

Strategic Presence: The Effect of the Tibetan Buddhist Chaplain's Presence
on the Family's Process during End of life Medical Feeding decisions

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General Introduction

The end of life is very problematic for many Americans. Families become overwhelmed when faced with the decision to use Artificial Nutrition and Hydration (ANH) after a loved one stops eating for a number of reasons. The chaplain's presence during this time can prove to be effective by allowing the families to uncover their Buddha nature through this confrontation with mortality.

Purpose

What effect does the chaplain's presence have on family decisions when they are presented with the option of feeding their loved one through a vein or tube? What creates presence, and how is it distinctly different than the talking that other services provide? In this qualitative study, an exploration of a Tibetan Buddhist construction of presence, the experience of approaching death, medical feeding, and medical ethics as it relates specifically to feeding and end of life issues are explored to provide compelling evidence about this effect. Authors in the fields of medicine, religious studies, and psychology speak to this subject, and this author's experience as a healthcare and hospice chaplain will elucidate the mystery of approaching death and its effect on the family.

Need for the Study

While many articles have been written about medical feeding, the lack of family education about this subject combined with the dearth of chaplain-focused research present the need for further understanding and a comprehensive overview of the chaplain's tools for presence and the problems he faces when visiting these patients. This will provoke the healthcare industry to utilize chaplains more effectively. While chaplains are busy in the ER, medical staff on other floors go outside their scope of training to provide spiritual care for this issue.

Methodology

The topics of this thesis question include presence, end of life issues, medical feeding and ethics. Texts on the subjects of Buddhism, presence, healing, grief, and ethics were enhanced by articles from OVID and ATLA searches. In addition, interviews with medical staff dealing with this issue were examined. These interviews were conducted from within the context of a Medical Ethics fellowship. Finally, the author's own experience with these topics as a hospital and hospice chaplain and caregiver provided over forty concrete examples of this topic.

The author's unique perspective is derived from his training and practice as a Tibetan Buddhist in the lineage of Chögyam Trungpa Rinpoche, his root guru, and Reginald Ray, his Vajra master, who supervises the author's practice of preliminaries as training for Vajrayāna practice. Both Trungpa and Ray emphasize a western approach to Tibetan Buddhism, stripping it from cultural tradition to deeply root it in American culture and, in Ray's case, exploring the body itself for the richness of its teachings through somatic exercises derived from Tibetan yoga.

Literature Review

This literature review crosses fields and subjects and will be divided into parts: beginning with the construction of Buddhist presence, end of life issues, Artificial Nutrition and Hydration, then Medical ethics as they relate to medical feeding. This reflects the journey of the author with understanding and hope for a clear and direct path.

Constructing Presence

The following sources all define presence from a Hīnayāna perspective as it relates to mindfulness: Edward Podvall's *Recovering Sanity* (1990), Miller and Cutshall's *The Art of Being a Healing Presence* (2001), and Karen Kisella Wegala's *How to Be a Help Instead of a Nuisance* (1996).

Mahāyāna Sources for this process include the following sources that speak of compassion: Chogyi Nyima Rinpoche's *Medicine and Compassion* (2006), John Welwood's chapter "The Healing Power of Unconditional Presence" in *Ordinary Magic* (1992), and Reginald Ray's *Secret of the Vajra World* (2001).

The usefulness of silence is highlighted in David H. Smith's *Partnership with the Dying* (2005), Kübler-Ross' *On Death and Dying* (1969), Mohrmann's *Medicine as Ministry* (1995), and Katherine Ingram's *Passionate Presence* (2000).

The following texts all define interbeing as being an idea that creates a connection that is commonly experienced as presence: Shāntideva's *The Way of the Bodhisattva* (trans. 2003), Ray's *Touching Enlightenment* (2008), Stephen Levine's chapter "Working with Dying People" in *Ordinary Magic* (1992), Podvoll's *Recovering Sanity* (1990), Peter Senge and colleagues' *Presence* (2004), Joanna Macy's *World as Lover, World as Self* (1991), and Irina Rockwell's *The Five Wisdom Energies* (2002)

The following Vajrayāna sources for the construction of presence all speak of space, created by buddha-fields, acknowledged by dākinīs, and sensed or seen in the chakra system: Stephen Levine's *Meetings at the Edge* (1984), Robert Thurman's translation of *The Holy Teaching of Vimalakīrti*, W. Randolph Kloetzli's *Buddhist Cosmology* (1983), Judith Simmer-Brown's *Dākinī's Warm Breath* (2001), Fabrice Midal's *Chögyam Trungpa: His Life and Mission* (2004), Trungpa's 1975 commentary of the translation of *The Tibetan Book of the Dead*, and Charles Meyer's *Surviving Death* (1991).

Pema Chodron's *When Things Fall Apart* (1997) and Simmer-Brown's *Dākinī's Warm Breath* (2001) speak of the charnel ground's presence in the hospital and its arrival in the confusion that the difficult decisions create.

Approaching Death

The patient's experience at the end of life is written extensively with research in Kübler-Ross' *On Death and Dying* (1969), Jane Dinnen's "Advance Care Planning" teleconference in 2004, Chögyam

Trungpa Rinpoche's 1975 commentary of the translation of *The Tibetan Book of the Dead*, Froma Walsh, in her chapter "Opening Family Therapy to Spirituality in Spiritual Resources in Family Therapy (1999, Margaret E. Mohrman's *Medicine as Ministry* (1995), Callanan and Kelley's *Final Gifts* (1992, and Dick Millspaugh's *Making Hard Choices*. These texts help the reader understand what the patient experiences. This experience creates the patient's presence.

The family's experience at a loved one's end of life is detailed and explored in Constance E. Putnam's *Hospice or Hemlock: Searching for Heroic Compassion* (2002), Jerry Gentry's 2008 article "Don't Tell Her She's on Hospice," Megory Anderson's *Sacred Dying* (2001), Kübler-Ross and Kessler's *On Grief and Grieving* (2005), Chokyi Nyima Rinpoche's *Medicine and Compassion* (2006), Kübler-Ross' *Questions and Answers On Death and Dying* (1974), and Callanan and Kelley's *Final Gifts* (1992).

A Buddhist View of death is explored in several sources, including Stephen and Ondrea Levine's *Who Dies?* (1982), Joan Halifax's *Being with Dying* (2008), Gavin Harrison's *In the Lap of the Buddha* (1994), Andrew Olendzki's translation of the *Visuddhimagga*, Carlos Castaneda's *Journey to Ixtlan: The Lessons of Don Juan*, (1972), and Catherine Ingram's *Passionate Presence* (2003).

Artificial Nutrition and Hydration

Definitions of ANH are provided by Chaplain Hank Dunn's widely used text *Hard Choices for Loving People*, Rev. Charles Meyer's *A Good Death* (1998), Barbara Coombs Lee's 2009 blog "300,000 Terri Schiavos" at dailykos.com

Family reactions to ANH are explored by Ira Byock's *Dying Well* (1997), Capron's 1984 article "Ironies and Tensions in Feeding the Dying," Ann Neumann's 2009 article in *Religion Dispatches*, "When Words Kill: A Health Care Glossary," Suter, Rogers, and Strack's 2008 article "Artificial Nutrition and Hydration for the Terminally Ill," and Esther Schmidlin's 2008 article about ANH in *The International Journal of Palliative Nursing*.

Ethics and Medical Feeding

The Ethics of Medical Feeding is discussed by many articles written by the medical profession. These sources ask the question of why medical feeding is offered: Lynn and Childress' 1983 Hastings Center article "Must Patients Always Be Given Food and Water?", George Annas' 2005 article "'Culture of Life' Politics at the Bedside – The Case of Terri Schiavo," Richard A. McCormick's 1989 article "The Cruzan decision," Schmitz and O'Brien, in *By No Extraordinary Means*, (1986), Eric J. Cassell's Hastings Center article "Life as a Work of Art" (1984), Diana Lynne's internet article "Will you be the next Terri?" (2005), Truog and colleagues, in their 2008 "Recommendations for end of life care in the ICU," nursing home administrator Wanda Turner's 2009 *Facebook* story, Chaplain Nancy Berlinger's 2009 *Plainviews* article "Responses to Complex Ethics of Moral Distress," Dala, del Fabbro and Bruera's 2009 article "Is there a role for hydration at the end of life?", Glick and Volandes' 2008 article, "The standard of caring: why do we still use feeding tubes in patients with advanced dementia?", and Gigli's "Ethical Problems in Low Level Neurological States" from 2004.

Buddhist Ethics as it relates to Medical Feeding is explored in Damien Keown's *Buddhism and Bioethics* (1995, 2001), his 2005 *Buddhist Ethics*, and in Philip Kapleau's *The Wheel of Life and Death* (1989). While Buddhists do not grasp onto the body at whatever cost, these sources promote thinking clearly about the intent of the treatment.

Resources and Supports

The Ruth Lilly Medical Library on the Indiana University campus of Indianapolis and Naropa University library were used remotely, in addition to my own texts.

I received feedback about gathering information from my thesis advisor and the faculty of the Warren Fairbanks Center for Medical Ethics in Indianapolis.

My ethics fellowship (2008-9) exposed me to researchers in geriatric ethics and surrogate decision making, in addition to clinical experience with patients as an ethics fellow and chaplain resident.

My second reader is John Smith Lontz, a hospice chaplain with experience with this topic and great interest.

I. Constructing Presence

Presence itself is very hard to define. It makes an appearance, and then the person exhibiting it is described in complimentary terms. What is presence? And yet, the presence and the person seem to originate in each other. How is the presence created? Is it a sign of holiness? Is the person enlightened? Is this a projection? This presence is a construction, directly or indirectly, as a result of actions and experiences of the ‘presenter.’ This goes beyond charismatic demonstrations and gestures, beyond words prescribed by the study of psychology, and beyond clothing choices and projections about a person’s role. It seems to just be there without tangible evidence. The presenter may be focused on this construction or the practice may be working unbeknownst to the presenter:

The chaplain stood in a corner of the room, pressed to the wall, while 15 staff members scurried to restart the patient’s heart, yelling numbers and directing actions. The chaplain simply watched in silence, or at least it looked like that was what he was doing.¹

While presence is difficult to describe in scientific terms, it is possible to define it in terms from the realm of spirituality.

The construction of the Tibetan Buddhist chaplain’s presence is a result of study and practice, which takes place within a mandala (group) of teachers, along with experience.² This can entail studying and practicing a linear sequence of topics, although each topic and subsequent practice can itself work to create presence. It is not necessary to study each of the seven topics with the grand result of ‘presence’; they are linked together by Tibetan Buddhist theology³, taught by a teacher. Studying can entail the reading of sutras with understanding, usually with a teacher’s direction. The understanding of a tantra requires a teacher’s lung or ‘breath of transmission’ to grasp its meaning and wisdom. Practice of teachings in meditation and life is often supervised by teachers and/or meditation instructors.

1. Donald Stikeleather, Journal Entry, March 15, 2009. The stories from the author are derived from his work as a chaplain.

2. The Tibetan Buddhist chaplain’s milieu in this study is the hospital or hospice environment. This work can easily be translated to other avenues for chaplaincy. Also, the chaplaincy role uses theology more intensely. This does not mean that Tibetan Buddhist practitioners outside of chaplaincy have a lesser understanding of these practices.

3. When the term Tibetan Buddhist is used, it refers to the author’s Tibetan Buddhist training, explained in the Introduction.

After study, the practice of presence is lifelong, building presence as the presenter's understanding of Tibetan Buddhist Theology and life circumstances increases with the merit of practice. While presence originates out of one's Buddha nature, it is obscured and needs uncovering by study, teachers and practice.

This chapter will explore writings and experiences about the construction of presence using seven topics of Tibetan Buddhist theology, beginning with Hīnayāna teachings, then Mahāyāna, and finishing with Vajrayāna ideas. The study is not meant to explore Tibetan Buddhist theology comprehensively, but to single out the portion that deals specifically with constructing presence. Stories of the use of presence are included within each section to help describe these ideas in action.

A. Hīnayāna Teachings related to Presence

Hīnayāna View

The Hīnayāna are the foundational teachings of the Buddha, first given at Deer Park in Benares, India. Tibetan Buddhists recognize these teachings as the first tier of teachings, dividing the teachings into three tiers or vehicles, with Hīnayāna providing the foundation for both Mahāyāna and Vajrayāna. "The Hīnayāna teachings outline the fundamental Buddhist ideas of suffering, karma, and non-ego that will be refined in the two higher vehicles. It also describes the basic Buddhist meditation practice of tranquility (shamatha) and insight (vipashyana) which, again are taken up and refined in Mahayana and Vajrayana... and it articulates the goals of renunciation and surrender that form the basis of Buddhist spirituality throughout."⁴

Mindfulness

The mind is at the foundation of working with presence, and the mind training practice of shamatha and vipashyana is necessary to cultivate the mind of enlightenment. A chaplain must work with thoughts that arise, given the activation that can occur around meeting strangers uninvited and serving in a spiritual role, not to mention encountering illness and death. Mindfulness requires acknowledging the

4. Reginald A. Ray, *Indestructible Truth: The Living Spirituality of Tibetan Buddhism* (Boston: Shambhala, 2002), 241.

present moment. First, the chaplain must use her senses to be in the now: Chögyam Trungpa asked students to see the colors of the surroundings, and later to see beyond language that is available to describe the moment. This leads to a fearlessness “to respond to the phenomenal world altogether.”⁵ We must see the reality of the situation without blinders. In the chaplain’s case, it is very important to see whom we are visiting. Miller and Cutshall describe healing presence as “being consciously and compassionately in the present moment with another or others, believing in and affirming their potential for wholeness, wherever they are in life.”⁶ The chaplain’s presence can create a whole where illness has left a broken part. Often, the body is not in the same place as the mind. It is important for body and mind to arrive together, to not stay in one thought for very long, to return to the present if separated by thoughts, and to become present in each moment of newness.⁷ This way, the chaplain remains in each new present moment.

As the chaplain entered the busy ER, he observed the thoughts racing through his mind and let them go. He listened to his own heart rate, felt his breathing, and noticed the colorful display as the EMTs arrived with the patient, and listened to information presented by staff. He did nothing yet, but just stayed there in the moment of arrival.⁸

The contents of these thoughts will be different for each chaplain. The trick is to know that they are thoughts which distance the chaplain from the moment. To give attention directly to a situation is necessary. Chokyi Nyima, in his *Medicine and Compassion*, likens mindfulness (drenpa) to a mother’s awareness of her child: “She gives the child unceasing attention. It is that degree of attention, of paying attention that a spiritual practitioner needs.”⁹ Podvoll cautions that this attention is not unceasing and is reflective of the other person’s mind:

To arouse that presence, you find that you have to work with your own state of mind in a special way. This does not mean that you are straining to be attentive all the time, or that your mind doesn’t wander at all. In fact, when you are alone with someone who is agitatedly absorbed in ‘trance,’ your own mind may wander very much more than usual,

5. Chogyam Trungpa, *Shambhala: The Sacred Path of the Warrior* (Boston: Shambhala, 1984), 52-4.

6. James E. Miller, with Cutshall, Susan C. *The Art of Being a Healing Presence* (Ft. Wayne, IN: Willowgreen, 2001), 12.

7. Karen Kissell Wegela, *How to Be a Help Instead of a Nuisance: Practical Approaches to Giving Support, Service and Encouragement to Others* (Boston: Shambhala, 1996), 190-1.

8. Stikeleather, Journal Entry, Jan. 5, 2009.

9. Chokyi Nyima and David R. Shlim, *Medicine and Compassion: A Tibetan Lama’s Guidance for Caregivers* (Boston: Wisdom, 2006), 93.

and with intense, raw emotions, as if the mental speed of the patient were somehow infectious.¹⁰

The groundless experience of confusion can be terrifying. The chaplain helps the patient gain comfort in this groundlessness directly and fearlessly.¹¹ The chaplain and the patient experience each moment together. This resonance creates presence - being with another.

Suffering

The Tibetan Buddhist chaplain has an understanding of the world as it relates to suffering, as taught originally by the Buddha Shakyamuni at Deer Park. The patient suffers in the now, and the acknowledgement of this suffering creates presence. This suffering originates in a grasping at any number of objects of desire. With practice, this suffering can end, once grasping ceases. Knowing this about suffering, the chaplain follows the eightfold path, using shamatha (mental quiescence) and vipaśyanā (insight) to gain prajñā (wisdom).¹² This prevents the Tibetan Buddhist chaplain from being flooded with the patient's sorrow and then seeking relief, perhaps seeking an outside theistic source to offer this suffering.

As the chaplain rounded on the cardio ICU, not exactly sure where he would visit next, he heard crying. He walked down the hall to see a woman writhing in pain as her nurse pressed buttons to make pain meds flow into her neck port. The patient noticed the face peering around the glass door and whispered, 'chaplain.' The chaplain entered the room and stood at the end of the bed, slightly clasping his hands on the patient's feet as she continued to scream and wiggle. After a few minutes, the patient quieted down, the nurse left to chart, and the chaplain sat in a chair and met the patient's eyes with his. Her eyes then shut as the meds took effect. The chaplain stayed a little longer to listen to the silence, then left.¹³

Suffering is in every room; in a hospital, it is the ground of experience, minute by minute. The Four Noble Truths reside in the chaplain's heart and shine into the suffering of both the hospital experience and life itself.

10. Edward M. Podvoll, *Recovering Sanity: A Compassionate Approach to Understanding and Treating Psychosis* (Boston: Shambhala, 2003), 267-8.

11. John Smith Lontz, personal communication, April 18, 2010.

12. Ray, *Indestructible Truth*, 72-4.

13. Stikeleather, Journal Entry, May 10, 2009.

The chaplain walks toward suffering on an hourly basis. One of the main tenets of chaplaincy is to present a non-anxious presence to others.¹⁴ This can be difficult when death, strong emotions, or physical danger is present.

Friedman emphasized the power of presence... is the trail of confidence, poise, bearing, calmness, focus, and energy one leaves wherever one goes... presence has to do with emotional maturity, the willingness to take responsibility for one's own emotional being and destiny.¹⁵

The Tibetan Buddhist chaplain uses fearlessness, a quality of generosity, to avoid “feeling completely tormented and freaked out about their existence” (and that of others).¹⁶ The chaplain and patient sit with suffering together, present to one another. This fearlessness must not be used to speak or act in an expression of neurosis or a suppression of wisdom, but to fearlessly walk in one's own fear and sit with that, in order to help others sit with theirs.

B. Mahāyāna Teachings related to Presence

Mahāyāna View

As the Hīnayāna practitioner looks at his suffering, he sees that he does not have to maintain ego boundaries so rigidly or put quite so much energy into maintaining his version of reality. Through Hīnayāna practice, one has become increasingly sensitive to the larger world and particularly to the suffering of others. In Tibetan Buddhism, this marks what is called the birth of bodhichitta, the heart of enlightenment. Beings with this motivation want liberation not only for themselves but for all sentient beings.¹⁷ The basic vision of the Mahāyāna is to open the mind, “to let people think bigger, think greater. We can afford to open ourselves and join the rest of the world with a sense of tremendous generosity,

14. Edwin Friedman, *Generation to Generation: Family Process in Church and Synagogue* (New York: Guilford, 1985), quoted in David Cox, “The Edwin Friedman Model of Family Systems Thinking,” *Empirical Research, Academic Leadership: The Online Journal*, Feb. 12, 2007, http://www.academicleadership.org/emprical_research/The_Edwin_Friedman_Model_of_Family_Systems_Thinking.shtml, accessed March 21, 2010.

15. Cox, 2.

16. Trungpa, *Training the Mind and Cultivating Lovingkindness* (Boston: Shambhala, 2003), 7.

17. Ray, *Indestructible Truth*, 311-315,

tremendous goodness, and tremendous richness.”¹⁸ The Tibetan Buddhist chaplain’s heart is dedicated to being open to the suffering of others.

Compassion

Allowing suffering to permeate the chaplain creates a healing, compassionate presence. The hospital experience, while holding the patient in a caring, mothering model of nursing, can also be one of invasive care, lack of privacy, aggressive treatment to sustain life, and ultimate disregard for the human while caring for the body. This cries out for compassion (*karuṇā*). The chaplain is the only service in a hospital that won’t be waking, haranguing, pricking, and prodding the patient. The chaplain brings compassion to the patient as a first priority. Compassion requires looking for one’s own wounded place, turning toward the pain of others, committing to being with the suffering of others, and seeking out this sorrow in the world.

Compassion is created from prior suffering. As humans, we all have a wounded place. This personal wound relates us to others. Trungpa, in *Training the Mind*, describes a sore spot as an analogy of compassion.¹⁹ A Tibetan Buddhist chaplain uncovers this wound from its protective suit of armor.

This is combined with the inner wound, that of Buddha nature, a heart sliced and bruised by wisdom and compassion. When the external wound and the internal wound begin to meet and to communicate, then we begin to realize that our whole being is made out of one complete sore spot altogether, which is called ‘bodhisattva fever.’ That vulnerability is compassion.²⁰

This vulnerability is gathered through exercises to open the heart to others, to reverse the practice of closing the heart to suffering, learned as the ego struggles to survive against the world.

Humans create many things to rationalize away compassion, using excuses not to feel, (she shouldn’t have smoked), neglecting to visit the ill, and finding things to ‘do’ for others instead of feeling. Life can be painful, and looking directly at it can cause bewilderment. Sakyong Mipham Rinpoche, in his *Ruling Your World*, describes compassion as the “foil of bewilderment... It is the mind’s genuine energy, radiating from basic goodness like the sun. It lifts us above self-involvement and brings us out of the Dark

18. Trungpa, *Training the Mind*, 8.

19. Trungpa, *Training the Mind*, 9.

20. *Ibid.*, 10.

Age.”²¹ Compassion can be painful and is difficult to sustain. The bodhisattva has learned to join *śamatha* and *vipaśyanā* together in order to practice compassion for great lengths of time, necessary for chaplain work. Chogyi Nyima Rinpoche describes three stages of a ‘compassionate attitude:’

The first stage is to try to stop thinking of ourselves as being more important than others. The second stage is to try to mentally put ourselves in another’s place - to be willing to exchange ourselves with others. The third stage is to regard others as more important than ourselves.²²

This multi-stage process strengthens the compassionate heart. It begins small, is easy to feel for those we like, is harder but possible for those we dislike, and can be tremendously difficult for the self.

The Tibetan Buddhist chaplain brings an awakened mind (*bodhichitta*) to the patient. Pema Chödrön writes of the gap in our meditation experience, where “we experienced a pause, as if awakening from a dream... this coming back to the immediacy of our experience is training in unconditional *bodhichitta*.”²³ As humans, we respond to suffering by turning away. Chaplains are trained to look underneath the turning away, which is probably tied to one’s own wounds, and to look toward. “To be encouraged to stay with our vulnerability... sitting meditation is our support for learning how to do this.”²⁴ Chaplains are actually willing to feel pain, a practice that allows compassion to flow. The heart is trained to stay open more and more to all circumstances:

The everyday practice is simply to develop a complete acceptance and openness to all situations and emotions and to all people, experiencing everything totally without mental reservations and blockages, so that one never withdraws or centralizes onto oneself.²⁵

The chaplain, a professional bodhisattva, is there for others: “the idea that our lives are ‘for us’ is actually incorrect. We live and are here ultimate and truly only for others. It’s the fundamental truth of the universe.”²⁶ This strenuous work immerses the chaplain in an ocean of sorrow and pain, necessitating thorough self care without escaping from the practice totally. Roshi Joan Halifax wonders who benefits

21. Sakyong Mipham, *Ruling Your World: Ancient Strategies for Modern Life* (New York: Morgan Road, 2006), 107.

22. Chogyi Nyima and David R. Shlim, 91.

23. Pema Chödrön, *The Places that Scare Us: A Guide to Fearlessness in Difficult Times* (Boston: Shambhala, 2002), 24.

24. *Ibid.*, 23.

25. Chögyam Trungpa and Rigdzin Shikpo, “The Way of Maha Ati,” in www.scribd.com/doc/8302474/The-Way-of-Maha-Ati, accessed March 17, 2010.

26. Ray, personal communication, November 18, 2009.

from this work: “Are we sitting with someone who’s dying, or with ourself? We don’t turn away from our own issues, just as we don’t turn away from a dying person.”²⁷ We bring ourselves to this work. It is mutually beneficial to both patient and chaplain. We must look in the face of suffering. It is hard, but we can’t turn away: “For Sister Helen (Prejean), being physically present for that inmate to look on her face as he went to his death was being compassionate. She was present there in his humanness. She heard his cry and she responded with her heart.”²⁸ This breaks the heart open, which is not a pleasant talk. The heart has to begin to feel again, maybe for the first time in the practice of taking and giving (tong len): “The heart must break open to receive the other. It will receive the world and its pain: On the in-breath your heart breaks, (and) on the out-breath, tenderness goes out and touches everything.”²⁹ Mikel Monnett, a Tibetan Buddhist hospital chaplain from the Zen Peacemaker’s Order, recalls Bernie Glassman’s idea of bearing witness, as it relates to the medical professional’s stamina for compassion:

We mean to see clearly the situation that’s there, no matter how painful. Many medical professionals build a wall between themselves and their patients to protect themselves from the misery of their patients’ suffering. Often they do this because they are afraid that, were they to be touched by every patient’s suffering, their own already overburdened hearts would break and they would no longer be able to do the work that they need to do. So they develop a veneer of professionalism that supposedly protects them from being overcome by the suffering they see every day.³⁰

By actually feeling the pain, allowing their hearts to break, they can experience the suffering with the patients. “There is a joy that comes from being fully a part of the process of illness and healing with a patient and their family, rather than being one step removed from it. This is how we bear witness.”³¹ It is incredibly important for those suffering to know they are not suffering alone. This connectiveness to other is presence in action.

27. Joan Halifax, *Being with Dying: Cultivating Compassion and Fearlessness in the Presence of Death* (Boston: Shambhala, 2009), 76.

28. Helen Prejean, from the lecture, “Developing a Theology of Discernment: A Chaplain Approach,” Sept, 12, 2009, quoted by Sheryl Nicholson in *Whose Face is It? Reflections from the September 2009 Regional Conference*, personal communication, Nov. 2009.

29. Ray, from the lecture, “Vajrayana Tonglen practice,” Seattle, Washington, February 3, 2010.

30. Bernie Glassman, *Bearing Witness* (New York: Bell Tower, 1998), quoted in Mikel Monnett, “Developing a Tibetan Buddhist approach to Pastoral Care: A Peacemaker’s View,” www.TibetanBuddhistchaplainsnetwork.org/profilesinwisdom/Monnett.htm, accessed October 17, 2008.

31. Monnet, 5-6.

Compassion takes the chaplain to places of deep sorrow, necessitating a strong emotional well of stamina:

The woman lay there in the ER, arms burned and black, eyes looking through a grey face, yet willing to give phone numbers of the parents of the abusive husband she shot and burned. He had been holding her dog captive and threatened to kill it. In her fury, she shot and killed the dog and turned the gun on herself, but it jammed. She grasped the chaplain's hand as he said 'I'm sorry for the way that he abused you.' In the silence, she cried. She will get 105 years for this crime. A few months later, she threw herself off the 2nd story balcony in prison and lived through it. She is now in hell.³²

The chaplain must 'sustain the gaze;' he cannot become numb. Joanna Macy's despair work "allows people their own responses of anguish to what is happening to their world. These responses... have been kept at bay, and the denial has, in turn produced psychic numbing... When we are open to our responses it frees energy, as any cathartic process will do."³³ Macy describes compassion as "suffering with our world."³⁴ The strength to not turn away from suffering creates a lasting and hearty presence.

Seeking the sorrow in the world, which starts with being with others as a commitment of the heart, the Tibetan Buddhist chaplain uses her own pain as a springboard to being present and not turning away.

Silence

Silence speaks volumes about attention to another person. It creates a presence that allows the other to flourish in the resultant space. Often, saying something does not help. Nothing can help. In David H. Smith's *Partnership with the Dying*, he speaks of "learning the importance of sitting quietly and not saying anything. And what appears to us often as not doing anything. We want to do something."³⁵ It is difficult for people to just sit. We want to fix. We want to fix the covers, go on an errand, talk about life, ask questions about how the patient is doing, and even sing songs to fill the silence. Yet, the silence fills the space with presence, the presence of companionship. Elizabeth Kübler-Ross speaks of a "time when it

32. Ibid., June 5th, 2009.

33. Joanna Macy, "Interview with Joanna Macy," by Catherine Ingram, Feb. 10, 1989, Berkeley, CA, quoted in *In the Footsteps of Gandhi* (Parallax: Berkeley, 1990), 165.

34. Ibid., 166.

35. David H. Smith, *Partnership with Dying: Where Medicine and Ministry Should Meet* (Boulder: Rowan and Littlefield, 2005), 55.

is too late for words... it is the time for the therapy of silence with the patient.”³⁶ At the end of her book, she quoted a brief poem by Tagore that epitomizes the effect of silence:

The water in a vessel is sparkling; the water in the sea is dark.
The small truth has words that are clear; the great truth has great silence.³⁷

Judith Lief points out another use of silence: “When we sit quietly with another person, we gradually become more aware of that person’s presence. We begin to accept and appreciate him. Those two qualities, awareness and acceptance, are the ground of kindness.”³⁸ Sometimes words are impossible. Minnesota hospital chaplain Ruth Johnston tells of listening to a Chinese woman’s story about her dying husband, told in her native language while holding the chaplain’s hand. The woman knew the chaplain could not understand Chinese, yet the chaplain seemed to understand with her heart. Johnston called this “ministry through pure presence.”³⁹ Saying less does more for someone than most of what is said in times like this. Often what is said is to comfort the visitor, not the patient or family member. Margaret Mohrmann describes a patient visit where there were no words, but only tears:

She started mumbling, and then she began talking louder and more distinctly as her litany of mourning became stronger... She asked, “Who’s going to sit on the porch in the evening with me... I had no answer but my own tears. By being there, I learned – in a way that nothing else could have taught me – exactly what that loss meant in that woman’s life. I learned the depth of her wound... I gave her the human companion she needed for a partner in her groping attempts to give voice to the meaning of her grief.”⁴⁰

Tears as part of work, while being exhausting, have a tremendous language of caring imbedded in them. “They are the language of the spirit.”⁴¹ With no words, we are actively present, doing nothing. Joanna Macy has described Gandhi’s words and life as “resting in action.”⁴² We do much by just being there. Resting achy chaplain feet is one thing, but resting the mind in silence has great merit for the creation of presence.

36. Elisabeth Kübler-Ross, *On Death and Dying: What the dying have to teach doctors, nurses, clergy, and their own families* (New York: Simon and Schuster, 1969), 275.

37. Rabindranath Tagore, from *Stray Birds*, CLXXVI, quoted in Kübler-Ross, 276.

38. Judith L. Lief, *Making Friends with Death: A Tibetan Buddhist Guide to Encountering Mortality* (Boston: Shambhala, 2001), 87.

39. Ruth Johnston, “The Language of Presence” in *The Journal of Pastoral Care and Counseling*, Fall 2004, Vol. 58, No. 3, 255-6.

40. Margaret E. Mohrmann, *Medicine as Ministry: Reflections on Suffering, Ethics, and Hope* (Cleveland: Pilgrim Press), 115.

41. Jeff Nixa, “Spiritual Care Volunteer Training,” Memorial Hospital, Sept. 5, 1999.

42. Macy, 152.

The family listened to the Organ Donation team as they explained the opportunity of donation. The team left, and the family and chaplain sat. The family's silence filled the room, punctuated by crying and questions about the decision, then laughter as stories were remembered. The chaplain listened, but did not speak, though his white jacket and name tag made clear his role. After awhile, the oldest family member suggested that they announce their decision. Everyone left the room.⁴³

The poet Yeats defines the power of silence: "We can make our minds so like still water that beings gather about us to see their own images and so live for a moment with a clearer, perhaps even with a fiercer life because of our silence."⁴⁴ Presence uses silence as a powerful tool to allow the other to blossom in the space of no words.

Silence does not have to be pretty and calm. It can be a powerful ally when mediating potential violence:

The two brothers stood facing each other, with the chaplain in between. The chaplain looked down as he listened to the men threaten each other. They towered over him. Another chaplain got the first chaplain's eye, mouthing 'Are you alright?' The first chaplain nodded. The men continued to listen to each other's painful feelings about their dying sister. They agreed to disagree and walked away from each other.⁴⁵

In the following situation, the room was not silent:

The daughter of the patient scared staff when she pushing through the code team working on her mother and collapsed on the floor the day before. The chaplain was paged when the patient coded again and the daughter arrived. This time, she knew for sure that her mother was dying. She entered the room, and the chaplain followed. The chaplain closed the door, sealing the room shut. The daughter sat in a chair and began to scream and sob. The room was filled with sound. The chaplain stood in the corner and listened.⁴⁶

Silence, like a tree standing quietly, breathing in air, creates presence during stressful encounters. This stress requires the use of shila or conduct to help the chaplain decide what to do next. Sometimes the best thing to do is nothing – saying something can be detrimental.

Listening

Listening is an important part of being with another person, tracking the presence of the other. It goes beyond hearing toward taking the words of the other person into the heart. Often it can help to repeat what has been said. Although this paper is not focusing on what is said, listening is a powerful way to

43. Stikeleather, Journal Entry, October 5, 2008.

44. William Butler Yeats, *The Celtic Twilight* (1902) as quoted in Miller, 30.

45. Stikeleather, Journal Entry, Jan. 10, 2009.

46. *Ibid.*, February 10, 2009.

create presence, the presence of the listening heart. Listening can be a product of compassion and silence, although some that listen are not necessarily compassionate. It is possible to judge and create distance with what one is hearing from the other person. We use all the senses in mindfulness to take in the other person, bringing much information in for a resonance and acceptance of the other as the self. This can be described as interbeing.

Interbeing

We are not separate from others. When we realize this, we share our presence with the world. Although we are trained in life to compete, to distinguish between, to rank, to create territory and to inflate one's ego, the Tibetan Buddhist chaplain works against these habits to be with another person in a way that allows the other to flow in and inter-be, as Thich Nhat Hanh described in his 1993 text *Interbeing*, "the phenomenon that occurs when persons interact with each other completely mindful of all persons in the interaction, their goals, concerns, and feelings, as well as the process of the interaction itself."⁴⁷ Nhat Hanh calls it interbeing (tiệp hien), referring to the concept of *paticcasamuppāda*, Pali for dependent co-arising. It is not clear who we really are or where we have come from, and for that matter, who is the chaplain and who is the patient?

No one is truly separated from suffering. The chaplain must look inward with meditation practice in order to see brokenness within. This is what the chaplain uses to work with others. Miller and Cutshall recognize the need to be open to one's own brokenness first, before attending to the brokenness of another.⁴⁸ The chaplain uses his brokenness - this tenderness to create resonance with others. Ray adds that "to be fully embodied involves an unconditional presence to our emotional life, not separating and not distancing ourselves by retreating into our heads into judgments, recriminations, or self-loathing."⁴⁹ The disembodied practitioner thinks, using head knowledge. The embodied chaplain senses with his body, listening with the heart. According to Joanna Macy, this practice uncovers the fact that caring is natural and also painful:

47. Thich Nhat Hanh, *Interbeing, Fourteen Guidelines for Engaged Buddhism* (Parallax: Berkeley, 1987)

48. Miller, 25.

49. Reginald A. Ray, *Touching Enlightenment: Finding Realization with the Body* (Boulder: Sounds True), 31.

It's in honoring the depths of our responses to what is going on in the world that we experience that the pain comes from caring, and that caring springs from interconnectedness. In other words, our responses are a direct doorway into, or proof of, interdependence. Realizing this can pop us out of that narrow prison of the separate ego.⁵⁰

The chaplain's practice must be strong in order to break out of the separateness of ego, class, and privilege. Shāntideva writes that meditation should focus on the sameness of oneself and others, that pain is simply pain, and there is no difference to distinguish between people. These labels are like mirages.⁵¹ Neurologist Richard Restak writes that people are naturally wired to be empathetic, but that some people "restrict their empathy to the people they can identify with... fortunately such empathic limitations can be overcome by the steady application of one's own effort."⁵² Restak asserts that meditation can work on these empathic areas of the brain, creating a 'homo empathicus.'⁵³ The Tibetan Buddhist chaplain has an evolved way of working with her mind, but this is not an overnight process. The work of meditation slowly leaks into daily life. After reading chart notes and listening to a patient's story, it would be easy to judge and separate from another.

The nurse placed the dead baby in the mother's arms. While the chaplain knew about the presence of illegal drugs and microfractures within the infant's body, he strove to not mentally leave this room of piercing screams, intense sorrow, and hospital blame. Breathing in the same rhythm as the mother, who clutched the baby to her chest, he stayed next to her on the couch.⁵⁴

While Western psychology and Theism fortifies the ego and encourages dependence on a higher being to provide solace, Tibetan Buddhist practice breaks ego and dependence apart, invading ego and separateness. Presence is sustained by the effort to be with, to suffer with, and to not turn away.

This effort to be with others can be a therapeutic exchange, according to Edward Podvoll: (It) is a 'giving up' and 'letting in'...when it happens, you cannot hang on to it. Exchange does not develop into a fascination or a mental indulgence... (but to) extend one's clarity. With this kind of gentle contact, a soft

50. Macy, 166.

51. Shāntideva, *The Way of the Bodhisattva: A Translation of the Bodhicharyāvatāra*, trans. by the Padmakara Trans. Group (Boston: Shambhala, 2003), 123-4.

52. Richard Restak, "'Empathic Civilization': Our Brains Were Built For Feeling Each Other's Pain," in Books/NYR, *Huffington Post*, February 15, 2010, http://www.huffingtonpost.com/richard-restak/empathic-civilization-our_b_460845.html, accessed February 15, 2010.

53. Restak, 2.

54. Stikeleather, Journal Entry, Dec. 12, 2009.

spot in the patient and oneself can become available.⁵⁵ While this is conceptual, a cerebral understanding of this is not good enough. Reginald Ray's somatic exercises explore the layers of separation that can fall away: "we realize that our body feels, senses, knows its interconnection with all things... ultimately, we are nothing other than 'interbeing.'"⁵⁶ Ray breaks down interbeing into different layers: the physical body (envelope of skin), interpersonal body (relationships) and cosmic body (primordial body of the earth). His study of the body reveals its personal, interpersonal, and then cosmic nature.⁵⁷ To actually experience through Ray's exercises what Śantideva described gives the practitioner much more information than reading or contemplating.

During and after this practice, the thoughts that seem to keep me comfortable and egoic seem to fall away and my body awareness expands infinitely. There is no skin separation or relationship that is certain; there is just space.⁵⁸

The practice of interbeing shows that we are not separate from others, we are not separated from the suffering of others, and that this practice requires strength of mind to embrace all others. This embrace can be therapeutic, causing change in both the patient and the chaplain. Presence occurs when the walls of ego come down and hearts beat as one.

The Mahāyāna view of presence is one of allowing the other in. Cultivating compassion, embodying the emptiness of silence, listening instead of filling space with thoughts, and exchanging self for other are all ways that the Tibetan Buddhist chaplain constructs presence.

C. Vajrayāna Teachings related to Presence

Vajrayāna View

"The distinctive feature of Vajrayāna Buddhism is ritual, which is used as a substitute or alternative for the earlier abstract meditations."⁵⁹ The Vajrayana view is provided by the Mahayana, along with meditation practices for attaining enlightenment in one lifetime. One visualizes oneself as a full

55. Podvoll, 271.

56. Ray, *Touching Enlightenment*, 130.

57. *Ibid.*, 130-1.

58. Stikeleather, Journal Entry, Dec. 23, 2009.

59. A. K. Warner, *Indian Buddhism* (Delhi: Motilal Banarsidass, 1999), 466.

enlightened buddha. This visualization gives imaginative representation to our own buddha-nature⁶⁰ within, which is otherwise inaccessible. Through enacting tantric⁶¹ liturgies, “one’s own sense of being a separate, egoic self gradually dissolves and is replaced by the buddha-nature... resting in the open, empty, cognizant nature that is the very core of our being.”⁶² Instead of the Mahayana’s effort to transmute and transform, life is taken fully with all its colorful display and energy.

Space

The Tibetan Buddhist chaplain uses space strategically to create presence. First, there is space in the mind that creates presence in the moment. Chaplain Mikel Monnett describes this as ‘not knowing’:

“what we mean is the ability to walk into a situation without a preset agenda. This means that you walk into the patient’s room with what we call ‘empty mind.’ This (does) not mean that you walk into the room with a blank mind. Rather... you bring with you everything that you have learned, everything that you have experienced, and everything that you are. But you do not plan on what you’re going to do until you take a look at the situation as it presents itself.”⁶³

This sacred space is called a buddha-field. Vimalakīrti⁶⁴ explains that a buddha-field is area of the practitioner’s merit of practice. It literally contains all the qualities of a Buddha, such as generosity, morality, tolerance, effort, meditation, wisdom and dedication.⁶⁵ It is the space where presence resides. The more practiced, the purer the Buddha field. The practitioner brings this practice, years of it, into the room with her. Kloetzli explains, that in a buddha-field, “a fully and perfectly enlightened Tathāgata resides and teaches the law for the benefit of countless beings.”⁶⁶ The Tathāgata is no longer human, but has ‘gone beyond,’ is enlightened, and is a living example of Tibetan Buddhist scripture. But is the Tibetan Buddhist chaplain enlightened? No, but her presence is created by the practice and study that

60. The inner, awakened state that dwells at the heart of all sentient beings as their inmost essence. Ray, *Indestructible Truth*, 48.

61. Secret, advanced, guarded, not to be confused with popular culture’s misinterpretation as purely sexual. .

62. Ray, *Secret of the Vajra World: The Tantric Buddhism of Tibet* (Boston: Shambhala, 2002), 91, 107.

63. Monnett, 5.

64. Vimalakīrti is considered the first Indian Zen master, famous for his writings on emptiness. He specialized in “a type of discourse that is subtle, in a lucidity that balances on the razor’s edge of paradox and yet quite logically coherent.” Robert A. F. Thurman, *The Holy Teachings of Vimalakīrti: A Mahāyāna Scripture*, trans. By Robert A. F. Thurman (Delhi: Motilal Banarsidass, 1976), frontispiece.

65. Thurman, 15-17.

66. W. Randolph Kloetzli, *Buddhist Cosmology: Science and Theology in the Images of Motion and Light* (Delhi: Motilal Banarsidass, 1989), 5.

eventually produces enlightenment. It is the presence of the promise of enlightenment.⁶⁷ Perhaps the practitioner stands within “a force-field of awake, created by enlightened facilitators.”⁶⁸ In this way, the field attracts bodhisattvas. It is a destiny toward awake. “All beings gravitate toward the awakened state.”⁷⁰ Ray would agree that this force field is created as beings sit together in meditation, and as awareness extends beyond the skin, the buddha field grows.⁷¹⁷²

This presence created by space fills the room. Judith Simmer-Brown’s *Ḍākinī’s Warm Breath* speaks of the Ḍākinī as a symbol of limitless space.⁷³ Perhaps the Ḍākinī enters a patient’s room first to create a space of non-thought. In Trungpa’s Shambhala teachings about warriorship, the warrior uses wangthang, or field of power. “Trungpa preferred to translate it as ‘authentic presence.’ Such a feeling of power provides profound confidence that radiates and puts us in direct contact with reality. It is the life force manifested at its peak.”⁷⁴

Space is infectious. Judy Lief writes of space reaching out, of presence filling the room and being palpable to others: “to the extent that we ourselves are present, we can radiate that same quality outward to the people around us.”⁷⁵ Trungpa compares this to focusing a beam of light with a mirror, like a beam of awareness, to project our feeling of presence.⁷⁶ As a practice, space can open up around the chaplain:

When the chaplain read the details of the trauma, he walked briskly to the code. As he walked, he visualized a space of unknowing around his body, like a bubble of quiet in the eye of a storm. As he entered the ER, the bubble was pierced, but he remained there at the center, generating no thoughts.⁷⁷

As a non-anxious presence, the chaplain is confronted by discursive thought processes, sometimes all around at once. In order to construct a presence that is consistent, practice is necessary.

67. One might also say that the chaplain is already enlightened, but does not know it. It is obscured.

68. Judith Simmer-Brown, lecture, “Second Turning of the Wheel of Dharma,” Nāropa University, January 27, 2005.

69. In Tibetan, ‘sal wa’ (སེལ་བ་ gsal ba), can be defined as radiance, clarity, luminosity, to be radiant, to be luminous.

70. Simmer-Brown, lecture.

71. Ray, dharma talk, during “Winter Dathūn,” Dharma Ocean Foundation, Crestone, CO, Dec. 23, 2009.

72. This buddha-field is both created and also uncovered.

73. Simmer-Brown, *Ḍākinī’s Warm Breath: The Feminine Principle in Tibetan Buddhism* (Boston: Shambhala, 2002), 51.

74. Fabrice Midal, *Chogyam Trungpa: His Life and Vision* (Boston: Shambhala, 2001), 215.

75. Lief, 157.

76. Midal, 199.

77. Stikeleather, Journal Entry, March 10, 2009.

This 'Mahayana space' transmutes the discursive environment when needed. 'Vajrayana space' accepts all energy coming toward it, working with it like a boat on a rough ocean, the boat moving with the waves. The chaplain uses skillful means to determine what kind of space would be most beneficial to all. In the hospital, the patient's care comes first, so this directs the chaplain's choice. Sometimes, the space needed is that of being completely alone, so the chaplain leaves.

Presence creates space and space creates presence. The space created in the mind fills the room and those affected by it. This sacred space fills the situation with potential, pointing to the dance of unknowing.

Charnel Ground

If a hospital is known as a place where life and death are confronted and examined, then the hospital milieu is a kind of charnel ground. This Tibetan graveyard is the ground of reality. There is much to learn in it about life.

Perhaps the closest thing to a charnel ground in our world is not a graveyard but a hospital emergency room. That could be the image for our working basis, which is grounded in some honesty about how the human realm functions. It smells, it bleeds, is full of unpredictability, but at the same time, it is self-radiant wisdom, good food that which nourishes us, that which is beneficial and pure.⁷⁸

The charnel ground is full of enlightenment. When the chaplain arrives, his presence is a reminder of life and death and their delicate dance. Whatever was happening before this moment is cut through by this presence. For this reason, chaplain presence is sometimes prevented by nurses who wish to manage the patient and family's emotions, especially when the nurse needs them to stay cognitively present for information gathering. Or, if the nurse cannot make the family understand the impending death of a patient, the chaplain might be called:

The nurse called about the dying patient's daughter. The chaplain could hear the daughter whimpering down the hall as he approached the room. He checked in with the nurse, and then entered. He noticed a non-responsive elderly woman in the bed with her daughter leaning on the patient's chest. When the chaplain introduced his role, the daughter's tears turned into screams and head shaking. The chaplain just stood as the daughter bargained with her brother: 'no, she can't be dying... but now the chaplain is here. Oh no. This can't be happening.'⁷⁹

78. Pema Chödrön, *When Things Fall Apart: Heart Advice for Difficult Times* (Boston: Shambhala, 1997), 124.

79. Stikeleather, Journal Entry, June 20, 2009.

In this situation, the shock of the chaplain's presence changes the hospital from a fantasyland of hope and denial to the crashing reality of impending death. This is a case where the stereotype of the chaplain representing death is very accurate. Simmer-Brown defines the charnel ground as "the landscape or the psychological environment in which one can commit to things as they are."⁸⁰ Tulku Thondup describes the charnel ground's beauty:

They are also enjoyable places of peaceful solitude, delightful groves, blossoming flowers... These charnel grounds are places of energy, power, and spirit both positive and negative... to transform into esoteric power and energy of enlightenment.⁸¹

There is no way to hide death in this context. Patients waiting for elective or non-emergency surgery can leave the operating room in a coma or dead. A post-surgical patient with a rip in her heart after a deadly car accident can suddenly open her eyes and speak, much to the surprise of family anticipating her death. This is truly the space of unknowing.

The silence after a death or code blue has subsided can bring a shocking moment of peace. The sounds, crowds, and emotional turmoil can all shift to just silence and space. A truth has been revealed, be it death or life, of which no one has control. The space of reality shines in. The chaplain brings experience of many, many deaths - some that look very similar to each other, only with different faces. This knowing creates a wisdom presence of the charnel ground. Some would call a chaplain a portable sanctuary. The chaplain as a portable charnel ground brings clarity to confusion.

The study of texts and listening to teachers has been named as part of what is necessary to create presence. Reggie Ray explains it differently in a recent quote:

The dharma is not found in books. It's not found in the things you hear. It's not found in what other people think. The dharma is the deepest truth of your own life; the deepest truth of your own being; the deepest truth of your own perceptions and feelings.⁸²

It would appear that, like the scholar Nāropa, it is not the book learning and commentary about doctrine, but the practice of life itself, a truth that communicates wisdom that the chaplain brings. This may be why

80. Simmer-Brown, 121.

81. Tulku Thondup, *Masters of Meditation and Miracles* (Boston: Shambhala, 1996), 366, as quoted in Simmer-Brown, 123.

82. Ray, dharma talk, *Winter Dathün 2006*, Dharma Ocean Foundation, Crestone, Colorado, Dec. 22, 2006.

the stereotype of the 'old man' exists in chaplaincy. It is not for the young. It requires life experience in addition to these tools.

D. The Construction of Presence

Study, practice and experience facilitate the Tibetan Buddhist chaplain's construction of presence, using the following ideas from Tibetan Buddhist theology: mindfulness, suffering, compassion, silence, interbeing, space, and charnel ground. Each of these practices creates presence by itself. The Tibetan Buddhist chaplain's presence is the fruition of his study, practice and experience.

For Madhyamaka effect, the question is asked: are these actually deconstructions?⁸³ Since mindfulness deconstructs discursiveness, suffering cannot be covered over and dismissed, compassion uncovers the guarded heart, silence deconstructs language, interbeing removes barriers between, space removes form, and finally, the charnel ground deconstructs a false reality, these ideas could also be viewed as deconstructions.

Later, this paper will show how a different set of circumstance affect patient and family presence, and then how these tools affect families making medical feeding decisions at the end of life.

83. Amy R. M. Stahl, personal communication, Feb. 17, 2010.

II. Approaching Death

A. The Struggle with Death in America

For the purposes of this study, death will be viewed not as simply a physical shutting down, but as a spiritual process. “The body will take charge on its own. The spiritual reality will not. Sacred dying means bringing the spiritual experience to the forefront. Deal with spiritual things, whatever they may be, first and foremost.”⁸⁴ Negative reactions to death will be emphasized.

The way a patient and family thinks and copes with approaching death creates a presence of its own. This is what the chaplain encounters in the space of the patient’s room. A chaplain who approaches death vigils daily has knowledge of what death has become in the modern world. What has gotten the patient and family to this point in life will have a strong effect on what the chaplain finds in the room related to emotions, values and opinions. Therefore, understanding death provides a map for the chaplain’s work. This understanding of death requires a thorough grasp of the American cultural view of death, the experience of one who is dying, the experiences of those who remain, and a Tibetan Buddhist view of death to ground the Tibetan Buddhist chaplain as she provides presence during this time.

1. American Cultural View of Death

Approaching death in the United States has changed over the years. Gone are the days of the Victorian viewing room next to the front door with the staircase arranged for visitor cueing. Americans want to die without machines, at home, in comfort, and not a burden. Instead, most Americans experience death with machines and ventilators, in a hospital or nursing home, in discomfort, and with the expenditure of savings.⁸⁵ It is also often a surprise to the patient, who does not even know she is dying, part of our ‘culture of life.’⁸⁶ In addition, spiritual delusion, delays, denial, an American style of polarized

84. Megory Anderson, *Sacred Dying: Creating Rituals for Embracing the End of Life* (Roseville, CA: Prima, 2001), 25.

85. Jane Dinnen, teleconference, “Advance Care Planning: Barriers, Cultural Shift, Success, Funding,” Munsen Healthcare, viewed online on March 12, 2004.

86. ‘The Culture of Life’ refers to the anti-abortion movement, as opposed to the ‘Culture of Death,’ a term Pope John Paul II used and resurrected in 2009 by the Republican Party when doctors asked for compensation for time talking to patients about end-of-life - stopping treatment. This was misinterpreted and exaggerated to mean that death would be decided by a group, a ‘death panel.’ See Daniel Schultz, “The New Craze That’s Sweeping the Nation: Killing Granny,”

thinking, and the notion of a ‘good death’ paint a picture of this hidden part of life. This chapter will focus on these realities and explore the reasons why. The Tibetan Buddhist view of death is presented not for basic comparison, but to share a different view of death with values that could be incorporated into American culture with a shift in the paradigm of how life is lived.

Aggressive treatment during the death process

Americans simply don’t want to die. “The notion of immortality pushes us to work to ensure that our lives have meaning, whereas death suggests that life adds up to nothing.”⁸⁷ Aggressive treatment is curative, trying to reverse the disease process. “While the dominant orientation of Western culture toward death is avoidance, for over 2,500 years, Buddhists have studied the question of how one can best live in the presence of death.”⁸⁸ Treatments try to repair the body with goals of moving toward health and living. When death is near, doctors will offer treatments available as they are useful to the patient. Often, the patient or family has a conference where they decide to either maintain an aggressive approach or switch to a palliative or ‘comfort care’ option. Elders are now provided palliative care sooner than before, although children with equally pessimistic prognoses are routinely taken through a regimen of treatments. It is harder to watch a child die. (Children aren’t supposed to die) Thus, most ethics consultations focus on whether a treatment is really what the patient would want and why it is being given. Death is thwarted for as long as possible. The death process is hidden as treatments mask death’s arrival. Sogyal Rinpoche describes his shock when confronted with Western teachings that

deny death, and taught that it means nothing but annihilation and loss. That means that most of the world lives either in denial of death or in terror of it. Even talking about death is considered morbid, and many people believe simply mentioning death is to risk wishing it upon ourselves. Others look on death with a naïve, thoughtless cheerfulness, thinking that for some unknown reason, death will work out all right for them, and that it is nothing to worry about.⁸⁹

http://www.religiondispatches.org/blog/religiousright/1734/the_new_craze_that%E2%80%99s_sweeping_the_nation:_killing_granny accessed August 14, 2009.

87. Ernest Becker, *The Denial of Death* (Tampa: Free Press, 1997), quoted in Martha R. Jacobs, *A Clergy Guide to End-of-life Issues* (Cleveland: Pilgrim Press, 2010), 7.

88. Halifax, *Being with Dying*, xi.

89. Sogyal Rinpoche, *The Tibetan Book of Living and Dying* (San Francisco: Harper, 1993), 7.

Why run from reality? Why run from death? The mystery of the unknown has created a form of modern torture. An ancient spiritual practice? No, the modern hospital ICU.

Institutional death

Aggressive treatments often necessitate a hospital or nursing home stay, especially if specialized care is necessary.⁹⁰ Often, family caregivers are not equipped with the knowledge, and more significantly, the stamina to provide care for a loved one. A living will⁹¹ is sometimes disregarded in a panic when death shows its face, which necessitates a trip to the hospital. Elders are resuscitated over and over, following the letter of the law when their wishes and doctor's orders have been neglected. Therefore, the patient wishing for a death in the comforts of home is subjected to the clinical atmosphere of the healthcare facility. "When a person dies in a hospital, he is quickly whisked away; a magical disappearing act does away with the evidence before it could upset anyone."⁹² The nurses try to tidy up the body, since the death process in a hospital often takes place with machinery nearby and tubes inserted. After the family leaves, the gurney is sheathed with a leather covering so that it looks like laundry.

His body was still in the ICU bay after the family left. The tech arrived and the chaplain offered to escort them. The tech seemed relieved but didn't elaborate. They all rode the elevator down to the morgue. At the morgue door, the chaplain murmured, 'Bye, Max' and continued down the hall, internally 'resetting,' or more likely adjusting to a new awareness, a new outlook on death. The funeral home would arrive later.⁹³

Death Alone

A patient experiencing death in a hospital or nursing home often does so alone. Visiting hours, family schedules, and fatigue prevent the presence available in a home. A rare spouse will spend a month camped out in a hospital waiting room, suitcase under the couch, just to be with her loved one who can't leave the hospital due to some surprising post-operative circumstance. The nurse whispers 'he will die here. There is no way he can leave now.' If the patient is lucky, family is called at the appropriate time,

90. A non-medically trained person can offer liquids, grind up pills, operate oxygen machines, adjust beds, and swab a dry mouth, but if the patient needs a respirator, continuous dialysis, chemotherapy, a skin puncture, or is in danger of heart failure, specially trained staff is necessary. Alexia Torke, lecture, "End of Life Decision-Making," Fairbanks Center for Medical Ethics, Indianapolis, IN, February 10, 2009

91. Instructions for families and medical staff about nutrition and hydration if the patient has exhausted treatment options.

92. Elisabeth Kübler-Ross, *Death: The Final Stage of Growth* (Englewood Cliffs, New Jersey: Prentice Hall, Inc, 1975), 5.

93. Stikeleather, Journal Entry, November 30, 2009.

especially if the patient is terminally weaned,⁹⁴ a procedure that is both formal and intimate and can be scheduled. If a chaplain can be present, there can be even more sacred space available to the death.

Death in Discomfort

Fear of the dying process and death are major factors in the ministry provided to both patients and families. Iya Byock describes patients' fear of when and how they will eventually die: "being abandoned, becoming undignified in terms of what they do, how they look, and how they smell; being a burden to their families... (and) dying in pain."⁹⁵ They would rather not deal with it. Moira McQueen writes that "euthanasia has also been performed on people with an illness that will progressively worsen, in anticipation of the terminal phase and to avoid enduring that stage... children younger than 16 with a serious illness or disability have been euthanized at the request of their parents... severely handicapped newborns are not to be treated (in the Netherlands) but rather should be euthanized, if the parents give consent."⁹⁶

Many do not want to be around for death. Some wish to be medicated, so as to be 'asleep' at the time of death. Pope Pius XII gave permission to Catholics to not be superhuman:

We may control pain and suffering even to the extent of lapsing into unconsciousness, as long as we had completed our spiritual duties. We may choose to endure the suffering for spiritual reasons but that nothing heroic is demanded of us.⁹⁷

How much suffering is needed and appropriate? Ethics consultants hear stories of families requesting that a loved one's pain medication be reduced so that they are more awake so the families can interact with them. The question becomes how much awake is good?

She lay with her twin daughters on either side, rubbing her arms. As she struggled to breathe, she began to writhe and wiggle. The rubbing arms became restraints. She had died without morphine. Later, when hearing this story, a hospice nurse responded, 'that's not fair.'⁹⁸

94. During a terminal wean, futile treatments, such as ventilation, are gently and gradually removed as pain meds are increased to provide a gentle, quiet death. The question remains as to just how much of the quiet death is actually for the family's comfort. Just how conscious is this death?

95. Iya Byock, *Dying Well: Peace and Possibilities at the End of Life* (NY: Riverhead Books, 1997), 241.

96. Moira McQueen, *Bioethics Matters: A Guide for Concerned Catholics* (London: Burnes and Oates, 2009), 93-4.

97. *Ibid.*, 95.

98. Stikeleather, Journal Entry, March 10, 2008.

Other families, exhausted emotionally, would prefer that the patient be medicated and asleep because of the ease of caring for them.

Death in debt

Death in a hospital is expensive. ‘Life insurance caps at 1 million,’ the discharge planner laments. The social worker helps the family apply for Medicaid, and the financial burden is a lasting reminder of the choice to be in the hospital.⁹⁹ But no one leaves the hospital because they can’t pay. Foundations pick up the tab for some. In addition to the financial burden, there is also a burden on resources, staff and space.

The ethics pager buzzed, and a phone call from an ICU nurse revealed the case of a young father whose family and doctor would not give up. The patient was no longer responding, and was losing blood at such a great rate that the nurses had to suction the mattress. The local blood supply completely ran out, his nurse called her supervisor, then ethics brought some wisdom to the struggle, the patient arrested a fifth time, and the decision was made to stop. Later, the doctor was reprimanded by a medical inquiry.¹⁰⁰

Americans die with specific wishes unfulfilled due to conflicting values about death itself. In the presence of cognitive dissonance (non-maleficence¹⁰¹ vs. young fathers don’t die), the needs of the dying continue to not be met.

Culture of Life (and Death)

What is true about death? Religious mythology gives various explanations about the afterlife, but what about what caused death? Sherwin Nuland’s book *How We Die* describes how body systems stop,¹⁰² but why do they stop? Charles Meyer’s *Surviving Death* lists several myths that try to explain death.

Some of them sound like rules:

- *Only old people die
- *Medicine can cure everything
- *Life is always the highest value
- *Money should not be a consideration
- *Death is evil, death means failure
- *Where there’s life, there’s hope
- *Suffering is redemptive

99. Traci Kaufmann, interview, Aug. 1, 2009.

100. Stikeleather, Journal Entry, Jan. 25, 2009.

101. Non-maleficence in medical ethics refers to the admonition to not provide treatment that causes harm to the patient.

102. Sherwin Nuland, *How We Die: Reflections on Life’s Final Chapter* (NY: Vintage, 1993).

- *Once you start something, you can't stop it
- *Pulling the plug is suicide or murder
- *To die of dehydration or starvation in a healthcare setting is inhumane, cruel, and immoral.¹⁰³

None of these are reflected in any religion's scripture, while they are held in church doctrine. They are cultural ideas passed from generation to generation. "After the idea of the living will was described to Mom, she said, 'You won't have to pay for anything.' After all that explanation, she fixated on the financial piece, which had nothing to do with the living will."¹⁰⁴ Each one of these myths is packed full of religious and cultural biases. The last one in the list, 'dehydration and starvation' will be discussed in depth at the end of this paper.

Spiritual Delusion

What the family sees in the patient's room and what the staff sees are often completely different, depending on the level of delusion present. While the staff might see a man dying with kidney failure, the family might see their father improving every day, based on their own data separate from the illness, including the patient's furtive smiles, which is perhaps the patient's way of managing the family's pain. Families sneak in food to give to patients without swallowing ability to soothe their own need to nourish and return the patient to health, then the nurse has to become the police, checking family for contraband. A caregiver feeding an 86yo elder admonishes her to eat more than she wants, which are a few bites. "She is not sick."¹⁰⁵ Neurologist Thomas Cochran's 2007 paper "Religious Delusions and the Limits of Spirituality in Decision-Making" brings to light the idea that

even the most self-identified religious or spiritual person's ethical and moral beliefs do not in fact originate from scripture or religious teachings, and in theory can always be translated into non-religious ethical and moral terms. Second, beliefs that directly contradict obvious facts are *delusions*, whether the beliefs are religious in nature or not.¹⁰⁶

What about hope? Nurse Florence Nightingale, quoted in a 1969 nursing text, leaves these words to speak to hope:

103. Charles Meyer, *Surviving Death: A Practical Guide to Caring for the Dying and Bereaved* (Mystic, CT: Twenty-Third, 1993), 27-34.

104. Stikeleather, Journal Entry, Nov. 10, 2008.

105. *Ibid.*, Sept. 15, 2007.

106. Thomas I. Cochran, "Religious Delusions and the Limits of Spirituality in Decision-Making," in *The American Journal of Bioethics*, July, Vol. 7, Number 7, 2007, 14.

I really believe there is scarcely a greater worry which invalids have to endure than the incurable hopes of their friends. I would appeal most seriously to all friends, visitors, and attendants of the sick to leave off this practice of attempting to cheer the sick by making light of their danger and by exaggerating their probabilities of recovery.¹⁰⁷

Nightingale's words should be spoken more. Her realistic outlook has been covered over by the Christian cultural attitudes taught to nurses, whose very practice was founded by nuns.

While hope is used with abandon by some chaplains, many families and medical staff, the Tibetan Buddhist chaplain prefers to see what is actually there in front of him. Instead of creating a mirage to soothe the fear of what is happening now, the 'now' is breathed in slowly and confidently in order to be present with 'what is.' Cochran implicitly states the need for the chaplain in this prescription: "Patience and sensitivity is required to help people overcome religiously-framed delusions while remaining respectful of their religious and spiritual beliefs."¹⁰⁸ Listening is an important skill that the chaplain uses to hear how the patient and family are making meaning of what is unfolding in front of them.

Death delay

Because of medical improvements, death can now occur later: "thanks to modern antibiotics, heart bypasses, cancer treatments, organ transplants, life-support equipment, dialysis, and intravenous fluids, medicine has changed the way this nation dies."¹⁰⁹ This does not mean that life has improved, but has simply been extended.

The patient with a left ventricle assist device does not continue to farm the land. He sits in a recliner all day watching TV with his wife beside him. The landline phone has battery backup in case he needs to call 911, along with emergency batteries for the battery pack clipped to his waist. His wife is afraid to go to the store without him. They go everywhere together. They got a few extra years, but it is like a stressful prison. In a couple years, the device will begin to fail. It's like a second death. We had our dress rehearsal.¹¹⁰

107. Florence Nightingale, quoted in Wainwright P. Gallagher, "Ethical aspects of withdrawing and withholding treatment," in *Nursing Standard*, Vol. 21, No. 22, 46-50, 2007, 49.

108. Cochran, 14.

109. Marilyn Webb, *The Good Death: The New American Search to Reshape the End of Life* (NY: Bantam, 1997), xxiii.

110. Stikeleather, Journal Entry, April 10, 2009.

The body stays, without the vibrancy of what made the person feel vital. The death process is longer than before, but not necessarily celebrated. Although many diseases have been cured, other issues now remain that make the death process less clear, with more steps:

Medical success may have even allowed death to become more hidden, lulling American into losing knowledge not just of the physical process of dying, but of the psychological and spiritual dimensions of death.¹¹¹

Like a bargain made with the medical research ‘devil,’ life is extended – albeit physical life only.

Denial

Mortality is not something that Americans accept well. This culture sends messages about being youthful and thin, celebrities erase age with surgery, with elders stretching the face into a mask of fear – of death. “We must recognize the extent to which the idolatry of health represents a fear of death and often a denial of death’s inevitability.”¹¹² Around the bedside and in the waiting room, the chaplain hears many religious slogans that show a resistance to the death process:

With her family silently watching, the patient breathed one last shallow breath and – it was finished. ‘This wasn’t supposed to happen.’ As Emma Hawley died, a large part of her family’s faith and belief died with her.¹¹³

Other slogans include the following:

- *God will cure him (expect a miracle)
- *If you have enough faith, you’ll be healed
- *It’s God’s will
- *There’s a reason for everything – the Lord works in strange ways
- *You have to be strong
- *You don’t die until your number comes up
- *God took her
- *Time heals all wounds.¹¹⁴
- *She’s in a better place now¹¹⁵

These misinterpretations of Judeo-Christian theology demand something from God. While they are meant to console, they tend to disturb everyone within earshot with their denial of an experience of anger around

111. Webb, xxiii.

112. Mohrmann, 17.

113. Meyer, *Surviving Death*, 81-91

114. Ibid.

115. John Smith Lontz, personal communication, April 18, 2010.

death.¹¹⁶ This is not limited to Christianity, since there are also slogans used by Tibetan Buddhists: ‘just breathe,’ ‘his karma was all burned up,’ ‘don’t get angry,’ and ‘try to stay calm.’ These latter slogans more overtly try to manage anger instead of placing ‘blame’ on a higher power. Meyer explains why these slogans exist:

Perhaps in our haste to deny our mortality, we gloss over the frightening and painful issues of death and dying, and in doing so have developed a theologically shallow and ultimately dysfunctional system of beliefs to protect and insulate ourselves from the inevitable.¹¹⁷

This is the American resistance to death. While it might not be exclusive to the US, it is a factor in the burgeoning healthcare industry. The ‘medical-industrial complex,’ a term coined in 1980 by the *New England Journal of Medicine*,¹¹⁸ describes how a country can be funded by the payments for medical procedures. This arose out of a fear of death. This resistance is collective, and is the cultural milieu, or ‘presence’ within a hospital setting, a Jungian view that each patient and family can espouse or, in some cases, refute.

American Polarity

The American mind likes to make choices, and has difficulty holding both choices in the mind without distinguishing and judging. Is this a masculine trait?

Polarizing, ‘either-or’ choices, debates, and rhetoric are peculiarly American. Superficial statements that overstate the positives of one’s own position while casting the opposition in the worst possible light are elevated to an art form in media ‘sound bites’... it sometimes seems we must choose between hospice- which ‘affirms life’ and ‘relieves suffering’ – on the one hand, and hemlock – which respects patient ‘self-determination’ and ‘individual choice’ – on the other hand... The forced choice between compassion and self-determination ultimately turns out to be a false choice.¹¹⁹

The stress of making choices about a patient’s care can both lift up family discord and cause new. Notice the disagreement in the following family statements:

She’s breathing.
She knows I’m there.

A machine is breathing for her.
That is a reflex.

116. Ibid., 82.

117. Meyer, *Surviving Death*, 82.

118. A.S. Relman, “The New Medical-Industrial Complex,” in *The New England Journal of Medicine*, Vol. 303:963-970, October 23, 1980, Number 17, 1.

119. Constance E. Putnam, *Hospice or Hemlock?: Searching for Heroic Compassion* (London: Praeger, 2002), x.

We have to wait for God to take her. We are playing God by continuing this.
 She looks comfortable, let's keep going. She's struggling, we have to stop.¹²⁰

We see what we want to see and believe what will keep us comfortable. In this way, what looks like taking care of others can become taking care of oneself.

A Good Death?

The idea of a good death has come to mean a death where the process is welcomed and there is little struggle. Death is individual; people die as they lived. A peaceful death is often seen as a good death. Iya Block notes that good deaths “were not random events or matters of luck; they could be understood and, perhaps, fostered.”¹²¹ This still sounds like people managing outcomes to protect oneself from one's future. Byock polled hospice workers about what constituted a good death, and heard about spiritual growth, coping of the family, and healing of patient and family dynamics as markers of a successful death experience. Byock later rejected this term's formulaic sense and that of avoiding reality.¹²² Joan Halifax dismisses the idea of a good death, saying that each death is individual, and the person dying chooses her own unique process.¹²³ Our nation does not embrace death.

In a culture with a goal to live, not to ever die, death is managed by both medical and emotional strategies to prevent the inevitable. With unmet wishes for how one wants to die, a culture of life, spiritual delusions delays, denial, polarized thinking, and definitions of a ‘good death,’ American culture has not matured its relationship to death. How could this change? Perhaps sweeping change is left to Oprah Winfrey. This milieu creates a presence that fills the patient's room with a dream that is not awake in reality. The wake chaplain strives to nudge toward awakesness using presence.

120. Stikeleather, Journal Entry, Jan. 10, 2009.

121. Byock, 31.

122. Ibid., 32

123. Halifax, personal communication, April 20, 2009.

2. *The Patient's experience*

The patient and family's experience of the death process happens in stages, although the stages are not linear. In addition to Kübler-Ross' stages of loss, there is also the chore of finishing the business of life.

Death and Kübler-Ross

The dying person's experience is both individual and universal in the scope of human experience of death. Elisabeth Kübler-Ross' landmark work *On Death and Dying* has long been used to help understand the emotions and process of the death experience. The now classic stages of Denial and Isolation, Anger, Bargaining, Depression and Acceptance (DABDA) have helped explain the myriad of feelings for both the dying person and family.¹²⁴ Up until this point, feelings were downplayed and this anticipatory grief was not acknowledged.

Kübler-Ross' argument was that patients often knew that they were dying, and preferred to have others acknowledge their situation. The patient is in the process of losing everything and everybody he loves. If he is allowed to express his sorrow, he will find a final acceptance much easier.¹²⁵

Instead of covering up death, why not seek to reclaim it as the transformational ritual that it is, instead of fighting against it? It is our life journey expressed so humanly, if allowed.

Many counselors misunderstood Kübler-Ross' idea of the stages' fluidity, instead believing that patients would experience the stages in a linear, forward-only fashion. Her chart shows both overlap of stages and back and forth between stages.¹²⁶ These five stages all point to resistance. She added two stages after the original five, called 'finishing old business' and 'transcendence.'¹²⁷ Acknowledgment of an experience does wonders for healing in the moment. If someone can see someone's pain, it seems to lessen it. Since Kübler-Ross, many have written about nuances that have been unacknowledged. Cancer survivor Dana Jennings writes of "grieving for the person I was before I learned I had cancer. Mortality is

124. Elisabeth Kübler-Ross, *On Death and Dying: What the Dying Have to Teach Doctors, Nurses, Clergy, and their Own Families* (NY: Touchstone, 1969), 51-146. This model is explained in many of Kübler-Ross' books and will not be explored here.

125. Ibid., as quoted in Meghan O'Rourke, "Good Grief," in *A Critic At Large*, *The New Yorker*, Feb. 1, 2010, http://www.newyorker.com/arts/critics/atlarge/2010/02/01/100201crat_atlarge_ourourke, accessed Feb. 6, 2010.

126. Kübler-Ross, 265.

127 Webb, 225-6.

no longer abstract, and certain innocence has been lost.”¹²⁸ Death brings up emotions with the opportunity for them be acknowledged without shutting them down.

Unfinished Business

Many dying patients try to finish the business of their lives. This agenda can give the patient a burst of energy and focus. Kim Sweeney, a grief educator, teaches five questions and statements that structure this business:

- *I love you.
- *Do you love me?
- *I forgive you.
- *Do you forgive me?
- *Goodbye.¹²⁹

Each of these can be simple conversations as the patient completes her life agenda. The chaplain must use “attentiveness and willingness to listen and understand. Dying people communicate in wondrous but sometimes strange ways, and it takes persistence and insight to catch and decipher their messages... unfortunately, these messages are often missed or misinterpreted.”¹³⁰

The heart surgery did not go well, and the middle-aged woman could not leave the recovery room, where she remained for several days, appearing to hang on, although her adult children had said goodbye. Finally, at the suggestion of the chaplain, the nurse contacted the patient’s estranged sister in New York. Although the patient was in a coma, the nurse held the phone to her ear. The sister told her over the phone that she loved her and could let her go. The patient died a few minutes after the nurse hung up the phone.¹³¹

This patient was scared before this heart surgery. Did she have *nearing death awareness*? Maybe this was fear of death, different from the innate sense that death is near, not just possible. She had very little time to finish her business except for a request for a prayer before her children.

The patient’s business at the end of life is not obvious to others, and it may not be apparent to the patient. The chaplain can sometimes notice these desires expressed indirectly, with the patient’s frustration being expressed. A hospital or nursing home patient complaining about the lack of visitors will

128. Dana Jennings, “After Cancer, Ambushed by Depression,” in *Well: Tara Parker-Pope on Health*, <http://well.blogs.nytimes.com/2009/09/29/after-cancer-treatment-waiting-for-the-sadness-to-lift/>, accessed Sept. 29, 2009.

129. Kim Sweeney, lecture, “Communication with Grieving Caregivers,” in Counseling Skills I, Naropa University, Boulder, CO, April 15, 2007.

130. Maggie Callahan and Patricia Kelley, *Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying* (NY: Bantam, 1992), 28.

131. Stikeleather, Journal Entry, October 10, 2003.

have a hard time reconciling with family that is not present. Sometimes the family does not want to have this kind of visit and may miss the chance. If the patient's illness is disturbing to family, their visits may cease until they attend the wake.

The dying patient proceeds through several grief stages during his emotional process, hopefully finishing life's business as it is possible, with the cooperation of the patient's health and family presence. Next, the effect of the family's presence will be explored.

3. The Family's experience

In addition to the personal experience of dying, the presence of the family's own systemic issues creates a force around the dying patient. These include the family's secrets, their dynamics, anticipatory grief, multiple losses, attachment, survivor guilt, conflict, and nearing death awareness.

The family's experience is much more complex, in that there are usually more people than the patient,¹³² and they are experiencing the approaching death vicariously. This sometimes creates more drama than if they were actually dying. In many ways, they are like an unrehearsed Greek chorus for the family system. "Patient and family exist as a unit – interacting and struggling together in what can become a perplexing maze of distress and anxiety."¹³³ While the patient is the tip of 'the iceberg of the family system,' the family's presence helps the chaplain with the cartography of how death will be received.

Secrets

Family systems have their own rules and their own secrets, creating a bond and more importantly, equilibrium to the system.¹³⁴ Some subjects and family members are not up for discussion. "In their attempt to avoid dealing with painful past experiences and unresolved emotional issues, families often

132. Some have a dying process with no family physically present, although their presence is palpable.

133. Callahan and Kelley, 28.

134. Murray Bowen, "Bowen Theory," in www.thebowencenter.org/pages/theory.html, accessed March 26, 2010.

rigidify their relationships and view of themselves.”¹³⁵ This rigidity to life and death surfaces when the family makes a request upon admitting a loved one to hospice:

they sometimes request that the patient not be told of the diagnosis and their enrollment in hospice – usually so the patient won’t be sad, saying ‘We don’t want any negative thoughts. We only want positive thoughts.’¹³⁶

The author qualifies by saying that often, the patient already knows that death is near. Still, the family system can struggle to manage information in order to control emotions of the patient and others. Death is the final taboo:

So long as we avoid and deny and distance the anxieties raised by the reality that we are going to die, death will continue to be the troublesome taboo that sex was in Freud’s age, lying repressed in our unconscious where it exacts from us an intolerable emotional recompense.¹³⁷

Hospital staff communication doesn’t make it easier for families to understand what is going on. Slate.com criticizes the practice of offering a patient’s condition in a way that confuses families. “The press has described the medical condition of Jessie Arbogast, the 8-year-old mauled by a shark in Florida, as ‘critical but stable.’”¹³⁸ How can he be both critical and stable? These words confuse information about the patient when they hear ‘critical’ in one breath, then ‘stable’ in another. Since we each hear differently, especially when listening to frightening information, it is no wonder that the family misunderstands what is really going on with the patient.

Family Dynamics

Approaching death brings family together in one space. Some families embrace this, and some would otherwise keep distance from each other. Some families stay apart in order to keep peace, but illness and approaching death force them together:

The chaplain walks by and hears the Visitor-Patient representative, a sort of secretary for the unit, say to two women, “Are we going to have a fight here?” One woman left, the other returned to the ICU. The VPR explained that the women were about to physically

135. Monica McGoldrick et al, *Genograms: Assessment and Intervention*, 2nd ed. (NY: WW Norton, 1985, 1999), 156.

136. Jerry Gentry, “‘Don’t Tell Her She’s on Hospice’: Ethics and Pastoral Care for Families Who Withhold Medical Information,” *The Journal of Pastoral Care & Counseling*, Vol. 62, Supplement 2008, No. 5, 441.

137. Margo Drummond, *Blessings of Being Mortal: How a Mature Understanding of Death Can Free Us all to Live Wisely and Well* (Sandwich, MA: North Star, 2001), 18.

138. Chris Suellentrop, What Does ‘Stable’ Condition Mean?": How can someone be ‘critical but stable’?, *Slate*, <http://www.slate.com/tollbar./aspx?>

fight in the lobby area while their relative lay dying. One wanted the treatment to end; the other wanted it to continue. They were both romantically involved with the patient.¹³⁹

During a chaplain orientation, the author was cautioned to call security if emotions got out of hand, such as a person ‘throwing a couch.’ This was explained with the example that a family member seeing ‘grandpa’ with tubes and wires can be too much for some to handle. Domestic violence outside the hospital with the injured spouse brought to the hospital has resulted in hospital security being called to protect other family members in case the abusive spouse might arrive at the hospital to finish the deed. At a Midwestern hospital ER, gang members dropped off injured members at the ER entrance – literally dropping their wounded bodies out the passenger side where the receptionist viewed their arrival through the glass.

The family system comes with the patient to the hospital. Sometimes emotions are displaced onto the chaplain:

After her young husband died suddenly of a head injury that occurred earlier that day, she and her husband’s family were escorted to a small living room near the ICU. The wife sat in silence, dazed. The silence was huge. Suddenly, the father-in-law berated the wife for not speaking. The wife tried, but she could not speak. The chaplain attempted quietly to normalize her silence as a part of grief, but the wife stood and faced the chaplain, yelling ‘GET OUT.’ Perhaps this young, grieving woman was speaking to God.¹⁴⁰

In this case, the slogan “only old people die’ may have been present in her thoughts. If so, she may feel very angry with God.

The chaplain and visitor, a construction worker, went into the ER together to see the father, who had fallen down concrete stairs and sustained a large head injury. After a brief visit, the son walked around the faulty glass sliding door of the cubicle, then stopped and slammed his hand against the glass, fixing the door. ‘I helped build this ER a couple years ago.’ The son’s anger was palpable to staff, and security strolled through the ER, nodding to the chaplain.¹⁴¹

Finally, the patient sometimes receives treatment meant for the family:

The hospice nurse noted that pain medication is prescribed with a range of dosage. If the family is disturbed by the patient’s visible pain, she will administer the high end of the range of dosage. She agrees that she is indirectly ‘medicating the family.’¹⁴²

139. Stikeleather, Journal Entry, April 20, 2009.

140. Stikeleather, Journal Entry, March 10, 2009.

141. Ibid., January 10, 2003.

142. Ibid., October 10, 2009.

Although these families' dynamics were unpleasant, other families balance faith and experience. They tend to struggle less.

Some families use this time to draw closer, reconciling with the extra time during vigils, sharing stories with honesty, including spontaneous family reunions. "I jogged into the ICU waiting room after getting the page to see the patient in the ICU, and discovered an entire wedding party camped out, still in the wedding gown and tuxedos. It was surreal, tragic and serendipitous."¹⁴³ With the help of a strong religious tradition, family support system, education and experience, families have better experiences with death. In no way does it ever seem to be 'easy.'

The chaplain arrived on the palliative care unit after receiving the page that a patient had died. The room was empty except for the patient in bed. She learned that the family has left that morning. The nurse mentioned that the family was fine and had decided to go home.¹⁴⁴

Anticipatory Grief

When will it end? Before it ends, feelings occur. "The anticipation of an event may be just as powerful as the event itself."¹⁴⁵ Ironically, once death happens, the emotional drama may be over, or sometimes just begin. Families experience a very similar, vicarious process as the patient, like dying with them. Families can experience all five stages of loss.¹⁴⁶ Death happens in its own time, without the predictability that the modern world uses to manage chaotic life. This kyros¹⁴⁷ nature of death's sense of time creates suffering in both the dying and those that love them. We may also experience the limbo of loss in anticipatory grief, those times when our loved one is not getting better and not dying yet.¹⁴⁸

She will become eligible for hospice when her heart capacity decreases to 20%. It took a whole year for her heart to go from 25 to 22%. In the meantime, her daughters take care of her as she lingers in a slow, lumbering twilight of mental fog and life review, sometimes reviewing stories over and over as she strives to deposit her stories in the family's ears. She uses birthdays and holidays as goals to live for, each one passing,

143. Stikeleather, Journal Entry, June 8, 2007.

144. Ibid., June 15, 2009.

145. Elisabeth Kübler-Ross and David Kessler, *On Grief and Grieving: Finding the Meaning of Grief through the Five Stages of Loss* (NY: Scribner, 2005), 4.

146. Kübler-Ross, *On Grief and Grieving*, 4.

147. Kyros refers to time stretched, dreamed, spacious as opposed to chronos time, which is measured and logical. See Stephan Rechtschaffen, *Timeshifting: Creating More Time to Enjoy your Life*, NY: Doubleday, 1997.

148. Kübler-Ross, *On Grief and Grieving*, 4.

sometimes celebrated early, with several ‘dress rehearsals’ of staying in bed for most of the day. These dress rehearsals continue, with furtive visits from out of town family.¹⁴⁹

Much has been written about caregiver exhaustion. Perhaps part of the exhaustion is within the dilemma of wanting the chores to end, but ending this means death. This race has an unknown finish line: “Instead of a last-gasp sprint, death can be a marathon.”¹⁵⁰ These marathons happen many times in a lifetime for families. Each death resonates with the next, vibrating with memories of previous deaths.

Multiple Losses

When we are hit with multiple losses because of illness, we may wonder who is next.¹⁵¹ The presence of grief is working all the time. It might even be present after the birth of a healthy baby. One person, perhaps the grandmother, who birthed in a time of fewer medical advances, remembers losing a baby. Grief is pervasive, so much so that unless someone is actively grieving, no one will know it. When a surgery is successful or a baby is born with no complications, it becomes clear to those with the memories of multiple losses just how things could have gone wrong, but for some reason, did not. This is part of the presence of the room, the mysterious wonder of outcome.

Attachment

For some, love is an attachment, and loving someone is the most important part of life. Chaplain Dick Millsbaugh’s *Making Hard Choices* speaks to the complex relationship dynamics of the survivor and the dying loved one. “You may have had such a rich and loving bond that you cannot and do not want to imagine what it would be like to live alone.”¹⁵² A person’s life can be so involved with another person that death of this person feels like death of oneself.

The family left the room where the matriarch had died in the middle of the night. The husband suggested the family stick around to be with the patient until the funeral home arrived while the family stared at him with coats on. A whispered question revealed that the husband simply could not leave his wife of 60 years. The family system jumped in and whisked the elder man out of the hospital, subverting a tender emotion.¹⁵³

149. Stikeleather, Journal Entry, Sept. 24, 2009.

150. Callahan and Kelley, 33.

151. Kübler-Ross, *On Grief and Grieving*, 174.

152. Dick Millsbaugh, *Making Hard Choices: When Patients Are Not Able to Speak for Themselves* (VA San Diego Healthcare System, 2006), 14.

153. Stikeleather, Journal Entry, April 10, 2004.

This attachment is turned on its side when the survivor has not had a loving bond:

You may hold on because you feel the patient owes you something. Maybe the person has been less of the mother, father, son or daughter than you wanted. Face his or her death means to let go of the hopes and dreams that someday you will have a better bond. It is sad to admit those dreams will not happen.¹⁵⁴

Millspaugh also recognizes that knowing that the dying person has a different worldview can create tremendous roadblocks to accepting death:

You may hold onto a loved one because you are concerned for his or her soul. Some people's faith teaches them that unless a person makes a specific faith statement, he or she will go to hell. Such a belief may cause great spiritual and emotional suffering for the family member who believes that he or she may never see a loved one again. This person may wish to look at his or her faith scriptures again.¹⁵⁵

Some feel that their afterlife will only contain those that believe as they do, and will go to great lengths to make sure the patient has received the opportunity to accept the faith of the family. This is merely an attempt to assuage one's own fear. Last minute conversions are most often coerced and an attempt for the dying person to take care of the living. In some states, such as Colorado, the *Five Wishes*¹⁵⁶ Document asks the dying person what religious practices he would like to be expressed in the room (in addition to many other preferences). This prevents unwanted religious interference. It is of utmost importance for the family to not soothe their own emotional and/or spiritual needs at the expense of the loved one. Those sticking around have their own work to do. This is no simple chore.

Survivor Guilt

Even though Americans have an aversion to death, sometimes replacing oneself with the dying is a wish. "Why was I spared?" is an often-asked question. "Why didn't I die instead of my child or my wife?"¹⁵⁷ Millspaugh describes guilty feelings that can be confessed at the bedside for both real and

154. Millspaugh, 14.

155. Millspaugh, 15.

156. See www.agingwithdignity.org/five-wishes.php

157. Kübler-Ross, 174.

imagined failures. Forgiveness is requested, even though the patient is unable to respond.¹⁵⁸ The family has its own business with the dying person before letting go.

Conflict

In addition to patient and family and inter-family conflict, conflict in communication in the hospital system takes a huge toll on the ‘nearing death’ process. This conflict can involve the family and staff and also between staff. A recent study of the value of ethics consultations revealed chronic conflict around who the decision maker is if there isn’t one, whether to pursue aggressive life-sustaining treatment or comfort care, and whether the current treatments are futile.¹⁵⁹ The conflict is commonly mitigated by the commonplace family conference, or by the last resort ethics consultation.

The hospital environment, especially the ICU, seems to breed conflict. “The transition from cure to comfort is one of the most difficult and important aspects of medical and nursing practice in the ICU.¹⁶⁰ ICUs, originally meant to be a specialized, temporary recovery area after surgery, have now become problem-solving, dilemma inducing ‘incubators’ for patients who did not meet the goals of surgery. Unfortunately, few studies recommend chaplaincy in these cases. Medical staff frequently struggle with family dynamics, but see the chaplain as a ‘pray-er’ not trained in conflict resolution, and summoned only if requested. They won’t call the chaplain if people are disrespectful or yelling unless the chaplain is right there. Medication and Security are called upon first. Conflict is either numbed or escorted from the hospital.

Lack of Nearing Death Awareness

When someone is dying, they often do not know it. This occurs because their medical diagnosis has not been given to them, they don’t understand it, or the sense that this is occurring is covered up by treatment and treatment goals. Some doctors are reticent to admit that they have given up and lack

158. Millsbaugh, 14.

159. Lawrence J. Schneiderman et al, “Effect of Ethics Consultations on Nonbeneficial Life-Sustaining Treatments in the Intensive Care Setting: A Randomized Controlled Trial,” in *Journal of the American Medical Association*, Sept. 3, 2003, Vol. 290, No. 9, downloaded from www.jama.com on October 28, 2009.

160. J. Randall Curtis, *Managing Death in the Intensive Care Unit: The Transition From Cure to Comfort* (UK: Oxford University Press, 2001), quoted in Robert D. Truog et al, “Recommendations for end-of-life care in the intensive care unit: A consensus statement by the American College of Critical Care Medicine,” *Critical Care Medicine* 2008, Vol. 36, No. 3. 953.

training needed to have this conversation.¹⁶¹ As was explained earlier, some families do not want the patient to know. Other patients do not have the cognitive ability to grasp their nearing death. Sometimes treatment and its side effects cause the patient to focus on this instead, e.g. side effects from chemotherapy. The goal of regaining health may cause the patient to ignore symptoms of nearing death. This awareness, for several reasons given, is not appreciated fully in American society.

‘Nearing Death Awareness’ is a special knowledge about – and sometimes a control over – the process of dying. Nearing Death Awareness reveals what dying is like, and what is needed in order to die peacefully; it develops in those who are dying slowly.¹⁶²

Callahan and Kelley’s *Final Gifts* explains a way that family members can become aware of this process: “By keeping open minds and by listening carefully to dying people, we can begin to understand messages they convey through symbol or suggestion.”¹⁶³ Callahan and Kelley tell many stories of this practice of awareness.

The chaplain said a pre-surgical prayer for the elderly woman the night before her surgery. She said that she was ‘ready to go’ and was confident that Jesus would be there to take her if He wanted. The next morning, the patient died in surgery. How did she know?¹⁶⁴

The patient and family’s struggle with death is apparent from the above writing. The Tibetan Buddhist chaplain encounters the presence created by these experiences with his own presence. A specific presence is created around the subject of death based on the Tibetan Buddhist worldview.

Western and Eastern Death

The commercialization of death in the US has just about removed it from our lives. Death in the United States left the home, as was discussed above, and is hidden away in funeral homes where makeup, glues and cotton perpetuate the myth of a younger person.¹⁶⁵ “Western Judeo-Christian belief systems heighten this dilemma in their emphasis on mastery and control over our destiny. The end of life is approached in terms of loss of control and the failure of treatments – or of will. In contrast, Eastern and

161. Also, Doctors complain that they are not reimbursed for the time they spend talking to patients about end-of-life planning.

162. Callanan and Kelley, 13.

163. Ibid., 28.

164. Stikeleather, Journal Entry, April 10, 2009.

165. For an explanation of western mortuary methods: www.baris.net/bfh/embalm.html

tribal spiritual traditions approach death as a natural part of the human life cycle. Buddhism teaches that in accepting death, we discover life.¹⁶⁶ When death became sanitized, the psyche began to suffer. Next, the Tibetan Buddhist view of death is presented to share a different way of experiencing death, one where the focus on the mind creates a presence consistent with the practice of meditation, where reality and, in this case, mortality is embraced.

B. A Tibetan Buddhist View of Death

The following is a Tibetan Buddhist view of death, using a five element approach with the idea that death is a solitary journey, is constant, and is actually a practice. This practice creates a loss of ground, abandons attachment, and ultimately questions the emptiness of the concept of the body and death.

Five Element Approach

Tibetan Buddhism views the death experience in relationship to the different elements of the body, going deeper and deeper. Physically, one begins to feel heavy when the earth element dissolves into water, then water dissolves into fire as circulation ceases to function. When fire dissolves into air, any feeling of warmth begins to dissolve; and when air dissolves into space, one loses the last feeling of contact with the physical world. Finally, when space or consciousness dissolves into the central *nāḍī*, there is a sense of internal luminosity, an inner glow, when everything has become completely introverted.¹⁶⁷

Solid food was discontinued before I met him. He drank Ensure and sipped water. His pee was a dark orange. No more poop. His arms and legs began to get cold and he responded by wanting to get up and even walk around to improve circulation. Deep inside, I know that he knew that this wouldn't just be a two week bad patch, that this was it. He said he didn't want to know, so that was that. He stopped breathing in his sleep the next afternoon. His friends piled into the house. It was really as if he had spread out into the house. His name was on everyone's lips and his music was everywhere. His body was done, but his essence was somehow infinite in the stories about him in blogs and the newspaper.¹⁶⁸

166. Stephen Levine, *Healing into Life and Death* (NY: Doubleday, 1987) as quoted in Froma Walsh, *Spiritual Resources in Family Therapy* (NY: Guilford, 1999), 40.

167. Francesca Fremantle and Chögyam Trungpa, *The Tibetan Book of the Dead: Liberation by Hearing in the Bardo* (Boston: Shambhala, 1975, 1992), 8-9.

168. Stikeleather, Journal Entry, March 20, 2010.

Instead of a diminishing, Stephen Levine describes the death process as being more like a flower blooming:

Death like birth is not an emergency but an emergence. Like a flower opening, it is nearly impossible to tell exactly when the bud starts to become the blossom, or when the seed-laden blossom begins to burst and release its bounty...we feel the lightness lifting us from our body... suddenly remember(ing) we are not the body... we cut the moorings and dive into the ocean of being, expanding from our body, floating free the mind.¹⁶⁹

In Levine's *A Year to Live*, he observed that people with terminal illnesses, if coaxed, tended to bloom like exotic flowers during their final year. They made choices they wouldn't have: quitting jobs, getting jobs, traveling, and most importantly, being honest with others. This allowed them to be free, unfettered from their bodies, to live life fully in the ocean of life.

Death is Alone

We do essentially die alone, even though we wish for companionship. No one can help us or do it for us. No chaplain or magical being can help. *The Tibetan Book of the Dead*, written to help dying people through the bardo or transition period, ironically denies its own use: "Nobody is going to save us; everything is left purely to the individual, the commitment to who we are. Gurus or spiritual friends might instigate that possibility, but fundamentally they have no function."¹⁷⁰ Each person makes this unique journey, not just once, but throughout life. Sogyal Rinpoche speaks of a student's understanding of this:

I made a vow to myself... that I just wanted to be happy. When I made that decision, I stuck to it. And this is very important in doing any kind of training of the mind. You must make the decision that you really want to change. If you don't want to change, no one is going to do the work for you.¹⁷¹

This is work that no one can do for another.

Death is Constant

Death is happening all around us. Life is impermanent. Loved ones die, as do ideas, thoughts, even the moment soon is gone. Trungpa writes that these little deaths have a five elemental aspect to them as well, with logic becoming vague, then reassuring oneself that the mind is still working, and then losing

169. Stephen Levine, *A Year to Live: How to Live Each Year as If it Were your Last* (NY: Bell Tower, 1997), 57.

170. Francesca Fremantle and Chögyam Trungpa, 4.

171. Sogyal Rinpoche, 382.

confidence in the mind's working, latching onto emotions of love and hate, then a faint experience of openness, and then a final release into luminosity.¹⁷² Death is not hidden away at the end, but is 'the now' and the now will soon be gone too. Chokyi Nyima explains how bardos are with us during our lives: the bardo of living and dying takes place between the first breath at birth until the first moment of one's final illness, and the bardo of dying is the space between the beginning of illness and the last breath. Next is the luminous bardo of our innate nature, where our minds remain unobscured for a short while, a 'luminous wakefulness.' For some, the last bardo accompanies the confusion that can take over the mind, causing rebirth. This is the bardo of becoming.¹⁷³ Therefore, death is happening throughout an incarnation. The time of our lives is not truly linear, but every time is now. Our death is now. Levine recalls Thai meditation master Achaan Chaa's story of a drinking glass:

You see this goblet?... For me this glass is already broken. I enjoy it; I drink out of it. It holds my water admirably, sometimes even reflecting the sun in beautiful patterns. If I should tap it, it has a lovely ring to it. But when I put this glass on the shelf and the wind knocks it over or my elbow brushes it off the table and it falls to the ground and shatters, I say, 'Of course.' When I understand that the glass is already broken, every moment with it is precious.¹⁷⁴

Life, like a drinking glass, is to be enjoyed, drank fully. This idea promotes a view of living life now as a precious moment to be savored. Dzogchen Ponlop writes that an understanding of impermanence is an understanding of the Dharma itself, the "true Dharma."¹⁷⁵ Reginald Ray describes a Bardo retreat practice, where

one follows a course of meditation that simulates the experience of death and the after-death state. The retreat itself is carried out in complete darkness, and because it is considered dangerous, facilities for it were found at only a few places in Tibet... The mental imagery associated with death appears spontaneously.¹⁷⁶

The bardo is part of life, and the bardo retreat is a practice of life and its relationship with death.

Death as Practice

172. Francesca Fremantle and Chögyam Trungpa, 9-10.

173. Chokyi Nyima with David R. Shlim, 153-5.

174. Stephen and Ondrea Levine, *Who Dies? An Investigation of Conscious Living and Conscious Dying* (NY: Anchor, 1982), 98.

175. Dzogchen Ponlop, *Wild Awakening: the Heart of Mahāmudrā and Dzogchen* (Boston: Shambhala, 2003), 50.

176. Ray, *Indestructible Truth*, 319.

Dying constantly is a practice. Each day provides a fresh opportunity to again see the impermanence of things. Levine decided to live his next year as if it were his last:

To practice dying. To be fully alive. To investigate the dread of, and resistance to, life and death. To complete my birth before it's over. To investigate that part of myself that refuses to take birth fully, and hops about as though it still had one foot in the womb. To enter the healing I have seen so many times as miraculous growth during a final illness. To place both feet on the ground at last. To explore this ground, the ground of being, out of which this impermanent body and ever-changing mind originate. To cut through a lifetime of confusion and forgetfulness. To undertake a life review with gratitude and forgiveness. To explore that which holds to its suffering, and cultivate a heart that cannot be distracted even by death.¹⁷⁷

Instead of hunkering down in life, saving ourselves for retirement or 'when the thesis is done,' it is important to live life fully in the moment. Thich Nhat Hanh writes a guided meditation where one breathes in different parts of the death process, to familiarize, to embrace, and to contemplate the transitions. The meditation starts with the body ill, progresses to after death, until later one sees worms and flies moving through the body and the bones turning to dust.¹⁷⁸ Nhat Hanh asks us to uncover our eyes to death, to be present to this reality that Americans cover over with funeral makeup and ornate caskets. Sogyal Rinpoche writes of a second student's practice:

She didn't seem to have any fear of dying, but wanted to feel that there was nothing left undone, and that she could then approach death without distraction. She derived a lot of comfort from the knowledge that she had done no real harm to others in her life, and that she had received and followed the teachings; as she said, 'I've done my homework.'¹⁷⁹

In addition to Plato's instruction to 'die daily,' Reggie Ray adds that "we must be prepared to meet death with the same simplicity, openness and humble anticipation that we meet a refreshing breeze on a warm summer's day."¹⁸⁰ Finally, Dzogchen Ponlop describes a choice about death: "To direct our story of living and dying now, or to wait, closing our eyes to the message of impermanence, until death itself opens them."¹⁸¹ It is a choice we must make soon. Our precious human birth is not forever.

Losing Ground

177. Levine, *A Year to Live*, 10.

178. Thich Nhat Hanh, *The Blooming of the Lotus: Guided Meditations for Achieving the Miracle of Mindfulness* (Boston: Beacon, 1993), 53.

179. Sogyal Rinpoche, 379.

180. Ray, personal communication, Nov. 25, 2009.

181. Ponlop, *Mind Beyond Death* (Boulder: Snow Lion, 2006), 5.

Losing ground is a basic practice of Buddhism. Our egos crave territory. When we lose ground, we open our awareness of life. As the ground we have created for security erodes, we slide into the unknown of an exciting reality, an avalanche of possibilities. As we begin to die, we begin to lose the ground of our egos.

I had never had such a deep meditation with the lights on, sitting in a chair, but when guided to look at my mind, then expand my awareness of it, then look at the observation of all this and let it go, until it was just awareness and no body, just awareness, I couldn't think. I was just the universe inside.¹⁸²

Trungpa, in *The Tibetan Book of the Dead*, describes the Bardo of the moment before death:

The first bardo experience is the experience of uncertainty about whether one is actually going to die, in the sense of losing contact with the solid world, or whether one could continue to go on living. This uncertainty is not seen in terms of leaving the body, but purely in terms of losing one's ground; the possibility of stepping out from the real world into an unreal world.¹⁸³

One lets go of the grasp on the world. It is impermanent. Chokyi Nyima quotes from the *Dhammapada* to describe impermanence with four major points as it relates to the dying process:

- *building ends in crumbling
- *gathering ends in depletion
- *meeting ends in parting
- *birth ends in death¹⁸⁴

This is part of all of life. It is not a discovered truth, but a reminder of something covered over by our ego, fixed on the eternal view. Paltrul Rinpoche writes of a way of saying goodbye to attachment:

On your way to wherever you might be going, say to yourself: 'Maybe I will die there. There is no certainty that I will ever come back' ... At night, when you lie down, ask yourself whether you might die in bed during the night.¹⁸⁵

Entropy, or order moving toward chaos (space), is present in nature:

The Raku party was well underway, with the pots in the kiln, ready to be thrown into the garbage can lined with newspaper, which produced an incredible rainbow of colors on the pot. I watched as each pot appeared red hot from the kiln, but one pot in particular was astonishing in shape. I watched it move from the kiln and almost fly into the can, except,

182. Stikeleather, Journal Entry, January 3, 2010.

183. Chokyi Nyima with David R. Shlim, 6.

184. Ibid., 143-4.

185. Paltrul Rinpoche, *The Words of My Perfect Teacher*, trans. By the Padmakara trans group (Boston: Shambhala, 1999), 55, as quoted in Ray, *Indestructible Truth*, 250.

the potter's haste caused the pot to hit the bottom too hard; we heard it smash into pieces. The teacher quickly implored, "it's reached its final form!" A student nearby chimed, 'that's very Chinese.' I felt sad, but knew deep down this must be true.¹⁸⁶

To reverse the lines of a well-known Christian hymn, 'what was found becomes lost.' What was solid is now in bits, filling space.

Abandoning Attachment

It is important to relinquish the attachment to the body by the time of death or before. Geshe Kelsang Gyatso describes this:

In some countries, the discarded body becomes a banquet for vultures and jackals. In others it is cremated and becomes little different from firewood. In still others, it is buried and becomes like the mud and dirt... If we can recognize that the body we care so much for now is potentially a banquet, firewood or dirt, we shall not cling to it with such strong attachment and feel it is truly ours.¹⁸⁷

This is very difficult for Americans to do, especially those whose careers depend on how their bodies look. Their bodies are their lives. The truth is that they are not their bodies. Levine speaks of not postponing death, but taking it within the body in order to experience the vastness of being, 'the deathless,' to confront the places where we don't allow the heart to go.¹⁸⁸ When death is shut out, it haunts us. In some cases, it is on display:

As his friends hovered nearby, Claude's mouth stood wide open in death, molars showing. He looked surprised. His skin was a pale green. I was so glad they didn't cover his face. I just wished that his beautiful, meaty pianist hands were on display, but I didn't dare rearrange him.¹⁸⁹

Sogyal Rinpoche describes his student's fastidious arrangements:

When the time came for Dorothy to go into the hospice, and leave her flat for the last time – a flat once full of beautiful treasures collected over the years – she left with just a small holdall and without even a backward glance. She had already given most of her personal possessions away, but she took a small picture of Rinpoche that she always kept with her, and his small book on meditation. She had essentialized her life into that one small bag: 'traveling light,' she called it.¹⁹⁰

Who Dies?

186. Stikeleather, Journal Entry, April 20, 2000.

187. Geshe Kelsang Gyatso, *Meaningful to Behold: The Bodhisattva's Way of Life* (London: Tharpa, 1980), 153.

188. Levine, *Who Dies?*, 147.

189. Stikeleather, Journal Entry, March 20, 2010.

190. Sogyal Rinpoche, 379.

Who dies if the body, at least our concept of body is not solid? Gavin Harrison writes about immortality:

The only death that occurs is the death of an idea, the idea of a personal and fixed being that is going to endure. And when the illusion of immortality breaks apart, we experience a powerful groundswell of relief. We let go of the deepest fear, and great inner compassion takes its place.¹⁹¹

If we don't die, were we born? Levine uses four-fold logic to understand: "Who you are, in reality was never born and never dies. Let go of who you think you are and become who you have always been."¹⁹²

One has just to sit and breathe to begin to feel the difference between the body as self and just the mind's awareness. After a woman told a Korean Zen master her struggles, the master said, "'don't worry. You won't die.' Because he knew that who she was was not her body or her mind, but something impermanent. That who she was never dies. Because awareness simply is."¹⁹³ With the study of awareness comes the beautiful present, not received but given up: "I could no longer sense where my body was. There wasn't even an I. Just awareness."¹⁹⁴

A Tibetan Buddhist view of death takes into consideration the tenets of Buddhism and relates them to a mysterious event, understanding death from a five element perspective, knowing that death is a unique journey accomplished alone, that death is a constant part of life, is a practice, is a process of losing ground, abandoning attachment, and ultimately practices Nagarjuna's claim that our ideas about our bodies and death is empty of concept.

A Mixture of Views

Many perspectives of death are at work when death presents itself in any community. Exploring typical American views of death, the dying person's experience as it relates to the family reaction, and then comparing this to a Tibetan Buddhist worldview shows how unusual a Tibetan Buddhist Chaplain's presence is in typical hospital situations. Where American culture wishes to preserve life and youth, Tibetan culture allows death to arrive as a natural process. Should life be preserved at all costs, or should

191. Gavin Harrison, *In the Lap of the Buddha* (Boston: Shambhala, 1994), 89.

192. Levine, *Who Dies?*, 179.

193. *Ibid.*, 185.

194. Stikeleather, Journal Entry, Jan. 10, 2010.

it be allowed to drain away on its own terms? Where life is a priority for American culture, death as a practice is a Tibetan priority. Does prioritizing death make life more meaningful? Should death be left until the end or should it be a part of life as a way of understanding life? We are not talking about cultural stereotypes, but of typical patterns for which there are exceptions. Some American families may have so-called Tibetan values related to death, but may not have ever studied Tibetan scripture. “I found that farm people handle death better because they’ve raised animals and are more used to it. They are a part of nature. There is a time for everything, the seasons. I think in the city, you only see death on the news, and you really don’t see it.”¹⁹⁵ Others choose their death season carefully. A Tibetan woman living in the US suffered through a thrice weekly schedule of dialysis. She then decided that she was ready to stop dialysis, which would hasten her death. Her son, a famous teacher of Buddhism, asked her to continue dialysis for the benefit of others, referring to the Bodhisattva vow of staying behind until all are enlightened. She agreed.¹⁹⁶

The chaplain’s presence colliding with the patient and family’s presence creates a dynamic that needs study. A specific type of death situation, that of providing medical feeding at the end of life, will be explored to help understand how the Tibetan Buddhist chaplain’s presence can affect these decisions.

195. Laura Wiebe Powell, interview, March 20, 2004.

196. Konchuk Palden, interview, February 10, 2006.

III. End of Life Medical Feeding Decisions¹⁹⁷

End of Life Medical Feeding decisions can be difficult for patients and their families, producing stressors that tax the family system and produce ethical quandaries. The chaplain, as part of the interdisciplinary team, is often called to provide conflict resolution between patient, family, doctor, staff and hospital administration. For the Tibetan Buddhist chaplain to work with the patient and family presence when faced with this conflict, one must understand the basics of medical feeding, the ethical implications, and the view of Tibetan Buddhist ethics as it relates to medical feeding decisions.

A. Medical Feeding Defined

Hospice and nursing home Chaplain Hank Dunn provides this definition:

When a patient can no longer take food or fluid by mouth, a feeding tube can sometimes be used to overcome this disability. Tubes usually come in one of two types. The nasogastric (NG) tube is inserted through the nose, down the esophagus, and into the stomach. The gastrostomy is a tube inserted surgically through the skin into the stomach wall. Liquid nutritional supplements, water, and medications can be poured into the tube or pumped in by way of a mechanical device. Sometimes this method is called a PEG (Percutaneous Endoscopic Gastrostomy) tube. There is also the less common Total Parenteral Nutrition (TPN), when a catheter or needle is inserted in a vein, often in the chest, and a liquid containing nutrients is pumped directly into the blood stream, bypassing the digestive system.¹⁹⁸

How It Is Used

Many patients are given medical feeding as part of their recovery process. For the patient with a temporary condition that makes eating by mouth impossible, this process is greatly beneficial in the short term. For example, it can help a newborn who is premature and cannot eat yet, a teenage skateboarder recovering from a head injury who will eat again, and a throat surgery patient whose healing prohibits eating by mouth at this time. Unfortunately, with medical advances such as ventilators, CPR and dialysis, people surviving catastrophic events are living longer but not well at first, causing the need for nutrition and hydration while they are recovering, although the possibility of recovery is not clear. For the patient with a stroke, Artificial Nutrition and Hydration (ANH) can help as the patient recovers slowly, returning

197. Given the theological focus of this paper, definitions of medical procedures strive to be only cursory, enough to help the chaplain understand exactly what is important to her work creating presence when these decisions are on the table. The medical field has written plenty about this subject. This is written for chaplains.

198. Hank Dunn, *Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Care, and the Patient with a Life-Threatening Illness*, 5th ed. (Lansdowne, VA: A & A, 1992, 2009), 17.

to eating by mouth later. Ethical issues arise when incapacitated patients whose recovery is unclear continue to receive ANH. In these cases, the benefits of ANH are not clear, and the burdens of the treatment begin to arise. There is an abundant discord around this subject: “There are few areas of medical care in which such a divergence in approaches exists as in the choice of hydration for terminally ill patients.”¹⁹⁹ When the focus of this paper was in discernment, The Fairbanks Center for Medical Ethics recommended that medical feeding receive the focus of ethical inquiry.²⁰⁰

Medical feeding brings up a particular energy in the patient and family that is dealing with it. Feelings and differences of opinion can cause conflict within the family, between patient and family, between the family and doctor, and among the doctor, family and staff. Each of these pairs can exhibit a distinct energy of tension. The quality of life, decision making, emotionally charged words, time-limited trials, religious delusions, and research needs all play subtle parts in the creation of a particular presence in the patient and family as they observe life ending. With the benefit of this offering of artificial food and water also come burdens.

Burdens of Medical Feeding

The burdens of medical feeding begin to provoke questions about the treatment and its delay of death, preventing nearing death awareness because of the symptoms caused by a treatment that can extend life:

Pneumonia can develop if the tube becomes displaced or if regurgitated fluid (vomit) enters the lungs. Ulcers and infections can also result from a feeding tube. A patient who repeatedly removes the tube will probably need to be restrained by tied hands or sedation. The immobility of most of these patients makes them prime candidates for bedsores and a stiffening of the limbs from lack of movement. Furthermore, patients can be more isolated with artificial feeding than hand feeding because they lose the personal interaction of someone sitting and feeding them three times a day.²⁰¹

There are also benefits to not offering ANH to the patient (withholding), according to Dunn:

There is less fluid in the lungs, and therefore, less congestion, making breathing easier; less fluid requiring suction; less pressure around tumors (less pain); less urination and therefore, less need to move the patient for changing the bed and less risk of bedsores;

199. Shalini Dalal et al, “Is There a Role for Hydration at the End of Life?” in *Current Opinion in Supportive and Palliative Care*, 2009, Vol. 3: 72-78.

200. Patricia Bledsoe, Fairbanks Center for Medical Ethics, Indianapolis, IN, November 10, 2009.

201. Dunn, 19-20.

less fluid retained in the patient's hands, feet, and the whole body in general. Forcing liquids into a person whose body is shutting down can create an uncomfortable buildup of fluid.²⁰²

Also, "a natural release of pain-relieving chemicals (happens) as the body dehydrates. Some have even described it as 'mild euphoria.'"²⁰³ Dunn distinguishes the different feelings about withholding this care vs. withdrawing it later: There is not an ethical difference, but the emotionally, "there is a world of difference."²⁰⁴ It is much easier to withhold than to withdraw, because of the emotions that withdrawing elicits.²⁰⁵

Is it always right to feed and hydrate a patient? Dunn provides a case for and against providing artificial feeding in all circumstances:

For: food and water are basic human rights that should not be denied to anyone.

Against: Many consider the use of artificial feeding tubes, in some cases, as causing excessive burdens, and we are not obligated to use them.²⁰⁶

Individual cases can rely on ethical principles that inform decisions. The ethics of medical feeding ask questions about autonomy, beneficence, non-maleficence, and distributive justice.

B. The Ethics of Medical Feeding

Autonomy

Each person has the right to make his or her own choices. In a healthcare milieu, this pertains most directly to treatment options. Things can become complicated when families are making a feeding decision for the incapacitated patient. The Living Will, which asks patients if they wish for ANH if they are not able to speak and treatment options have been exhausted, was specifically created to add clarity to treatment decisions after Karen Ann Quinlan lingered for several years after a ventilator was removed. A patient's autonomy should be carefully regarded. In a family conference where a patient is unable to

202. Dunn, 23.

203. R.J. Sullivan Jr., "Accepting Death Without Artificial Nutrition or Hydration," in *Journal of General Internal Medicine*, 1993, Vol. 6, 220-3.

204. Dunn, 24.

205. Patricia Bledsoe, interview, November 10, 2008.

206. *Ibid.*, 20.

attend because of illness, and treatment is being discussed, an oft-asked question is ‘What would the patient have wanted?’ Sometimes, the chaplain probes with questions about the patient’s lifestyle. In some cases, lying in bed with tube feeding is not seen as having any quality of life. One particular patient, although she had a mental illness, knew what a feeding tube was from a career in healthcare. Her decisional capacity²⁰⁷ around this particular aspect was clear: “‘I don’t want a feeding tube,’ she cried. ‘Please don’t give me a feeding tube.’ The chaplain created a power of attorney document with the words ‘No feeding tube’ in the instructions.”²⁰⁸ Living life is a complex of matters, carefully considered. When is life not worth living? Chaplain John Lontz reframes this question, asking “Why are we preventing the beauty of death from entering and pervading our lives?”²⁰⁹

Quality of Life?

What measures quality of life? This becomes important when trying to decide for another how they would want to live. Would lying in bed with a feeding tube offer any quality of life? What was the person’s life before? Would the patient continue to have a meaningful existence in this state? Who decides whether it would be meaningful, and is this decision influenced by how the decider feels about it?

The cases of Quinlan (1975), Nancy Cruzan (1990) and Terry Schiavo (2005) are worth reviewing so that the chaplain knows how Advance Directives are a result of this history, still in the making. The plights of these women changed the history of end –of-life decision making forever.²¹⁰

Beneficence

People should receive care that will benefit them. Every treatment available may not be helpful. Will ANH help the patient? What is it treating?²¹¹ Will it help the person recover or simply extend life? Esther Schmidlin, a Swiss palliative care nurse, names a particular family’s actions as a form of

207. Recent strides in decisional capacity study have asserted that people with mental illness can still make decisions about specific topics when asked over a period of time. Alexia Torke, interview, January 28, 2010.

208. Stikeleather, Journal Entry, Jan. 20, 2009.

209. John Smith Lontz, personal communication, April 18, 2010.

210. George J. Annas, “‘Culture of Life’ Politics at the Bedside – The Case of Terri Schiavo,” *The New England Journal of Medicine*, Vol. 352:1710-1715, April 21, 2005, Number 16, in <http://content.nejm.org/cgi/content/short/352/16/1710>, accessed on March 24, 2009.

211. Whether ANH is a medical treatment or simply a fundamental life offering is of concern to ethicists.

helplessness. The son of a patient admits, “It is just so hard to be here and do nothing.”²¹² What is at hand here is the mystery of how families can truly express their care to a loved one.²¹³ Studies have shown that food itself has a nurturing effect. Food produces

pleasant sensations on the palate and connect with fond memories of meals past. They may alter the patient’s mood or attitude, or be the one thing that makes him or her feel normal for a few moments, or provide the joy of sharing a meal with loved ones and friends.²¹⁴

When food is taken away, what is left? Perhaps this is where real love begins.

Non-Malfesance

It is important to always keep the patient from harm. Non Malfesance in healthcare can relate to both offering a treatment and not offering. Families may make decisions for their own benefit: “he has to last 3 more months until his life insurance benefit kicks in.”²¹⁵ This is actually called ‘secondary gain.’

This secondary gain can also appear when a treatment offered is denied:

A resident having sleep disturbances at night was given a test to check his night time oxygen consumption, and it was decided by his doctor that oxygen may help him at night. The oxygen would not prolong his life, but make sleeping more comfortable (palliation). The resident’s son refused to pay for the oxygen, saying that ‘it’s not going to help him. This will prolong his life.’ The chaplain stepped in to ask some questions. There was some reason to believe that this refusal was related to the idea that the lingering father’s expenses were draining away more of the anticipated inheritance. The facility decided to pay for this service.²¹⁶

Family members that have been estranged can use this time and power to over-provide treatment for the patient, in effect, ‘I wasn’t here then, but I’m here now.’²¹⁷ Some patients make the family promise to care for them, and the family sees the continuation of this care as keeping the promise. Chaplain Martha

212. Esther Schmidlin, “Artificial Hydration: The Role of the Nurse in Addressing Patient and Family Needs,” in *International Journal of Palliative Nursing*, 2008, Vol. 14, No. 10, 486.

213. M. R. Glick and A. E. Volandes, “The Standard of Caring: Why Do We Still Use Feeding Tubes in Patients with Advanced Dementia?” in *The Journal of American Medical Directors Association*, June 8th, 2008, 9(5): 364-7, quoted in “Caring and Tube-Feeding,” *Pallimed: A Hospice and Palliative Medicine Blog: Artificial Nutrition*, www.pallimed.org/search/label/artificial%20nutrition, accessed October 15, 2009.

214. Meyer, 16.

215. Stikeleather, Journal Entry, April 15, 2009.

216. *Ibid.*, July 10, 2008.

217. Saily Guerra, interview, Aug. 1, 2009.

Jacobs disagrees that it is food: “Artificial nutrition is not ‘food.’ It is a chemically balanced mix of nutrients and fluids. It is being forced into the body to keep a body functioning.”²¹⁸

The patient’s interest should be first, and if not, there should be a good reason. A treatment can be withheld for reasons that are not in the best interest of the patient, such as not offering someone emergency dialysis because of visa status without looking at the whole picture. If the patient is denied care, there must be ethical reasoning.

Distributive Justice

No decision is in isolation without affecting many things. ANH is expensive, and the decision to spend the money on this treatment needs to take into account the financial burden to the family, and in some rural areas, the availability of this resource.²¹⁹ Many hospices do not offer it because of the cost, and also the idea that ANH is a treatment for the living as opposed to care for the dying.

Ethical questions can be helpful when making decisions about medical feeding. The author has yet to meet a family who could easily discuss a decision using these methods. The typical family will have several family members in one room, probably a conference room near the ICU: one member will be visibly angry and possibly crying if the family will accept that, others will appear to be numb, unable to think straight, and others will be almost asleep because of a disturbance to their rest patterns. Finally, a child might be present with no understanding of the situation, with the adults enjoying the distraction, an excuse to not feel and think about the task at hand. This milieu creates a presence that the chaplain encounters.

Decision-making

Chaplains are uniquely equipped to help families with decisions because of their listening, reasoning, conflict resolution training and empathy. After other services have given the facts, the chaplain’s presence can offer immeasurable support. The chaplain creates a non-anxious presence, opening space to think clearly, listening to all points of view and validating feelings and responses.

218. Jacobs, quoted in David J. Zucker, “A Clergy Guide to End-of-Life Issues,” Review, *PlainViews*, March 17, 2010, Vol. 7, No. 4, <http://www.plainviews.org/Review.php>, accessed March 17, 2010.

219. The availability of resources is not limited to rural areas. Expensive treatments, usually only available in urban medical centers, are rationed based on need.

Families making decisions receive education that comes from the media, including soap operas, medically-themed shows, news reports, including the news about Terri Schiavo's case, their church's response to this issue, prior experience with decision-making (which they apply to the current, unrelated case erroneously), and their family system, explored in the previous chapter. In some hospitals, education is provided to families in pamphlets such as Hank Dunn's *Making Hard Choices*. Educational opportunities do not necessarily create sane and diplomatic dynamics. A palliative educator laments: "I thought that this would be a breeze. The patient was a CEO at the hospital. Even with all the staff around, they just couldn't let go of him. I've had an easier time with families with absolutely no education around this."²²⁰ While sweeping generalizations create bias ahead of time, at one Indiana hospital, a social worker saw some patterns in family decision-making that helped her understand how families in one geographic region coped. Education wasn't as important as some cultural underpinnings:

I've found that White families are more confident about choosing the hospice route. Black families here want to do everything (treatment-wise). They don't want to talk about hospice. There is mistrust, especially with a black family and a White doctor. If a family doesn't want hospice, they tend to say a statement about their faith or something, but can't back it up; you can't challenge it, and they repeat it over and over. Hispanic families like to consult with a Catholic priest. It's not cut and dried, but that is a norm here.²²¹

How can these views change, or do they need to? In this same region, there were legends about hospitals: "Why did they bring her here? That hospital is the fast hospital. This is the hospital where Black people die!"²²² An Indiana nurse practitioner responded to the notion of racial differences in this particular region: "White families will have the daughter that makes decisions for her parents, and Black and Hispanic families tend to band together to make a decision."²²³ These are merely observations of cultural differences and not rules. Emotions can run high around a death passage. The words that are used can provoke.

Emotionally-charged words

220. Tammy Allee, interview, Aug. 1, 2009.

221. Traci Kaufmann, interview, July 25, 2009.

222. Stikeleather, Journal Entry, February 10, 2009.

223. Rebecca Russell, interview, March 3, 2010.

The words used to describe medical feeding and its effects can create a storm of emotions in the family's understanding. How this is described is paramount to bringing reality to the present situation.

'Starvation'

The word 'starvation' reminds one of children starving in Africa. When ANH is withheld or withdrawn, it is because the body no longer requests food. This can confront very directly the family's need to provide nurturing, as stated earlier. Food has a caring and nurturing quality built into it, possibly derived from nursing an infant. Once that is taken away, the family has little left to offer task-wise. In 1975, When Karen Ann Quinlan's father agreed that medical staff remove her ventilator, he refused to agree to remove her feeding tube, seeing it as vital to her life. As a result, she remained in the bed, alive for 10 more years.²²⁴ The myth that she woke up and left the hospital is simply that.

'Dehydration'

Some death certificates will state 'Dehydration' as the cause of death. This can bring to mind dying of thirst in the desert, when it was stated earlier that hydration itself can cause further pain. "The only uncomfortable symptoms of dehydration are a dry mouth and a sense of thirst, both of which can be alleviated with good mouth care and ice chips or sips of water but are not necessarily relieved by artificial hydration."²²⁵ Another chaplain, Charles Meyer, writes in his *A Good Death* that it is normal for dying patients to quit eating and drinking. They are not hungry or thirsty and become azotemic. Waste products build up in the body and serve as a natural analgesic to insulate the body from pain.²²⁶ Schmidlin describes this procedure as 'terminal dehydration.'²²⁷ In Boulder, a doctor with a terminal illness found very little research on the benefits of not eating and drinking at the end of life, except for a little encouragement. He was the subject of the film, *Dying Wish*, where the filmmaker interviewed him daily so he could describe how he felt. This is described as 'Patient Refusal of Nutrition and Hydration

224. Daniel R. Coburn, "In Re Quinlan," 70 N.J. 10, 355 A.2d 647, 1976.

225. Dunn, 23.

226. Meyer, 17-18.

227. Schmidlin, 485.

(PRHN).²²⁸ Viewers of the film saw the doctor's daily reports of his experience, where he spoke of airiness, an experience of drifting, and finally, he stopped speaking.

'Killing'

The word 'Killing' can bring up an Old Testament commandment: 'Thou Shalt Not Kill.' Allowing someone to die is very different from killing them. With medical advances, hospitals could house people on ventilators and feeding tubes for a long time.²²⁹ Allowing them to die is much more natural than this. As one doctor stated, "I tell families that I could bring up a body from the morgue and ventilate it. It doesn't mean the patient is really alive, just ventilated."²³⁰ The phrases 'Intentionally Arranged Death,' 'Physician Assisted Suicide,' and 'Aid-in-Dying' all point to the idea that at some point, treatment will stop, and someone is 'midwifing' this process.

'Euthanasia'

The word 'Euthanasia' and 'euthanized' reminds one of pets being put to sleep and the outdated stigma of folks with depression and death wishes attached to the 'Hemlock society.'²³¹ Euthanasia is no longer used to describe assistance with death because of the connotation of 'deciding for God.' In American culture, one might say that God makes decisions about death and healthcare professionals try to defy this decision, 'playing God.'

The Time-Limited Trial

Making decisions to proceed with a treatment requires clear thinking about its purpose and time. Hank Dunn recommends that families ask for a time-limited trial in his 2009 edition of *Making Hard Choices*: "If there is little or no improvement in the patient, or no possibility of regaining consciousness or the ability to swallow, then the artificial feeding may be withdrawn."²³² This recent compromise gives sanity and reality to this treatment idea. It is not never, it is not forever, but it is just for now. "Families

228. Karen Van Vuuren, "The Story," www.dyingwishmedia.com/dyingwishmedia/About.html, accessed November 4, 2009.

229. At some point, the burdens of medical feeding can begin to cause infection, leading to sepsis, another road to death. An autopsy of Terri Schiavo's brain revealed a cavity with fluid.

230. Kristin Strathun, personal communication, January 20, 2009.

231. See <http://www.compassionandchoices.org/hemlock>

232. Dunn, 27.

need to see it happening, see for themselves how uncomfortable the patient is, and once they see it, they give the go ahead to withdraw.”²³³ Ann Cotton, a Clinical Nutritionist, described a trophic feed, which means to give feeding at a low rate, a kind of compromise: “It gives the family peace and the patient is not so dehydrated, makes the last couple of days workable for everyone.”²³⁴

Time-limited trial or not, there are circumstances where feeding would not be withdrawn – with young children. After the case of Baby Doe in 1982, where a family decided to withdraw support from a newborn with Down’s syndrome, and a court intervened temporarily,²³⁵ the withdrawal of treatment from children is far trickier. Chaplain Mike Hoppe describes an experience at a children’s hospital: “They will never withdraw feeding. They will withdraw other things, but not that. The nurses say, ‘we have to feed babies.’”²³⁶ In American culture, the promise of a new life makes these decisions unbearable. Religious conviction makes it even more complicated.

Religious Delusions

Families can create a strong presence, standing on mental constructions that have spiritual delusions, showing their denial:

In a meeting with oncologists and ethicists, the African-American family refused to acknowledge that their father was dying. ‘We only want to talk about TPN, nothing else.’ After a period of discussion, the family stood up together and left the meeting. Those remaining discussed the hospital’s untested policy to refute family decisions when they provide futile care. Later, an elder chaplain was curious about who receives the patient’s ‘check.’ A few weeks later, the patient grasped the chaplain’s hand tightly, but did not speak. A few hours later, he was dead. The family arrived later and expressed shock.²³⁷

African American families have received sub-standard treatment in hospitals in the past,²³⁸ and these memories color their belief in the words of mostly white medical staff.²³⁹ Denial is definitely not specific to this ethnic group. *Reuters* Health writer Anne Harding notes that decision makers are skeptical when doctors tell them there are no more treatments. This is ironic because of the admitted difficulty doctors

233. Guerra interview.

234. Ann Cotton, interview, July 20, 2009.

235. Ann Constable, Claudia Wallis, and Sheila Gribben, “Medicine: The Stormy Legacy of Baby Doe,” U.S., *Time*, Sept. 26, 1993, <http://www.time.com/time/magazine/article/0,9171,949828,00.html>, accessed March 4, 2010.

236. Michael Hoppe, interview, July 20, 2009.

237. Stikeleather, Journal Entry, July 5, 2009.

238. See *The Tuskegee Syphilis Experiment*, <http://www.tuskegee.edu/Global/Story.asp?s=1207586>

239. Alexia Torke, lecture, “Diversity Issues in Medical Care,” Fairbanks Center for Medical Ethics, Indianapolis, IN, Jan. 10, 2009.

have with giving this information to patients and families. Families don't believe that doctors can predict the future; they want to see for themselves, want more information, and believe that God will intervene.²⁴⁰

Douglas B. White's research concluded that

32% said they would want to continue treatment if the patient had less than 1% chance of survival, while 18% said they would ... if the patient had no chance of survival. The people who questioned the futility hypothesis based on their religious beliefs were four times as likely as people who didn't have doubts to say they would want to continue life support for someone with 'a very poor prognosis.'²⁴¹

Religious beliefs and the way they impact healthcare is tremendous:

A man lies in bed, feeding tube in place, staring at the student chaplain. His wife cries privately that she made the wrong decision. The nursing home chaplain responds with directness: 'This decision has been made. We have been over this.'²⁴²

In this case, a Catholic healthcare facility determined that the patient was benefitting from the feeding tube, but his wife carried guilt. Should he relieve her guilt by dying?

The 90 year old woman still lived at home until she had a stroke. Now she lay in the hospital bed, not conscious. The family asked for a feeding tube. 'She was so alive. We must have hope!'²⁴³

The idea that a 90 year old can bounce back from a stroke is rare, though possible. The line they are crossing puts hope before reality. They aren't there yet, but in a week, they will need to decide if their time-based trial is working. "We have to have a feeding tube. What if she wakes up in ten years?" This is magical thinking about the limitations of recovery and is dependent on many variables, such as age and type of brain injury.

Research

Healthcare does not exist in a vacuum; doctors and other medical professionals often hold dual appointments as faculty with research and publishing expectations. After a particularly difficult case, a doctor may write about it. Sometimes the line of autonomy and research gets blurred. This was popularized in the movie *Wit*, where the cancer researcher's fascination with cancer interfered with a

240. Anne Harding, "Doctors' Views on Treatment Futility Often Doubted," in *Reuters*, August 13, 2009, www.reuters.com/articlePrint?articleId=USTRE57C51320090813, accessed August 18, 2009.

241. Douglas B. White, quoted in Harding, 1.

242. Stikeleather, Journal Entry, March 10, 2004.

243. *Ibid.*, April 10, 2009.

patient's code status when it was discovered that her heart had stopped. He simply did not want his research project to end. This does happen in life, and the IRB²⁴⁴ strives to prevent it.

The patient had a stroke after surgery and received a g-tube. After the second stroke, the daughter asked that the feeding tube be removed. The physicians refused because they felt her condition was 'reversible' with rehab, and expressed concern that death without ANH would be unpleasant. The daughter, a nursing home administrator herself, requested an ethics consult. One physician revealed that he was writing an article for JAMA²⁴⁵ and was fascinated by the patient's quick recovery from surgery (despite the strokes). The tube was removed and the patient died.²⁴⁶

At the end of life, the subject of medical feeding provides complicated issues, both medical and emotional. It has both benefits and burdens, ripe with ethical dilemmas. The quality of life, decision making, emotionally charged words, time-limited trials, religious delusions, and research needs all play subtle parts in the creation of a particular presence in the patient and family as they observe life ending. It is important for the Tibetan Buddhist chaplain to have both a strong grasp of what can create this presence and also knowledge of Tibetan Buddhist ethics, and in this case, the ethics specifically relating to feeding.

C. Tibetan Buddhist Ethics of Medical Feeding

Buddhism and Medicine

The ultimate foundation for Tibetan Buddhist ethics is the Dharma,²⁴⁷ which was originally taught to address specific situations and is adaptable to the individual, modern situation. Professor of Tibetan Buddhist ethics Damien Keown, in his *Tibetan Buddhist Ethics*, speaks of the use of skillful means (upāya) as a way for the Bodhisattva²⁴⁸ to show compassion (karuṇā) without rules and regulations, such as those written in the Lotus Sūtra.²⁴⁹ This moved compassion from being limited toward an ultimate usefulness in a variety of situations as a way to reduce suffering.²⁵⁰ Compassion is applied to a multitude of situations with very specific action. R.L. Soni, author of *Buddhism and the*

244. Institutional Review Board.

245. *Journal of the American Medical Association*.

246. Wanda Turner, personal communication, October 12, 2009.

247. Tibetan Buddhist scripture, teachings, doctrine.

248. An awake being.

249. A Mahāyāna text describing skillful means.

250. Damien Keown, *Tibetan Buddhist Ethics: A Very Short Introduction* (Oxford: Oxford University Press, 2001), 18-19.

Indian Outlook, wrote that “the noble profession of Medicine and... Buddhism are both concerned in their own way in the alleviation, control and ultimately the removal of human sufferings.²⁵¹ The healthcare milieu as charnel ground is a perfect practice ground for the Tibetan Buddhist chaplain’s understanding and embodied practice of Tibetan Buddhist ethics. Although feeding tubes have a history that goes back to Ancient Egypt,²⁵² Buddhism’s ancient scholars have spoken about this ‘modern’ subject, and the treatment of monks would correlate now with householders and monks.²⁵³ Compassionate action, the relationship of medicine to food, and the preciousness of life are major considerations of a Tibetan Buddhist view of medical feeding decisions.

Bodhisattva activity

In Keown’s chapter, “Suicide and Euthanasia,” he speaks of the preservation of life ‘at all costs’, quoting Buddhaghosa, a 5th-century Sri Lankan Theravadan²⁵⁴ Buddhist commentator and scholar:

If one who is sick ceases to take food with the intention of dying when medicine and nursing care are a hand, he commits a minor offence (dukkata). But in the case of a patient who has suffered a long time with a serious illness the nursing monks may become weary and turn away in despair, thinking ‘when will we ever cure him of this illness?’ Here it is legitimate to decline food and medical care if the patient sees that the monks are worn out and his life cannot be prolonged even with intensive care.²⁵⁵

In the first part of this quote, Buddhaghosa is first distinguishing the difference between causing an early death and acquiescing to death that is occurring naturally. The phrase ‘weary monks’ reminds one of weary caregivers and the limbo described earlier in this paper about caregiver exhaustion. The patient is also a Bodhisattva himself here, noticing how tired his caregivers are and deciding to stop eating. Does

251. R. L. Soni, “Buddhism in Relation to the Profession of Medicine,” in *Religion and Medicine* 3, Vol. 3, ed. D. W. Millard (London: SCM Press, 1976), 137.

252. The history of enteral feeding goes back about 3500 years to the ancient Greeks and Egyptians, who infused nutrient solutions into the rectum to treat various bowel disorders. See Ronni Chernoff, “History of Tube Feeding: An Overview of Tube Feeding, from Ancient times to the Present,” in *Nutrition in Clinical Practice*, 21:408-410, August 2006.

253. Keown clarifies later why the ancient scholars would write specifically about monks instead of all people, although caste could play a role. Householder in this case means a non-monastic Tibetan Buddhist.

254. The oldest surviving Tibetan Buddhist school, from India.

255. Buddhaghosa, *Visuddhimagga*. 430. C.E, VA, ii., 467, quoted in Keown, *Tibetan Buddhist Ethics: A Very Short Introduction*, 112.

this diminish his autonomy, putting others' needs before his own? Keown writes that this quote helps the Tibetan Buddhist recognize the inevitability of death as a central element in Tibetan Buddhist teaching.²⁵⁶

Medicine and Food

The relationship between medicine and food, discussed earlier, is also of concern to Tibetan Buddhists. Keown points to the close relationship in India between medicine and food, naming butters, honey and oil as the primary 'materia medica':^{257 258}

It was permissible for monks to take any food as medicine provided it was not consumed primarily for nutrition. If the patient was a layman, the distinction between food-as-medicine and food-as-nutrition would lose its restrictive significance, since the laity is not obliged to observe the monastic dietary restrictions.²⁵⁹

So, in the time of this writing, monks had a different set of restrictions than the laity. Keown later reminds the reader that Tibetan Buddhist precepts prohibit taking a person's life, but "it does not follow that there is a duty to go to extreme lengths to preserve life at all costs. There is no obligation, for example, to connect patients to life-support machines simply to keep them alive... Buddhism would have no objection in principle to doctors discontinuing a treatment that was either futile or excessively burdensome to the patient in relation to its expected benefits."²⁶⁰

Value of Life

A Tibetan Buddhist ethics must address impermanence and lack of attachment.

Although a Tibetan Buddhist considers life to be extremely precious, he does not imagine it to be sacred, divine. He is therefore not committed to stubbornly preserving a spent, doomed and suffering-ridden life for its own sake and at all costs. For him, there are no 'souls' that can be 'saved' or 'lost' or 'returned' to their Maker.²⁶¹

This author refers to the controlling behavior of some needing to save souls before death. In this case, there is no soul to save.

256. Keown, *Tibetan Buddhist Ethics: A Very Short Introduction*, 113.

257. 'Materia medica' can mean collected medical knowledge, now called pharmacology.

258. Damien Keown, *Buddhism and Bioethics* (London: Palgrave, 1995, 2001), 162.

259. *Ibid.*

260. Keown, *Buddhism and Bioethics*, 167.

261. Louis H. van Loon, "A Tibetan Buddhist Viewpoint," in *Euthanasia*, eds. G.C. Oosthuizen, H.A. Sharior and S.A. Strauss (Cape Town: Oxford University Press, 1978), 72, quoted in Keown, *Buddhism and Bioethics*, 180.

The Tibetan Buddhist Ethics that relates to medical feeding decisions is rooted in the Dharma, is the compassionate action of Bodhisattvas - both patient and caregiver, takes into careful consideration how food and medicine are related and defined, and carefully considers life as precious but not worth preserving at any cost.

The atmosphere of the medical feeding decision-making process is impacted by family dynamics and ethical implications, creating a presence that the Tibetan Buddhist chaplain encounters, viewing the death process through the lens of Tibetan Buddhist ethics. The final chapter of this paper will explore how these two 'presences' or buddha-fields work together in an exchange of human energy and love.

IV. The Application of Presence during End of Life Decisions

This paper has defined a Tibetan Buddhist chaplain's construction of presence, explored the nature of the death process for the patient and family, and shed light on the specific death process involving medical feeding and the decision-making process that precedes it. The patient and family also create their own presence, created by what their minds are doing. One might say 'they are what they think.' The Tibetan Buddhist chaplain works with the thoughts rumbling around in a patient's room. In this chapter, this presence will be defined by the following Hīnayāna, Mahāyāna and Vajrayāna principles: mindfulness, suffering presence, the buddha-field's effect, the exchange between chaplain and patient/family, the body itself as presence, seeing crisis as the appearance of buddha nature, and the mandala or team approach. Each of these ideas shows how presence is effective.

A. *Hīnayāna Applications*

Mindfulness

The Tibetan Buddhist chaplain brings mindfulness to the chaos inherent in the unpredictable hospital environment. When is the doctor coming? When is my discharge? Where is the nurse? What will the doctor say? When will I get a visitor? The chaplain's practice provides a trained mind for the visit:

The patient suffered from ICU-related psychosis, causing temporary, yet terrifying thoughts and dreams. He envisioned a demon crawling down his throat. As he described this to me, I focused my mind very quickly to a very flat, quiet landscape and held it carefully as he described the demon. As he spoke, he started to sweat and his face contorted in terror. He agreed that meditation might help him. I asked him to see the room, smell the room, and listen to sounds from the hall. He began speaking about the demon again. I said 'stop' quietly and he stopped the story. He returned to describing his sensory information in the present.²⁶²

This mindfulness is useful to encourage staying in the present instead of following thoughts into storylines and emotions.

Suffering Presence

The chaplain acknowledges suffering, which is pervasive. In a hospital, it is especially important for this to be acknowledged. Patients are showered with flowers, told to think positively, even told by family to be quiet:

262. Stikeleather, Journal Entry, Oct. 1, 2008.

After her baby died at birth in the night, the mother was rushed to the ICU to stabilize her blood pressure. As she recovered the next morning, she began to weep for her child. Her Aunt admonished her to trust God's plan for her baby. 'She's one of God's angels now.' The chaplain was present when maternity staff brought the baby to the mother's room at the mother's request. The baby was placed in the mother's arms, and the Aunt continued to manage her emotions. The chaplain felt his anger rise. Underneath the anger was deep sorrow for this horrific picture of the dead baby in her arms. A single tear rolled down the chaplain's face, much to the chagrin of the controlling Aunt. The mother moaned low and rocked the baby as tears flowed. Suffering was no longer shut out.²⁶³

When suffering is acknowledged, healing can begin.

B. Mahāyāna Applications

Effect of the Buddha-field

The ultimate effect of meditation is the creation of a buddha-field. Group meditation in an intensive environment, such as a group retreat, can create this spontaneously.²⁶⁴ The buddha-field created by a bodhisattva is not selfish. He intends to gather everyone into it. It is

for the sake of all sentient beings as well as for his own sake... (a) cultivation of a whole 'field' of living beings, those who... have destinies intertwined... Hence, his purification of a buddha-field is a mode of expressing his ambition to cultivate a whole world or universe while he cultivates himself, so that he and his field of living beings may reach enlightenment simultaneously.²⁶⁵

The chaplain is on her own journey toward enlightenment, but this a for the benefit of others. This purification is one of love. It cannot be forced; it is not aggressive, not proselytizing, and not coercive. It is simply aspirational. It is simply offered. This field is transformative:

To the extent (chaplains) can maintain a non-anxious presence in a highly energized anxiety field, they can have the same effects on that field that transformers have in an electrical circuit. They reduce the negative energy in the field by the nature of their own presence and being, as well as by the field they, in effect, set up.²⁶⁶

Being in a buddha-field may mean that the wisdom is collected while anxiety is high:

The wife of the patient mentioned casually that she cleans when she's anxious. In the middle of the night, I found myself cleaning things thoroughly, embracing her way of dealing with anticipatory grief and being present to her emotions as they arose when she

263. Stikeleather, Journal Entry, March 10, 2009.

264. Ray, Dharma talk, *Winter Dathūn 2009*, Dharma Ocean Foundation, Crestone, Colorado, December 20, 2009.

265. Thurman, 111.

266. Cox, 7.

wandered back downstairs, unable to sleep. She could feel the intensity of his approaching death passage. She didn't exactly say it, but we both knew and stood together in that. Her husband said he did not want to know he was dying, but deep down, his anxiety gave it away as he paced the floor at 4am. When I returned the next day, they mentioned coming to terms with reality of what was approaching. Death arrived the next day.²⁶⁷

Collective wisdom helps reality appear unsullied by mental constructions. It is eye opening in this modern, updating of a quote from Vimalakīrti:

So, the hospital families purified their immaculate, undistorted Dharma-eye²⁶⁸ in regard to all things. They were liberated from their mental defilements, attaining the state of non-grasping, were devoted to the grandeur of life as it actually is, having understood that all things are by nature but magical creations, all conceived in their own minds the spirit of unexcelled, totally perfect enlightenment.²⁶⁹

One might expect for Asian Buddhist families in America to be thoroughly versed in death practice and for this to be apparent:

Each of the patient's daughters visited individually, because one daughter had converted to Christianity and this caused conflict between them. This daughter's influence delayed the end of treatment, until the mother patient and other daughters put their collective foot down. The mother stated to staff, 'Chemo makes mama sick. I don't want to eat. I hate looking out this window at the other building. I want to see out far.' Staff joked that the patient was paying expensive rates for the corner room, although no treatment was offered. Her daughter announced to the chaplain, 'We're Buddhists – we understand death.' The mother patient enjoyed the view for the rest of her days.²⁷⁰

This effect is not immediate, but has a powerful effect on denial:

He spoke of his remission being permanent. His wife looked over and seemed to gaze right through me as he ate his applesauce, the only thing he could hold down. The caregiver spoke of his recent client's obituary in the paper and felt the room shake emotionally a bit. What is really going on here? Is this the end or, like the husband says, 'We're gonna fight this Leukemia bug once and for all!' The husband left the room to vomit.²⁷¹

This presence is immaculate, grand, magical, unexcelled, and perfect. The chaplain is not in the buddha-field alone, but interacts with the energy of those in the patient's room.

267. Stikeleather, Journal Entry, March 18, 2010.

268. Dharmacakṣu, one of the 'five eyes,' representing superior insights of the Buddha and bodhisattvas, from Thurman, 113.

269. Thurman, 19.

270. Stikeleather, Journal Entry, April 10, 2009.

271. Ibid., March 20, 2010.

Exchange

What is happening in the middle of all these thoughts? When the chaplain's presence collides and colludes with that of patient and family, there is genuine exchange. Dr. Edward Podvoll, a Tibetan Buddhist and psychiatrist, wrote that this is a "conscious process (that) happens because one has gradually developed the full intention of 'giving up' and 'letting in.'"²⁷²

They sat on the couch together in silence. The client's neurological events caused brief gaps in thought patterns that created silences and confusion. The chaplain attending him allowed this confusion to permeate his own mind, sitting beside the client. This allowed for basic attendance²⁷³ that offered companionship to the client.²⁷⁴

This basic attendance requires skillful means to allow this permeation of the other. It is not easy, but requires much practice.

C. Vajrayāna Applications*The Body as Presence*

What gets into a patient's room first, the chaplain's body or mind? The presence that is created before speech must be in the body itself, a karma body produced by the mind.²⁷⁵ Reginald A. Ray, in his

Touching Enlightenment, states that

the body itself is the buddha nature... the mysterious, open-ended darkness out of which our life is continually emerging, involving personal, interpersonal, and cosmic dimensions. It is in the body that we meet the buddha nature in its most naked form. By entering ever more deeply into the body and receiving the unending flow of experience that arises when we do, we are in intimate relation with the buddha nature.²⁷⁶

No thoughts are concrete in assuredness. The now contains the past and future also. It is completely full of possibility.

The chaplain learned of the Burmese patient and her struggles with staff and Christian daughter. After speaking briefly with the daughter, who welcomed the visit, he entered the room and bowed. Her daughter introduced him, translating into their language. The

272. Podvoll, 271.

273. Companionship. See *Ibid.*, 226.

274. Stikeleather, Journal Entry, February 21, 2010.

275. Our bodies, and ultimately, our incarnations are the result of karma. Ray, dharma talk, *Winter Dathūn 2004*, Shambhala Mountain Center, Red Feather Lakes, CO, Jan. 2, 2005.

276. Ray, *Touching Enlightenment*, 223, 226.

chaplain described sadness for her struggle with loneliness and anger with the nurses. The patient wept and sighed, then spoke of the compassion in the chaplain's face and thanked him for his blessing.²⁷⁷

What was the chaplain's facial expression? Was it his face or his body? This presence is important in a crisis ministry.

Working with Crisis

In many patient rooms, the chaplain will encounter a crisis. A portion of these involves an impending death with difficult decisions precluding it. The buddha nature of all involved has an effect:

Through the profound existential crisis, the ego has been temporarily weakened, depotentiated in psychological terms. This depotentiation allows the larger, unbiased intelligence of our 'true nature' to break through and be heard. Even perceiving our disrupted situation as a fundamental existential crisis with no apparent way out is, in itself, an expression of the buddha nature, of a primordial level of intelligence within us that is no longer distorted by the wishful thinking or self-absorption of the ego.²⁷⁸

Reality can be especially painful in a hospital, given the possibility of death. Dreams of renewed life after illness are shaken awake by setbacks and medical failures. Hospitals bring palm trees, fountains, soothing music, butterfly gardens, comfort food and Starbucks into their midst to help soothe families. They need soothing because they want to change the outcome, improve health and defy the gravity of death's natural weight. But there is no need to change this experience. Pema Chödrön writes about working with this chaos of the mind created by crisis: "(We) regard whatever arises as the manifestation of awakened energy. We can regard ourselves as already awake; we can regard our world as already sacred."²⁷⁹ The chaplain's presence wakes us from our dreams:

Jan watched as the chaplain joined the weekly family conference for the first time. As he sat down, she began to weep. She put her head down and listened as the doctor gave the poor prognosis that her husband would not recover, for sure this time. She raised her head and implored, 'So we're giving up?' She sighed and quietly looked at the chaplain, who summarized, saying, 'Jan, we're giving in.' Jan left the conference room, walked past her visitor chair and climbed into her husband's ICU bed for the last time.²⁸⁰

277. Stikeleather, Journal Entry, Jun 10 2009.

278. Ray, *Touching Enlightenment*, 244.

279. Chödrön, *When Things Fall Apart*, 124.

280. Stikeleather, Journal Entry, November 20, 2008.

As explored as part of the Vajrayana view of the charnel ground in the hospital, this crisis is simply an opportunity to wake up again. If the very presence of the chaplain points to a charnel ground, then perhaps the body of the chaplain is a charnel ground of sorts, full of life experiences and reality. This may be the reality that has created the stereotype of the chaplain as ‘angel of death.’ Does the chaplain bring death or simply point to the reality of it? As in the previous story of the daughter suddenly crying harder when the chaplain arrived,²⁸¹ this presence carries the weight of reality, bringing reality to a heady, bewildering environment of denial and delays.

This presence uses skillful means in its timing. As stated earlier, a family may not grasp that they are present in a death passage. The visit from the chaplain does not have to be lengthy to be powerful. This presence reminds families that the illusion of control is a dream and asks them to see deeply into the mysterious truth of life itself.

Mandala approach

As a team or mandala, the chaplain, family, patient, and medical staff all provide presence, working together in disparate groups arriving momentarily as strangers with common knowledge and hearts. The family and staff model the use of the mandala, working as a group. Each part of the mandala contains the holonic²⁸² buddha nature of the whole in that, as humans, each breath taken exhales away, acknowledging a constant letting go, sometimes kept secret from even ourselves. This letting go is a requirement, even of young mothers:

A woman driving on the highway with her infant girl crossed the center line and collided with a truck. The mother went to one hospital and the infant to the children’s hospital. The chaplain gathered the infant’s family, who then witnessed her tragic death from injuries. At the other hospital, a week later, the mother asked about her daughter, and the family did not know what to say or how to say it. They asked the young attending doctor and chaplain to speak to the mother. After the doctor expressed his sorrow about the daughter’s death, the mother simply did not believe it. An elder relative whispered, ‘It’s denial.’ The elder asked the chaplain to say a prayer and to go ahead and tell the truth. The chaplain knelt beside the mother and cried about the infant’s death, acknowledging his presence at the moment of death. The mother lay stunned, still not speaking, just staring at the ceiling. Her family, with prior knowledge of this reality, stood around her offering their loving presence. This grief would be a long road. Afterwards, the doctor

281. See page 17.

282. Something that is simultaneously a whole and a part. See Arthur Koestler, *The Ghost in the Machine* (New York, Penguin, 1967), 48.

asked the chaplain how he did. The chaplain responded, 'You stayed there after you spoke. That was very helpful.'²⁸³

The truth of life is pushed away by the ego. This mother could not bear life without her child, and reality pressed in after she recovered from her physical injuries. She would now begin to heal from emotional ones.

Viewed through the lenses of Hīnayāna, Mahāyāna and Vajrayāna, the presence of the patient, family, medical staff and chaplain all work together through the chaplain's modeling to create a luminous time of clarity, working with mindfulness, suffering, and the effect of the buddha-field; using the body as presence, participating in exchange, working with crisis as buddha nature, and using a mandala approach.

283. Stikeleather, Journal Entry, June 20, 2009.

V. Discussion

A. Conclusion

The Tibetan Buddhist chaplain's effect on a family during end of life medical feeding decisions is created by the construction of his presence, which is the result of study and practice. This study and practice of Hīnayāna, Mahāyāna and Vajrayāna Buddhist concepts creates a presence that uncovers both the chaplain and decision maker's buddha nature. This resultant buddha nature relaxes the mental constructions created by the patient and family's emotions elicited by approaching death and the ethics of medical feeding. This wisdom helps provide the most loving and compassionate care to loved ones at the end of life.

B. Need for a Quantitative Study

A quantitative study would give more tangible evidence to this idea of presence having an effect. In a medical world of empirical evidence, combined with the religious studies milieu of ideas and doctrine, the idea of the chaplain's presence is hard to measure. It is only within the body that one knows of presence, both in construction and application.

Here is a possible quantitative study: 100 stroke patients in one hospital system enter the study when they lose the ability to eat. Each patient receives a standard script of treatment options from one doctor. A chaplain visit is requested for half the patients following the presentation of the treatment options with recommendations. The medical staff's recommendation and the patient/family's decision to feed or not to feed would be notated. Is there a correlation between chaplain visits and withholding medical feeding that is futile?

Chaplains rarely write quantitative studies, although they read censuses of patients and count visits to fulfill quotas for mission effectiveness. They write about suffering in journals that other chaplains read, write pamphlets that help families understand the end of life, and some have tried recently to begin justifying their presence in the hospital, but writing in journals that only they read. This may be related to their assignment: to minister to hospital and hospice patients, offenders, etc. Sitting in the office

and typing is not viewed as the hospital's understanding of this role.²⁸⁴ Evaluations usually revolve around indirect knowledge of patient visits, actual visibility on the unit, and not articles published. There are always more ministry needs than a chaplain can accomplish. After work, writing at home is not part of this culture; the chaplain needs to offer self-care. The chaplain will be sitting by the lake, whereas the medical professional will be writing at the dining room table. Given the academic milieu of many medical professionals, where they have dual appointments in both clinical work and teaching, the pressure to write is greater than for the chaplain whose expectations are not as quantifiable or just beginning to be quantified.^{285 286} There are always more medical staff than chaplains, and even an 800 bed hospital with 10 chaplains and four residents cannot cover all the ministry needs that arise.

Chaplains also complain that end of life research is difficult to obtain, given the reluctance of patients and families under duress. The literature says otherwise, finding that families are actually eager to participate and talk about their experiences. While chaplains have written about medical feeding decisions, the written evidence about the chaplain's effect on medical decision-making comes from doctor-initiated research. This research tracked families a year after they made a decision to withdraw or withhold life-sustaining support. Though the findings are not specific to medical feeding itself, it points directly to the issue: "Forty-eight percent of family members reported the reassuring presence of clergy" and "Families identified pastoral care and prior discussion of treatment preferences as sources of psychosocial support during these discussions."²⁸⁷ This finding lends some credence to the role of chaplain. It is unclear from research whether a chaplain is wanted by patients. One study, polling patients about their desire to seek a chaplain's visit, found that a majority of patients did not want a chaplain visit when asked upon admission. One of the reasons for this may be that chaplains often arrive just after bad

284. In the author's experience as a chaplain at Midwestern hospital, time that staff chaplains spent in their offices was not viewed as ministry, negating the value of the chaplain's presence on campus. Job descriptions are patient-focused, not research-focused. Only special circumstances made it possible for a chaplain to write. There is also a movement to make chaplains 'faculty' which might help serve the need for writing.

285. This impression grew out of observing medical and chaplain staff at a large teaching hospital.

286. Some chaplains are experiencing a shift in evaluation that is based on numbers of patients seen in any one day. Creativity is needed to document staff ministry, since these 'parishioners' do not have electronic charts.

287. Katherine H. Abbott, Joni G. Sago et al, "Families Looking Back: One year After Discussion of Withdrawal or Withholding of Life-Sustaining Support," in *Critical Care Medicine*, 2001, Vol. 29, No. 1, 197.

news. Once a chaplain did appear, patients appreciated the visit.²⁸⁸ The idea of a chaplain visit is much different than the actual visit, it seems.

C. Limitations

a. Religious focus

This study focuses on the presence of the Tibetan Buddhist chaplain with a Tibetan Buddhist worldview. Sources that spoke of a Christian presence were not included, and those with other religious worldviews were not considered.

b. Locality

The chaplain's stories were obtained in conservative environments in Colorado and Indiana, in a context of mostly Christian families. While these environments were both urban and rural, with even amounts of White and Black families, a broader spectrum of experience would help show both the universality of the family responses and delineate differences along racial, cultural and socio-economic lines.

D. Further Study

The profession of chaplaincy needs validation to help it to thoroughly take its place at the healthcare table of professions. The medical literature does not show a clear understanding of the chaplain's role, if it is acknowledged at all. Some believe that the social worker can do the chaplain's job, and that spiritual rituals are best handled by visiting clergy, whenever they arrive. Doctors are being trained to probe spiritual questions.

The study of different cultural views of the dying process could shed light on the richness that some cultures give to this process without hiding it away. A Hindu's pilgrimage to Benaras at the end of life is one example of a culture that begins to practice death early in the process. What is the effect of Jesus' presence or the presence of the Holy Spirit?

288. Michael R. Saxton, lecture, "The Role of the Chaplain," Saint Joseph Regional Medical Center, South Bend, IN Dec.10, 2003.

What is the difference between a tulpa (nimita or thoughtform) and presence created by a chaplain? How do the wisdom *ḍākinīs* Sukhassiddhi and Niguma help to transform the conflicting emotions during family crisis?

A study of suffering described by different religious texts could help the chaplain understand how this is viewed specifically for their work as chaplains. For instance, how is the idea of a Tibetan Buddhist suffering to burn karma similar to a Catholic's suffering toward redemption?

Death will not go away. Doctors will continue to announce the end of treatment options, and families will continue to gather to decide how to proceed. With the chaplain's presence, wisdom will arise as those gathered uncover their true nature.

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