

**WURZWEILER SCHOOL OF SOCIAL WORK  
YESHIVA UNIVERSITY**

**PALLIATIVE CARE: SOCIAL WORK PRACTICE WITH ADVANCED,  
SERIOUS ILLNESS  
SWK 6825  
FALL 2015**

**COURSE DESCRIPTION:**

This course will provide a comprehensive study of issues related to palliative and end-of-life care. Palliative care is an exciting, relatively new specialty in health care social work, and presents dynamic practice opportunities for social workers with a knowledge base in this arena. This course will integrate an interdisciplinary approach to caring for individuals facing life-limiting and serious chronic illness and their families. Readings, class discussion, and student research will include medical, psychosocial, legal, and ethical perspectives. This course is an elective for students in the Certificate Program in Aging, but is open to all students. There are no prerequisites for this course, but it is highly recommended that students take Social Work in Health Care (SWK 6241) as background prior to enrolling in this course.

**CORE COMPETENCY OUTCOMES**

Upon successful completion of this course, students should be able to:

1. Advocate for client access to the services of a social worker (CSWE competency 2.1.1).
2. Recognize and manage personal values in a way that allows professional values to guide practice (CSWE competency 2.1.2).
3. Distinguish, appraise, and integrate multiple sources of knowledge, including research-based knowledge and practice wisdom (CSWE competency 2.1.3).
4. Analyze models of assessment, prevention and evaluation (CSWE competency 2.1.3).
5. Demonstrate effective oral and written communication in working with individuals, families, groups, organizations, communities, and colleagues (CSWE competency 2.1.3).
6. Recognize and communicate understanding of the importance of difference in shaping life experiences (CSWE competency 2.1.4).
7. Use research evidence to inform practice (CSWE competency 2.1.6).

8. Critique and apply knowledge to understand person and environment (CSWE competency 2.1.7).
9. Continuously discover, appraise, and attend to changing locales, populations, scientific and technological development, and emerging societal trends to provide relevant services (CSWE competency 2.1.9).
10. Use empathy and other interpersonal skills (CSWE competency 2.1.10a).

### **REQUIRED TEXTS:**

Kastenbaum, R.J. (2012). *Death, society, and human experience*. 11<sup>th</sup> ed. Upper Saddle River, NJ: Prentice Hall.

List: \$125.00 ISBN-10: 0205001084

Brody, J. (2009). *Jane Brody's guide to the great beyond: A practical primer to help you and your loved ones prepare medically, legally, and emotionally for the end-of-life*. New York: Random House.

List: \$22.81 ISBN-10: 1400066549

Lynn, J., Harrold, J., & Lynch Schuster, J. (2011). *Handbook for mortals: Guidance for people facing serious illness. Second edition*. New York: Oxford University Press.  
(Available as an e-book from YU Library)

List: \$18.72 ISBN-10: 0199744564

### **RECOMMENDED REFERENCES:**

Altilio, T. & Otis-Green, S. (Eds.)(2011). *Oxford textbook of palliative social work*. New York: Oxford University Press.

List: \$99.95 ISBN-10: 0199739110

Berlinger, N., Jennings, B., & Wolf, S.M. (2013). *The Hastings Center guidelines for decisions on life-sustaining treatment and care near the end of life*. New York: Oxford University Press.

List: \$39.95 ISBN-10: 0199974551

Berzoff, J. & Silverman, P.R. (Eds.)(2004). *Living with dying: A handbook for healthcare practitioners*. New York: Columbia University Press.

List: \$96.50 ISBN-10: 0231127944

Byock, I. (2012). *The best care possible: A physician's quest to transform care through the end of life*. New York: Avery/Penguin Group.

List: \$16.00 ISBN-10: 1583335129

Didon, J. (2007). *The year of magical thinking*. New York: Knopf. (Available on e-res)  
List: \$14.95 ISBN-10: 1400078431

Hitchens, C. (2012). *Mortality*. New York: Twelve.  
List: \$22.99 ISBN-10: 9781455502752

Levine, C., & Murray, T.H. (2007). *The cultures of caregiving: Conflict and common ground among families, health professionals, and policy makers*. Baltimore, MD: Johns Hopkins University Press.  
List: \$25.00 ISBN-10: 0801887712

McPhee, S.J., Winkler, M.A., Rabow, M.W., Pantilat, S.Z., & Markowitz, A.J. (eds.) (2011). *JAMA evidence: Care at the Close of life: Evidence and experience*. New York: McGraw Hill Medical.  
List: \$70.00 ISBN-10: 0071637958

## **METHODS OF INSTRUCTION:**

Lecture, discussion and interactive exercises will be used as the principle means of learning. Students are expected to attend class, do the assigned reading prior to class, participate in class discussion, and hand in their assigned materials on time. Students will integrate material from field practice into their class discussions and assignments. Guest faculty may be invited to provide a broad interdisciplinary perspective.

## **GRADING:**

Grades will be computed on the following basis:

Mid-term paper – 30%

Final paper – 50%

Meaningful class participation – 20%

Participation will be judged on the quality of a student's involvement in the classroom, characterized by attention to the learning process, contributions to the learning climate, questions asked, opinions stated and how defended, sensitivity to the feelings of others, an awareness of his/her unique input within the classroom setting, and classroom presentations. This is a cumulative assessment based on the entire period of the course. More than two absences may result in a lower grade for the class.

Students with disabilities should identify themselves to the instructor at the beginning of the semester so that any needed special considerations can be made to accommodate the student.

## **MID-TERM ASSIGNMENT: Due at Session 7**

Select one of topics below for in-depth discussion. At least five scholarly references, in addition to your texts, should be used; websites may be used, but they do not count towards the five scholarly references. The paper must be in APA format.

Page length: 8 pages

Some possible topics are:

- a. Obituary and death anniversary notices – what is their essential message? What need(s) do they meet on the part of the bereaved? On the part of society? What effect do they have on the reader? On society as a whole? Should the practice be encouraged or discouraged? Why?
- b. Widows – Discuss the realities of the plight of widows around the world. Begin your research by looking at the subjective experience of a widow you know well or to whom you have ready access. Think about the customs, statistics, and relevant laws effecting widows around the world and in the US.
- c. Bereavement – What are the common representations of bereavement we see in the media? What images of grief do we see in the movies? Magazine/newspaper articles? News reports on TV? What differences do you think the terrorist attacks on September 11 are having on the ways the nation views and understands the grief process?
- d. Disenfranchised grief – Discuss the multiple types of disenfranchised grief in this culture. What are they? Why are members of these particular groups not supported in their grief as others are? What can be done to eliminate the sense of ostracism felt by those who are disenfranchised as a result of the death of someone they love?
- e. Madison Ave. culture -- Consider the messages of Madison Avenue advertising and the youth worshiping culture in which we live alongside the level of violence in movies and TV, and the depictions of elderly in all of the above. What are the essential messages conveyed in all of these about the value of elderly persons and those who are ill?
- f. Near-death experiences – What is meant by the term “near-death experience?” What information is circulated on the internet about this phenomenon? What impact do you see it having on patients and their families?
- g. Hospice – What is hospice? What role does a hospice play in a terminally ill patient’ life? What is palliative care? How widespread is palliative care in US health care practices today? How many people die on hospice services today? Are hospice service equally distributed across all segments of society? Why or why not?

- h. Suicide and suicide prevention – Discuss suicide and suicide prevention resources. What resources are readily available to the general public concerning suicide and its prevention? How do you evaluate them? In your view, is there a “rational suicide” that we need not “prevent?”
- i. Other topics must be pre-approved by your professor.

(CSWE core competencies: 2.1.1, 2.1.2, 2.1.3, 2.1.4, 2.1.6, 2.1.7, 2.1.9, 2.1.10a)

### **FINAL ASSIGNMENT: Due at Session 12**

Select one of the below topics for in-depth analysis. At least five scholarly references, in addition to your texts, should be used; websites may be used, but they do not count towards the five scholarly references. The paper must be in APA format.

Page length: 8-10 pages

Topics:

a. Cultural Perspectives – Select a culture or community with which you are unfamiliar. Discuss the cultural meaning of illness and death, including the culture’s rituals surrounding death and the mourning process. You may be creative, but discuss your ideas with your professor.

b. Alzheimer’s Care – Explore the ethical issues faced by families/surrogates making end-of-life decisions on-behalf family members with Alzheimer’s Disease. Include a description of the biological process of this disease. Give special consideration to the ethics of withholding or withdrawing artificial nutrition and hydration (food and fluids).

c. Advance Care Planning – Research whether or not advance care planning has been an effective tool for documenting individual wishes regarding end-of-life care. Consider the tools that are used for advance care planning, including the POLST approach. What has worked and what has not. Explore challenges presented by cultural perspectives, or practices around family decision-making (as opposed to decisions made by individual patients).

d. Other topics must be pre-approved by your professor.

(CSWE core competencies: 2.1.1, 2.1.2, 2.1.3, 2.1.4, 2.1.6, 2.1.7, 2.1.9, 2.1.10a)

## COURSE OUTLINE

### Session 1 – Introduction to End-of-Life Care

- In-class viewing of the video, *Wit*.

### Session 2 – Talking about Death

- Attitudes and experiences about death
- Self inventory: Can we talk?
- Biological criteria of death
- Examples from literature and film (Didion & *Wit*)

#### Required readings:

Didion, J. (2005). *The year of magical thinking*. New York: Knopf, pp. 3-41.

Hitchens, C. (2012). *Mortality*. New York: Twelve. Chapter 1, pp. 1-9.

Kastenbaum, Ch. 1, pp. 3-30; Ch. 2, pp. 42-47

### Sessions 3 - 4 – Understanding Hospice and Palliative Care

- Principles of palliative care
- Distinguishing/integrating palliative care from hospice
- The interdisciplinary care team
- Social work roles and the interdisciplinary team
- Examples from literature and the humanities

#### Required readings:

Kastenbaum, Ch. 5, pp. 143-165.

Brody, Ch. 2, pp. 9-22; Ch. 7, pp.73-93; Ch. 9, pp. 114-128.

Gwande, A. (2010). Letting go. *The New Yorker*, 86(22), 36.

Jackson, K. (2013). Transitions to hospice care: Social workers foster meaningful conversations about dying. *Social Work Today*. 13(4), 22.

Center to Advance Palliative Care (2011). 2011 Public Opinion Research on Palliative Care: A Report Based on Research by Public Opinion Strategies. Download at: <http://www.capc.org/tools-for-palliative-care-programs/marketing/public-opinion-research/2011-public-opinion-research-on-palliative-care.pdf>

### **Session 5 – Pain and Symptom Care**

- Medical terminology
- Major symptoms and treatment
- Life-sustaining/life-prolonging interventions
- Behavioral symptoms, including anxiety and depression
- Issues of specific populations (children, substance users, HIV, oncology)

#### Required readings:

Lynn, J., Harrold, J., & Lynch Schuster, J. (2011). *Handbook for mortals: Guidance for people facing serious illness. Second edition.* New York: Oxford University Press, Chapters 7, 8, and 9; pp. 87-149.

Van Pelt, J. (2012). Pain care advocacy in an era of opioid abuse. *Social Work Today*, 12(5), 16.

### **Session 6 – Effective & Ethical Communication**

- Truth-telling
- Informed consent
- Delegating decision-making to family members
- Relaying bad news
- Social work and physician codes of ethics

#### Required readings:

National Association of Social Workers (2008), *Code of Ethics*. Washington, DC: NASW.

American Medical Association (2008), Fundamental elements of the patient-physician relationship. *Code of medical ethics: Current opinions with annotations, 2008-2009.* Opinion 10.01. Chicago, IL: American Medical Association Press.

Kastenbaum, Ch. 4, Box 4-2, p. 115; pp. 121-126.

Brody, Chapters 12 & 13, pp. 159-190.

Girgis, A., & Sanson-Fisher (1995). Breaking bad news: Consensus guidelines for medical practitioners. *Journal of Clinical Oncology*, 13(9), 2449-2456.

Kapp, M.B. (1991). Health care decision-making by the elderly: Get by with a little help from my family. *The Gerontologist*, 31(5), 619-622.

### **Session 7 – Cultural Perspectives**

- Role of culture in end-of-life care
- Unique cultural concerns
- Diversity within cultural traditions
- Religion and spirituality
- Bias and discrimination
- Health disparities

#### Required Readings:

Koenig, B., & Gates-Williams, J. (1995). Understanding cultural difference in caring for dying patients. *Western Journal of Medicine*, 163(3), 244-249.

Bullock, K. (2006). Promoting advance directives among African Americans: A faith-based model. *Journal of Palliative Medicine*, 9(1), 183-195.

Gonzales-Ramos, G. (2007). On loving care and the persistence of memories: Reflections of a grieving daughter. Chapter 2. From C. Levine & T.H. Murray (eds.). *The cultures of caregiving: Conflict and common ground among families, health professionals, and policymakers*. Baltimore: Johns Hopkins University Press.

Stein, G.L. & Bonuck, K. A. (2001). Attitudes on end-of-life care and advance care planning in the lesbian and gay community. *Journal of Palliative Medicine*, 4(2), 173-190.

Carlis, P., 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*, 157, 316-322.

### **Session 8-9 – Health Care Decision-Making & Advance Care Planning**

- Primary role of communication
- Social work role in advance care planning, facilitating communication, and conflict resolution
- Surrogate decision-making
- Understanding documents
- Doing your own plans



- Do-not-resuscitate orders
- Organ donation

Required readings:

Stein, G.L. (2004). Improving our care at life's end: Making a difference. *Health and Social Work*, 29(1), 77-79.

Wolff, M. (2012, May 28). A life worth ending. *The New Yorker*, p. 26. Download at: <http://nymag.com/news/features/parent-health-care-2012-5/>

Lynn, J., Harrold, J., & Lynch Schuster, J. (2011). *Handbook for mortals: Guidance for people facing serious illness. Second edition*. New York: Oxford University Press, Ch. 11, pp. 167-178.

Schaeffer, J. (2013). Supporting end-of-life decisions: The social worker's role in advance directives. *Social Work Today* (Special White Paper Report)

Fins, J.J. & Maltby, B.S. (2003). *Fidelity, Wisdom & Love: Patients and Proxies in Partnership*. New York: Weill Medical College of Cornell University.

Brody, Ch. 3, pp. 23-45.

Complete state-specific advance directives

New York State Advance Directive, download from:  
[http://www.caringinfo.org/files/public/ad/New\\_York.pdf](http://www.caringinfo.org/files/public/ad/New_York.pdf)

New Jersey Advance Directive, download from:  
<http://www.caringinfo.org/files/public/ad/NewJersey.pdf>

Other state advance directives, download from:  
<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289>

In re Quinlan, 70 N.J. 10 (NJ 1976)

Bouvia v. Superior Court, 225 Cal. Rptr. 297 (Cal. Ct. App. 1986)

Powell, T., & Lowenstein, B. (1996). Refusing life-sustaining treatment after catastrophic injury: ethical implications. *Journal of Law, Medicine & Ethics*, 24(1), 54-61.

## **Session 10 – Assisted Suicide and the Right to Die**

- Understanding distinctions between assisted suicide and euthanasia
- Understanding distinctions between assisted suicide and foregoing life supports
- Terri Schaivo and disorders of consciousness
- Legal background
- What social workers may do with requests for help in dying

### Required Readings:

Kastenbaum, Ch. 9, pp. 267-296.

Washington v. Glucksberg, 521 U.S. 702 (1997).

Hartocollis, A. (2009, December 27). Hard choice for a comfortable death: Drug-induced sleep. *The New York Times*. Downloaded at:  
[http://www.nytimes.com/2009/12/27/health/27sedation.html?pagewanted=1&\\_r=1&sq=comfortable death&st=cse&scp=1](http://www.nytimes.com/2009/12/27/health/27sedation.html?pagewanted=1&_r=1&sq=comfortable%20death&st=cse&scp=1)

Brody, Ch. 14, pp. 191-209; Ch. 6, pp. 67-72.

Lynn, J., Harrold, J., & Lynch Schuster, J. (2011). *Handbook for mortals: Guidance for people facing serious illness. Second edition*. New York: Oxford University Press, Ch. 12, pp. 179-189.

Eisenberg, D. (2005, April 4). Lessons of the Schiavo battle, *Time*, 22-30.

Gorman, C. (2005, April 4). When does the brain go blank? *Time*, 26-27.

## **Session 11 – The Critical Role of Family Caregivers**

- Appreciating the roles and responsibilities of family caregivers
- Who are family caregivers, and what do they do?
- Cultures and values implicated in home care

### Required readings:

Lynn, J., Harrold, J., & Lynch Schuster, J. (2011). *Handbook for mortals: Guidance for people facing serious illness. Second edition*. New York: Oxford University Press, Ch. 5, pp. 54-68.

Reinhard, S.C., Levine, C., & Samis, S. (2012). *Home Alone: Family Caregivers Providing Complex Chronic Care*. Retrieve from:  
<http://www.aarp.org/home-family/caregiving/info-10-2012/home-alone-family-caregivers-providing-complex-chronic-care.html>

Surpin, R., & Hanley, E. (2007). The culture of home care: Whose values prevail? Chapter 6. From C. Levine & T.H. Murray (eds.). *The cultures of caregiving: Conflict and common ground among families, health professionals, and policymakers*. Baltimore: Johns Hopkins University Press.

## **Session 12 – Pediatric Palliative Care**

- Special needs of children
- Decision-making by minors
- Family approaches
- Innovative service models
- Social work roles

### Required readings:

Kastenbaum, Ch. 10, pp. 301-334.

Brody, Ch. 11, pp. 142-158.

Jones, B.L. (2005). Pediatric palliative and end-of-life care: The role of social work in pediatric oncology. *Journal of Social Work in End of Life and Palliative Care*, 1(4), 35-62.

Weir, R.F., & Peters, C. (1997). Affirming the decisions adolescents make about life and death, *Hastings Center Report*, 27(6), 29-40.

## **Session 13 – Grief and Bereavement**

- Understanding loss and grief
- Stages of grief
- Coping skills
- Spiritual care

### Required reading:

Kastenbaum, Ch. 11, pp. 339-371.

Brody, Ch. 15, pp. 210-234; Ch. 10, pp. 130-141.

Didon, J. (2005). *The year of magical thinking*. New York: Knopf, pp. 3-41.

## **Session 14 – Self-Care for Caring Professionals**

- Protecting ourselves against burnout
- Supporting bereaved staff
- Family and professional caregivers

### Required readings:

Kastenbaum, Ch. 14, pp. 459-475.

Brody, Ch. 8, pp. 94-113

## BIBLIOGRAPHY

### A. Print Media

- Barg, G. (2001). *The fearless caregiver*. Sterling, VA: Capital.
- Barham, D. (2003). The last 48 hours of life: A case study of symptom control for a patient taking a Buddhist approach to dying. *International Journal of Palliative Nursing*, 9(6), 245-251.
- Biebel, D.B. (1981). *Jonathan: You left too soon*. NY: New American Library.
- Billings, J.A. (1998). Palliative care: Definitions and controversy. *Principles and Practice of Supportive Oncology Updates*, 1(1), 1-10.
- Bramblett, J. (1991). *When good-bye is forever: Learning to live again after the loss of a child*. NY: Ballantine.
- Byock, I. (1997). *Dying well: Peace and possibilities at the end of life*. NY: Riverhead Books.
- Byock, I. (2004). *The four things that matter most: A book about living*. NY: Free Press.
- Christ, J. (2000). *Healing children's grief*. NY: Oxford.
- Coberly, M. (2003). *Sacred passage: How to provide fearless, compassionate care for the dying*. Boston: Shambhala.
- Collett, M. (1997). *Caring for the dying at home*. Kansas City, MO: Andrews McMeel.
- Csikai, E.L. (2004). Social workers' participation in the resolution of ethical dilemmas in hospice care. *Health and Social Work*, 29(1), 67-76.
- Davies, B., Reimer, J.C., Brown, P., & Martens, N. (1995). *Fading away: The experience of transition in families with terminal illness*. Amityville, NY: Baywood.
- Diver, F., Molassiotis, A., & Weeks, L. (2003). The palliative care needs of ethnic minority patients attending a day-care centre: A qualitative study. *International Journal of Palliative Nursing*, 9(9), 389-396.
- Doka, K.J. (2002). *Disenfranchised grief: New directions, challenged, and strategies for practice*. Ottawa, CA: Research Press.
- Doka, K.J. (1993). *Living with life threatening illnesses: A guide for patients, their families and caregivers*. San Francisco: Jossey-Bass.
- Doka, K.J., & Davidson, J. (Eds.). (1997). *Living with grief: When illness is prolonged*. NY: Taylor & Francis.
- Drattell, A. (1996). *The other victim*. Santa Ana: Seven Locks.
- Ferrario, S.R., Cardillo, V., Vicario, F., Balzarini, E., & Zotti, A.M. (2004). Advanced cancer at home; Caregiving and bereavement. *Palliative Medicine*, 19, 129-136.
- Fins, J.J., & Maltby, B.S. (2003). *Fidelity, wisdom & love: Patients and proxies in partnership*. NY: Partnership for Caring.
- Fitzgerald, H. (1995). *The mourning handbook*. Fireside.
- Frank, A.W. (1991). *At the will of the body: Reflections on illness*. NY: Mariner Books.

- Freyer, D.R., (2004). Care of the dying adolescent: Special considerations. *Pediatrics*, 113(2), 381-388.
- Gatrad, R., Choudhury, P.P., Brown, E., & Sheikh, A. (2003). Palliative care for Hindus. *International Journal of Palliative Nursing*, 9(19), 442-448.
- Gatrad, R., Panesar, S.S., Brown, E., Notta, H., & Sheikh, A. (2003). Palliative care for Sikhs. *International Journal of Palliative Nursing*, 9(11), 496-498.
- Heffner, J.E., & Byock, I. (2002). *Palliative and end-of-life pearls*. Hanley & Belfus.
- In Re Quinlan. (1976). 70 N.J. 10.
- Kemp, C. (2001). Culture and the end of life: Hispanic cultures. *Journal of Hospice and Palliative Nursing*, 3(1), 29-33.
- Kobylarz, F.A., Heath, J.M., & Like, R. (2002). The ETHNIC(S) mnemonic: A clinical tool for ethnogeriatric education. *JAGS*, 50, 1582-1589.
- Kramer, K., & Kramer, H. (1993). *Conversations at midnight: Coming to terms with dying and death*. NY: Avon.
- Kubler-Ross, E. (1983). *On children and death*. NY: MacMillan.
- Kubler-Ross, E. (1969). *On death and dying*. NY: Macmillan.
- Kuhl, D. (2002). *What dying people want: Practical wisdom for the end of life*. NY: Public Affairs.
- Lattanzi-Licht, M., & Doka, K.J. (Eds.). (2003). *Living with grief: Coping with public tragedy*. NY: Brunner-Routledge.
- Lewis, C.S. (2001). *A grief observed*. San Francisco: Harper.
- Lifton, R.J., & Olson, E. (1974). *Living and dying*. NY: Praeger.
- Luptak, M. (2004). Social work and end-of-life care for older people: A historical perspective. *Health and Social Work*, 29(1), 7-15.
- Lynn, J., & Harrold J. (2001). *Handbook for Mortals: Guidance for People Facing Serious Illness*. NY: Oxford University Press.
- Matter of Conroy, 98 N.J. 321 (1985).
- McCue, K. (1994). *How to help children through a parent's serious illness*. NY: St. Martin.
- McIntyre, R. (2002). Nursing support for families of dying patients. Phila: Whurr.
- Meisel, A., Snyder, L. & Quill, T. (2000). Seven legal barriers to end-of-life care. *JAMA*, 284(19), 2495-2501.
- Mitchell, K., & Anderson, H. (1983). *All our losses, all our griefs*. Philadelphia: Westminster.
- Myser, C. (2003). Differences from somewhere: The normativity of whiteness in bioethics in the United States. *American Journal of Bioethics*, 3(2), 1-11.
- Neufeld, E.K. (1990). *Dancing in the dark*. Waterloo, Ontario: Herald.
- Partnership for Caring. (1996). *Advance Directives: Planning for important healthcare decisions*. Washington, DC: Author.
- Pattison, N. (2004). Integration of critical care and palliative care at end of life. *British Journal of Nursing*, 13(3), 132-139.
- Quill, T.E. (2000). Initiating end-of-life discussions with seriously ill patients. *JAMA*, 284(19), 2502-2507.
- Rando, T.A. (2000). *Clinical dimensions of anticipatory mourning: Theory and practice in working with the dying, their loved ones, and their caregivers*. Champaign, IL: Research Press.

- Rando, T.A. (1984). *Grief, dying, and death: Clinical interventions for care givers*. Champaign, IL: Research Press.
- Roth, D., & Levier, E. (1990). *Being human in the face of death*. Santa Monica: IBS.
- Roth, P. (1993). *Patrimony*. NY: Random House.
- Sittser, G. (1998). *A grace disguised*. Grand Rapids, MI: Zondervan.
- Stein, G.L. (2008). Providing palliative care to people with intellectual disabilities: Services, staff knowledge, and challenges. *Journal of Palliative Medicine, 11*(9), 1241-1248.
- Stein, G.L. (2008). Advance directives and advance care planning for people with intellectual and physical disabilities. U.S. Department of Health and Human Services/Assistant Secretary for Planning and Evaluation electronic publication. Retrieved January 28, 2010, from <http://aspe.hhs.gov/daltcp/reports/2007/adacp.pdf>.
- Stein, G.L., & Sherman, P.A. (2005). Promoting effective social work policy in end-of-life and palliative care. *Journal of Palliative Medicine, 8*(6), 1271-1281.
- Stein, G.L. (2004). Improving our care at life's end: Making a difference. *Health and Social Work, 29*(1), 77-79.
- Stein, G.L. (2002, Fall). Welcoming elder lesbian and gay patients in palliative care settings. *American Academy of Hospice and Palliative Medicine Bulletin, 3*(1), 6-7.
- Stein, G.L., & Bonuck, K.A. (2001). Attitudes on end-of-life care and advance care planning in the lesbian and gay community. *Journal of Palliative Medicine, 4*(2), 173-190.
- Stein, G.L., & Bonuck, K.A. (2001). Physician-patient relationships among the lesbian and gay community. *Journal of the Gay and Lesbian Medical Association, 5*(3), 87-93.
- SUPPORT Principle Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients, *JAMA, 274*(20), 1591-1598.
- Taylor-Brown, S., & Sormanti, M. (2004). End-of-life care. *Health and Social Work, 29*(1), 3-5.
- Thomas, N.D. (2001). The importance of culture throughout all of life and beyond. *Holistic Nursing Practice, 15*(2), 40-46.
- Tolstoy, L. (1960). *The death of Ivan Ilych*. NY: New American Library.
- Vacco v. Quill. (1997). 521 U.S. 793.
- Walsh, F., & McGoldrick, M. (1991). *Living beyond loss: Death in the family*. NY: W.W. Norton.
- Washington v. Glucksberg (1997). 521 U.S. 702.
- Werth, J.L., Gordon, J.R., & Johnson, R.R. (2002). Psychosocial issues near the end of life. *Aging and Mental Health, 6*(4), 402-412.
- White-Snowden, S. (1985). *Everything to live for*. NY: Simon & Schuster.
- Worden, J.W. (2001). *Grief counseling and grief therapy: A handbook for the mental health professional*. 3<sup>rd</sup> ed. NY: Springer.
- Zimmerman, C., & Rodin, G. (2004). The denial of death thesis: Sociological critique and implications for palliative care. *Palliative Medicine, 18*, 121-128.

## B. Non Print Media

*On our own terms: Bill Moyers on dying.* Parts 1-4. PBS Special

## C. Websites

<http://www.swhpn.org>, for Social Work Hospice and Palliative Care Network

<http://www.nhpco.org>, for National Hospice and Palliative Care Organization

<http://www.aahpm.org>, for American Academy of Hospice and Palliative Medicine

<http://www.caringinfo.org>, for comprehensive consumer education about advance

care planning, including state-specific advance directives

<http://hospice-cares.com/hands/signs.html> for general articles about dying

<http://www.hospicenet.org> for general articles about dying and hospice care

<http://www.npr.org/programs/death/trns.html>

<http://www.depression.about.com>, click on “Grief and Loss” section

<http://www.fortnet.org/WidowNet/index.html>, especially the section marked

“Comments and Ideas from Other Widows”; see “Dumb Remarks and Stupid

Questions” in this section. Also check the section “Demographics” to read “Gay

Widowers: Grieving in Relation to Trauma and Social Supports.”

<http://www.compassionatefriends.org>, click on Grief in the News and read “Talking

with Friends Who Have Lost a Child.”

<http://www.pomc.com/>, Parents of Murdered Children website with general articles

<http://www.griefnet.org/KIDSAID/welcome.html> for articles about children and

dying

<http://www.soros.org/death>

<http://www.law.about.com/msub26.htm> for articles about assisted suicide

<http://www.suicidology.org> for articles about suicide

<http://www.kidshealth.org> for articles about adolescents and suicide