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DEATH, DYING AND BEREAVEMENT

General Description

Participants in this course are invited to embark on a journey to explore their understanding of the divine in the human experience of mortality, exploring spirituality and personal growth at life's end. Students are asked to view these topics through the lenses of both their personal and professional lives. Students will be guided through a didactic and experiential exploration of critical end-of-life issues and clinical and pastoral interventions. We will examine mortality, spirituality, today's health care system and the impediments to access endemic to the disadvantaged, the interdisciplinary model of e delivery and the roles of social workers, spiritual care providers and faith communities in helping the dying and their loved ones. We will focus primarily on the experiences of those who are dying from disease or injury, whose dying is anticipated; we will touch on sudden or unexpected death slightly.

Patients with life-threatening diseases or injuries and the people they value are usually deeply affected by the diagnosis, treatment and changing condition of the patient. These changes often stimulate both heightened psychosocial need and increased spiritual or existential distress. In fact, five interdependent domains of the patient/caregiver ecosystem are usually affected by a dying process: the physical, psychological, spiritual/existential, material and relational.

Dying and death experiences vary greatly from one person to the next. Some of these variations are based in culture or ethnicity. In addition to more obvious racial/ethnic and global cultural considerations, issues such as primary language, immigration status, sexual orientation, culturally derived styles of communication, support and decision-making, intergenerational differences in acculturation or assimilation, biculturalism, and the variety of viewpoints concerning illness, disease, dying, death and bereavement contribute to this variation.

Other differences are based in demography and ecology: gender, age, disease type, physical location (of both the person and the disease or injury), abilities, socio-economic standing, level of education. Still other variation is rooted in the psychological development of the individual and the support system surrounding them. Individual beliefs and faith history/ current faith community participation/ spiritual expression are other crucial domains of diversity and may also account for substantial variation. Most often, a complex blend of many of these factors comes together to shape the dying experience for the individual and their loved ones and/or caregivers. Developing and maintaining sensitivity to these variations and working in the patient's milieu are critical skills for spiritual care providers encountering dying individuals and affected populations. This course seeks to cultivate the skills that will allow participants to be fully present and attuned conduits of the divine to the dying and those dear to them with an unerring eye toward ministry that serves to counter oppression and create just and sustainable communities.

The preferred approach for providing end-of-life care to the terminally ill involves an interdisciplinary team. Social work and chaplaincy are two of the disciplines integral to this team; the instructor's background and contemporary work setting are in the realm of social work. Yet part of the motivation for originally conceiving and designing this course arises from a recognition that the spiritual, the existential and the psychosocial cannot be viewed as discrete silos of patient/caregiver experience, but rather are inextricably interwoven, parts of a greater, integrated whole. This course is intended to deepen all participants' knowledge of terminal illness, while providing an overview of important processes for accessing health care and making health care decisions. Subjects including advance medical planning, the dying process as part of the life cycle and the dynamic relationship between the patient, caregiver(s) and the professional care team are integral to the course. Built on this foundation, the participants will explore patients' psychosocial and spiritual strengths and needs, and will inevitably touch upon their own mortality as well.

Course Objectives/ Student Learning Objectives

- Students will engage in exercises intended to foster an examination of individual mortality as well as an exploration of one's personal beliefs concerning the spiritual or existential.
- Students will demonstrate an understanding of the dying process, particularly as it relates to chronic or terminal illness. This understanding will encompass patient and caregiver/ loved ones' perspectives in the appropriate spiritual and socio-cultural ecosystem. Included in this understanding will be an awareness of how ethnicity, culture, religious preference and denomination, age, gender and other factors affect perspective and may affect medical decision-making and how these, in turn, affect outcomes.
- Students will develop an informed individual understanding of the spiritual or existential issues raised by many patients and "family" members ("family" as defined by the congregant/ patient) in response to progressive, chronic or terminal illness. This understanding will include enhanced ability to differentiate between psychosocial and spiritual concerns.
- Students will experience and reflect on spiritual or faith traditions with which they are not initially familiar.
- Students will discuss the implications of belief systems and of progressive or terminal illness in guiding treatment and interaction with patients/clients/congregants and families by chaplains and other spiritual care providers. Based on each student's prior training and experience, students will incorporate pastoral counseling theory and practice and enhance pastoral skills.
- Students will demonstrate a basic understanding of the central ethical issues associated with the treatment of chronic, progressive and/or terminal illness.
- Students will be able to conduct a comprehensive spiritual assessment of a patient/caregiver system, identify concurrent spiritual or existential issues, identify and prioritize needs and develop a plan of care.

Teaching Method

The instructor uses dynamic and diverse teaching methods, in recognition that adult learners benefit most from a multi-modality learning environment. The course format will integrate individual and group experiential exercises; small group and whole class discussion and didactic modules, as well as guest presentation/discussions and the use of various audiovisual and written media. Content and process have equal importance in this course, making attendance and

participation imperative. The instructor will pay particular attention to diversity content in all aspects, and case discussions will affirm this diversity. Students will be encouraged to share professional and/or personal experiences that will further enrich the diversity dialogue. Moreover, the conjunction of Starr King School for the Ministry's mandate of *Educating to Counter Oppression and Create Just and Sustainable Communities* and the Social Work Code of Ethics will be explored, as the instructor's background is predominantly in social work, and the overlap is, in the instructor's view, substantial and substantive

Student Requirements

Attendance is required for this course. Much of the learning is based on in-class exercises and discussions. **Missing more than one half day or its equivalent during the term may result in an unsatisfactory or failing grade.** In addition to attendance, the following requirements apply:

- **Participation in a book group (reading one of three books, 1 meeting during class time, one in-class group oral report).** During the first class session, each student will choose one of three books to read; please have a first and second choice in order for us to have a fairly equitable distribution. Please see the book list (page 5 of this syllabus) for the three books from which you may choose. Groups will meet to discuss the book and draft a report to the class. Specific details of the contents of the report to the class will be distributed in class. You are encouraged to use the book group meeting to share ideas beyond the scope of the book but within the scope of the class. Creativity is welcomed and encouraged in making these presentations.
- **Two tasks with accompanying reflection papers (see below). The reflection portion of the paper should be no more than 4 pages, double-spaced.** The main goal is to enter fully into the task or experience, then examine the attitudes, feelings and thoughts you have about it, how these impact your understanding of issues surrounding spirituality, dying and death, and how this understanding is related to the professional practices and interventions of pastoral spiritual care.
 - **Task One: Complete an Advance Directive for Yourself.** Use either 1) one of the forms specifically valid in California, or 2) the "Five Wishes" document. Write an accompanying reflection. Examples of three forms will be provided (including the "Five Wishes" document); if you have another that you prefer and that is valid in California, feel free to use it. In your reflection, pay particular attention to the choices you make regarding your care and regarding the person/people you designate to carry out your decisions if you cannot. The emotions generated by this exercise hold equal weight with the content of the exercise itself; please include these in your reflection. If you have an Advance Medical Directive already in force, please review it, consider whether or not you want to revise it, and reflect on the process you went through in completing it as well as any process changes you would make in completing one today. In addition to the completed forms (photocopies are preferred), your reflection should be no more than 4 pages, double-spaced, in length.

The reflection paper must be submitted electronically, in MS Word or MS Word-compatible format, as an attachment, not embedded text. A copy of the Advance Health Care Directive document should be turned in to me during the regular class period.

Task Two: Observe and/or participate in a service or ritual of a spiritual/religious tradition other than your own: briefly describe the particulars of the service you attend (when, where, what and with whom, maximum one page), and write the accompanying reflection. This exercise may or may not contain components examining end-of-life issues. Primarily this is intended to broaden your exposure to and appreciation of the diversity of beliefs and practices that comprise more organized religious or spiritual expression. If, in this process, you have the opportunity to learn about particular beliefs or practices concerning rituals for or care of the dying, the dead, caregivers and the bereaved, so much the better. Should an individual's beliefs prohibit participation in or observation of faith practices other than their own, please see the instructor early in the semester, and an alternate assignment will be jointly formulated. Again, your reflection (excluding the description of the service) should be no more than 4 pages, double-spaced.

This reflection paper must also be submitted electronically, in MS Word or MS Word-compatible format, as an attachment, not as embedded text.

Educating to Counter Oppressions and Create Just and Sustainable Communities

Educating to Counter Oppression (ECO) and build Just, Sustainable Communities is a central theme in this course. This course highlights the marked disparities in health care access and care, encouraging critical thought and creativity in formulating practical actions that spiritual care providers can engage in themselves and/or can mobilize in their congregants to counter oppressions and privilege as reflected particularly in care at the end of life. To that end, diversity material is integrated into each of the daily topic areas. The Fadiman text and many of the readings in the course reader address specific issues of diversity and specific populations at risk. Throughout the course, diverse content is explicitly encouraged as part of in-class discussions as well as in exercises and written assignments.

Required texts

- * Fadiman, A. (1997). The spirit catches you and you fall down. New York: Farrar, Straus and Giroux. ISBN 0-374-52564-1. {Instructor strongly recommends that you read this prior to the start of class.}
- * Groves, Richard F; Klauser, Henriette Ann. (2009). The American Book of Living and Dying: Lessons in Healing Spiritual Pain. Berkeley, Ten Speed Press. ISBN 1587613506.

Electronic Reading Material

- * Topical articles, compiled by the instructor. Distribution will be electronic. Due to the structure of the course, readings will be somewhat limited.

Recommended Reference Work

- * Worden, J.W. (2002). Grief counseling and grief therapy: A handbook for the mental health practitioner (3rd ed). New York: Springer.

You will be asked to choose one of the following three books for ‘book group’, described on page 3 above. Sign-up will occur on the first day of class.

- Didion, Joan (2005). *The Year of Magical Thinking*. Knopf/Vintage. **ISBN:** 978-1-4000-7843-1. Paperback, 240 pages, \$14.95.
- Monette, Paul (1995). *The Last Watch of the Night*. New York, San Diego, London: Harcourt Brace & Company. ISBN-10: 0156002027, paperback, 320 pages, \$23.95
- Sebold, Alice (2002). *The Lovely Bones*. Boston: Little, Brown and Co. ISBN: 9780316044936, paperback, 368 pages, \$14.99/\$17.99

COURSE CALENDAR, February – April, 2011

Before presenting you with the daily plans for our five days together, I want to offer a few reflections.

I have some serious concerns about teaching this material in this format. Quite frankly, structuring the course this way is mostly a matter of expedience. It also sounded like a good idea at the time. Subsequently, upon reflection, I have a number of concerns.

The last time this course was taught, it was as a 4-day intersession intensive. Suffice to say that was too intense for participants and instructor alike. Further, there was no opportunity to synthesize the material, to let the ideas and impact of the course percolate. Hence the different configuration this year.

As I always do, I will be asking you each time we convene how you think things are going, what is working and what isn't. We share ownership of this class, and I rely on your feedback to make adjustments as we move through the material.

I am primarily a clinician, not a theologian or a spiritual care provider. Consequently, what I have to bring to our time together is a great deal of professional and a fair amount of personal experience in the realm of death and dying. I do also bring a background from time spent in the Catholic seminary as a high school and college student; I will talk more about the values that guide my life and work and where those come from in class. But much of the insight into the divine in this work will come from you. Together, I think we will have, present in the room, a powerful mix of the worldly and the ethereal, the clinical and the spiritual, the personal and the professional. I think the opportunities to co-create a truly profound experience abound.

This course content always evokes strong emotional reactions in some or all participants. I suspect the day-long structure of the course may intensify those responses. We will talk about this in the first part of the first day, and together formulate a way to respond that is safe, supportive and in keeping with the 'process' aspect of the class.

As noted elsewhere, this class has traditionally been equal parts content and process. What happens within each of us and between and among us is of great importance over the five days of classes, so know I will be attending to these aspects as the instructor and guide for this class, but each of us has responsibilities to the group and our process.

In order to strike the balance between sufficient structure and a responsive and dynamic learning environment, you may find the following overview of the five days somewhat lacking in detail, particularly later in the session. Believe me, we have plenty of material. I am leaving myself lots of room to follow your lead/interests while making sure we cover essential topics, so participants will help set some of the educational content later in the course.

Okay, with that lengthy caveat, here's what our five course sessions look like right now.

Day One – Friday, February 4, 2011

Opening ritual.

Introduction:

- Creation of safe and sacred space for our exploration of mortality and the transcendent
- Review of the course, syllabus and requirements
- Introduction to one another. [Prepare Ahead: Please give thought to the following questions]
 - What do you want out of this class; put another way, what motivates you to take this class?
 - What have your real-life personal experiences been with death and mourning
 - What have your professional experiences been with death and mourning
 - What is something you would consider unexpected yet true about yourself
 - Please share one of your 10 most treasured activities, and tell us when you last engaged in that activity.
 - Which lenses are most important and influential in your views of death and mourning (this could be things like religious perspective, personal experience, culture, family traditions, your anticipated role as a spiritual care provider to others, etc.)

(I encourage you to write down answers to these questions ahead of time, though you won't have to turn anything in)

I expect this to take most of the morning. We will take a 15 minute break sometime mid-morning

Lunch

- Overview of the principles of Educating to Counter Oppression and Create Just and Sustainable Communities (ECO) as it relates to death and dying
- Review of ECO statement and comparison with social work code of ethics (slides), then discussion

Break

Touching Our Own Mortality.

- Exercise to heighten mortality awareness
- Group discussion of exercise

Break (at some point I will distribute the materials for your written assignments, particularly the prototype advance medical directives – see Task One.)

Setting the Stage: the Social Construction of Death.

- The dominant Western model and how it has evolved
- The medicalization of death and its implications
- Alternative voices and different constructs

Individual and Societal Coping with Death

- Coping with a terminal diagnosis (video segment and discussion)
- Didactic and group sharing about experienced, observed and familiar coping models
- Opening the dialogue about culture as a mediator of death and bereavement practices

End of Day One

Day Two – Friday, February 18, 2011

Tentatively, we will be joined for the second half of the day by Tom West, OFM, Ph D. His dissertation explored “the experience of being with someone as they are dying; an existential, phenomenological study”. Tom co-taught this course with me the first year it was offered at UC Berkeley, Spring 2002. He also has taught pastoral counseling at the Franciscan School of Theology.

Assessment of Patients and their Loved Ones: Questions to Ask and Ways of Asking

- Group discussion of whether or not assessment matters, if it does, why, and what do we want to gain from such an assessment
- Introduction to assessment tools/ creation of an assessment tool.
- “Questions” from Sacramento Healthcare Decisions Clergy Education “Partners in Caring” session.
- Role playing.
- Faith communities as venues to explore end-of-life

Break

Diverse Cultural Approaches to Healing and Dying

- Didactic and discussion, using the book *The Spirit Catches You and You Fall Down* as the guide for a conversation about what happens when collisions occur between culture, medicine and spirituality. Please consider sharing your own cultural experiences and perspectives as your voices are an integral part of this dialogue.

Lunch

Ethics and End-of-Life Decision-Making

- Lecture on bioethics, followed by group discussion
- Slides accompany this discussion.

Break

Providing Pastoral Care in various contexts

- Video vignettes (2-3) with small group and class discussion about intervention strategies

Break

- Opening the dialogue about death as a spiritual and existential phenomenon.

End of Day Two

Day Three – Friday, March 4, 2011

Tentatively, we will be joined for half the day by representatives of Islam and Judaism, who will share presentations on Islamic and Jewish precepts and practices regarding end-of-life and engage the class in discussion/ Q & A.

Presence and Communications at end-of-life, a congregational and chaplaincy exploration.

Religious and Spiritual Traditions and End-of-Life Care and Rituals Associated with End-of-Life

- Small work groups design rituals based on course content and your particular spiritual perspectives, placing emphasis on ECO principles.
- Present rituals to the group, group discussion

Break

Dying Children, Children of Dying Parents or Siblings

- Lecture on issues related to children and death
- Group discussion: the role of the spiritual in work with dying children and more broadly, the spiritual lives of children (selected readings on this topic)
- Discussion of resources for children and families

Resources for parents/guardians:

(three of these are ‘.pdf’ files that will also be distributed electronically)

- http://www.cancercare.org/pdf/booklets/ccc_helping_children.pdf
- <http://www2.mdanderson.org/depts/oncolog/pdfs-hc/07/housecall7-8-07.pdf>
- <http://www2.mdanderson.org/app/pe/index.cfm?pageName=opendoc&docid=1582>
- <http://www.cancer.org/Treatment/ChildrenandCancer/HelpingChildrenWhenaFamilyMemberHasCancer/DealingWithDiagnosis/index.htm>

Lunch

Suicide and end-of-life, including assisted suicide; lecture, followed by video and discussion. Invariably this involves further discussion of the ‘good death’.
(DVD).

Break

Small Groups meet to prepare presentations on one of the three books read prior to the start of class.

Assignment due: Advance medical directive. Reflection paper is to be transmitted electronically, **prior to the start of class**, a copy of the actual advance medical directive document is to be turned in during class.

End of Day Three

Day Four – Friday, March 18, 2011

Presentations by the Three Book Groups with Class Discussion. I anticipate each group taking 30-45 minutes, including a presentation by the group and discussion among the class. The exact format of these discussions is a work in progress, awaiting some discussion as a class about how best to accomplish this. We will hear from 2 groups, take a

Break,

then hear from the other 2 groups.

Lunch

In search of the ‘good death’, perhaps by way of the ‘good life’.

(DVD)

Discussion: Meaning-making as a critical component of the human death experience.

Break

Return of the Advance Medical Directive papers and documents;
didactic and class discussion.

Assignment due: Reflection paper on your observation and/or participation in a service or ritual of a spiritual/religious tradition other than your own. Reflection paper is to be transmitted electronically, **prior to the start of class.**

End of Day Four

Day Five – Friday, April 1, 2011

The nature of suffering, how suffering fits into the realm of the divine.

“Wit”, the movie.

Break

Discussion.

Lunch

Bereavement Practices

Community/congregational dialogue and interventions

Break

Conclusion

Review of the course

Final questions and discussion

Ending Ritual

End of Day Five – End of course.