

End-of-Life Research: What We Know and What We Don't

James L. Werth, Jr., Ph.D.

Selected References

For an overview of these issues, see Working Group on Assisted Suicide and End of Life Decisions. (2000). *Report to the Board of Directors*. Washington, DC: American Psychological Association. (Available at: <http://www.apa.org/pi/aseolf.html>)

For a comprehensive book, see Chochinov, H. M., & Breitbart, W. (2000). *Handbook of psychiatry in palliative medicine*. New York: Oxford.

A. The Role of Psychosocial Issues

Block, S. D. (2001). Psychological considerations, growth, and transcendence at the end of life: The art of the possible. *Journal of the American Medical Association*, 285, 2898-2905.

Caplan, A. L., Snyder, L., & Faber-Langendoen, K. (2000). The role of guidelines in the practice of physician-assisted suicide. *Annals of Internal Medicine*, 132, 476-481.

Cherny, N. I., Coyle, N., & Foley, K. M. (1994a). Suffering in the advanced cancer patient: A definition and taxonomy. *Journal of Palliative Care*, 10, 57-70.

Cherny, N. I., Coyle, N., & Foley, K. M. (1994b). The treatment of suffering when patients request elective death. *Journal of Palliative Care*, 10, 71-79.

Emanuel, E. J., & Emanuel, L. L. (1998). The promise of a good death. *Lancet*, 351(suppl. 2), SII21-SII29.

Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Tulsky, J. A. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *Journal of the American Medical Association*, 284, 2476-2482.

Wilson, K. G., Viola, R. A., Scott, J. F., & Chater, S. (1998, April). Talking to the terminally ill about euthanasia and physician-assisted suicide. *Canadian Journal of Clinical Medicine*, 68-74.

B. Depression and Hopelessness

Barracough, J. (1997). ABC of palliative care: Depression, anxiety, and confusion. *British Medical Journal*, 315, 1365-1368.

Block, S. D. (2000). Assessing and managing depression in the terminally ill patient. *Annals of Internal Medicine*, 132, 209-218.

Breitbart, W., Rosenfeld, B. D., & Passik, S. D. (1996). Interest in physician-assisted suicide among ambulatory HIV-infected patients. *American Journal of Psychiatry*, 153, 238-242.

Breitbart, W., Rosenfeld, B., Pessin, H., Kaim, M., Funesti-Esch, J., Galietta, M., Nelson, C. J., & Brescia, R. (2000). Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *Journal of the American Medical Association*, 284, 2907-2911.

Chochinov, H. M., Wilson, K. G., Enns, M., & Lander, S. (1998). Depression, hopelessness, and suicidal ideation in the terminally ill. *Psychosomatics*, 39, 366-370.

Chochinov, H. M., Wilson, K. G., Enns, M., Mowchun, N., Lander, S., Levitt, M., & Clinch, J. J. (1995). Desire for death in the terminally ill. *American Journal of Psychiatry*, 152, 1185-1191.

Ganzini, L., Johnston, W. S., McFarland, B. H., Tolle, S. W., & Lee, M. A. (1998). Attitudes of patients with amyotrophic lateral sclerosis and their care givers toward assisted suicide. *New England Journal of Medicine*, 339, 967-973.

Ganzini, L., Lee, M. A., Heintz, R. T., Bloom, J. D., & Fenn, D. S. (1994). The effect of depression treatment on elderly patients' preferences for life-sustaining medical therapy. *American Journal of Psychiatry*, 151, 1631-1636.

Lee, M. A., & Ganzini, L. (1992). Depression in the elderly: Effect on patient attitudes toward life-sustaining therapy. *Journal of the American Geriatrics Society*, 40, 983-988.

Lee, M., & Ganzini, L. (1994). The effect of recovery from depression on preferences for life-sustaining therapy in older patients. *Journal of Gerontology*, 49, M15-M21.

C. Anxiety and Fear

Barraclough, J. (1997). See section B.

Block, S. D. (2000). See section B.

Covinsky, K. E., Landefeld, C. S., Teno, J., Connors, A. F., Jr., Dawson, N., Youngner, S., Desbiens, N., Lynn, J., Fulkerson, W., Reding, D., Oye, R., & Phillips, R. S. (1996). Is economic hardship on the families of the seriously ill associated with patient and surrogate care preferences? *Archives of Internal Medicine*, *156*, 1737-1741.

Emanuel, E. J., Fairclough, D. L., Slutsman, J., & Emanuel, L. L. (2000). Understanding economic and other burdens of terminal illness: The experience of patients and their caregivers. *Annals of Internal Medicine*, *132*, 451-459.

Ganzini, L., Nelson, H. D., Schmidt, T. A., Kraemer, D. F., Delorit, M. A., & Lee, M. A. (2000). Physicians' experiences with the Oregon Death with Dignity Act. *New England Journal of Medicine*, *342*, 557-63.

Lavery, J. V., Boyle, J., Dickens, B. M., Maclean, H., & Singer, P. A. (2001). Origins of the desire for euthanasia and assisted suicide in people with HIV-1 or AIDS: A qualitative study. *Lancet*, *358*, 362-367.

Strang, P. (1997). Existential consequences of unrelieved cancer pain. *Palliative Medicine*, *11*, 299-305.

Sullivan, A. D., Hedberg, K., & Fleming, D. W. (2000). Legalized physician-assisted suicide in Oregon -- The second year. *New England Journal of Medicine*, *342*, 598-604.

Sullivan, A. D., Hedberg, K., & Hopkins, D. (2001). Legalized physician-assisted suicide in Oregon, 1998-2000. *New England Journal of Medicine*, *344*, 605-607.

D. Delirium

Barraclough, J. (1997). See section B.

de Stoutz, N. D., Tapper, M., & Fainsinger, R. L. (1995). Reversible delirium in terminally ill patients. *Journal of Pain and Symptom Management*, *10*, 249-253.

Farrell, K. R., & Ganzini, L. (1995). Misdiagnosing delirium as depression in medically ill elderly patients. *Archives of Internal Medicine*, *155*, 2459-2464.

Inouye, S. K., Bogardus, S. T., Charpentier, P. A., Leo-Summers, L., Acampora, D., Holford, T. R., & Cooney, L. M., Jr. (1999). A multicomponent intervention to prevent delirium in hospitalized older patients. *New England Journal of Medicine*, *340*, 669-676.

National Institutes of Health. (1997). *Symptoms in terminal illness: A research workshop*. Rockville, MD: Author.

Tune, L. (2001). Assessing psychiatric illness in geriatric patients. *Clinical Cornerstone*, *3*(3), 23-36.

E. Autonomy/Control/Self-Determination

Back, A. L., Wallace, J. I., Starks, H. E., & Pearlman, R. A. (1996). Physician-assisted suicide and euthanasia in Washington state: Patient requests and physician responses. *Journal of the American Medical Association*, *275*, 919-925.

Chin, A. E., Hedberg, K., Higginson, G. K., & Fleming, D. W. (1999). Legalization physician-assisted suicide in Oregon: The first year's experience. *New England Journal of Medicine*, *340*, 577-583.

Coombs Lee, B. & Werth, J. L., Jr. (2000). Observations on the first year of Oregon's Death with Dignity Act. *Psychology, Public Policy, and Law*, *6*, 268-290.

Ganzini, L., Nelson, H. D., Schmidt, T. A., Kraemer, D. F., Delorit, M. A., & Lee, M. A. (2000). See section C.

Singer, P. A., Martin, D. K., & Kelner, M. (1999). Quality end-of-life care: Patients' perspectives. *Journal of the American Medical Association*, *281*, 163-168.

Sullivan, A. D., Hedberg, K., & Fleming, D. W. (2000). See section C.

Sullivan, A. D., Hedberg, K., & Hopkins, D. (2001). See section C.

F. Cultural Considerations

Blackhall, L. J., Murphy, S. T., Frank, G., Michel, V., & Azen, S. (1995). Ethnicity and attitudes toward patient autonomy. *Journal of the American Medical Association, 274*, 820-825.

Braun, K. L., Pietsch, J. H., & Blanchette, P. L. (2000). *Cultural issues in end-of-life decision-making*. Thousand Oaks, CA: Sage.

Braun, K. L., Tanji, V. M., & Heck, R. (2001). Support for physician-assisted suicide: Exploring the impact of ethnicity and attitudes toward planning for death. *Gerontologist, 41*, 51-60.

Canetto, S. S. (1995). Elderly women and suicidal behavior. In S. S. Canetto & D. Lester (Eds.), *Women and suicidal behavior* (pp. 215-233). New York: Springer.

Canetto, S. S., & Hollenshead, J. D. (1999). Gender and physician-assisted suicide: Analysis of the Kevorkian cases, 1990-1997. *Omega, 40*, 165-208.

Canetto, S. S., & Hollenshead, J. D. (2001). Older women and mercy killing. *Omega, 42*, 83-99.

Caralis, P. V., Davis, B., Wright, K., & Marcial, E. (1993). The influence of ethnicity and race on attitudes toward advance directives, life-prolonging treatments, and euthanasia. *Journal of Clinical Ethics, 4*, 155-165.

Carrese, J. A., & Rhodes, L. A. (1995). Western bioethics on the Navajo reservation. *Journal of the American Medical Association, 274*, 826-829.

Cicirelli, V. G. (1997). Relationship of psychosocial and background variables to older adults' end-of-life decisions. *Psychology and Aging, 12*, 72-83.

Gallagher-Thompson, D., & Osgood, N. J. (1997). Suicide in later life. *Behavior Therapy, 28*, 23-41.

Hallenbeck, J., Goldstein, M. K., & Mebane, E. W. (1996). Cultural considerations of death and dying in the United States. *Clinics in Geriatric Medicine, 12*, 393-406.

Hern, E. H., Jr., Koenig, B.A., Moore, L. J., & Marshall, P.A. (1998). The difference that culture can make in end-of-life decisionmaking. *Cambridge Quarterly of Healthcare Ethics, 7*, 27-40.

Irish, D. P., Lundquist, K. F. & Nelsen, V. J. (Eds.) (1993). *Ethnic variations in dying, death, and grief*. Washington, D. C.: Taylor & Francis.

Koenig, B. A. (1997). Cultural diversity in decisionmaking about care at the end of life. In M. J. Field, & C. K. Cassel (Eds.), *Approaching death: Improving care at the end-of-life* (pp. 363-382). Washington, DC: National Academy Press.

Lo, B., Quill, T., & Tulsky, J. (1999). Discussing palliative care with patients. *Annals of Internal Medicine, 130*, 744-749.

McKinley, E. D., Garrett, J. M., Evans, A. T., & Danis, M. (1996). Differences in end-of-life decision making among black and white ambulatory cancer patients. *Journal of General Internal Medicine, 11*, 651-656.

Morrison, R. S., Zayas, L. H., Mulvihill, M., Baskin, S. A., & Meier, D. E. (1998). Barriers to completion of health care proxies: An examination of ethnic differences. *Archives of Internal Medicine, 158*, 2493-2497.

O'Brien, L. A., Grisso, J. A., Maislin, G., LaPann, K., Krotki, K. P., Grecco, P. J., Siegert, E. A., & Evans, L. K. (1995). Nursing home residents' preferences for life-sustaining treatments. *Journal of the American Medical Association, 274*, 1775-1779.

Taylor A., & Box, M. (1999). *Multicultural palliative care guidelines*. Sydney, Australia: Palliative Care Australia. [Available at: <http://www.pallcare.asn.au/mc/mccontents.html>]

G. Research Considerations

Field, M. J., & Cassel, C. K. (Eds.) (1997). *Approaching death: Improving care at the end of life*. Washington, DC: National Academy Press.

National Institutes of Health. (1997). See section D.

Quill, T. E., Meier, D. E., Block, S. D., & Billings, J. A. (1998). The debate over physician-assisted suicide: Empirical data and convergent views. *Annals of Internal Medicine, 128*, 552-558.

Rosenfeld, B. (2000). Methodological issues in assisted suicide and euthanasia research. *Psychology, Public Policy, & Law, 6*, 559-574.