

University of Washington
School of Social Work
Social Work 514
Caring for Persons with Life Limiting Illness: A Lifespan Approach

CourseTime: Fridays, 9:30 – 12:20 p.m.

Course Location: SSW, 26-30

Instructor: Taryn Lindhorst, PhD, LCSW

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Office Hours: Fridays, 1:30 – 2:30, or by appointment

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Course Description

“Caring for Persons with Life-Limiting Illness: A Lifespan Approach” is a foundation practice course with a focus on multi-systemic social work practice with seriously ill people who have a life-limiting condition. In childhood, conditions that could end in death include diseases such as cancer, cystic fibrosis, and AIDS, as well as congenital birth anomalies and neurodegenerative disorders. For adults, common end of life conditions are endstage organ diseases, various cancers and endstage AIDS. Traumatic injuries can also create situations where the anticipation of death requires symptom control and care planning.

A strengths-based, multigenerational and multicultural framework undergirds the SW 514 practice courses. In this course we will examine how families care for a member who is critically ill, and the differences that occur across the lifespan when the seriously ill person is a child or adolescent, a mid-aged adult, or an elder at the end of life. In each family, the culture of the family in terms of its ethnic and spiritual heritage, values, and beliefs drive decision making about end of life care. Families have differential levels of access to institutional and community resources based on economics, legacies of racism and homophobia, and gendered caregiving demands. These differing experiences have profound implications for end of life care.

Families state that they want helpful communication and coordinated care throughout the course of an illness, no matter its length, in an institution that feels safe. To accomplish this goal, the focus of this course is on developing skills in empowerment-oriented social work practice within the context of the current service delivery system. To work effectively, social workers need skills in identifying multigenerational family strengths based in an appreciation of the client’s culture, as well as the capacity to work effectively within interdisciplinary teams of care

providers. This framework is consistent with the social change and social justice mission of the MSW curriculum.

Topics in this course will develop skills in three areas: theoretical knowledge; development of self-awareness in issues related to death, dying and grief; and application of this knowledge to social work practice with families. Foundational theories related to grief, loss and attachment are used to interpret case examples from a variety of settings. Students will become familiar with tools for psycho-social-spiritual assessment and decision-making. Hospice and palliative care models appropriate for social work practice at the end of life will be presented and critiqued.

Course Objectives

At the end of this course, students will have acquired the following skills in self-awareness, theory and practice:

Self-Awareness Skills

1. Demonstrate awareness of one's own assumptions, beliefs, values, and behaviors with regard to death, dying and grief and one's own mortality.
2. Affirm and respect one's own and others' cultural identities as they interface with choices regarding death and grief.
3. Be mindful of the role of power differentials and social inequalities in influencing family and professional staff behavior and relations in end of life care.
4. Demonstrate awareness of the role of self in group dynamics and decision-making conferences related to care planning.

Theory Skills:

1. Understand the complexity and reciprocity of multicultural, multigenerational dynamics across different populations and families.
2. Use theory on grief and loss and information on differing cultural views on death and dying to inform understanding of family functioning.
3. Apply theories related to grief, loss and attachment to understand family decision making processes.
4. Identify developmental issues for children, mid-life adults and elders as they apply to end of life care.
5. Evaluate models of end of life care, including hospice and palliative care models and what they offer that differs from the standard practice of hospital-based death.
6. Identify issues related to the professional caregiver's experience of grief, attachment and loss.

Practice Skills

1. Develop the ability to bring a multigenerational, multicultural lens to their assessment of the strengths of individuals and families.

2. Perform bio-psycho-social-spiritual assessments of families encountering life-limiting conditions.
3. Understand skills to co-facilitate family decision-making conferences with professional interdisciplinary care teams regarding end of life care options.
4. Evaluate common ethical dilemmas facing social work practitioners working in end of life care.
5. Identify methods to empower families and teams to work collaboratively to develop a plan of care.

Academic Accommodations

If you would like to request academic accommodations due to a disability, please contact Disability Resources for Students, 448 Schmitz, 206-543-8924 (V/TTY). If you have a letter from the office of Disability Resources for Students (formerly Disabled Student Services) indicating you have a disability that requires academic accommodations, please present the letter to me so we can discuss the accommodations you might need for this class.

Teaching Methods

This course will be taught using interactive and participatory exercises and focuses heavily on the development of self-awareness, so students should be prepared to “wrestle” with their own fears, beliefs and hopes about the living/dying process. We will use stories, art, videos, guided discussion, role plays and other activities to explore the content and processes of the course.

Student/Faculty Responsibilities

We are a learning community. Part of functioning as a learning community is to engage in dialogue in a way that supports learning for all of us. Here are some guidelines that I try to use in my learning process:

- Assume that I might miss things others see and see things others miss.
- Raise my views in such a way that I encourage others to raise theirs.
- Inquire into others' views while inviting them to inquire into mine.
- Extend the same listening to others I would wish them to extend to me.
- Surface my feelings in such a way that I make it easier for others to surface theirs.
- Regard my views as a perspective onto the world, not the world itself.

Course Expectations for the Student:

1. Students are expected to attend all class sessions regularly and on time. Because this course focuses on the practicing of skills, class attendance is required. Students are expected to notify the instructor (in advance, whenever possible) regarding unavoidable absences and make appropriate arrangements to cover the missed course material.
2. Students are expected to complete all assigned reading prior to the class for which it has been assigned and are expected to be able to integrate that reading into class discussions and activities.

3. Students are expected to make use of academic libraries and resources for assignments.
4. Students are expected to offer the instructor clear constructive feedback regarding course content and teaching methods. Students are also expected to complete confidential evaluations of the course using the University's standardized forms.

See also the MSW Student Handbook for additional School policies and procedures.

Course Expectations for the Instructor(s):

1. The instructors will use a variety of instructional methods including lectures, large and small group exercises, discussions, videos, and dyadic activities.
2. The instructors will provide a clear structure for the course and each class session through the use of handouts, clarification of objectives, guiding discussion, providing appropriate linkages between topics, and summarizing progress throughout the quarter.
3. Student assignments will include clear expectations and, where possible, opportunities for student selection of alternatives. When possible, student assignments will be returned within one week of submission.
4. The instructors will be available as resource persons on issues related to class assignments or content during office hours, by phone, e-mail, or by appointment.
5. The instructors will work to facilitate an atmosphere in the classroom that is conducive to learning, is non-threatening, and is respectful of a variety of learning styles.
6. When students are asked to work together in groups, the instructors will be available for consultation and to assist groups in completing their tasks.
6. The instructors will provide feedback to students that identifies strengths and areas for improvement in a constructive manner.

Evaluation Methods

The grade for this course is based on five areas, four of which include mini-writing assignments (under 5 pages). Points for each are noted at the left. The assignments are graded based on four criteria: a) thoroughness and completeness of content, b) clarity and logic of presentation c) evidence of critical thought and self-reflection, and d) writing and editing quality. Feedback will be provided to students which critiques the student's strengths and need for improvement in each of these areas. These assignments are designed to meet the course goals of increasing self-awareness, understanding of theory, and application of practice skills.

Self-Awareness Skills Development

- 15% **Personal Death Awareness:** This 3-5 page paper is a personal reflection on your own beliefs, values and concerns regarding death and dying issues. Instructions will be provided in the first class session.
- 15% **Planning Your Advanced Directives:** During the second week of class, you will receive advanced care planning documents designed to help you determine your wishes for end of life care. Your assignment will be to fill out the guidelines for yourself and discuss these with the person you identify as your health care proxy. You will turn in a 2 – 3 page paper that discusses your experiences with this assignment and the implications this has for work with people with serious illnesses.

Application of Theory to Social Work Practice

- 15% **Reflections on the Readings:** Three times in the quarter, you are asked to briefly post to the course discussion board one of the following: 1) A question that has arisen for you from the readings; or 2) Something from the readings that has affected you, or stood out to you in some way. Twice in the quarter, you are asked to respond to another person's postings on the readings. At the mid-quarter point, you should have posted to one reading and responded to another classmate's comments one time.
- 15% **Class Participation:** Throughout the class, we will be engaging with the stories of people facing serious illness, therefore, it is very important that you attend every class. Class time will include small group discussion, participation in role plays and observation of an interview with a person with a serious illness. At three times, we will be asking you to write 1 page reflection papers on these experiences (sometimes in class, sometimes after class). We believe that participation does not always mean talking, but can be reflected in active listening to others' comments.
- 40% **Case Assessment:** In this 7-10 page paper, you will present a written case assessment and summary discussion of your learning. More information on this assignment will be presented in class. The case assessment will be based on a case study presented in the book, Barnard, D., Towers, A., Boston, P. & Lambrinidou, Y. (2000). *Crossing Over: Narratives of Palliative Care*, New York: Oxford University Press. The four narratives include:
- Joey Court: A child who is ill
 - Shamira Cook: A parent who is ill
 - Klara Bergman: An elder experiencing despair
 - Paula Ferrari: An adult triumphing over despair

Late Assignments and Incompletes

All assignments are due on the date noted. In fairness to students who turn their work in on time, late assignments will receive a minimum 5% deduction. You must make PRIOR arrangements with the instructor to turn in an assignment late with minimal penalty. Assignments turned in

late without prior authorization will be accepted with an additional deduction for each day late. Assignments more than 1 week late will not receive credit unless PRIOR arrangements have been made with the instructor. Please make ADVANCE arrangements with the instructor for any due dates that you may miss.

Summary of Course Due Dates

Assignment/Activity	Date Due
Personal Death Awareness	April 8
1 page written reflection	April 22
Advanced Directives	April 29
1 of 3 readings postings; 1 of 2 response postings to Discussion Thread	May 5
1 page written reflection	May 13
1 page written reflection	May 20
Final readings postings and responses	June 3
Case Assessment paper	June 3

Course Readings

The following are **required texts** for the course:

David W. Kissane & Sidney Bloch. (2003). *Family focused grief therapy*. Philadelphia, PA: Open University Press.

Timothy E. Quill. (2001). *Caring for patients at the end of life: Facing an uncertain future together*. New York: Oxford University Press.

A reader with additional required readings will be made available through the e-reserve system and through the Rams Copy Center.

The following are supplemental texts for the course:

Joanne Hilden & Daniel R. Robin with Karen Lindsey. (2003). *Shelter from the storm: Caring for a child with a life-threatening condition*. Cambridge, MA: Perseus Press.

Joanne Lynn & Joan Harrold. (1999). *Handbook for mortals: Guidance for people facing serious illness*. New York: Oxford University Press.

Additional supplemental readings will be available through the e-reserve system.

Course Outline

THE BIG PICTURE: Understanding the intersections between systems of care and the culture of the family.

Week 1: Systems of Care: The Case for Dignity-Conserving Care

Objective: Contrast varying models of care for persons with life threatening illness from a social justice stance.

Quill, Chapter 1, 2, 3, 4, 10

Chochinov, H. M. (2002). Dignity and psychotherapeutic considerations in end-of-life care. *Journal of Palliative Care*, 20, 134 – 142.

Week 2: Culture, Values and Illness

Objective: Use readings related to class, ethnicity, gender and religion/spirituality as doorways into understanding how culture and values may intersect with systems of care .

(Students assigned to groups of readings to discuss in class – these readings are on the e-reserve system, and not in the reader)

Class

Williams, B. R. (2004). Dying young, dying poor: A sociological examination of existential suffering among low-socioeconomic status patients *Journal of Palliative Care*, 7, 27 – 37.

Kirchhoff, L. S. (2003). Case study of Milton, “The Cowboy”. *Smith College Studies in Social Work*, 73, 463-478.

Ethnicity

Kagaway-Singer, M. & Blackhall, L. J. (2001). Negotiating cross-cultural issues at the end of life. “You got to go where he lives.” *JAMA*, 286, 23, 2993 – 3001.

Del Rio, N. (2004). A framework for multicultural end-of-life care: Enhancing social work practice. In J. Berzoff & P. R. Silverman (Eds.) *Living with dying: A handbook for end-of-life healthcare practitioners*, pp. 439-461.

Blackhall, L. J. et al. (1999). Ethnicity and attitudes towards life sustaining technology. *Social Science and Medicine*, 48, 12, 1779-1789.

Gender

Noppe, I. C. (2004). Gender and death: Parallel and intersecting pathways. In J. Berzoff & P. R. Silverman (Eds.) *Living with dying: A handbook for end-of-life healthcare practitioners*, pp. 206-225.

McGoldrick, M. (2004). Gender and mourning. In F. Walsh & M. McGoldrick (Eds.) *Living beyond loss: Death in the family*, pp. 99-118.

Religion and Spirituality

Clarfield, A. M., Gordon, M., Markwell, H., & Alibhai, S. M. H. (2003). Ethical issues in end-of-life geriatric care: The approach of three monotheistic religions – Judaism, Catholicism, and Islam. *Journal of the American Geriatrics Society*, 51, 1149-1154.

Jacobs, C. (2004). Spirituality and end-of-life care practice for social workers. In J. Berzoff & P. R. Silverman (Eds.) *Living with dying: A handbook for end-of-life healthcare practitioners*, pp. 188-205.

CLINICAL ASSESSMENT ACROSS THE LIFESPAN: Understanding the Developmental Needs of Children, Adults and Elders

Week 3: Assessment from a Family Perspective

Objective: Identify basic components of assessing family dynamics in situations of critical illness.

Kissane & Bloch, Chapters 1 – 5, 7

Klass, D. (1999). Developing a cross-cultural model of grief: The state of the field. *Omega*, 39, 3, 153-178.

Farber, S., Egnew, T. & Farber, A. (2004). What is respectful death? In J. Berzoff & P. R. Silverman (Eds.) *Living with dying: A handbook for end-of-life healthcare practitioners*, pp. 102-127.

Week 4: Families Caring for a Critically Ill Adult

Objective: To identify mid-life developmental concerns using as a case study a gay couple facing critical illness

Thompson, B. & Colon, Y. (2004). Lesbians and gay men at the end of their lives: Psychosocial concerns. In J. Berzoff & P. R. Silverman (Eds.) *Living with dying: A handbook for end-of-life healthcare practitioners*, pp. 482-498.

Werner-Lin, A. & Moro, T. (2004). Unacknowledged and stigmatized losses. In F. Walsh & M. McGoldrick (Eds.) *Living beyond loss: Death in the family*, pp. 245-271.

Kutzen, H. (2003). The positive outcomes of HIV palliative care consultations: Five meaningful cases. *HIV Clinician*, 15 (1), 1 – 5.

Week 5: Families Caring for a Child who is Critically Ill

Objective: To identify developmental concerns for families caring for critically ill children, and strategies for effective social work practice.

Institute of Medicine. (2003). Pathways to a child's death. In *When Children Die: Improving palliative and end-of-life care for children and their families*, pp. 72 –103.

Jones, B. & Weisenfluh, S. (2003). Pediatric palliative care and end-of-life care: Developmental and spiritual issues of dying children. *Smith College Studies in Social Work*, 73, 3, 423- 443.

Week 6: Decision-Making Conferences

Objective: To identify dynamics in interprofessional team meetings, and understand social work roles and skills in these meetings.

Ambuel, B. (2000). Conducting a family conference. *Principles & Practice of Supportive Oncology*, 3, 3, 1-12.

Rabow, M. W., Hauser, J. M. & Adams, J. (2004). Supporting family caregivers at the end of life: "They don't know what they don't know." *JAMA*, 291, 483-491.

Zilberfein, F. & Hurwitz, E. (2003). Clinical social work practice at the end of life. *Smith College Studies in Social Work*, 73, 3, 299 – 324.

Week 7: Relentless Self Care

Objective: Exploring our own understanding of suffering and service by reflecting on how we care for ourselves while giving care to others.

Ostaseski, F. (1996). Exploring our intention in service. *Alternative Therapies in Health and Medicine*, 2.

Browning, D. (2004). Fragments of love: Explorations in the ethnography of suffering and professional caregiving. In J. Berzoff & P. R. Silverman (Eds.) *Living with dying: A handbook for end-of-life healthcare practitioners*, pp. 21-42.

Week 8: Families Caring for a Critically Ill Elder

Objective: To explore dynamics related to ageism and how this affects end-of-life decision making.

Kutzen, H. & Lindhorst, T. (1996). What to expect as the end of life approaches. In *End of Life: Information for Caregivers*. New Orleans, LA: Delta Region AIDS Education and Training Center.

Moss, M. S. & Moss, S. Z. (1989). Death of the very old. In K. J. Doka (Ed.) *Disenfranchised grief: Recognizing hidden sorrow*, p. 213-227.

Quill, Chapters 6, 7, 8

SPECIAL TOPICS

Week 9: Palliative Care in Prisons – Special Guest Speaker

Objective: We will have a brief discussion of biomedical ethics related to end-of-life care and then have a special presentation on work in prison settings with the terminally ill.

Ethics section: Quill, Chapters 9, 11, 12

Prison readings: Enders, S. R. (2004). End-of-life Care in the prison system: Implications for social work. In J. Berzoff & P. R. Silverman (Eds.) *Living with dying: A handbook for end-of-life healthcare practitioners*, pp. 609-627.

Granse, B. L. (2003). Why should we even care? Hospice social work practice in a prison setting. *Smith College Studies in Social Work*, 73, 3, 359 – 376.

Week 10: Making Meaning of Endings

Objective: To reflect on endings and meaning making in the context of end-of-life care.

Breitbart, W., Gibson, C., Poppito, S. R. & Berg, A. (2004). Psychotherapeutic interventions at the end of life: A focus on meaning and spirituality. *Canadian Journal of Psychiatry*, 49, 6, 366-372.

Puchalski, C. M. (2002). Spirituality. In A. M. Berger, R. K. Portenoy & D. E. Weissman (Eds.) *Principles and practice of palliative care and supportive oncology*, 2nd Ed. Pp. 799-812.