

“Not everything that can be counted counts, and not everything that counts can be counted.” Albert Einstein

Palliative medicine addresses the relief of suffering on the levels of mind, body and spirit. To fully grasp the nature of this suffering and to work toward its relief, the illness experience for the patient must be elicited and understood for goals of care and treatment to be most effective. (1) Narrative medicine allows the patient’s story to teach us about the nature of suffering and our role in assisting in its relief. (2) To fully understand the suffering of another, the wholeness in the clinician must be engaged. Too often, medicine, and in particular, palliative medicine, is taught in a highly clinical, fact oriented and detached manner. (3) The emotional connection between the clinician and the patient is frequently dismissed in our educational efforts, and learners do not appreciate the art of giving comfort, facilitating the dying process, being silent and present when needed, and engaging in effective communication about patient and family goals and decision-making. The strong emotions associated with grief and loss, death, isolation and loneliness lie within the fabric of medicine and are heard through illness narratives. Can our educational methods help learners effectively address the wholeness in our patients, their families, and in ourselves? Can we touch the raw emotion that comes with mortality or with pain, be it spiritual, emotional or physical pain? Or must our educational processes stay “clinical” and therefore detached from life? We value what can be counted, but the essence of our most compassionate and effective work with patients is often beyond what can be quantified, cured or fixed.

Teaching what is needed requires that we include stories about what people experience as they become ill and what will help them heal. The use of narrative through

prose, video, stories with music, collage and poetry brings learners into the experience of being ill and dying, as well as in greater touch with their own feelings of anxiety, fear, and awe. In doing so, narrative draws learners closer to the deep well of relationship-centered care. This kind of care honors the wisdom and connection of patients and clinicians that lie deeper than intellect and facts. Without this felt experience, we are robots dispensing mechanical interventions for wounds touching the soul. The disconnection is profound, and our patients are left in isolation and pain. Medical practitioners can feel frustrated as they miss the profound opportunity of the practitioner/patient relationship, which ultimately leads them to their best work and service. The tools of medicine cannot be confused for the medicine itself. This paper describes over ten years experience I have had with incorporating the arts and humanities into palliative medicine education with resident physicians, medical students and clinicians.

In the first week of residency, the palliative medicine curriculum begins with death pronouncements. Many resident physicians experience their first death pronouncement at this time. Many will dread this moment, and this discomfort may continue throughout residency if not addressed. Residents tend to denigrate this aspect of caring, because they see no therapeutic value in it. The person is dead, and there is “nothing to do” other than the distasteful, often inconvenient, legal duty. Yet, the death pronouncement is an important ritual in medicine that reminds us that all our patients will eventually die and we will die. How do we continue caring for patients knowing this inevitability? How can we help the family and friends of the deceased at this point? Learning how to comfort family in the face of death is a very important lesson. How do

we comfort with our presence? How can we be fully present to the final significance of this moment? What can we learn about life and medicine, knowing that the life cycle must include death, just as it includes birth?

Stories help us learn what is important about our work. The specific methods and protocols we use in teaching about death pronouncement are described in previous articles. (4-6) There are many written accounts of the emotions and experiences surrounding death pronouncements from learners and families. (7-9) Excerpts from a number of these pieces are read during the introduction to the workshop and discussed. The most powerful teaching tools, however, are the stories from senior residents, passing on their wisdom to junior residents. The transfer of knowledge, experience and emotion help these junior residents feel the power of this profound ritual. Stories encourage us to confront our fears within a community of colleagues supporting us and witnessing the deep commitment we collectively hold to comfort and care for others during difficult times.

In teaching clinical aspects of palliative medicine, I incorporate the developmental schema created by qualitative researcher and clinician, Bernice Harper, a social worker, who studied how health professionals emotionally cope with dying patients in their professional development. (3) Her schema of this developmental process results from analysis of her research data, and contains five stages of growth: intellectualization, emotional survival, depression, emotional arrival and deep compassion. (See figure II in Harper's book for summary table of stage characteristics and differences of the schematic growth and development scale.)

Intellectualization, which characterizes how medicine is predominantly taught and practiced, and which reflects the developmental phase of most clinicians, is the stage where mental processes such as analysis predominate. The focus is on the disease, and its diagnosis and treatment, rather than on the person. Emotion is seen as irrelevant and distracting. The dying patient is avoided, or the dying process is denied. Relationship-centered care is hampered, and the patient can feel isolated and abandoned emotionally and often spiritually.

Emotional survival describes the stage when the clinician is first significantly touched by strong emotions when a patient is dying, and he/she must deal with his/her own anxieties about death and dying. Working with dying patients is traumatic, and working through this trauma is essential. In this stage, detached caring transforms to connection and relationship with the patient. The learner may feel overwhelmed by the patient situation, and this discomfort reflects the need to survive very difficult emotions. This can be a difficult stage for the clinician and is often accompanied by frustration and guilt that the patient is dying. Effective mentoring is crucial at this stage. The learner will either be supported through this stage or will be encouraged to return to intellectualization by a mentor who has not progressed beyond this stage or from the learner's own fear and discomfort. Unless a mentor or teacher has worked through these developmental stages, he/she may be unable to effectively support a learner through this process. Emotional support can also come from fellow learners at rounds or more informally from family and friends.

The next stage of development is depression, a turning point for the clinician. At this stage, the learner experiences grief and loss concerning the patient's death, as well as

the realization of his/her own mortality. Even deeper levels of emotion are experienced. At this point, the learner may choose to return to the stage of intellectualization with a sense that emotions and emotional connection to patients are dangerous and are best avoided. The clinical attitude here is one of separation from the patient for the clinician's protection. Yet, processing of these difficult emotions with the support of mentors can lead to professional and personal growth. If the learner works through the stage of depression, emotional arrival can occur.

Emotional arrival is a stage when emotions are accepted as an essential component of effectively caring for patients. Emotions are viewed as normal rather than avoided as dangerous. A clinician learns to cope with the loss of the relationship with the dying patient, and there is increased comfort with death. Harper writes: "An important aspect of this stage is appropriateness of emotional responses. The professional has the sensitivity to grieve and the resilience to recover." (3: p. 71)

The final stage is deep compassion, where the connection with patients is deepened, and death is seen as a normal part of the life cycle rather than failure, with an accompanying sense of freedom and satisfaction on the part of the clinician in sharing the dying process with the patient. This stage is accompanied by greater self-awareness and self-actualization. Grief and joy can co-exist, and the wholeness of the dying experience is appreciated.

Intellectualization, therefore, is the beginning stage for the health professional unfamiliar with caring for dying patients. Emotional survival and depression are the middle phases of difficult professional growth, and the end phases of emotional arrival and deep compassion characterize the mature, self-aware health professional stages of

growth. The process is not linear, and movement from one stage to another is a dynamic one. (3)

It is this schema that becomes the underpinning of narrative exercise I assign to resident physicians, medical students, health professionals and physicians in seminars and workshops. In a workshop experience, the timeline for the clinician's professional development is explored with time for reflection on the experiences they have had with patients, and what support they need or needed to continue on this developmental journey. They then engage in discussion on the merits of progressing in this developmental process and follow up by writing a brief narrative about any stage in the schema that is meaningful to them. In small groups, dyads, or large groups, the narratives and reflections are shared, if the learners are willing to share their work. I often use poems that I have written about my own growth through the developmental stages (10-13) and share them if they are needed to stimulate discussion, or if the learners do not feel comfortable sharing their own work. I have also used this schema in working with individual resident physicians and medical students when supervising their clinical care, or when they have approached me with difficult clinical situations in the care of dying patients.

Pain is a complex clinical issue, and it is easy to misunderstand or blame the patient. If learners have not experienced significant pain themselves, it may be difficult to empathize with patients. The under-treatment of pain remains a disturbing issue in palliative medicine. I often begin my workshops and seminars on pain assessment and management with a compelling poem called the "Prey of Pain" by Bonnie Raingruber. (14) The poem highlights how spiritual, physical, and psychological pain is difficult to

differentiate, and how attention to all these dimensions is essential in the effective management of pain. This poem was also recently incorporated into a monograph on pain management for family medicine residency education. (15)

Near death awareness and near death experiences are confused at times with delirium and hallucinations if not understood. Near death awareness is the dying person's experience of contact with persons who have died previously, and/or knowledge and perhaps control over their dying process. Stories of near death awareness help us, if we are open, to the awe and mystery of the dying process and help us become more comfortable with death, since it is usually experienced by many patients as a peaceful and life affirming event. (16,17)

Teaching on grief and loss is brought to life with stories about these topics that also point toward recovery, reconciliation, and even transformation. There are countless books, poems and stories about grief and loss in the popular and professional literature. Almost all health professional journals incorporate a column on reflections, poems and stories. Superb videos exist that help me teach how grief and loss are experienced through the patient and caregiver perspective. (18) I have also used collage in workshops on grief and loss with health professionals to explore the inner experience of grief and loss, and use it to help restore well-being. (19)

Narrative medicine honors the story the patient brings to us about the illness experience, which includes the patient as whole person and accentuates the need for deep listening. (20) Dr Rachel Remen writes many heartfelt stories of grief and healing that are useful in palliative education. (21,22) Michael Stillwater and Gary Malkin have produced

artful pieces that combine narrative and music to speak to the healer's soul, which can be powerfully used in educational workshops. (23)

Palliative medicine needs the arts to bring the emotion, connection, wholeness, and relationship back into medicine. The use of narrative, via poetry, stories, and other reflections can connect the practitioner with the patient. Mind/body/spirit medicine cannot be an abstraction nor separate from our real experiences caring for patients. As teachers and clinicians, our creativity awaits to be of service to our hands, hearts and minds. Intellectualization is a lonely place for the patient and clinician. The art is needed to balance the science. The heart is needed to balance the mind.

References:

1. Marchand L. An integrative approach to end of life care. In Rakel, D ed. *Integrative medicine 2nd edition*. Philadelphia, PA: Elsevier Publishers. In press, 2007.
2. Kleinman A. *The illness narratives: suffering, healing and the human condition*. Basic Books, 1988.
3. Harper B. (1977) *Death: the coping mechanism of the health professional*. Greenville, S.C.: Southeastern University Press, 1977.
4. Marchand L, Kushner K, Siewert L. Death pronouncements: survival tips for residents. *Am Fam Physician* 1998; 58: 284-85.
5. Marchand L, Kushner K. Death pronouncements: using the teachable moment in end-of-life residency training. *J Palliat Med* 2004;7: 80-84.
6. Marchand L, Kushner K. Death Pronouncements: Surviving and Thriving through Stories. *Fam Med* 2004; 36: 702-704.
7. Temte J. Late night call to 6 West. *WI Med J* 1991; 90: 509.
8. Johnson-Magill V. Mother's day trauma. *Fam Pract News* 1998; June 1: 10.
9. Lermen R. Death rituals. *Ann Intern Med* 2003; 139: 384.

10. Marchand L. Be not afraid. Unpublished poem.
11. Marchand L. Outrage. *Families, Systems and Health*. 2000; 18:377.
12. Marchand L. Listen. *Families, Systems and Health* 2001; 19:451.
13. Marchand L. Letting go. *J Palliat Med* 2002; 5:425.
14. Raingruber B. Prey of pain. *JAMA* 2002; 287: 2329.
15. Douglass AB, Bauer L, Jonas P, Marchand L, Marvel K, Maxwell T, Rosenthal M, Whitecar P. Pain education in family medicine. (Monograph) Leawood, KS: *Society of Teachers of Family Medicine*, 2005.
16. Marchand L. Fast facts and concepts #118: near death awareness. End-of-Life Physician Education Resource Center www.eperc.mcw.edu. Milwaukee, WI, 2004.
17. Marchand L. Facing death. *All Things Considered*. National Public Radio, 2004.
18. Pickard C, Pickard A. Turning toward the morning: stories of love and loss, grief and hope. (Video) Rites of Passage. An Imagica Production. www.ktc.net/ritesofpassage, 2003.
19. Marchand L. Collage: work of the soul. *American Academy of Hospice and Palliative Medicine Bulletin* 2004 Winter: 8-9.
20. Frank AW. Just Listening: Narrative and Deep Illness. *Families, Systems and Health* 1998; 16:197-212.
21. Remen RN. *Kitchen table wisdom: stories that heal*. New York: Riverhead Books, 1996.
22. Remen RN. *My grandfather's blessings*. New York: Riverhead Books, 2000.
23. Stillwater M, Malkin G. Care for the journey: sustaining the heart of healthcare. Companion Arts by Wisdom of the World, Inc. Portland, OR. www.innerharmony, 2005.