Response to "Difference and the Delivery of Healthcare" (Special Section) (CQ Vol 7, No 1)

Multicultural Perspectives in Bioethics: End-of-Life Decisionmaking

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In a special issue of this journal, a range of authors addressed the critical problem of difference in bioethics. To what extent do class, culture, ethnicity, and race affect the ethical decisions that patients and professionals must make in a medical context? Those arguing for an understanding of cultural influences in bioethical decisionmaking—for example, Hern, Koenig, Moore, and Marshall—typically argue from the perspective of individual case studies to demonstrate the importance of these social constructs.[1] Others, like Erika Blacksher, however, worry that this approach will obscure the uniqueness of individual decisionmakng patterns, allowing all persons of a single group to be aggregated as if their class, cultural construct, or religious affiliation were the single motive element in their medicolegal decisionmaking.[2] There is, she cautions, a risk of misuse if a professional care provider reflexively assumes individual patient or surrogate reactions on the basis of ethnicity or culture.

A broader, empirical approach may present an ethnic group's general value set without offering assumptions about individual decisionmaking. The intention of this approach is not to generate specific rules applicable to individual members of a single group or class, but to reveal a general backdrop of values against which individuals may make specific choices. In addition, the empirical perspective offers bioethicists an opportunity to consider broadly differing sets of values and principles. Indeed, its greatest utility may be the ability to illustrate the limits of currently accepted bioethical principles through the presentation of alternate but not necessarily inferior value sets.[3]

We demonstrate this through discussion of one section of an 85-question, end-of-life decisionmaking survey administered in 1997 to members of Honolulu, Hawaii's multiethnic community.[4] The general questions we sought to answer were, first, whether there were strong differences among members of different ethnic groups in their views on end-of-life issues, and if so, how they might be explained. Twenty-five seniors from the Caucasian, Filipino, Japanese, Chinese, and [native] Hawaiian communities,[5] each with at least one adult child also willing to participate in the study, were surveyed. This created a uniquely multigenerational as well as multicultural respondent base ($N = 250$) for a study of the degree to which ethnic or cultural values may affect patient or surrogate choices in an end-of-life context.

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Hawaii is uniquely suited to this type of work. Contemporary Hawaiian society permits and encourages the maintenance of cultural and ethnic traditions in dispersed communities whose continuance is largely unrelated to economic class. Almost 20% of the state's 1,108,229 residents are native Hawaiians. Approximately 26% are Caucasian. Another 23% are Japanese-American, 15% are Filipino-American, and 6% are Chinese-American, most of whom are descendants of laborers imported from Asia starting in the mid-1800s rather than recent immigrants.[6] Interviews were conducted in English by student interviewers of the same ethnic background as the participants.

Views on Euthanasia and "A Good Death"

A general assumption of the popular and technical literature is that euthanasia is, first and foremost, a terminally ill patient's response to untreatable pain: "The paradigm case of euthanasia is the giving of a lethal injection to a suffering, terminally ill person who requests and gives informed consent to this."[7] Thus we were not surprised by the results of answers to the question, presented here as Table 1.

With the exception of Filipino participants, most of whom listed Roman Catholicism as their religious preference, the majority of respondents—more than 70% of each group—believed persons in pain who had a terminal illness should be allowed recourse to help in dying. Chinese and Japanese respondent scores (90% and 84%, respectively) were especially high in this area. Only 52% of seniors and 53% of their adult children believed, however, it should be an option for those "in pain, but not terminally ill." Further, 60% of all senior respondents—and 52% of their adult children—said help to die should be offered to those "living with a physical disability." Why was this?

If the issue is untreatable pain, why are so many prepared to consider euthanasia for those with conditions leading to physical disability? Although Filipino responses may be explained through religious affiliation, why did Hawaiian participants generally reject the premise that persons with conditions causing physical (or mental) disabilities should perhaps be helped to die?

An explanation for these responses comes in a close reading of the responses to other questions. Table 2, for example, presents responses to the question, "What would influence your decision about medical treatment if you were fatally ill?" Although the potential of a painful death remains a concern, it is by no means uppermost in the minds of these participants. Fear of being physically dependent, and the related fear of becoming a burden on one's family, were the most frequent response by seniors and their adult children. Conditions leading to physical or mental disability, in this context, reflect fear of both personal dependence and familial burden in most groups. That these scores are generally higher among seniors than their adult children reflects, we believe, concern by those seniors that they may be the recipients of care most have, according to a prior survey question, provided to their own elders. Their children's lower level of response presumably reflects a greater willingness than their seniors might expect to take on the responsibilities for another's care.

Similarly, differences among ethnic constituencies may be explained in part through reference to religious affiliations, economic position, and cultural principles. As a principally Roman Catholic constituency, Filipinos are generally less willing to accept euthanasia than respondents with Buddhist or other

Table 1. Should a person be allowed to get help to die in these conditions?

Condition	Caucasian	Chinese	Filipino	Hawaiian	Japanese	Seniors	Adult Children
Terminal illness w/pain	76	90	35	78	84	80	71
Terminal illness, no pain	24	33	22	19	35	20	34
In pain, not terminally ill	63	59	22	63	51	52	53
Current physical disability	68	67	30	41	58	60	52
Condition leading to physical disability	42	62	26	11	44	45	36
Condition leading to mental disability	39	62	26	19	49	48	37
Depression	3	21	0	0	11	11	6

Table 2. What would influence your treatment decision if you were fatally ill?

	Caucasian	Chinese	Filipino	Hawaiian	Japanese	Seniors	Adult Children
Religious beliefs	48	38	82	60	41	58	50
Fear of burdening family	79	60	90	60	90	78	87
Concerns about money	44	64	80	46	65	52	67
Fear of a painful death	65	73	86	42	76	65	72
Fear of being dependent	81	75	92	56	90	76	82

religious allegiances. Even in cases of physical pain, the Roman Catholic prohibition would naturally diminish responses here. As the least advantaged group economically, Hawaiian respondents diminished concerns about money, burden, and dependence make sense. They have less, and tend to live a more communal and interdependent life. Thus "burden" from physical incapacity holds, for them, less concern. Culturally and practically, they expect to care for their family's more fragile members whether those persons' disabilities are physical, mental, or economic.

These suppositions can be tested in various ways. First, the survey included questions designed to test for consistency. To the extent one can show that group responses followed a consistent pattern across multiple questions, the presumed validity of any one response is strengthened. In this vein we note that when asked to define what they meant by a "dignified death," about 20% of all groups (but only one Hawaiian) included in their definitions "not [being] dependent on others," or "not burdensome to others."

Issues typically discussed in the broad bioethical literature—self-determination and a diminished "quality of life"—are not at issue here. Rather, what appears is a cultural perspective in which euthanasia becomes a personal option when one becomes highly dependent on family members, and perhaps a financial and social burden on their lives. Here the paradigmatic case is not end-stage cancer but a post-stroke patient or a person with Alzheimer disease, conditions resulting either through the exigencies of home care or the cost of nursing home residencies in increased familial responsibility (financial or in terms of daily care) and potential burden. Within this context it is not surprising that the most economically disadvantaged and culturally interdependent group, the Hawaiians, would be least concerned about this factor. Care of the fragile remains a part of their ethos, an assumed part of cultural daily life.

Conclusion

Clearly, there are consistent differences among members of Hawaii's distinct ethnic communities in their general perception of issues surrounding end-of-life decisionmaking. More importantly, however, survey results suggest that one cannot consider end-of-life issues as if they occurred outside cultural, ethnic, familial, social, or religious contexts critical to any single person's life.

We believe this approach represents a middle ground between the primarily principled approach of professional bioethics and the concrete, case study and case report perspective of medical ethnography and anthropology. For example, it places the euthanasia debate, typically framed as one based solely on an individual's view of his or her existential life and life quality, in a very different context. Religious and cultural restrictions may influence decision among groups like Filipino respondents. So too, however, may issues of class and economic advantage affecting issues like familial burden and dependence. The emphasis of different cultures in this regard reflects broader religious, social, and economic issues influencing individual members of those groups.

Notes

1. See, for example, Koenig B, Gates-William, J. Understanding cultural difference in caring for dying patients. *Western Journal of Medicine* 1995;16:3:244–9; Hern HE, Koenig BA, Moore LJ, Marshall PA. The difference that culture can make in end-of-life decisionmaking. *Cambridge Quarterly of Healthcare Ethics* 1998;7: 27–40.

2. Blacksher E. Desperately seeking difference. *Cambridge Quarterly of Healthcare Ethics* 1998; 7:11–16.
3. Thomasma D. Bioethics and human rights. *Journal of Law, Medicine & Ethics* 1997;25:4295–306.
4. Braun K. Surveying community attitudes on end-of-life options. *U. Hawaii Center on Aging: School of Public Health Publication No. 7*, 1998:1–36.
5. In this context "Hawaiian" is a census definition describing persons descended from original Polynesian settlers resident in the Islands prior to the 18th century.
6. Nordyke EC. *The Peopling of Hawaii*. Honolulu: University of Hawaii Press, 1977; *State of Hawaii Data Book* Honolulu: Department of Business, Economic Development, and Tourism, 1993.
7. Somerville M. Euthanasia by confusion. *UNSW Law Journal* 1997;20:1–20.