adapt, or fail to adapt, to the physical environment. Focusing as it does on the individual, our current approach to death seems to presume culture is irrelevant. Nothing, however, could be further from the truth. Missing from this debate is a discussion the social consequences of hidden expectations and obligations with respect to access to health care, allocation of resources, terminal and

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1. The literature concerning euthanasia and physician-assisted suicide is voluminous, but focuses primarily on legal and moral issues pertaining to the individual. See, e.g., MARGARET PABST BATTIN, *ETHICAL ISSUES IN SUICIDE* (1995) [hereinafter BATTIN, *ETHICAL ISSUES IN SUICIDE*]; MARGARET PABST BATTIN, *THE LEAST WORSE DEATH* (1994); EUTHANASIA: THE MORAL ISSUES (Robert M. Baird & Stuart E. Rosenbaum eds., 1989); RONALD DWORKIN, *LIFE'S DOMINION* (1994); CHOOSING DEATH: ACTIVE EUTHANASIA, RELIGION, AND THE PUBLIC DEBATE (Ron Hamel ed., 1991); HANS KUNG & WALTER JENS, *DYING WITH DIGNITY: A PLEA FOR PERSONAL RESPONSIBILITY* (John Bowden trans., 1995); EUTHANASIA: THE GOOD OF THE PATIENT, THE GOOD OF SOCIETY (Robert I. Misben ed., 1992); NEW YORK STATE TASK FORCE ON LIFE AND THE LAW, *WHEN DEATH IS SOUGHT: ASSISTED SUICIDE AND EUTHANASIA IN THE MEDICAL CONTEXT* (1994).

chronic illness, disability, difference, suffering, and the nature of death itself.

I. Hidden Dimensions of Culture

Every culture has hidden dimensions that operate at the level of the unconscious. When constructing models of culture, therefore, anthropologists consider varying levels of behavior: covert and overt; implicit and explicit.² Each of us is socialized from birth to particular sets of behavioral expectations (roles) governing specific statuses (positions in patterns of reciprocal relationships, for example, "husband" vs. "wife"). So ingrained are our expectations with respect to given statuses that we are jarred when they are violated, having come to view them as natural rather than learned behaviors. This is what makes it difficult for us to accept cultural differences on the part of others or even nonconforming behavior in our own society. It has been argued that conformity to cultural, and thereby shared, standards of behavioral expectations is the byproduct of the benefits of inclusion in cooperative activities, resulting in selective pressure for a sensitivity to others' opinions of one.³ Changes in one set of behavioral expectations may affect changes in many others in a rippling effect, though these often occur without our conscious awareness. This slow transmutation of experience comes about through "taken-for-granted cultural processes of representation in the popular culture that infiltrate the ordinary practices of living."⁴ For example, organ transplant technology has led to a redefinition of death in the United States. As Margaret Lock cogently asserts:

This relatively quiet remaking of death has been masked throughout by a focus on the heroics of medicine and the prolongation of life. Two impending deaths are, of course, involved — that of the donor and that of the recipient — but the public imagination has been fired in North America by the idea of the

2. This does not mean that the Jungian hypothesis of a pan-human collective unconscious is shared by all anthropologists; though more recent work on the nature of memory raises some tantalizing areas for investigation. See RUPERT SHELDRAKE, *THE PRESENCE OF THE PAST* (1988); EDWARD T. HALL, *BEYOND CULTURE* (1976).

3. See Daniel M.T. Fessler, *Towards An Understanding of the Universality of Second Order Emotions* (forthcoming 1998) (manuscript on file with author). Fessler argues as follows: "Individuals seeking inclusion must be especially sensitive to such a shared standard. The benefits of participation in cooperative activities thus created selective pressure for an affect-laden attention to norms. This, in turn, may have provided the foundation for the elaboration of culture."

4. Arthur Kleinman & Joan Kleinman, *Cultural Appropriations of Suffering in Our Times*, 125 *DAEDALUS* 1, 15 (Winter 1996).

“gift” of life. The life and death of the patient from whom organs are “harvested” is left unmarked except as “donor.” . . . The media usually focuses our attention on the life that will be “saved,” and particularly on the moments during and immediately after surgery when the proclamation of success is made; survival rates beyond the first few weeks fail to make more than serendipitous coverage, and very few people know about the prognosis for transplant patients, long-term outcomes, or about their “quality of life” after surgery.⁵

For these reasons I use the term “hidden” when referring to social expectations and obligations. What we must address when considering whether or not to legalize physician-assisted suicide is the ways in which our cultural expectations are likely to change.

Anthropologists have long known that attitudes toward suicide and assisted suicide vary cross-culturally. Likewise, research indicates that suicide rates themselves vary both cross-culturally and sub-culturally. While there is debate about the specific causes of suicide, it is clear that cultural expectations play a considerable role. Emile Durkheim first articulated this view in his seminal work, *Suicide*.⁶ One form of socio-genic suicide is *altruistic* suicide. In the Durkheimian view, altruistic suicide is the product of social forces beyond the individual’s control. The individual in such cases is highly integrated into the society and the individual’s life is rigorously governed by the customs of the society. As Pabst Battin notes, examples of this are plentiful and can be seen in the Japanese *seppuku* or suicide of honor by disemboweling; India’s *suttee* or self-immolation by widows; and the nineteenth century military practice wherein suicide was *de rigeur* for officers unable to pay gambling debts.⁷ The second order emotions of shame and pride as reactions to the opinions of an “other” may be at work here, pro-

5. Margaret Lock, *Displacing Suffering: The Reconstruction of Death in North America and Japan*, 125 *DAEDALUS* 207, 217-18 (Winter 1996). Lock provides an insightful and detailed look at the way organ transplant technology changed the definition of death in North America resulting in the routinization of organ transplants prior to public discussion of the remaking of death. Any discussion now is “colored by the pressures that a perceived escalating ‘shortage’ of organs adds to the debate.” *Id.* at 218. This is in stark contrast to Japan where organ transplants are rare and although the diagnosis of brain death is made it is used “not as a signal to turn off the respirator, but to prepare relatives for impending death.” *Id.* at 218. The public discourse in Japan has focused on a search for a national consensus about death which is perceived as a process rather than as an event. *See id.*

6. *See generally* EMILE DURKHEIM, *SUICIDE: A STUDY IN SOCIOLOGY* 361-93 (1951).

7. *See* BATTIN, *ETHICAL ISSUES IN SUICIDE*, *supra* note 1, at 10-11.

moting conformity to social norms.⁸ Japanese culture in particular has been noted for its emphasis on making other people's opinions the criterion of action. In *The Chrysanthemum and the Sword*, anthropologist Ruth Benedict used the term "shame culture" to describe this characteristic of Japanese culture.⁹ For Durkheim, such suicides involved no moral discredit because they were the product of relentless social forces, and thus were *involuntary*.¹⁰

This point deserves elaboration for it bears directly on the current debate. What seems on the surface to be a voluntary act, the rational decision to end one's life, may actually be the product of social expectations. Few people in societies discussed above hark back to "the good old days" when such social forces were at work. Let us consider another set of cross-cultural examples pertaining to altruistic suicide, in this case, of the aged and infirm. The examples I would like to consider here come from two distinct types of social organization: that of the western Shoshone, who were nomadic hunter-gatherers like the Eskimo, and that of sedentized peasant populations in Italy and Japan. Each of these societies had institutionalized practices where the aged/infirm were left to die.

In the case of the Shoshone and the Eskimo, individuals who could no longer keep up were abandoned by the group. The Japanese and Italian villagers, on the other hand, were taken to a high mountain where their children (usually an elder son) facilitated their deaths by pushing them off the mountain. When these practices first came to light in the literature they were viewed with abhorrence as being cruel and indicative of the low value their respective practitioners placed on the sanctity of human life. This proved not to be the case. Later, fieldwork conducted by ethnographers revealed a picture that was more complex, though no less disturbing. In most cases the abandonment or death was initiated by the old/infirm person, apparently to avoid becoming a burden to the group. This was the case even when, as Asen Balikci reports in his study of the Netsilik Eskimo, "the sick person's relatives try to dissuade him from committing suicide."¹¹ While a socio-genic explanation of suicide clearly does not cover all suicides, it is equally apparent that altruistic suicide seems to increase under conditions

8. See Fessler, *supra* note 3.

9. See RUTH BENEDICT, *THE CHRYSANTHEMUM AND THE SWORD: PATTERNS OF JAPANESE CULTURE* 223 (1946).

10. See BATTIN, *ETHICAL ISSUES IN SUICIDE*, *supra* note 1, at 11.

11. ASEN BALIKCI, *THE NETSILIK ESKIMO*, 166-67 (1970).

of scarcity, particularly when food is scarce. The examples presented here occurred under near-starvation conditions.

In the Durkheimian view, it was futile to attempt to stop individual suicides because success could only be piecemeal in the face of larger social forces.¹² Nevertheless, suicide rates for each of the aforementioned situations have dramatically decreased following changes in social institutions and organization, in other words, by altering cultural expectations. This generally occurs as a result of changing cultural contact and the introduction of a new set of expectations.

In our own society, as philosopher Margaret Pabst Battin opined in her book *Ethical Issues in Suicide*, "The Durkheimian model of suicide as socio-genic has had less evident public impact, perhaps because its demands — to change society — are much more difficult, and the theory itself has been confirmed only on a simplified model not apparently applicable to all societies."¹³ She goes on to point to a philosophical problem with Durkheim's theory by raising the question, "If suicide rates can be genuinely and significantly decreased only by large-scale changes in the institutions and organizations of society, what changes, so to speak, are worth the gain?"¹⁴ A far more significant question in the debate over physician-assisted suicide is, "If suicide rates have been genuinely linked to socio-cultural expectations, what is to be gained by altering these expectations in such a way as to favor increased rates of suicide?" In order to examine the ways in which our cultural expectations are likely to change with the legalization of physician-assisted suicide and active euthanasia it is imperative that we consider some of our current hidden social expectations, and the ways in which the more vulnerable segments of our society may be affected by new expectations.

II. Euthanasia from the Perspective of the Disabled

Proponents of physician-assisted suicide frame the legalization debate in terms of the individual facing the last stages of a terminal illness and voluntarily electing a "death with dignity," thereby avoiding or curtailing debilitating pain and suffering. Such a framework involves several covert assumptions. First, linking euthanasia policy with "death with dignity" suggests that one should

12. See BATTIN, *ETHICAL ISSUES IN SUICIDE*, *supra* note 1, at 12.

13. *Id.*

14. *Id.*

“go gentle into that good night.”¹⁵ In other words, that a policy of active voluntary euthanasia is exactly what its Greek origin implies, “a good death.” Under the guise of objectivity, however, lies a hidden premise that responses to debilitation and pain are uniform. This ignores voluminous evidence in both medicine and the social sciences to the contrary.

The appropriation of the term “death with dignity” encompasses another hidden assumption as well: that life with profound disability is lacking in dignity. There is a genuine and warranted fear on the part of many people with profound disabilities that their lives will be devalued, considered not worth living. Indeed, several states have laws permitting the abortion of fetuses deemed deformed, suggesting that a child born with a handicap is “terrible.”¹⁶ As the Bloomington Baby Doe controversy revealed:

Recognizing the difficulty of openly placing the parents interests ahead of the child’s, proponents of parental or parental-medical discretion over newborns with handicaps do not rely on the reproductive choice cases. Instead, they attempt to support parental discretion as euthanasia, mercy killing, or the “right to die.” They do not claim that parents have a protectable right so much as babies do. The decision the parents would make becomes a decision “for the child” and “in the best interests of the child” rather than for the distressed parents, for the siblings, or for a society that will have to bear many of the child’s expenses in life. It is the child’s “right to die” that is defended.¹⁷

This is of paramount concern to many disabled people whose grassroots civil rights movement over the past two decades has sought to deconstruct disabling environments, empower themselves and change the image of disability. By structuring the debate over physician-assisted suicide with individual case scenarios,

15. Dylan Thomas, *Do Not Go Gentle Into That Good Night*, in *THE POEMS OF DYLAN THOMAS* 207 (Daniel Jones ed. 1971).

16. See, e.g., 1992 Kan. Sess. Laws 183; 1991 Tenn. Pub. Acts 509; 1991 Iowa Acts 103, 267. See also Martha A. Field, *Killing ‘the Handicapped,’* 16 *HARV. WOMEN’S L.J.* 79 (1993). Field argues, “sometimes when abortions for handicap are called therapeutic, it seems to be the health of the fetus—the ‘defect’ in the fetus—that is being referred to, rather than the health of the mother. . . . how can an abortion possibly be therapeutic to the very fetus it eliminates?” *Id.* at 112. It should be obvious that such statutes discriminate against handicap, but our cultural expectations that the lives of people with profound disabilities are so devoid of ‘quality’ that they are not worth living has allowed such laws to go relatively unchallenged.

17. Field, *supra* note 16, at 84-85. See also Marian Blackwell-Stratton et al., *Smashing Icons: Disabled Women and the Disability and Women’s Movements*, in *WOMEN WITH DISABILITIES: ESSAYS IN PSYCHOLOGY, CULTURE, AND POLITICS* (Michelle Fine & Adrienne Asch eds., 1988).

often with the focus on the severely disabled individual electing death, "the message to society is that being severely disabled is being without hope or promise."¹⁸ What is hidden in this message is the nature and history of cultural prejudice towards the disabled in our culture. This was documented in the 1984 amicus brief for the U.S. Supreme Court case *Consolidated Rail Corp. v. Darrone*, which reads:

Disabled people throughout history have been regarded as incomplete human beings — "defectives." In early societies this view of disabled people resulted in persecution, neglect, and death. These practices gradually gave way to the more humanitarian belief that disabled people should be given care and protection. Persecution was largely replaced by pity, but the exclusion and segregation of disabled people remain unchallenged. Over the years, the false belief that disabled people were incompetent and dependent on charity, custodial care, and protection became firmly imbedded in the public consciousness. The invisibility of disabled Americans was simply taken for granted and the innate biological and physical "inferiority" of disabled people was considered self-evident.¹⁹

The key concern of disabled consumers regarding euthanasia is that "medical and legal professionals serve as the primary 'gatekeepers,' controlling access in euthanasia."²⁰ Thus far, clinicians, resource managers, lawyers, journalists and bioethicists have dominated the debate concerning euthanasia policy. Disabled consumers view these individuals as controlling information given to terminally ill patients about future quality of life and prospects for pain and suffering.²¹ As medical anthropologist Joseph Kaufert noted in an article on euthanasia policy from the perspectives of disabled consumers, "[i]n focusing upon the impact of public and professional values determining the 'social worth' of the lives of disabled people, disability organizations have also recognized the

18. See Joseph M. Kaufert, *Euthanasia Policy: Disabled Consumers' Perspectives in EUTHANASIA IN THE NETHERLANDS: A MODEL FOR CANADA?* 55, 58 (Barney Sneiderman & Joseph M. Kaufert eds., 1994) (quoting an article in the *Winnipeg Free Press* dated February 12, 1992, in which John Lane, President of the Canadian Paraplegic Association, was concerned about the ease with which the public accepted as worthless the life of Nancy B., a paraplegic who requested euthanasia).

19. Amicus Brief, *Consolidated Rail Corp. v. Darrone*, 104 S. Ct. 1248 (1984) (quoted in Kaufert, *supra* note 18). This brief was submitted in support of the argument that Section 504 of the Rehabilitation Act covers employment.

20. Kaufert, *supra* note 18, at 55.

21. See *id.*

hazards of such devaluations in the formation of public policy."²² Such concerns are legitimate when we recall that suicide often means the removal of social burdens, including psychological, emotional, and/or financial burdens imposed by the chronically or terminally ill. Margaret Pabst Battin put it succinctly by stating:

The social-burdens argument is particularly problematic in the circumstances associated with physician-assisted suicide — terminal illness, and perhaps even severe chronic illness, severe disability, and extreme old age — since the costs of medical treatment, hospitalization, palliation, rehabilitative treatment, domestic assistance and other terminal and chronic care can be enormous.²³

There has been a general silence in the debate with respect to this assumption, although it is held by both proponents and opponents of the legalization of physician-assisted suicide. Those who most often give voice to concerns that the debate will be based on the narrow perception of economic efficiency are opponents of the policy who fear that it will inevitably lead to a chilling conclusion. Though often dismissed by philosophers as a "slippery-slope" argument, the fears of vulnerable populations, particularly the disabled and the poor who comprise a significant and growing portion of our society, are well founded when we consider another hidden assumption within this debate, that is, that the legalization of physician-assisted suicide and euthanasia would actually be cost-effective. This is reminiscent of the rationale underlying not only the practices of the previously mentioned hunter-gatherer and village populations, which faced starvation, but also of the T4 euthanasia policy of Nazi Germany, which did not.

While those favoring legalization argue that safeguards against abuses on the scale of the Nazis could be put in place, there is a flawed logic here. Few safeguards can be placed on cultural expectations.²⁴ As anthropologists Arthur and Joan Kleinman have stated:

22. *Id.* at 65.

23. BATTIN, *ETHICAL ISSUES IN SUICIDE*, *supra* note 1, at 210.

24. Proponents of the legalization of physician-assisted suicide and voluntary active euthanasia often view the mention of the Nazi T4 program as another "slippery slope" argument which, as all such arguments, fails to identify a causal force. It is also rejected as a fair comparison to voluntary euthanasia in that it was clearly murder. These dismissals miss the point raised by disabled consumers who argue that the Nazi T4 program began touted as a 'merciful' policy for the physically and mentally disabled who were considered to be 'grievously suffering' and who requested euthanasia on 'therapeutic' grounds. See GITTA SERENY, *INTO THAT DARKNESS: FROM MERCY KILLING TO MASS MURDER* 49-50 (1974).

The American cultural rhetoric, for example, is changing from the language of caring to the language of efficiency and cost; it is not surprising to hear patients themselves use this rhetoric to describe their problems. Thereby, the illness experience, for some, may be transformed from a consequential moral experience into a merely technical inexpediency.²⁵

Legalization of physician-assisted euthanasia would accelerate this process. We cannot formulate health and social policy in the context of limited resources without resorting to prioritization. Assigning priorities requires valid economic indices of illness and its social consequences, but these alone are not enough. We need ethnographic input from the full spectrum of our society, particularly those most likely to be immediately affected by policy changes. At a 1989 Disability Ethics Conference it was argued that:

In the United States, health and social welfare policy have disenfranchised many disabled consumers from basic medical and social benefits. It has thus been questioned whether procedural safeguards could insure that euthanasia would truly be maintained as the measure of last resort. In short, if the resources are not there to ensure that the patient has been able to explore all options short of death, how can we say that euthanasia is in fact the measure of last resort?²⁶

Seeking to address these concerns, disabled consumers focus on the following ethical and communication issues:

1. Providing severely disabled and terminally ill people with options, including community-based, self-directed care.
2. Ensuring that consumers' decisions to discontinue life-prolonging treatment or request euthanasia are durable.
3. Ensuring that consumers' decisions are made autonomously and reflect meaningful informed consent.
4. Providing continuity of care and access to universal health care, palliation and social service benefits.
5. Providing access to peer counseling by other disabled and/or terminally ill persons.
6. Developing quality of life criteria which reflect consumer preferences and avoid application of external standards of social worth to the lives of the disabled or terminally ill.²⁷

25. Arthur Kleinman & Joan Kleinman, *The Appeal of Experience; The Dismay of Images: Cultural Appropriations of Suffering in Our Times*, J. AM. ACAD. ARTS & SCIENCES, Winter 1996, at 14-15.

26. Kaufert, *supra* note 18, at 65.

27. *Id.* at 57.

Social scientists acknowledge that while industrial societies have moved towards Herbert Spencer's ideal of individuation, bringing amenities of life within the reach of millions, many people, indeed arguably most, are prevented from enjoying such amenities by economic deprivation, prejudice, and the unequal and inadequate access to information inherent in the socio-economic system. Autonomy too, exacts its own price. The increased shouldering of personal responsibilities in isolation and often in competition with others generates insecurity in the context of rapidly changing social norms.²⁸ Particularly in our culture, where independence and self-reliance are valued while dependence is stigmatized as undignified and shameful, old age, disability, dependence, and deprivation pose serious challenges to the formation of social policy. The irony in the debate over the legalization of physician-assisted suicide and euthanasia is that in the name of autonomy legalization turns over control over the end of life to the state. The words of Yolán Koster-Dreese, vice president of The Netherlands Council of the Disabled, eloquently summarize the very real fears and constraints facing the disabled in the context of widely held public values defining "social worth." She argued:

Biomedical ethicists are creating only the illusion of freedom of choice, when discussing the clients' right to discontinue treatment (or choose active euthanasia). We need the emergence of an ethical debate which will properly engage the question of the extent to which such choices are constrained, if the resources necessary to sustain a high quality of independent life are not available.²⁹

I would add that the debate must include reflections on the ways that euthanasia policy is likely to initiate long-term changes in social relations in our society.

28. MERVYN SUSSER ET AL., *SOCIOLOGY IN MEDICINE* 553 (3d ed. 1985).

29. Kaufert, *supra* note 18, at 66 (quoting Yolán Koster-Dreese, Oral Presentation at the World Rehabilitation Fund Symposium (Denver, June 23, 1989)).