

Contemplative Caregiving and a DeathFest

An Interdisciplinary, Interreligious Experiment

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A dozen undergraduate women students lie on yoga mats and blankets on the floor of a large, darkened classroom. They are positioned far enough apart to have some sense of individual privacy. A professor invites them all to bring one hand into the air and to experiment with the shapes and movement patterns they can make. They explore how far the hand and arm can move in different directions, and where they can come to rest. The professor then invites the students to think about someone or something they are concerned about, bring an image of that person or concern clearly to mind and hold it there. She then invites them to listen to a recording of instrumental music and do a solo “Hand-Dance on Behalf Of” that concern, moving with or against the music.¹ Each woman begins her own “dance,” witnessed by her two professors. After the music ends, the students rest for a few moments, absorbing the experience. This is one of several contemplative practices they will learn this semester, inside class and out. The lights go up, and the women are told to find a partner and share for a few minutes what they noticed about the experience. They then gather around tables arranged in a rectangle, and class discussion begins.²

These women were members of an interdisciplinary honors course called Caregiving at the End of Life, cotaught by a member of the nursing faculty and a professor of religious studies at a Catholic liberal arts university in Baltimore during the spring semester of 2017. Cross-listed in both instructors’ departments, the course (which had been in development for a year) was intended to appeal not only to students earning bachelor’s degrees in nursing but to those in other majors as well. The authors of this chapter were its instructors. Hannah is a theologically trained critical and palliative care nurse and nurse-educator, ordained as a deacon in the Presbyterian Church, USA. Wakoh, formerly a professor of religious studies, is ordained as a Sōtō Zen (Buddhist) priest and is also a professional chaplain with experience in both university and medical settings. As educators who practice different academic disciplines and different religions, we wanted to model constructive interreligious and interdisciplinary dialogue for students. The course description follows:

Everybody dies. This course explores a variety of theories and methods for caregiving at the end of life and is designed for both nursing and non-nursing students. We will explore

the medicalization of death, structural inequalities in access to medical care, palliative and hospice care for people facing terminal illness, and clinical dimensions of death and dying. We will focus on contemplative practices that enable caregivers to care for themselves and provide effective support for patients and their loved ones. We will introduce various religious and spiritual perspectives on dying, death, and the afterlife, and learn about rituals for grief and mourning.

In designing this course, we wanted to create a rigorous, interdisciplinary, interfaith experience that would challenge students intellectually and give them practical skills they could apply in their personal and professional lives. If they had not yet encountered death and dying, every one of them ~~would~~ do so eventually. We agreed that the most basic caregiving skill one can bring to someone who is ill or dying is a non-anxious presence, so the course had to be built upon a foundation of contemplative practices.

Contemplative Practice in Caregiving and in the Liberal Arts

The use of such practices might not seem like an obvious choice, but it made sense to us for a variety of reasons. One is practical, grounded in our clinical experiences as a nurse and a chaplain: caregivers, both professional and lay, must temporarily bracket their own needs in order to attend fully to a person needing care, but they must also remain aware of their own needs and find healthy ways to meet them outside the caregiving situation. Contemplative practices help train people for this by teaching them to bear witness, accept, and attend compassionately to their own physical, mental, and spiritual discomfort, without either feeding or disregarding it. One's capacity to do this for oneself in times of distress translates directly into being able to do this for others.

Other reasons relate to the goals of both liberal arts and nursing education. The university's nursing curriculum focuses on six goals: (1) presence, which helps to create a caring environment; (2) praxis, a process of clinical action and reflection that informs new actions; (3) leadership; (4) advocacy for patients, families, and communities regarding health policy, social justice, and ethical decision-making; (5) scholarship; and (6) self-care.

In addition, the course satisfied a general-education requirement of an upper-level course in religious studies as well as requirements specific to the honors program. The general-education goals included integrating insights from the arts and sciences, developing a global perspective, refining a personal value system, growing one's capacity to think critically, and enhancing one's oral, written, and visual communication skills. Toward these ends, our course learning outcomes asked students to

- Describe how evidence-based medicine and the medicalization of death affect caregivers and patients.
- Analyze differences between routine medical care of the dying and practices used in palliative and hospice care.
- Explain how structural inequalities affect morbidity and mortality rates and end-of-life care.
- Explain how contemplative practice can inform a caring-healing practice of caregiving at the end of life.
- Discuss the different effects of expected and sudden death for patients, families, and caregivers.
- Demonstrate reflexivity and empathy; that is, recognize how one's social location shapes personal beliefs and assumptions about dying, death, and the afterlife; and shapes how one relates emotionally to people whose views and attitudes differ from one's own.
- Compare and contrast personal beliefs and practices about caregiving, death, and afterlife with those of at least two different religious traditions, one Abrahamic and one Dharmic.
- Describe signs and symptoms of dying and define clinical death.
- Reflect on ethical issues related to end-of-life care and organ donation and state personal preferences about these in an advance directive and physician's order for life-sustaining treatment.
- Design and execute an on-campus teaching-learning program that reflects issues from the course.
- Maintain a contemplative practice of the student's choice, at least five days per week, throughout the course.

We wanted students to think seriously about whether they ~~are~~ really willing to make the necessary commitment. Our welcome message before the first meeting said:

We are excited about embarking together on an exploration of some of the most intimate and tender aspects of what it means to be human: aging, illness, death, mourning, and beliefs about the afterlife. We know that different people are ready to deal with these aspects of life and death in different ways, at different times. We aim to create a learning community that includes room for these differences. At the same time, we will be asking you to engage in rigorous, critical analysis of books, films, and your own experiences. It will be intense, we guarantee. We want you to be sure you're ready for it, this particular semester, given whatever else is going on in your life. Please review the attached syllabus [and other course materials] and give that some serious consideration.³

On the first night of class students introduced themselves by describing their experiences of death or dying thus far and their hopes for the course. We were de-

lighted, but not surprised, to find how diverse they were. Seven were white, three Asian American, one Black African, and one Pakistani American. Six identified as Christian, including one Catholic and one Armenian Orthodox; one as Muslim; two as “none” or “spiritual but not religious”; and two as atheist. Six were majoring in nursing, two in pharmacy, two in other science programs, and one in criminal justice. Some had no direct experience with death; some had lost multiple family members; some had family members living with life-threatening illnesses. During the semester, some students (and both instructors) dealt with serious illnesses or deaths among their family members and friends.

Course Structure

For the first ten (of fifteen) weeks, our core text was *Being with Dying* by Joan Halifax, an American woman Zen teacher with long experience training professionals and volunteers to offer end-of-life care.⁴ We assigned two chapters in every week except the tenth. Each chapter concludes with a contemplative exercise, so in addition to whatever regular practice they were doing (sitting or walking meditation, hand-dancing, etc.), we asked students to choose one, try it, and write about it in weekly “contemplative journals.” Students grappled in these with the stresses of college life, anxieties about their futures, deaths and illnesses affecting themselves and their loved ones, and struggles with and questions about the religious traditions in which they had been raised as well as their experiences of contemplative practice. As instructors, we did not want to grade the content of their experiences, so we focused on how clearly they expressed themselves in writing and how well they tied their personal reflections to specific materials from the course.

We assigned several other texts that provided practical guidance on end-of-life care: *Stay Close and Do Nothing: A Spiritual and Practical Guide for Caring for the Dying at Home* by Merrill Collett, a former volunteer for the Zen Hospice Project in San Francisco; *The Patient’s Playbook: How to Save Your Life and the Lives of Those You Love* by Leslie Michelson, a guide to advocating for oneself and others in the medical system; and Ira Byock’s *The Four Things That Matter Most*, which explores the roles of apology, forgiveness, gratitude, and loving acceptance at the end of life.⁵ We also assigned Atul Gawande’s *Being Mortal: Medicine and What Matters in the End*, which explores the medicalization of death and its consequences, and *Religion, Death, and Dying*, a three-volume set edited by Lucy Bregman that explores a variety of religious and cultural issues and practices related to care of the dying and dead.⁶ The latter texts and several videos introduced students to various beliefs and rituals around death and dying within Jewish, Christian, Muslim, Hindu, and Buddhist cultures and to the challenges for members of these religious cultures when interacting with the culture of Western biomedicine.

We began the course by providing historical context for the contemporary medi-

calization of death. Until very recently in American society, people typically died at home, within multigenerational households. With the rise of modern biomedicine—in which most doctors are socialized to regard death as a failure—and with the increasing mobility of American families, the dying process has shifted to nursing facilities and hospitals, in which ever-more-invasive procedures can prolong lives in ways unimaginable a century ago. *Being Mortal* is helpful in describing this process and explaining why so many doctors have difficulty discussing death candidly with patients and their families. We examined structural inequalities in access to medical care as well as the socioeconomic risk factors for serious illness and early death. We explored the history of racism in medical care and experimentation and its consequences today.

One assignment asked each student to consider and discuss with loved ones their own wishes for an advance directive and physician's order for life-sustaining treatment. Another was a structured, contemplative dialogue with someone religiously different from themselves, called a "Careful Conversation."⁷ Our university's student body was quite religiously diverse, and our International Students Program was happy to help pair some members of our class with visiting students who needed to practice English. The final project required our students to share what they had learned with the wider campus community. The campus International Center hosted this evening event, dubbed the "DeathFest."

Our students that semester were strong writers, so we focused on helping them refine their analytical reading skills by requiring them to develop questions about the readings that could guide conversation during class. They quickly found this was much harder than it sounded because each question had to meet several specific criteria.⁸ During class, students helped one another refine the questions that directed their break-out, small-group conversations. Students led these discussions as well, which gave them a new appreciation for the demands of teaching. Midterm and final exam questions were tied directly to course objectives, for easy assessment.

Contemplative Practices in Caregiving

Regular contemplative practices helped most of our students quiet their minds enough to begin to experience themselves and their lives in new ways. Many reported break-through moments in which they gained insights about painful issues in their lives and began to deal with them differently. One woman began to explore her feelings about an accident that her sister had survived but that had left the sibling quite disabled and living in a board-and-care facility. Although the sisters had been estranged, this student wrote extensively in journals and spoke openly in class about how the course material helped her to begin conversations with her family about healing and reconciliation.

Others wrote about how contemplative practices helped them navigate major life

events or better manage stress. One moderately religious student described caring for her devoutly religious, terminally ill relative. She worked through anxiety and guilt about not being more devout herself, and not being able to help more. She gained confidence by learning practical skills and developed her ability simply to be with her family member calmly, which improved their relationship and enabled more candid discussion. One of her classmates observed, “These meditations have made me more aware of how much I neglect my problems, both physically and emotionally. I much prefer to send my thoughts and will out towards helping others, even in a general sense, [than to dwell] on myself. I hope that by acknowledging this in myself, I can work to be more self-aware and take better care of myself—inside and out!” Another wrote, “I found that on the days that I spent ten to fifteen minutes doing one of my meditations that I was less stressed about everything that had to be done, and [more] capable of getting more done efficiently.” Contemplative self-care made it easier to avoid “helper’s disease,” in which a person neglects herself by over-focusing on others’ needs and ends up ineffectual and exhausted.

Studying funerary practices from multiple cultures offered students new perspectives on their own cultures. One remarked, “During class this week, we discussed [an] African approach to death [that] involved . . . ‘choral lamentations, dirge singers, and drum music’ during a funeral procession. As a child of immigrants, I recognize the cultural and spiritual value that music can play in one’s life. For this reason, I decided to breathe along with the steady beat of [a] drum while engaging in my sitting meditation practice during the week.”

We also taught some hands-on skills. One week we took everyone to a nursing-skills lab so they could learn how to turn a bedbound person and change linens with someone in the bed, plus simple bed-bath techniques. Many had never been in such a lab before. One student nurse who had already begun her clinical training assisted Hannah with demonstrations while Wakoh served as “patient.” Together Hannah and the student repositioned Wakoh and placed pillows in different positions for comfort. Students practiced these skills in groups of three, taking turns being the patient and caregivers. In course evaluations some students expressed a desire for more of this practical training while others could not yet see how it might eventually become relevant to their lives.

Caring and Careful Conversations

To help students consider and articulate their own end-of-life wishes, we used a packet called “Caring Conversations for Young Adults” from the Center for Practical Bioethics.⁹ Students worked through a list of nineteen questions that required them to consider their preferences and values while they learned about a durable power of attorney for health care. Students identified a health care proxy (actual or hypothetical) who could make decisions for them if they became incapacitated and

wrote a letter to that person describing their wishes about life-sustaining treatment, organ donation, and end-of-life care. An optional step was either to read the letter to the proxy or to have a detailed conversation with that person about its content. Students wrote heartfelt letters to their proxies, and some were able to share those letters and discuss their wishes with them. In class discussion and journals, students reflected on their wishes in ways that honored their own preferences but also clearly considered the values and religious practices of their families and loved ones.

The most explicitly interreligious exercise was a “Careful Conversation” (as developed by Sid Brown), a structured, contemplative dialogue with a person who is significantly different from oneself religiously (or nonreligiously).¹⁰ Over about an hour, partners take turns providing spontaneous answers to a series of questions about themselves. They recall positive and negative religious experiences (or experiences reflecting their values and beliefs, if they are nonreligious), identify things they value in their own traditions and others they have studied, and explain common misconceptions about their beliefs or practices they wish they could correct. Most students were pleasantly surprised to discover they had a lot in common with people whose worldviews and life experiences differed greatly from their own. One Christian, whose partner is Jain, remarked on the diversity she discovered within a tradition she might otherwise have assumed to be monolithic. She was able to recognize that individual Jains’ approaches to their religion vary, just as Christians’ do. She added that she learned more about her friend in this one discussion than she had over the preceding two years of their friendship.

Contemplative Practices in Interreligious Studies¹¹

Asking students to engage directly in contemplative practices drawn from different spiritual traditions, to participate in a contemplative dialogue with someone religiously different from themselves, and ultimately to share what they had learned with the campus community made this course more consistent with the aims of interreligious studies than of traditional religious studies. As an academic discipline among the liberal arts, religious studies aims to develop students’ knowledge about unfamiliar religious ideas, practices, objects, and stories and to hone their reading, writing, and critical-thinking skills. Religious studies is inherently interdisciplinary, employing methods from history, textual studies, linguistics, archaeology, anthropology, sociology, and so on. Unlike theology, in which one assumes certain religious claims or values to be normative (such as that God or gods exist, and require[s] sacrifices), in religious studies, one adopts a neutral stance toward any such claims. Students can develop this sort of “objective” religious literacy at arm’s length and from the neck up within the confines of a classroom.

Interreligious studies is also inherently interdisciplinary, but unlike religious studies, it may not insist on a neutral stance. It entails developing both religious

literacy and the *attitudes* necessary to engage constructively with religious others. It focuses on the spaces between groups and has the explicit goal of fostering pluralism as a social norm: religious differences are not merely to be understood but *appreciated* or *valued* in some way, regardless of whether one accepts them personally.¹² Pedagogically, interreligious studies employs more embodied, engaged, affective, and integrative methods. As in this course, students are often asked to encounter “others” directly, both interpersonally and at unfamiliar religious sites, and are sometimes invited to “try on” unfamiliar practices. They may be encouraged to use concepts and resources from other religions to think *with*.¹³ They are also encouraged explicitly to connect the world of the classroom with the worlds outside it.

This kind of study requires students to cultivate the dispositions of reflexivity, empathy, and humility. Reflexivity means self-awareness about one’s “social location”—that is, how one’s racialization, sex, gender, sexual orientation, age, socio-economic class, education level, religious background (or lack thereof), ethnic and cultural heritages, regional upbringing, and so on, shape one’s perceptions, assumptions, beliefs, attitudes, and biases. Such self-awareness is a prerequisite for constructive engagement with people or groups one perceives to be “other.” We are all situated somewhere, and we each approach studies and interpersonal encounters from particular perspectives. The limits of our perspective become especially clear when we respectfully encounter those who do not share our point of view. Intersecting forms of power and privilege also affect relationships among and between members of groups, and these must be considered as well. Reflexivity enables one to do this better.

Empathy is the ability to imagine oneself in the place of others. This requires one to notice and relinquish one’s tendency to assume that one’s own assumptions, beliefs, or needs apply universally. Empathy is associated with intellectual and cultural *humility*: remembering and accepting that our knowledge and perspectives are finite; that we can be wrong; and that even well-intentioned errors sometimes have consequences we don’t intend. Empathy and humility are also fundamental values of liberal education, what William Cronon described as education for human freedom in the service of community: “[It] is not something any of us ever achieve; . . . it is a way of living in the face of our own ignorance, a way of groping toward wisdom in full recognition of our own folly, a way of educating ourselves without any illusion that our educations will ever be complete.”¹⁴

The dispositions cultivated in interfaith studies help to foster societies “characterized by respect for people’s religious (and other) identities, positive relationships between people of different religious backgrounds, and common action for the common good.”¹⁵ Of course we want our students to think critically: to identify and question assumptions and biases in various sources of information, to notice whose interests are being served in particular situations and whose are not. However, critical analysis must be tempered by reflexivity, empathy, and humility because cri-

tique can become destructive when uninformed by self-awareness or unmodulated by compassion.

The DeathFest

While contemplative practices invited students to direct their gaze inward, the final project offered them a chance to share what they had learned with the wider university community. Students planned an evening event called the DeathFest and raised money from multiple campus sources to provide decorations, supplies, food and beverages, and a basket of self-care items to give away in a drawing. They set up a series of educational and experiential stations where visitors could explore topics related to death, dying, and bereavement. One room held a “Death Café” festooned with balloons and streamers, in which students shared baked goods and beverages and received conversation prompts to help them explore beliefs, values, and preferences about end-of-life matters. One student wrote and performed an original song on a spiritual theme; another delivered a monologue about her grief experience when her grandfather died unexpectedly in a situation involving poor medical management and some very painful interactions with health care providers. She said,

The dictionary defines grief as keen mental suffering or distress over affliction or loss. Sharp sorrow, painful regret. It may be a thing we all have in common, but it looks different on everyone. There are five stages of grief and different people follow different paths through the grieving experience. The order and timing can change for each individual. With my grandfather, bargaining came first, yet no deal I offered changed the words my mother spoke. Denial—he couldn’t be dead. He was getting a biopsy the next day and then coming home. Anger—I lashed out, spitting words of hatred to my father, blaming my mother. Acceptance—a stage I’ve yet to reach after four years. The feeling of loss can be debilitating. The painful emotions can be severe and long lasting. In psychiatry, this is referred to as complicated grief. Grief comes in its own time and in its own way. You can’t control it. The best we can do is try to let ourselves feel it as it comes and let it go when we can. The worst part is that the minute you think you’re past it, it can start all over again. Ignoring reality changes nothing. Face your loss, don’t fight your grief.

Several others displayed paintings and other artwork, alongside a poster describing the therapeutic effects of making and engaging with different forms of art. Other stations illustrated the relationship between wealth and health in the United States; engaged participants in letter-writing to support a statewide bill expanding palliative care services in rural health centers; examined ethical implications of the death penalty; demonstrated hands-only cardio-pulmonary resuscitation and gave participants an opportunity to practice on a training mannequin; compared various burial practices across cultures; and surveyed beliefs about the afterlife across major religions.

Dozens of students, faculty, and staff attended, a great turnout for the small campus. One student opened the event with song; another closed it by inviting participants to try a five-minute meditation practice called “Strong Back, Soft Front.” When it ended, the quiet room erupted into joyous chatter as students expressed both relief that the evening had gone so well and feelings of accomplishment about how much interest the wider community had shown in their presentations.

Three years later, as we reflect on the course and the ways the COVID-19 pandemic has upended health care (and everything else), our concern for the heart and spirit of clinical practice grows. Nurses and chaplains wade elbow-deep into the physical and psychospiritual needs of our patients, and this requires us to develop meaningful self-care and reflexive praxis. Otherwise we risk developing a defensive shell to protect ourselves emotionally from the daily realities of our jobs. During a pandemic—when resources are scarce, patient censuses and disease burdens are high, grief of many kinds is pervasive, and the risks of the job are unprecedented—the possibilities of burnout are higher than ever. A recent comment from a (Christian) nurse who was one of our students in *Caregiving at the End of Life* demonstrates how our educational approach prepared her for the current situation:

Because I see forty people a day and everyone is freaking out [about COVID-19], it’s really helpful to be able to come home and practice yoga and use positive self-talk exercises to de-stress. The exercises of meditation and self-reflection [from the course] taught me skills that help me to be compassionate toward other people. One activity, [a Buddhist practice for cultivating lovingkindness], asked us to imagine someone that you don’t like and then imagine kind things you would say to them or about them. Now, if I have a patient who is really hard or who is being hard on me, it helps me to imagine being nice to them and then it helps me to actually do that. It makes it easier for the patient and for myself. It helps me to have the energy to do it again the next day.

In fact, in their final evaluations of our course, most class members said they found the contemplative practices enormously helpful; they gained new appreciation for the healing power of simply showing up fully and listening with undivided attention to their own hearts, and then to those of others. They valued the respite they got from the demands of their lives and their own drives to excel. Only one complained that contemplation “took a lot of time and effort for nearly no effect on the grade.” She was headed to medical school, so we hope the course planted a few seeds in her that may yet ripen in time.

Notes

1. The “Hand Dance” and “Dancing on Behalf Of” are among the many improvisational exercises belonging to a group creative practice called InterPlay, which Professor Hickey is certified to lead. See www.interplay.org.

2. The evening of the “Hand Dance,” we were joined by researchers associated with the Wabash Center for Teaching and Learning in Theology and Religion and the Interfaith Youth Core who were studying innovative methods of teaching interfaith engagement at universities across the country. They were particularly interested in our use of contemplative methods to foster interfaith understanding and appreciation. They attended class and interviewed students.

3. Meditation is contraindicated for some people, and we feel strongly that students should not be asked to engage in contemplative practice unless it is supervised by someone with extensive personal experience in it as well as training in how to recognize possible adverse effects and when to refer students to mental health professionals.

4. Joan Halifax, *Being with Dying: Cultivating Compassion and Fearlessness in the Presence of Death* (Boston: Shambhala, 2009).

5. Merrill Collett, *Stay Close and Do Nothing: A Spiritual and Practical Guide for Caring for the Dying at Home* (Kansas City, MO: Andrews McMeel, 1997); Leslie Michelson, *The Patient’s Playbook: How to Save Your Life and the Lives of Those You Love* (New York: Vintage, 2015); and Ira Byock, *The Four Things That Matter Most* (New York: Atria, 2004).

6. Atul Gawande, *Being Mortal: Medicine and What Matters in the End* (New York: Metropolitan, 2014); and Lucy Bregman, *Religion, Death, and Dying*, 3 vols. (Santa Barbara, CA: Praeger, 2010).

7. Sid Brown, *A Buddhist in the Classroom* (Albany: State University of New York Press, 2008), 121–26.

8. Nine criteria for a good discussion question were developed by Dr. Grace Burford, formerly professor of religious studies at Prescott University and currently Buddhist chaplain at Davidson College.

9. “Caring Conversations for Young Adults,” n.d., <https://www.practicalbioethics.org/files/caring-conversations/FINAL.Caring%20Conversations%20for%20Young%20Adults.022208.pdf>.

10. Brown, *A Buddhist in the Classroom*, 121–25.

11. We generally prefer the term *interfaith studies* to *interreligious studies* because *interreligious* seems to imply encounters between people of different but specific religious commitments, which would exclude those who identify as nonreligious. Atheism, agnosticism, and claims to a nonreligious “spirituality,” on the other hand, could be understood as *faith* claims even though they do not entail religious affiliation. (For an example of application of this preference, see Wakoh Shannon Hickey and Margarita M. W. Suárez, “Meeting Others, Seeing Myself: Experiential Pedagogies in Interfaith Studies,” in *Interreligious/Interfaith Studies: Defining a New Field*, ed. Eboo Patel, Jennifer Howe Peace, and Noah J. Silverman, 108–21 (Boston: Beacon Press, 2018). However, these meanings are contested, and for purposes of consistency within this volume, we use “interreligious” throughout.

12. Hickey and Suárez.

13. Hickey and Suárez. See also Wakoh Shannon Hickey and C. Denise Yarbrough, eds., special section on Contemplative Pedagogies, *Buddhist-Christian Studies* 33 (2013): 1–162.

14. William Cronon, “Only Connect . . .: The Goals of a Liberal Education,” in *American Scholar* 67, no. 4 (Autumn 1998).

15. Eboo Patel, *Sacred Ground: Pluralism, Prejudice, and the Promise of America* (Boston: Beacon, 2012), 71.