



ADEC Forum:

The quarterly publication of the Association for Death Education and Counseling

Volume 36, Issue 2

April 2010

The Thanatology Association®

End-of-Life Issues for the Elderly

It Is Time for Our Generation to Act Courageously



By Ira Byock, MD

We live in unprecedented times, the result of historic demographic trends and successive advances in public health and medical treatments. Very soon, for the first time in human history, older people will outnumber younger people on the planet (Kinsella & He, 2009). Serious, chronic illness is an invention of the latter part of the 20th century. People used to die quickly of many diseases, such as heart failure, COPD and cancer, which they now live with for many months and years. We can forestall and treat osteoporosis and reduce the number of related fractures. These and many more advances are cause for celebration, but they are also the cause of a vastly increased burden that has fallen to family caregivers. Then there are the financial challenges of our times: soaring costs of treatments, including medications, coupled with cutbacks in employer-based insurance, reductions in Medicare and Medicaid coverage, swelling numbers of medical bankruptcies and home foreclosures. None of this is new to ADEC members who confront these problems in their clinical practices, teaching and research. Those of us in professions concerned with aging and end-of-life care

have seen it coming. For over three decades we have called attention to the rising tide of elders who will need comprehensive care through the end-of-life, but our society has done relatively little to correct the current deficiencies or prevent a flood of unmet need from overwhelming America's families and communities.

Reasons for Hope

Even today, this is one crisis – or set of crises – that we can solve. Each component deficiency or dysfunction within our systems and patterns of practice has workable solutions. We have witnessed exciting advances in innovative residential models for frail elders, including the emergence of naturally occurring retirement communities such as Program of All-Inclusive Care for the Elderly (PACE), Eden, Greenhouse, and Plaintree facilities for people with complex needs, including those with dementia (Gross, 2007; Eng, 2002; Thomas & Stevens, 1999). Research affirms what we instinctively knew: Social connections are as important as medical treatment in preventing physical and functional decline. Mental and physical exercise, gardening and pets delay progression of memory loss and work as well as drugs in alleviating depression. Pairing frail elders with school children

Continued on Page 3

Inside This Issue

| | |
|---|----|
| It Is Time for Our Generation to Act Courageously..... | 1 |
| Note from the Editor..... | 1 |
| President's Message..... | 2 |
| The Physician's Role in End-of-Life Care..... | 6 |
| Hospice Care of the Elderly in Nursing Homes..... | 7 |
| End-of-Life Decisions in the Context of Gerotranscendence..... | 8 |
| Dementia: Holding on to Hope..... | 9 |
| Milt & Esther: Sharing Care, Stories, and Bonding..... | 11 |
| Creating Caring Communities: Finding Meaning in Later Life..... | 14 |
| Art and the Brain in Partnership: College Students Sharing Art Activities With the Frail Elderly..... | 15 |
| PLUS Forum Features | |
| Teaching Thanatology..... | 19 |
| Clinical Issues in Thanatology..... | 20 |
| Diversity in Thanatology..... | 21 |
| ADEC News..... | 22 |

Special Note:

Our hearts go out to all the victims and their relatives and friends in Haiti, Chile and elsewhere as they cope with the grief and loss of the earthquake and as they move us with their courage and resilience and compassion for one another. Please take a moment to read the special Diversity Issues feature written by Tashel Bordere on "Capitalizing on the Resilient Nature of Haitian Culture through Loss" (p. 21).

A Note From the Editor

"Remind Me Who I Am"



By Kay Fowler, PhD, FT

*"Darling, do you remember the man you married? Touch me, remind me who I am."
(Stanley Kunitz)*

With this issue, *The Forum* turns to the challenges and the opportunities of older adults particularly as they face the end-of-life. It is increasingly ur-

gent that we – as individuals, as citizens, as practitioners, and as an organization – attend to the concerns and needs of older adults. The U. S. Census Bureau (2010) estimates that there was a global increase of 10.4 million older adults between July 2007 and July 2008. In the U.S. alone, the population of adults 65 and older is projected to increase from 12% today to 20% in 2050 (Kinsella & He, 2009). We must attend to the palliative

needs of older adults and to ways to foster psychological, emotional, and spiritual vitality. Of course 73% percent of the U.S. deaths in 2006 were of people 65 and older (U. S. Census Bureau, 2010).

Furthermore, these demographic shifts, along with changes in how we collectively conceptualize and experience later life have dramatic implications for policy makers

Continued on Page 5



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ADEC's Mission

The Association for Death Education and Counseling is a professional organization dedicated to promoting excellence and recognizing diversity in death education, care of the dying, grief counseling and research in thanatology. Based on quality research and theory, the association provides information, support and resources to its international, multicultural, multidisciplinary membership and through it, to the public.

President's Message: "M" Number 3 -- Membership

By Howard Winokuer, PhD, FT

It has been a joy and a privilege to be your president this year and to work with your Board of Directors and your Executive Committee who have worked very hard on your behalf. As I prepare to leave this office, I am confident that ADEC continues to be strong with an excellent group of leaders ready to carry us forward.

As you know I am focusing my *Forum* articles on ADEC's near-term concerns: "the three M's." Money, Marketing and Membership, all essential to support our overall mission. Here I focus on the third area: Membership.

I will begin with a state of the union report on ADEC. As you know, our biggest foray into the world is through our conferences. With ADEC Conference Director Liz Freyn's help, we have now confirmed hotels and locations through the year 2014. In June 2011, we will co-sponsor an international conference with the International Conference on Grief and Bereavement in Contemporary Society at the Intercontinental Hotel in Miami, Florida. This promises to be the largest meeting in ADEC's history. The amazing gathering of speakers from throughout the world is unlike any event ever held in our field. Our five keynote speakers represent the US – Pauline Boss and Joan Halifax; Australia – David Kissane; Holland – Paul Bolen and South Africa – Solomon Benetar. Invited symposia will feature (among others): Carl Becker (Japan), Amy Chow (China), Emmanuelle Zech (Belgium), Ron Barrett, (US), Katherine Shear (US), Henk Schut (Netherlands), Cecilia Chan (China), Heidi Horsley (US), Pal Kristensen (Norway), Chris Hall, (Australia), Bill Worden (US), Margaret Stroebe (Netherlands), Colin Murray Parkes, (UK), Dana Bliss (US), Joe Currier (US), Stephen Connor (US), and Barbara Monroe (UK). The two-day Preconference Institute will include: Introduction to Thanatology, Grief Counseling, Complicated Bereavement, and Grief Therapy. Full-day workshops include Suicide Bereavement, Mourning Losses in a Family, Clinical Applications of the Continuing Bond with the Deceased,

and Complicated Grief after Traumatic Events. Half-day workshops include Teen Grief, Children's Grief, Ethics in Clinical Settings, Disenfranchised Grief, Exercising Our Therapeutic Imaginations, Music of the Soul: Composing Life out of Loss, Parental Grief, and Disaster Response.

The conference in 2012 will be held at the Hilton Hotel in downtown Atlanta; 2013 will be held at the Renaissance Hotel and Spa in Hollywood, California and 2014 will be held on the waterfront at the Renaissance Hotel in downtown Baltimore. Besides the member discount to conferences, ADEC members receive a number of benefits including discounts for our monthly webinars; online access to our professional journals, *Grief Matters*, *Death Studies* and *Omega*, quarterly electronic copies of *The Forum* and bi-monthly issues of ADEC Connects, and access to our member's only section on the ADEC Web page. One of my predecessors, Tom Attig once invited the membership to each bring one new member into the organization. I offer that same challenge to you. If in the next two years, each of us brought just one person into our ADEC family, our membership would grow from 1,800 to 7,200 by 2012, ensuring we remain the largest thanatology-related organization in the world. These numbers would ensure ADEC's success by providing money from member fees, marketing in getting the word out, and increased membership. That will also help me accomplish my goal of leaving ADEC on a solid and secure foundation.

In closing, I would once again like to thank you for your trust and confidence and I thank the Board of Directors and Executive Committee for their friendship, guidance and support. I really appreciate the privilege of being your president and I will value this for the rest of my life. Know that I won't be too far away from what's happening; not only will I be the immediate past president, but I will co-chair the international conference in Miami. See you there.



It Is Time for Our Generation to Act Courageously

Continued from Page 1

enriches the lives of both young and old. Geriatric case managers are often able to ensure access to services, coordinate care, enhance social interactions and facilitate effective communication between clinicians, social services and families. Still, knowing what to do and applying this knowledge on a social scale, are very different things. The hard truth is that all of our progress to date has been sorely insufficient. Older adults in fragile health still commonly encounter a paucity of planning or prevention and little coordination of health care and social services.

Consider Dennis, an 83-year-old man who was hospitalized after a fall caused by low blood pressure, kidney failure and worsening heart failure due to a calcified heart valve. When I met him, Dennis described a steady decline in his ability to care for himself over the past eight months, but found that basic help at home was hard to come by. Only when he developed an acute medical problem did the health system kick into gear. Three times in as many months, he was admitted to the hospital with chest pain on one occasion, a sudden fever and confusion on another, and most recently, his fall. Medicare reliably pays each ambulance ride, blood test, EKG, MRI. Medicare will cover his cardiac catheterization, and it would have paid for his heart valve surgery if Dennis had not declined the procedure.

His three-times-a-week kidney dialysis is covered, but because he goes to church most Sundays and to his barber once a month, he does not qualify to have a nurse come by to check his blood pressure and help keep his medications straight. Medicare will not pay for the daily help Dennis needs for getting up and dressed, bathing and preparing meals. He does not qualify for hospice under Medicare either, unless or until he decides to give up dialysis and embrace his dying. So once he was stable, we had to discharge Dennis from the hospital with inadequate support services, sending him home to fend for himself and lurch from one costly emergency to the next.

My own field rightly celebrates evidence that hospital-based palliative care programs now exist in nearly a third of American hospitals. From a larger social perspective, however, this means that in two-thirds of our hospitals seriously-ill patients (and families) do not have access to specialized services for their comfort and well-being. And to be honest, many of the current hospital-based programs are minimally staffed, representing a diluted, “hospice lite” version of palliative care that our field has worried about for years. Similarly, while hospice programs are on track to care for over 1.5 million patients this year, it is troubling that the majority of those patients and families will receive hospice care for just three weeks or less – and a third for only seven days or less. The situation is bleaker in long-term care. Despite numerous reports and recommendations, our nation’s nursing homes remain woefully understaffed and the direct care workers who care for our vulnerable parents, brothers and sisters are treated as entry-level workers with inadequate compensation, no job security and little stature. As a national community – as a moral society – we have work to do.

During the recent financial crisis and health care reform debate economists and politicians have warned of mortgaging our children’s future. The coming flood of aged and chronically ill may well force our adult children to decide between replacing old, deteriorating schools or building new facilities and services for their decrepit, feeble parents (a.k.a. us!)

Many of us will say: “Invest the money in our grandchildren and their future. Don’t spend it on us.” Of course, even that won’t fix the problem. Boomers may be willing to accept the consequences of our generation’s negligence, but remember, one person receives a diagnosis, but illness and dying happen to the family. Anyone who has cared for a dying parent or in-law in the fragmented dysfunction of our health care and social service systems knows the toll it takes on a family. Perhaps we need to be asking: “Who will protect our children from the emotional strain and guilt of our future suffering?”

Barriers to Doing What Is Necessary

I believe we are a moral society that truly cares about our elders and ill members. If we have known about the dangers and have workable solutions, why haven’t we acted sooner? Three reasons come to mind. First, let’s face it, this topic is depressing. Americans don’t want to think about it! Cultural avoidance is pervasive and made worse by the truly complex nature of the social and systemic challenges we face. Secondly, there always seem to be more pressing problems to attend to: hurricanes, floods, wars, the bursting of financial bubbles and the near collapse of our economy. It is true that all these problems are compelling; but like passengers on a raft, headed toward a precipice, the longer we wait to act, the harder it is to avoid disaster.

Finally, and most troublingly, mortality has become a polarizing issue. That statement would be comical if it weren’t true. On one hand, some ardent proponents of legalizing physician-assisted suicide accuse hospice and palliative care clinicians of forcing people to suffer by refusing to prescribe lethal medications. On the other hand, increasingly vehement elements of the pro-life movement accuse clinicians of killing patients each time we write or honor a DNR order or permit someone to die without a feeding tube.

The ethos of our professions rightly honors the diversity of people’s political and religious beliefs. Still, some assertions are biologically false, and some demands and allegations are ethically abhorrent. To the general public, which is rightfully worried about the status of end-of-life care, our silence is easily misconstrued as defensiveness. Uncorrected accusations about “death panels,” “pulling the plug,” and “killing grandma” reverberate within the media echo chamber. More importantly, as seen in the summer of 2009 kerfuffle over health care reform, such vitriol can derail socially responsible, constructive actions.

We have been too polite or timid to confront distrust that is rooted in religious or political beliefs. People who work in the fields represented by ADEC, including hospice and palliative care, are among the most life-affirming segment of our society. An unwavering affirmation of life is what leads most of us to oppose legalizing assisted suicide and euthanasia. We understand that to fully affirm life, one must affirm all of life – and that includes dying, death and grief. At this point, to ignore this smoldering cultural chasm is to tolerate social inaction and ensure catastrophe.

Reclaiming Optimism through Leadership and Action

If we want to reclaim a sense of optimism about our future – and our children’s futures – we must act courageously and decisively. We need to build the infrastructure of processes, services and expertise to people’s independence and quality of life through their aging and with

Continued on Page 4

It Is Time for Our Generation to Act Courageously

Continued from Page 3

their ailments across the full spectrum of home, assisted-living, skilled nursing and acute care settings. We are coming late to this task. So, we need to hurry. Being reactive is better than being inactive – but being proactive is better still. Cultural leadership is fundamental to shaping a brighter future for my generation – and by extension for our children and grandchildren in their experiences of our own aging, frailty, feebleness and death. Without a clear vision of what it means to live well with serious illness, to retain dignity despite physical debility and feebleness, and to die well, society will be hobbled in moving forward.

A simple and yet very powerful way to exert cultural leadership is to tell stories. Every one of us has stories from our personal or professional experience that inspire us and others with a visceral sense of what the best care possible looks and feels like. These stories are an antidote for discouragement, which is disempowering, and a bright spot on the horizon – a compass point – to guide our individual and collective efforts. Stories are an essential tool for social and cultural change. They do more than just make people feel good. Stories of success raise people’s expectations and clarify what specific types and quality of services they can demand for themselves or those they love. Stories that describe highly successful clinical or social service programs or institutions can challenge the ownership and management of similar programs to reach higher. As an intermediate step, higher expectations may deepen people’s frustration; but this is often a necessary stage in the process of substantive change.

Similarly, we can invite journalistic inspection of programs that exemplify excellence in their approach to care and the outcomes they achieve. A story in the newspaper, or on public radio or television, or the network evening news can command policy makers’ attention in a way that few peer-reviewed publications can. Our comments and explanations in the lay media can help readers or listeners – including policy makers – make sense of complex and confusing situations while highlighting constructive solutions.

This brings me back to political matters that impact the quality of care and quality of life of frail elders, dying people and their families. I used to think that those of us in the fields of aging and end-of-life care should *demand* attention of policy makers and politicians. But I have come to believe that the notion of demand attention still confers undue power to officials in authority. Instead we must *command* attention of those in power. It can be our decision that these issues are addressed. Collectively, we have the capacity to require elected officials and bureaucrats to engage in substantive discussion and planning.

Suppose our respective organizations collaborated to develop an ambitious public policy initiative out of a shared commitment to expand access to services and improve quality of care for frail elders, seriously ill people and family caregivers. This initiative would reflect a broad public health perspective, going beyond parochial regulatory and reimbursement issues that affect their own disciplines.

We can substantially improve quality without raising costs by connecting the dots between social services, community services, health care and even basic civic services. For my patient, Dennis, that might mean having someone from Meals on Wheels check in on him regularly, in addition to delivering dinner. It would include reliable transportation from his apartment to

the local Senior Center to share group lunches and noon-time discussions on advance directives for health care, practical tips for weatherizing his home and Internet basics to help him keep in touch with his family. Perhaps a parish or Stephen’s Ministry nurse from his congregation could teach him to check his own blood pressure. A local service club, such as Kiwanis, Lions, Elks or Rotary, might install hand rails in his bathroom tub or shovel his front walk after it snows. Dennis is one of the roughly 25% of men and 50% of women more than 75 years of age who live alone. They are at risk for dangerous delays in getting help when they fall or have other emergencies. In small communities, like the one Dennis lives in, there are roles for police, firemen, mail carriers and delivery service personnel as resources to monitor and aid vulnerable elders. Laws and government policies can support such efforts in myriad ways.

The table below lists examples of potential policy objectives that are adapted from published studies and surveys of what people say matters most to them and their families related to aging and dying, and from recommendations of citizen groups and blue ribbon panels (National Association of Attorneys General, 2004; Asp, Spring & Sokolowski, 2005; Jennings, Ryndes, D’Onofrio & Baily, 2003; Task Force for Quality at the

| Key components of a Citizen-Consumer Initiative to Improve End-of-Life Care |
|---|
| • Connecting standards for safe and prudent minimum staffing in nursing homes and assisted living facilities to licensure and reimbursement. |
| • Requiring a “living wage,” including basic health benefits, for aides and other direct care workers in long-term care. |
| • Expanding education in pain management, care planning, communications, geriatrics, hospice and palliative care of all medical and nursing students tied to accreditation and funding. |
| • Setting minimum standards for geriatrics and palliative care training of physicians, nurses and allied clinicians as conditions for certification and public financial support. |
| • Eliminating the arbitrary distinction between “curative” and palliative care under Medicare, Medicaid and private insurance plans. |
| • Requiring health insurers to include hospice and palliative care as a basic benefit. |
| • Publishing clinical standards and “reasonable expectations” for patients and families related to home care, hospice care and other end-of-life care. |
| • Making available on the Internet comparative “report card” information regarding the quality of hospitals, nursing homes, assisted living facilities, home health and hospice programs. |
| • Providing expanded funding for Senior Centers and Aging Services to support community-based case management and care coordination. |
| • Funding research into health service delivery of frail and seriously-ill elders and their family caregivers. |
| • Balancing efforts to curtail drug diversion and abuse with access to effective pain prescribing. |

It Is Time for Our Generation to Act Courageously

Continued from Page 4

End-of-Life, 2000; Field & Cassell, 1997; Citizens Health Care Working Group, 2006; and Shugarman, Lorenz & Lynn, 2005).

In a survey of participants at public forums that my colleagues and I convened during the 2007 presidential primary season in New Hampshire, more than 80% indicated it was very or extremely important to have their dignity respected, preferences honored, pain controlled, and to not leave family with debt. Over 80% strongly endorsed palliative care requirements, clinical licensure and reimbursement, expansion of family caregiver leave, respite care and bereavement support. In contrast there was a clear divergence of opinions on some emotionally charged matters. Less than half of the public forum participants strongly endorsed being kept alive as long as possible, or having assisted suicide available or being prayed with or being prayed for as they were dying.

These findings suggest that even in the current culturally charged environment it is readily possible to craft positive political agendas that address root causes of problems. By directly acknowledging and deliberately setting aside divisive issues such as physician-assisted suicide and religious beliefs and practices regarding end-of-life care, political leaders can use the broad areas of public agreement and support to correct documented deficiencies in clinical education and training, licensure, quality standards and staffing levels in acute and long-term care.

Conclusion

Extraordinary times demand extraordinary action. Such times also bring extraordinary opportunities. Caring well for the unprecedented numbers of elderly and chronically ill people who are facing the end-of-life will require – already requires – strong, clear social and political actions. We can draw strength from our core values and guidance from the principles which undergird our professions. They will not fail us. More importantly, in acting from our values and principles, we will not fail the people and society we serve.

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Editor's Note: "Remind Me Who I Am"

Continued from Page 1

(See Byock, p. 1), for health care providers (see Dyer, p. 6), for institutions and hospices (see Miller, p. 7), for developmental psychologists (see von Dras, p. 8), for counselors (see Werth, p. 20), for expressive arts therapists (see Noppe-Brandon, p. 14 and Peck, p. 15), for family/friend caregivers (see Gorman & Gibson, p. 9 and Dolgin, p. 11), and for death educators (see Green, Schim, & Doorenbos, p. 18). And, of course, they have vital meaning for each of us personally as we ourselves inhabit or anticipate later life.

Kunitz' evocative lines remind us of our profound human need to be touched and to be reminded who we are – especially when we experience loss, illness, pain, frailty. As we, as caregivers, seek to meet that need—to “touch” and to “remind” others of who they are and how they are valued—we find that they, in turn, reach back to remind us who we are.

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The Physician's Role in End-of-Life Care*



By Kirsti A. Dyer, MD, MS, FT

Doctors are still too often taught in medical school to view death as a failure and to see the terminal diagnosis as a time when “there is nothing more the physician can do.” A test, a study, a surgical treatment, a medication, or an x-ray no longer lead to a cure. All of the technical skills of modern medicine can only help to make a person more comfortable. Nothing more.

In March 1999, I learned an invaluable and unfortunately unflattering lesson about my profession as I witnessed the medical treatment of my sister's father-in-law. I watched how Bob and his family were treated by surgeons at a premier Bay Area teaching hospital. The family came to the hospital with hope and the implicit promise that something could be done surgically to cure his esophageal cancer. They left with their hope shattered, their faith in physicians shaken, and the clear impression from the medical team that “He's broken. Let's not waste time now.”

This encounter gave me a greater understanding of a patient's and family's frustrations with medical treatment and the impact of poor physician communication skills. I found myself questioning the medical team's interpretation of the basic covenants of the doctor-patient relationship that I had been taught: the promise to treat, to heal and to restore. I realized these physicians had a much different view of this sacred relationship. The team judged that a dying patient was less deserving of time and consideration. “We have time to care only for the living”, was the clear unspoken message. The entire experience left me feeling embarrassed, disappointed and disillusioned with my own profession and renewed my conviction of the need for medical education in the areas of death and dying.

More than a decade later we have seen an increase in death education, end-of-life care and communication awareness for physicians. My alma mater, for example, now includes an EOL tutorial for medical students and residents. Unfortunately, there are still too many experiences like those of my family that remind us how far we have yet to go to learn how to care for our patients after curative interventions cease. Primary care physicians must recognize that their role does not end when their patient receives a terminal diagnosis. As a profession, we still need to do more to underscore the importance of communication and caring for physicians in dealing with patients and their families. One of the most difficult roles of a physician is knowing when to let go of treatments and when to just “be” with our patients.

Physicians still need to learn better how to deliver bad news with sensitivity, to choose their words with care and compassion, to help the patient and the family cope with difficult issues, painful choices and provide all the care options available.

Some strategies for enhancing the physician's role in end-of-life care:

- Death education or education on End-of-Life Care needs to be part of medical school and residency curriculum. For those not in training, courses should be offered as continuing medical education.
- Multidisciplinary teams can help coordinate end-of-life care issues

across the specialties, in particular, when the patient's physician or consultants are uncomfortable with providing end-of-life care.

- Physician's adept at End-of-Life Care – particularly those comfortable with exhibiting care and compassion – could accompany teams on attending rounds to share their expertise with medical students and residents.
- A new type of position—“Physician Grief Counselor”—could serve as medical liaisons between the medical staff and the patient and family members to translate the medical terminology, enhance communications and provide support.

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Online Resources

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Portions of this article have been updated from a presentation at the American Medical Students Association's 2001 Conference, available at http://www.journeyofhearts.org/kirstimd/AMSA/bob_d_d.htm

Hospice Care of the Elderly in Nursing Homes



By Susan C. Miller, PhD

Each year a half million older Americans spend the final chapter of their lives in nursing homes. These dying elderly are often frail and die of chronic progressive terminal illnesses after long nursing home stays. Others enter the nursing home near the end-of-life, bringing with them complex medical and psychosocial needs. In either case, there is wide variation in the quality of symptom management and in the availability of palliative care expertise and support (Miller, Teno & Mor, 2004). Palliative care is described as “both a philosophy of care and an organized, highly structured system for delivering care”, offering pain and symptom management and psychosocial and spiritual care appropriate to the family’s values and needs (National Consensus Project for Quality Palliative Care, 2004). Hospice is the most prevalent form of palliative care in nursing homes. In 2008, about one fourth of the almost 1.5 million hospice patients resided in nursing homes (National Hospice and Palliative Care Organization, 2009). Miller, Teno, & Mor (2004) have found that providing hospice in long-term care facilities leads to better pain management, fewer end-of-life hospitalizations, and greater family satisfaction with end-of-life care.

Nursing homes can offer Medicare hospice care by developing working relationships (including formal contracts) with certified Medicare hospice providers. Medicare certified hospices provide interdisciplinary team support to patients/families including spiritual care. While hospice spiritual care in nursing homes has received little study, Daaleman et al. (2008) have found that spiritual care and support (hospice and non-hospice) are associated with better overall family ratings of care at the end-of-life. In nursing homes, hospice has also been associated with a different configuration of services: lower levels of daily nursing visits, but higher levels of daily social work, nursing aide, and clergy visits (Miller, 2004). Such differences are consistent with the differing case mix in nursing homes (more persons with chronic terminal illnesses and/or dementia).

Last summer my 91 year old mother died in a nursing home. At the time I had been conducting research on end-of-life care in nursing homes for over a decade, but, of course, that could not prepare me for experiencing my mother’s long slow decline and her final days of life. Fortunately, my mother’s and family’s burdens were eased because, in addition to the services provided by a caring nursing home staff, my mother also received expert care and support from a hospice nurse, aide, social worker and minister. The minister made my mother laugh and provided comfort. He led us in prayer at her deathbed and sang at her funeral. My sisters and I can attest to how this high volume of hospice clergy involvement lessened our anxiety and helped with our grief. I also noticed this minister comforting many other nursing home residents who otherwise often sat in silence or slept in wheelchairs with chins resting on their chests. We need more of such comfort provided in U.S. nursing homes, through nursing home, hospice and voluntary efforts.

Recent Medicare Proposals

Many older Americans dying in nursing homes lack the kind of support my mother received. Even for those who do receive hospice, stays are often very short (about 30% are for seven days or less, NHPCO, 2009). For persons with non-cancer chronic terminal illnesses, determination

of the Medicare-required six-month prognosis for hospice is challenging, often resulting in long (over 180 days) or short (≤ 7 days) hospice stays. Given the costs to Medicare, there has been concern about the increasing number of long hospice stays occurring in nursing homes. Because research has shown hospice visits to be most frequent immediately after admission and again as death approaches, the Medicare Payment Advisory Commission (2009) has recently recommended strengthening eligibility assessments as well as lowering reimbursements for Medicare expenditures (i.e., per diem hospice payments) for the intervening period. While this may appear to jeopardize access, the recommendations may, in fact, ensure continuing access to hospice care in nursing homes by lessening Medicare expenditure concerns.

Recommendations

A multifaceted approach is needed to expand and enable the provision of end-of-life palliative care in U.S. nursing homes. To ensure continuing access to Medicare hospice, it is important for any new payment policies to explicitly acknowledge the challenges inherent in the timing of hospice referral for many nursing home residents, recognizing that “early” referrals will occur and deeming them “acceptable” in the presence of well-documented physician evaluations and eligibility determinations. At the same time, nursing homes need to seek ways to increase staff’s palliative care knowledge and access to expertise in order to ensure the availability of high-quality symptom management for persons who do not qualify for or choose hospice. Finally, more nursing home- and hospice-community collaborations (including collaborations with religious communities) are needed to extend the availability of spiritual and other kinds of support to dying nursing home residents and their families.

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End-of-Life Decisions in the Context of Gerotranscendence



By Dean D. VonDras, PhD

As Bruner posits in *Acts of Meaning* (1990), key to our understanding of behavior is an awareness of the context in which it occurs. Characterized from a life-span development perspective, this contextualism is much like the narrative of one's life story, that reflects "an ongoing texture of multiple, elaborated events, each being influenced by collateral episodes and by the efforts of multiple agents" (Hermans, 1992, p. 362). In this brief essay, end-of-life decisions and the importance of ethical wills in the context of later life gerotranscendence are discussed.

Taking into consideration a developmental context for end-of-life events, it is noted that throughout young adulthood and into mid-life, a person's mortality schema, i.e., one's latent conceptualizations of death and dying, is most likely to reflect assumptions of immortality (Lawton, 2001). However, in old age, as the person experiences health declines, and death of loved ones and friends become more common, there is an increasing awareness of one's own mortality. Gerotranscendence theory is a developmental perspective whose focal point is the acknowledgement of one's own death and dying as a completion of the life cycle (Tornstam, 1996). Descriptively, gerotranscendence is a phase of development occurring at the very end of life beyond Erikson's (1963) final stage of Integrity versus Despair. With gerotranscendence there is greater individuation, a growing sense of oneness with nature, and an acceptance of both negative and positive aspects of self. This is also a phase of life in which there is a greater awareness and personalization of death, a time where the person may focus on and anticipate one's own death and dying. Gerotranscendence may also be seen as a psychological process by which the person discovers new existential meaning, understanding, and wisdom about processes of aging, death, and dying. These discoveries support positive coping behaviors such as accepting the challenges of illness and disease, framing end-of-life events in positive ways, and being optimistic and open toward the future (Lawton, 2001). Indeed, gerotranscendence may afford a "vision of aging (that) can lead us beyond the limitations of our human self ... a vision that invites us to a total, fearless surrender in which the distinction between life and death slowly loses its pain" (Nouwen, 1976, p. 79).

From this contextual orientation, mechanisms that aid the person and family members in meeting the gerotranscendent need of accepting death include living wills and advanced directives, both of which communicate treatment preferences to physicians and family members who may make medical decisions for the person if they become incapacitated (cf. Doukas & Reichel, 2007). Beyond the medical perspective, as Fischer and Simmons (2007) note, there is also a need to acknowledge the meaningfulness of one's life and to provide an opportunity for the person to pass on a wisdom concerning the fruits and fullness of life. The ethical wills is a means of meeting the gerotranscendent needs of sharing life's meaning,

understandings, and wisdom. As described by Cohen-Mansfield et al. (2009), ethical wills differ somewhat from values histories (e.g., Doukas & McCullough, 1991) which pertain to personal preferences about possible medical treatments and end-of-life care. Rather, ethical wills are documents that describe the person's values, advice, and life lessons for the benefit of others. As exemplified in an instrument constructed by Cohen-Mansfield et al. (2009), an ethical will may include questions that permit expression of the person's (a) thoughts, values, and beliefs that are important to be passed on and shared with children and grandchildren; (b) advice and words of wisdom to share with others; (c) lessons learned from life experiences; (d) expression of regrets and gratitudes; (e) important decisions made in life; and (f) thoughts about the future and about possible changes that one would make. Thus conceptually, much like a life-review, ethical wills are intended to facilitate a reminiscence and understanding of happy and memorable events of life as well as the expression of the person's beliefs, values, and lessons learned. Research exploring the benefits of ethical wills in persons with cancer has indicated a decline in the report of pain and overall suffering as well as decreases in loss of enjoyment, spiritual distress, worries about loved ones, feelings of having unfinished business, and fear of the future (Gessert et al., 2004). Other investigation has suggested that writing an ethical will provides the person a cathartic experience that helps in taking control of challenging life situations (Baines, 2003). Therefore supplemental to living wills, advanced directives, and values histories, ethical wills are suggested to provide the person a therapeutic experience that reduces stress and affords an adaptive transition as death approaches (Cohen-Mansfield et al., 2009).

As Fischer and Simmons (2007) suggest, at the final transition, dying well means letting go and surrendering to the transcendent and unknown. Thus in the context of gerotranscendence—just as essential as advanced directives and living wills—is the recognition of the person's need to reflect on personal life events and to express to others their personal values, beliefs, thoughts, hopes, and dreams. As Lawton (2001) and others (e.g., Gessert et al., 2004) have observed, reflection on what has been important in one's life and in one's living provides a needed comfort to the person and to their family as death nears. These new insights and understandings may further inform the person and family members concerning end-of-life decisions, and be useful in lessening the physical and emotional pains that occur as death nears.

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End-of-Life Decisions in the Context of Gerotranscendence

Continued from Page 8

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Dementia: Holding on to Hope



By Eunice Gorman, RN, PhD, RSW and Maggie Gibson, PhD, CPsych

Dementia is characterized by loss of cognitive capacity and memory resulting in a decline in a person's ability to function socially, physically and emotionally over time. This leads to profound difficulty understanding facts, changes in language, impairment of thinking and reasoning and shifts in perceptions of the world. Alzheimer's disease (AD), Vascular Dementia (VaD), Frontotemporal lobar degeneration (FTLD), Dementia with Lewy Bodies (DLB), dementia associated with Parkinson's disease, Young Onset Dementia (YOD), Korsakoff syndrome, and Creutzfeldt-Jacob disease are the most widely

known of the over sixty conditions that are characterized by dementia (Radin & Radin, 2003). Over 4% of people over the age of 70, and 13% of those over the age of 80 will be diagnosed with dementia. The median length of survival from diagnosis to death is eight years but can be as long as twenty (Davies & Higginson, 2004).

At onset, dementia may be confused with normal signs of aging, but this is a progressive disorder that can ultimately become so severe that every aspect of the person's activities of daily living is altered. Signs and symptoms include apathy, lack of empathy, rigidity, bizarre or socially inappropriate behaviors, altered relationships, deficient motivation, and depression. Memory loss and confusion coupled with the loss of intellectual capacity and changes in emotional control and social behaviours lead to problems for the person who is suffering with the condition as well as for their friends, family, and caregivers. As the disease progresses many people suffer hallucinations, delusions, or false beliefs that compel them to hide money, fear that they are under surveillance or feel threatened by known, or unknown, real,

or unreal, assailants.

Loss arises as a defining feature of dementia very early on as memories begin to fade.

There is grief associated with the myriad of losses along the way from the early stages, at the time of diagnosis, throughout treatment, when the placement question arises, at the end-of-life, and – for families and friends – also after the death. Thus, grief is prolonged for the individual with dementia and their family, friends, formal and informal caregivers. Early on the loss of the person's usual and familiar ways of being in the world can be devastating. Later, as the disease progresses and loved ones are no longer recognized, and communication becomes difficult, grief can overtake all other emotions.

In the face of loss and pervasive grief, hope becomes central to coping, enduring, and facing the fear related to mounting disability. Hope is dynamic; it shifts, evolves and changes over time. Hope is an emotion, a need, an experience; it can be realistic or unrealistic. Hope needs to be created, promoted, and supported not only by the person but by their family and friends, by the professionals caring for the patient and by society at large. Viewing a diagnosis of dementia as hopeless robs us of the opportunity to connect with, care for and support people living with dementia fully and compassionately. Duggleby (2009) and her colleagues in a recent study of family caregivers of people with dementia found that hope took on many meanings including fading hope, and renewing everyday hope primarily through seeing the possibilities, coming to terms, and finding positives.

Creating hope in the face of progressive deterioration is not as onerous a task as it might seem. Ways to foster hope include assisting people to focus on the moment, to let go of expectations, to listen, connect, touch, and comfort their loved ones. Brackey (2006) outlines numerous methods to support people with dementia and their families. These include remembering what is still good, searching for possibilities, letting go of expectations and making small differences in

Continued on Page 10

Dementia: Holding on to Hope

Continued from Page 9

the day to day lives of patients and families. Interventions that have proven helpful in the past include music therapy, validation therapy, narrative therapy and reminiscence. Kitwood (1997) speaks about the centrality of personhood and the right to care in acceptance for people with dementia. He reminds us that people still need social interaction as well as excellent physical care. They need a role in making decisions for as long as possible. Elements of celebration, collaboration, creation and facilitation are highlighted in this approach. Giving, holding, negotiation, play, recognition, relaxation and validation are all ways to reach people who have dementia. He also points to 'timalation' or linking people with sensations such as touch, taste and aromas in order to give pleasure, reassurance, and contact with the outside world. All these activities promote integrity and dignity. Loss of dignity is associated with high levels of psychological and spiritual distress and in some people the loss of the will to live. Focusing on remote memory using photos, music from another era, and memory books can assist people to connect with their social world. Sharing circles and family group support can instill hope in the day to day struggle to maintain quality of life despite dementia.

Professionals send a clear message to clients and families that the person is still valued and there is hope for the best outcomes possible when they provide supportive services such as speech language pathology, physiotherapy, occupational therapy, exercise and activities that promote socialization and exemplary personal care. Necessary medications, the opportunity to participate in clinical trials and non-pharmacological interventions should not be withheld because the person suffers from dementia. Other activities that support hope include information, education, communication, safety, and simplifying routines and environments to make it easier for people with dementia to function as well as they are able.

There are multiple losses and transitions throughout the experience of living with dementia. Interventions that preserve integrity and dignity, and generate and maintain positive self-esteem or enhance well-being are highly encouraged. Such interventions create hope in what might otherwise be experienced as a hopeless situation.

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If to conquer love, has tried,
To conquer grief, tries more ... as all things prove;
For grief indeed is love and grief beside.
(Elizabeth Barrett Browning, "Grief")

"Just tell me a story. Will you?
Among the maple leaves, tomatoes
And brown clay softened with fire."
(Rini Das, "We are drifting, aren't we?")

I closed his eyes
too long open --
at last tonight
snow on the mountain
(Robert Dilly, Haiku)

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Helping Someone Who is Grieving

Milt & Esther: Sharing Care, Stories, and Bonding



By Ellen Dolgin, PhD

Extended family life may be part of our heritage, but not necessarily our lived experience these days. Yet the embedded “shoulds” remain. People need/want to take care of their frail elders, and make peace with the evolving role reversals this implies. Too often though, given long geographical distances, sharply divergent work schedules within different generations, and

long-term “emergencies” that seem to follow no recognizable pattern, anxious concern eclipses nurturing conversation. Guilt reigns and communications crisscross rather than clarify. Is this depicted scenario becoming “typical,” or even stereotypical? Our particular story is deeply personal – but it has its corollaries in the stories of countless others. Colello (2007) in a Congressional Research Service Report on “family caregiving to the older population” notes: “More than 90% of older care recipients receive informal care, either alone or in combination with formal care” (p. 2). The study calls this “the most typical informal caregiving in the U. S.” (p. 11).

Over a period of five years from 2004, when they were living independently in Florida, to 2009 when they died within several months of each other, my parents had traveled episodically (but inexorably) through virtually every element of what Novelli (2002) calls the “spectrum of care” – home care, informal care, assisted living, formal care, rehab, and hospice. Their nervousness about coming north for grandson Andrew’s wedding to Trella in 2004 should have become a more obvious warning signal for us. Yet the visit couldn’t have been better, and now stands as the final occasion for Milt and Esther to shine as they had always done: loving every moment of the time spent at my home, and dancing till 2:00 in the morning at the wedding. As my mother would say later, “I wouldn’t have traded it [the wedding] for anything!”

The lingering, and eventually overlapping, illnesses of my parents over the course of five years were the inverted image of the sudden loss of my life partner. He died in 2003, just about a year before the decline of my two parents began. Watching their slow decline stung twice as much sometimes, and felt like the completion of the cycle at others. My daughter, Eva, and son, Andrew, loved their grandparents deeply and enjoyed the story-filled memories they had shared, but while Milt and Esther lived independently in Florida, visits were infrequent and responsibility intermittent; my daughter-in-law would only come to know Nana and Papa intimately once they moved to the New York area in 2008. The intervening years between 2004 and 2008 became the bridge—as well as the chasm—between the lifestyle we had known to the one that would change us individually and as a family.



The Dolgin Family, Passover, 2008.

The Twists, Plunges, and Cycles of Decline

As an only child, responsibility belonged to me alone; it was a struggle to obtain a health proxy and legal power of attorney from two individuals who gave me the work ethic and survival skills to always act on my own behalf. Sometimes I could coordinate and guide transitions, but other times found me helplessly reacting to sudden emergencies and abrupt change in needs, frustrated and bewildered that my recent interventions had backfired. Within months of the wedding, things began to shift; by May, 2005, I was called down to Florida just before I had to give my final exams—a pattern that would replicate each semester for almost three years. My parents had had a turbulent relationship all my life, but it was clear that my father had lost more than his temper this time. He was exhausted, agitated, and confused, and my mother was very thin, nervous but apparently oblivious to the deterioration in

my dad, as she kept asking him to drive around on errands. I took him to a neurologist the following day; neuropathy and dementia were the diagnosis, and the keys to the car had to be taken away. For a man who had driven since adolescence and made his living as a sales representative by driving, this was unthinkable. I told him only that his leg reflexes were gone, due to the 40+ years he’d had diabetes type II. He cried but accepted the inevitable. But from that day until his death in January, 2009, he continually looked for and asked for his keys in varying states of sadness, agitation, and fury. My mom admitted she had suspected the diagnosis but hadn’t wanted to say it aloud even to herself. She had long since stopped driving, so they had to rely on neighbors and friends, an aversion for both of them. Although we had discussed their returning north for two years by then, the climate and more affordable health care and cost of living in Florida won out. The compromise was home health aides.

Daily phone calls began, as well as the fight to obtain my power of attorney from my self-made dad. If I offered help, Esther, as primary caregiver echoed the phrases from the McSkimming and colleagues (1999) study of family caregivers of frail elders: “I know my loved one best,” “I am exhausted,” “I don’t have the energy to ask for the help I need.” By the summer of 2006, Esther had lost weight, but stalwartly stuck to the routine of meals, medication monitoring, and trying to stay in touch with her friends as well as her family.

Every three months or so I went down for a 5-day visit, ensuring that they were “set” with coverage. But the financial outlay on top of the lessened independence drove either Milt and/or Esther to distraction, so aides would be fired weeks after they were hired. The search began for a suitable place up north. My daughter and I visited several places and realized with a mixture of relief and panic that Milt and Esther weren’t

Continued on Page 12

Milt & Esther: Sharing Care, Stories, and Bonding

Continued from Page 11

quite ready for these. We also knew that the “status quo” was far from fine. The subject became a broken record between my parents and me as well as my children and me. Sandwich generation conflicts abounded. With each visit to Florida I convinced my mother that moving was desirable and inevitable. These conversations largely took place when my father was asleep.

The National Caregiver Association and American Association for Retired Persons conducted a study in 2004 on family caregivers. The most frequently reported unmet needs of caregiving are finding time for myself (35%), managing emotional and physical stress (29%), and balancing work and family responsibilities (29%) (NCA/AARP 2004 Key findings, p. 2). It was clear that both Esther and I experienced variations on these themes. I was exhausted and worried all the time, and took on extra classes to cover the escalating costs of frequent plane tickets, car rentals, and packages in the mail. They could no longer get out, so I shopped for their clothes and sent VHS tapes to keep them entertained and at peace with each other. I never felt free to plan even a weekend away. Milt’s decline into dementia precluded consistent awareness of all of these activities, but Esther was cognizant of the financial, emotional, and physical stresses on me and fretted over these.

Complications and Resolutions

Crisis catapulted us onto the next pathway. In December, 2006, my mom had a squeamous-cell foot cancer removed— a simple procedure we were told. My five-day visit became 2 ½ weeks and I had to back out of a professional conference. By late February, 2007, multiple falls had landed my father in the hospital. My mother took the bus to see him— unbeknownst to anyone—and fell in his room while trying to hand him a covered plate of food. Their friends called me down for what became the last Florida trip. My mother was almost helpless at home; my father was in rehab where he believed he had been left to die alone. With help from their friends over the next two weeks, the apartment was packed and a mover engaged. My children meanwhile chose an apartment for them in an assisted living facility in New York.

Assisted Living and Family Stories: Expanding the Repertoire

For awhile, we all settled into a routine. My mom loved the assisted living facility. Freed of meal preparation and transportation worries, she settled in to the activities and social aspects of communal dining. My dad took longer but also adapted, especially due to the kindness and respect of the aides on staff. My children and I learned to “share the care.” Family members travelled a distance to see my parents, and my friends were also welcomed into the “circle.”

Despite my father’s obvious decline, and my mother’s more gradual one, I was determined to give us as many happy occasions as possible. Over the next year or so, every birthday, one Passover, one series of High Holy Days, and one Thanksgiving were shared, either at my house, “their” place, or at a restaurant. Our favorite was Passover, 2008, at my house (see family photo). We used their seder plate and good china and each of us explained the story of the holiday to my guests. Milt continued to flirt with women of all ages—as he had always done – and Esther to engage everyone in stimulating conversation. Milt gave all the grandchildren individual advice and Esther offered them interest and

support. Topics ranged from career goals to personal integrity, enriched by stories from their own lives. Esther modeled the need to be independent and to stand up for oneself. Working in the garment industry from age 17, Esther had become an assistant designer and showroom coordinator for a prominent dress and suit manufacturer, and had befriended the then-novice designer, Anne Klein. When Esther was asked to do the equivalent of two full jobs during the war, she demanded two salaries! Milt’s war stories became not only more frequent, but more revealing; in the last two years of his life his dementia allowed him to tell us about his house arrest of a Nazi entrepreneur at the end of the war. He spoke German and just followed through with his assignment. The officer told him that no matter what else he had done in the war, this would be enough to make him feel like he contributed.

In the winter of 2008, worry shifted to mom. Suddenly, she began falling and exhibiting signs of confusion. The staff doctor found a huge breast mass which my mother had hidden for probably two years. Now 92, she was no candidate for surgery. The tests and chemo wore her out; her balance was off and she couldn’t remember to use a walker. Esther seemed to be cascading down a waterfall, losing her energy and ability to engage. My father’s shock that anyone other than himself was endangered allowed us all to have fuller, clearer conversations about how well they had lived, and how much we wanted them to remain where they were. By this time, Eva, Andrew and Trella were as prominent in their care as I was. Hospice entered our lives in May, and made their last months possible – if painful – for all of us.

In June, 2008, my dad suffered a subdural hematoma increasing his confusion and sharply limiting his mobility. Once again he moved to rehab. His fears of dying alone returned; he cried and cried. My mom insisted on daily visits despite her own increasing frailty. She implored him to recognize that rehab would allow him to get better. His determination to regain some mobility and dignity won out and he returned “home” within two weeks. A hospice aide was assigned to be with them for 4 hours/day, M-F. She appreciated their sense of humor, knew how to get them to cooperate with her and each other, and brought strong spiritual strength with her every day. My children and I gratefully welcomed her; we now had consistent care and conversation from an individual my parents loved and trusted.

The last few months were a rollercoaster. Milt slipped in and out of awareness regarding his confusion. His flashbacks to WWII intensified. Middle of the night emergencies accelerated and Eva alternated with me in handling these. Esther began sleeping constantly and by October told us she was “going to God.” My father broke down, unable to fathom her dying first. We dreaded that as well since we had been warned that Milt might forget her dying and have to re-live it daily. In mid-November we had our own version of the deathbed scene from *Little Women*; Esther would not wake up for Milt, for my friend who had become their second daughter, or for me. When Andrew took her hand, however, and said “Nana,” her eyes flew open. She later told the staff she had “come back.”

Andrew maintains that seeing people we love degenerate in front of our eyes creates an emotional dichotomy: we don’t want them to live

Milt & Esther: Sharing Care, Stories, and Bonding

Continued from Page 12

that way but feel guilty that we're relieved that they've gone. I think Esther had similar experiences even if she did not put it into words. Once she realized Milt could not cope, and was losing self-control in all ways, Esther announced that she could not leave me alone with Milt in this condition. Her indomitable faith and spunk prevailed, and she kept that promise.

By January, Milt's overwhelming feeling of uselessness wavered between depressive, sleepy moods and violent outbursts, especially aimed at my mother. By now, her cancer was in the brain and "conversations" between them were so incoherent that we did not know whether to laugh or cry. Still, in his final three days, Esther rallied completely, sitting in her wheelchair by his bed and telling him he needed to go to God.

For the shiva/memorial gathering, Andrew took the war medals out of the boxes that Milt had never opened and arranged these on a table along with photographs of Milt and his prized possession: "Mission Accomplished," a paperback report about the Allied victory. Esther, still very much herself, greeted everyone. In her heart she knew the gathering was for both of them and she enjoyed being part of it. All of us spent time with her for days and she was lucid and loving. Then she began again to slip in and out of lucidity. She died in late April.

At their bidding, we scattered their cremains this fall near my hometown. We shared the task, said prayers, sang their favorite songs and

took turns speaking about them. We then drove past my childhood home and had a late lunch in the restaurant they had visited for their last outing nearly a year before. Here we shared with each other how much we had all learned about honoring the living as well as the dead. It was a powerful, positive send-off.

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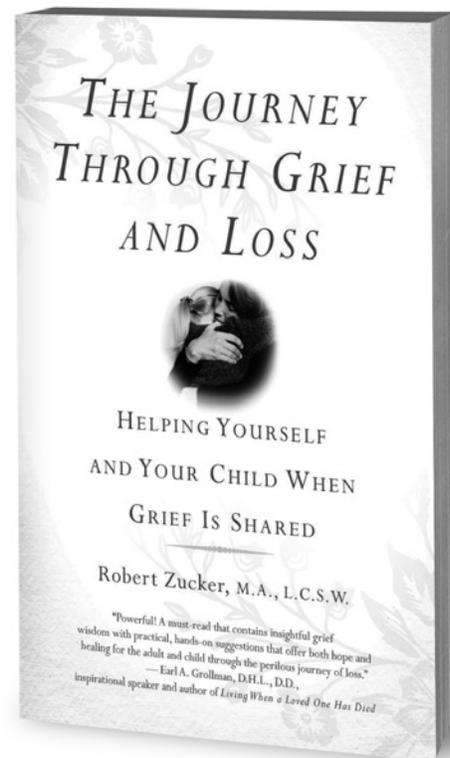
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 ST. MARTIN'S GRIFFIN

Creating Caring Communities: Finding Meaning in Later Life



By Gail Noppe-Brandon, MA, MPA, MSW

Twenty-years ago in a college classroom, and then later at the Children's Aid Society, I developed Find Your Voice (FYV), a method that helps people create, re-create and enact their stories. FYV encourages clients to consider alternate plot lines and resolutions to their [own] forward-going narratives. I have led hundreds of participants through this exercise, and know well that telling our stories is a basic human need, and a necessity for healing.

Last year I conducted a Find Your Voice Workshop at The Caring Community, a NYC based agency that provides services to seniors. Beginning with a core group of members, I discovered that these seniors had led complex lives, although they were all too often treated like simpletons. For example, Jim had been a psychotherapist before developing dementia and Marcella had travelled the world and collected art before succumbing to major depression. It was hoped that the FYV Workshop would strengthen the participant's ability to interact with others, as part of an effort to reduce their isolation and resistance to services. It was also intended to provide a vehicle to help them to reflect upon the events of their lives, both for the inherent therapeutic value of reminiscence and for the sense-making opportunity that reflection offers. Additionally, as "dialogue" is sorely lacking from the lives of many seniors, the playwriting format would allow the participants to engage in reading one another's work aloud, together.

Seniors have a large wellspring of memories to draw upon; to help them voice these, we began with a free-write in response to a photograph, which narrowed the field and jogged their memories. I then posited a series of in-depth questions that led them to the articulation of two potential characters with one potential conflict. The free-writes were then shaped in to ideas for short two-character plays, which were re-written many times in response to the group's feedback. This process of revision encouraged the participants to develop a degree of craft surpassing that of private, uncrafted diary writing, and the development of this craft required discipline, thus heightening brain activity. Similarly, the workshop process of offering and listening to helpful feedback boosted interactive social skills. We also held a concluding activity; a public reading of the plays to provide closure for the group.

At first, I was struck by how little the participants knew about one other's lives – despite dining together at the agency for months, or even years. The mainstay of their conversation had been their medical conditions, by the weather and the food – none of which was very positive! I asked questions about where each person had grown up, their families of origin, their schooling and the work they went on to do. The diversity, commonalities and depth of experience in the responses were notable. As we shared our stories, the speakers – and the listeners – morphed in to their best selves, listening with increasingly greater attentiveness, stifling outbursts, and speaking to one another as peers rather than as incorrigible children. I modeled nonjudgmental questioning and responding, and assured them that no one would ever

be made to feel that their responses were ridiculous in any way. By the end of the second session, they had already started to become a higher functioning group. Their free writing had elicited deeply personal stories: a pregnant woman trapped with an unloving husband in Iran, a man leaving his wife and speaking about their dead baby for the first time, a promiscuous sixty-year-old woman waiting to learn whether she is HIV positive. These play ideas were drawn from the lives of the writers, but I encouraged them to free themselves of biographical accuracy.

The process of developing the plays allowed the seniors to work through painful memories, and challenged them to think like professionals, rather than people of diminished capacity. Creating characters who were neither all good nor all bad, also allowed them to achieve greater understanding of the characters who had populated their real stages, whether an abusive husband, an unloving parent, or an inconsiderate friend. It was clear to everyone who encountered the work, that a creative, problem-solving activity, with a strong self-reflective component, raised the bar on the meta-cognitive and social skills of these aging people ... and that they enjoyed the challenge.

It was also a challenge for me, as the seniors had not been learners for a long time, and kept threatening to quit. However, over six months they each completed a solid, two-character, five to ten page play. Friendships were forged outside of the classroom, and new skills were acquired; in fact, one participant began publishing editorials almost weekly in a local paper. As with all of the other groups I have led, these elderly participants began to advocate for one another, reading one another's work with respect and admiration, and massaging one another's egos after I offered particularly challenging feedback. The final presentation of the plays featured professional actors who were happy to donate their time, and to be offered scarce, age-appropriate roles. An unprecedented turnout of over fifty seniors assembled to hear them. This elderly audience sat spellbound, and even remained for a Q&A at the conclusion. During that discussion, they expressed awe about the work, disbelief that these were first plays, and an ability to relate deeply to such stories as Don's struggle with the way he'd left his father's home fifty year's ago, and Annette's attempt to make sense of her sexuality as a seventy-year old. After the applause, one writer said, "How talented we feel today, when at our age... triumphs are few." I encouraged everyone present, not just the Workshop participants, to continue respectfully sharing their stories over lunch each day... not just to come to The Caring Community, but to become the caring community.

About the Author

Gail Noppe-Brandon, MA, MPA, MSW, has been featured on PBS, authored *Find Your Voice* (Heinemann Press, 2004), founded Find Your Voice, Inc. (www.findyourvoice.us), and works part-time at the Fifth Avenue Center for Counseling & Psychotherapy. E-mail: gnb@findyourvoice.us

Art and the Brain in Partnership: College Students Sharing Art Activities With the Frail Elderly



By Judith Peck, MA, EdM, EdD

“Nice knockers!” This praise from a veteran of World War Two is directed at Melissa, a twenty-two year old psychology major: a junior enrolled in the Art & Interaction class at Ramapo College of New Jersey. The remark slides off her, along with Tony’s picturesque compliments about her other feminine endowments. Her interest is focused instead on the oil pastel he is creating of tall trees in a forest greeting a crimson sunset. Melissa blends oil pastels on her own charcoal paper where tall gray buildings rise to greet an overcast New-ark sky. “So, will you marry me, Honey, when you graduate? I haven’t got so much time but I’ll wait.” Melissa would have walked out on an ordinary guy on campus with the “Honey” appellation, but Tony had his culture and she had hers. She had learned his language in the five weeks working here and translated: “You’re sweet” and “Thank you” rolled into one. Tony, missing a leg below the knee, has no complaints, only gratitude that the joint was saved and guilt that his buddy trekking beside him on the forced march wasn’t. Melissa is doubly amazed at his cheerful disposition, knowing it was “friendly fire” that changed his life.

On the other side of the table in the Veterans Hospital Day Room, Christine helps Arthur (who is blind) choose colors for the seascape they are making together. Arthur had been in the Navy in “The Big One” (WW2) and all his life had loved boats. He tries to describe a 24-foot sloop so that Christine can draw it. This is the boat on which his father had taught him to sail. Tacking across Long Island Sound on that skinny ship was one of the last times he saw his father who himself went off to sea as a Merchant Marine, leaving wife and children behind.

Around the table words are passed and parried, stories told and re-told, loud guffaws are heard and silent smiles are shared. There are smells of coffee and cinnamon doughnuts and less appealing smells as well, while some men only sit in wheelchairs looking on, dozing, kibbitzing now and then, as attentive staff respond to needs and inattentive staff flip magazines.

Art & Interaction

The Art & Interaction program, begun at Ramapo College in 1973, has continued for 36 years as a regular college course, offering a program of art and informal socialization to residents in such facilities as nursing homes, psychiatric facilities, homes for abused, delinquent, or disadvantaged youth, substance abuse rehabilitation centers, veterans hospitals, shelters for battered women and their children, and jails. The program, funded under Title I for three years in the seventies by the New Jersey Department, grew out of the author’s sense that her own creativity – through sculpture and writing – was rejuvenating, energizing and liberating. Might it not be equally healing and liberating

for older adults or children or others who are confined by prison walls or physical infirmity or mental illness, addiction or poverty?

The overall intent is to increase self-image and confidence in vulnerable populations and to promote positive social behavior and enrich life in situations of confinement. The art projects are spontaneous and imaginative and designed to evoke memories and experiences. They are presented in an informal, join-in atmosphere of shared engagement. The participating college students also benefit by coming into direct contact with individuals out of the mainstream of their own society and, thereby, learning about the major domestic issues of our time: aging, mental illness, abuse, crime, and tangentially, war. In the vibrant mix of creative art with friendly social interaction, unexpected kinships are formed – kinships that are more accepting of differences and less mindful of labels. As is often the case, it is up for grabs as to who leads whom in these art sessions.

Working with the Frail Elderly

The most overt consideration in working with the frail elderly is physical disability. Limitations may include partial blindness, deafness, missing or inadequate use of arms and legs, trembling, lack of muscular strength and mobility, memory loss, emotional disturbances, and neurological impairments due to strokes. Students need advance preparation since simple tasks such as cutting and connecting can be taxing and may defeat the aims of the projects before they can get underway.

In our society, strength and power have perhaps been stressed to the point that weakness may be equated with failure. The frail elderly are in weakened physical condition, but they have succeeded, not failed, to arrive at that time in the natural order of life in which physical weakness occurs. Our students must learn the implications of weakness in a new way. They must develop empathy with this state of the elderly, not merely display kindly but insipid notions of respect. One way is to experience some of the handicaps. This can be done by such efforts as wearing someone else’s glasses while trying to thread a needle; by inserting ear plugs and trying to hold a conversation; by drawing or painting with the non-dominant hand. Another act, more subtle, is to sit in one place and wait for someone else to meet your need for a glass of water, a trip to the bathroom, a move to privacy or to a bed to lie down.

More complex even than physical disability is the impact of the alienation of the frail elderly from that world of which they were once the center. The endurance of repeated loss—of persons and of power—can be severe. Alienation from the mainstream is particularly evident in contemporary American society which places high value on youthful energy. The images portrayed on popular news and TV entertainment send messages to the elderly population that life is behind them. Science, however, now tells a different story. In the last



A student works with two seniors on an art project.

Art and the Brain in Partnership: College Students Sharing Art Activities With the Frail Elderly

Continued from Page 15

decade, momentous research on the brain reveals the fact that cells regenerate. The frail woman we see staring out the window waiting only to be wheeled into a silent lunch is capable, with techniques she can acquire, to stimulate that regeneration.

Life Style Plays a Role

A 15-year study on 678 nuns (the so-called Nun Study) revealed significant links between lifestyle (having remained actively engaged, physically and mentally, throughout their lives) and the likelihood of developing dementia (Snowden, 2003). Neuroanatomist, Dr. Marion Diamond (see Diamond, 2001), cites five key factors: diet, exercise, challenge, newness, and social interaction as contributing to the health of the brain. Further studies reveal that external stimulation in reading, writing, and taking other cues from the outside world, can cause affected cells to regenerate and reproduce.

It is easy then to see how artistic activity with its plethora of visual and sensual stimulation, choice and decision making, attention to outside action as opposed to internal physical ailments, can provide brain stimulation and provide a life style change that might extend mind and body function. "Challenge, newness, and social interaction" (three of Diamond's key factors) are all integral to the experience of the art activity session. Linda Levine Madori has built on this thesis with the TTAP Method (Therapeutic Thematic Arts Programming) which she has devised and is implementing with some successful results among recreational and art therapists working with older adults (Madori, 2006).

When undergraduates enter an institution carrying the various colors and textures of their art materials, they bring more than artistic exposure. Institutions are built for the most part with concern for low cost construction, easy maintenance, and the safety and security of the occupants. Color, softness, comfort, and explorative nooks and crannies have little place with those priorities. Nor is there much space for spontaneity or variation in the daily routines. The art workshops, however, bring new stimuli in the form of materials, ideas, and people – a hubbub of activity in color, texture, and movement.

Transitioning from Apathy to Responsiveness

A complex mobilization of resources is needed to transition from lethargy to involvement. The elderly must break through psychological, social, and physical barriers: pain and immobility, fear of being incompetent or looking foolish. Forced continually to recognize new failings, the frail elderly rightly develop caution in their approach to new experiences. Any movement from the theoretical safety of the chair is likely to be hesitant.

Because the contrast between past performance and present predicament is so great in the frail elderly, college students can be a less threatening social presence than sons, daughters, grandchildren, who had known them when they were strong. The students provide friendship without judgment, share new ideas and old stories, and receive residents not as they were, but as they are. A circle of energy begins to flow with the art activity in its vortex. The known impermanence of

the "friendship" may even help to reduce the sense of potential failure in the eyes of residents.

The future, of course, is not as compelling as the past in a nursing home or in a hospitalized veteran's center. Still, in exploring the past with its rich resources of experience and memory, there is the promise of a compelling present. Therefore, the art projects offer ways to summon the past creatively. "The Dinner Party" is one such example.

The Dinner Party

Everyone likes a warm, hospitable invitation to dinner, especially when you can have whatever on earth you want to eat. That is the premise of The Dinner Party project at the Senior Care Center. But Gladys is an Italian woman, aged 85, whose daughter-in-law brings her to the Center every weekday. She sits demurely facing the dinner party table (white mural paper serving as tablecloth), her posture straight and elegant, but she is troubled as she chooses lasagna and salad for her dinner and glues magazine pictures of this food onto the circular "plate" which the students have traced for her "setting." She recalls dinners she prepared for her husband's parents. "Never good enough!" she says. "Always Mama called me the best cook in the family. And my sisters ..." she crosses herself, "passed now, all passed ... even they agreed, I was the best." She shakes her head as she finds a picture of carrots to add to her plate. "But not Mama Fachio! Too salty, not salty enough, too rich, not hearty enough, whatever! A mama's boy he was, my husband, and he listened. Never stood up to her." She crosses herself again. "But we had a life. He couldn't enjoy it, but we had a life."

A make-believe dinner party it is, but real life happens around the table just as it tends to in actual life. Remembrances associated with food summon emotions, some melancholic like the unfairness which Gladys harbors, but some ecstatic: a milestone birthday in which Dorothy is honored by three generations of family; Christmas dinner with gushing praise for Betty's perfectly roasted turkey; Shabbas dinner every Friday night related by Mimi: "Ida with a napkin covering her head recites the blessing over the candles and Sol, he should rest in peace, cuts the challah."

Self-Identity

The sense of self-identity which emerges naturally through creative, self-directed activity contrasts with the break-down of self-identity which often occurs in any institutional setting. Personal qualities, not apparent in monotonous routines, emerge in the art sessions, resulting in staff members becoming more sensitive to the distinctive personalities, interests and abilities of their charges. In the limited period of time in which Tony or Arthur or Gladys or Mimi is socially engaged and making art with a lively college student like Melissa – who herself has chosen the course because she wants to be engaged – each individual is in intimate touch with the dynamics of self and of life. That the experience is temporal and occasional does not negate its impact. All experience, either long or short, is temporal in the span of one's life, and most of life's memorable events are occasions.

Continued on Page 17

Art and the Brain in Partnership: College Students Sharing Art Activities With the Frail Elderly

Continued from Page 16

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Judith Peck, MA, EdM, EdD, is a sculptor and professor of art at Ramapo College of New Jersey and author of a number of books including: *Leap to the Sun: Learning through Dynamic Play and Sculpture* and *Experience: Working with Clay, Wire, Wax, Plaster and Found Objects*. She is a member of the American Art Therapy Association. Her sculpture is in approximately eighty collections, including the Yale University Gallery and the Ghetto Fighters Museum in Israel. Peck's art is visible at <http://www.judithpeck.com> and her books are available at www.iapbooks.com. E-mail: jpeck@ramapo.edu.

It is my plan to go with you
as far as the border. I've been that far—
Did I come back from there morally improved?
Somehow better equipped to support you
(Kumin, "Last Days")

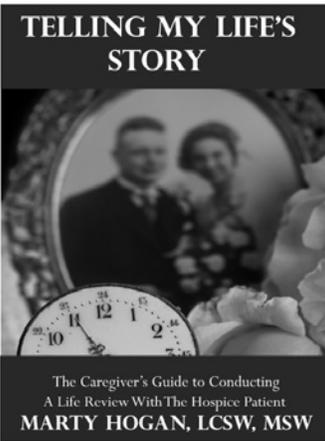
the old wife whispering everything twice
the old husband cupping a palm over his ear.
as the late sun lit up an orchard
behind the strip mall,
and they sat in the dark holding hands.
(Patrick Phillips, "Matinee")

How am I to live until the darkness falls?
Fine rain is falling, too, into the wu t'ung trees;
Plodding drop by drop down into the dusk's uncertainties.
(Li Ch'ing Chao, "P'u-Shen Shang Man" trans.
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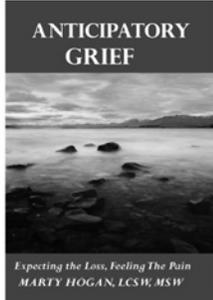
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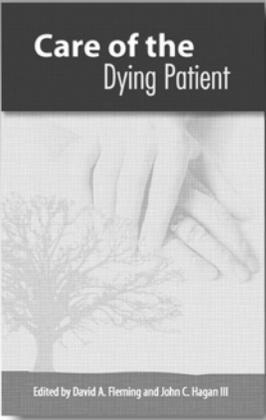
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Teaching Cultural Competence in EOL Care



By: Meghan H. Green, MN, Stephanie M. Schim, PhD, RN, & Ardith Z. Doorenbos, PhD, RN

A great deal of recent interest has centered on enhancing cultural competence among healthcare providers as a means of eliminating some of the chronic disparities that mark the American healthcare system (Fortier & Bishop, 2004). It is vital that we find ways in our death education courses in undergraduate and graduate programs to foster openness to learning about cultural diversity and to teach the concepts and the tools for cultural competence in end-of-life care. At the same time, as we will discuss a little later, we must also seek other innovative modalities to provide such education and such support to those who are already working in the field as professional caregivers.



Our definition of cultural competence includes interdependent elements of (a) cultural diversity, (b) cultural awareness, (c) cultural sensitivity, and (d) cultural competence behaviors. Cultural diversity is a fact in today's healthcare and social environments. Although much of the extant work on cultural diversity has focused on issues of race, ethnicity, language, and religious difference, we endorse a

broader diversity perspective that includes many dimensions of difference and similarity both between groups and within groups. Issues of age, gender, sexual orientation, socioeconomic status, and education also must be considered when working with concepts of culture. Cultural awareness is a cognitive construct. Regardless of the facts of an individual's diversity environment, knowledge and thought are necessary to appreciate the ways in which cultures vary and are similar, the ways that cultural contexts influence personal meaning, and the profound effects that culture has on healthcare. Cultural sensitivity is an affective or attitudinal construct. A readiness to learn about cultural dimensions and diversity is essential to cultural sensitivity. This includes being open to self-exploration of personal cultural heritage and experiences, as well as conscious examination of the disciplinary heritage into which clinicians are socialized and the organizational cultures within which services are provided. Cultural competence is a behavioral construct consisting of actions in response to the demands of cultural diversity, awareness, and sensitivity. It is demonstration of behaviors in practice that help to bridge the differences and barriers that often occur when people of diverse cultures interact and communicate. Cultural competence is dynamic over time in response to changing diversity environments and experiences, acquisition of new awareness (knowledge and insights) and skills, and growing sensitivity to

self and others (Schim, Doorenbos, Benkert, & Miller, 2007).

Healthcare provider cultural competence is necessary to the provision of culturally-congruent care across the entire lifespan and is particularly relevant in providing end-of-life care. Culturally-congruent care is the process through which providers and clients create an appropriate fit between professional practice and what clients need and want in the context of relevant cultural domains. Through culturally-congruent care, client desires and needs are skillfully addressed in interaction with providers who adapt care to meet the clients' unique needs. Although culture provides the context for all health and illness care, it has particular relevance as people face the effects of life-limiting illnesses and grapple with the facts of limited life expectancy for themselves or those they love.

The concept of culture describes the patterns of "beliefs, practices, habits, likes, dislikes, norms, customs, rituals, and so forth that we learned from our families...and transmit to our children" (Spector, 2009, p.9). In other words, culture profoundly influences how we perceive and behave in the world. It also profoundly influences our religious and spiritual experiences and the meaning we find in human existence. Through most of our lives culture exists as a largely unexamined background that exerts complex influences, but does not require or stimulate conscious thought. When a life-limiting illness or injury is diagnosed, however, issues of the meaning of life, the nature of death, the potential for life after death, and other weighty issues often come to the foreground. Culture also determines to a large degree our very conceptualizations of life and death, our language and narratives related to such issues, and our expectations regarding rituals, symbols, and legacies. In providing end-of-life care, assessment of the dying person's cultural background and how those perspectives influence the care that is desired is essential to ensure that end-of-life care is appropriate for the client, the family, and the larger community.

Given the heightened influence of one's cultural background during the end-of-life, enhancing the cultural competence of healthcare providers may help to improve end-of-life care services and reduce ethnic disparities (Doorenbos & Schim, 2004). Both the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and the U.S. Department of Health and Human Services Office of Minority Health (HHS/OMH) have set mandates for healthcare organizations to assure cultural competence among providers. These organizations need to balance long-term effectiveness, accessibility, and time and cost restrictions when they choose an educational program aimed to improve cultural competence among providers. Traditional in-service conferences and lectures are often popular due to their cost effectiveness, but this strategy relies heavily on passive learning. It is our opinion that active teaching methods provide more opportunities for knowledge, awareness, affective, and skill-oriented learning of cultural competency essentials (Schim, Doorenbos, & Borse, 2006).

Web-based educational programs have the potential to address many of the problems that exist in providing accessible and sus-

Continued on Page 19

Teaching Cultural Competence in EOL Care

Continued from Page 18

tainable cultural competence education. They can (a) reduce costs associated with scheduled in-service education, (b) increase active learning by providing a self-paced format, (c) increase the consistency of instruction and experiential learning within and between sites, (d) allow for rapid customization of content to accommodate the unique needs of providers in diverse communities, and (e) facilitate online tracking of cultural competence training at the organizational level and provide organizations with feedback on problem areas (Cook, et al., 2008). Furthermore, programs incorporating interactive video vignettes that showcase culturally complex situations that commonly occur in end-of-life care, can teach and promote the application of new skills through behavior modeling. By viewing examples of best practice of a given situation, learners engage on a deeper level prompting critical thinking and self-assessment and reflection.

Becoming culturally competent is a dynamic process of life-long learning in which the interdependent elements of (a) cultural diversity, (b) cultural awareness, (c) cultural sensitivity, and (d) cultural competence behaviors are developed and cultivated (Schim, et al., 2007). End-of-life care organizations and healthcare providers must be especially committed to the development of cultural competency in order to provide culturally-congruent care to all end-of-life clients and their families. Web-based educational programs are cost effective, accessible, and promote active learning strategies that can lead to sustainable culturally competent behaviors, making them a wise choice for teaching cultural competence to end-of-life healthcare providers. Lastly, educators and administrators of hospice and other end-of-life organizations must be committed to the journey of developing their own personal cultural competence (Bednars, Schim & Doorenbos, in press). Through demonstration and modeling of their personal efforts, they will foster an environment in which striving for cultural competence is an important and valued process for improving the care of end-of-life patients and their families.

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Upcoming Themes for *The Forum*

- July, 2010..... ADEC 2010 Conference Report
Deadline May 15
- October, 2010..... Historical Perspectives in
Deadline July 15 Thanatology
- January, 2011..... The Arts and Thanatology
Deadline October 15
- April, 2011..... Public Disasters:
Deadline January 15, 2011 Resilience and Support



Seminar Schedule

Continuing Education for Grief and Bereavement Professionals

Foundations of Bereavement Conference

April..... WA

Advanced Bereavement Conference

June..... MN

Trauma & Addiction

March AZ

April PA

Trauma, PTSD & Traumatic Grief

March PA, IL

April WA

May ME, NH, VT, FL

End Of Life Issues:
Best Practices & Applied Ethics

March NJ, PA

April WI, NJ, PA

May CA, OR

Ethics

March WI

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Journey From Loss to Renewal:
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Helping Older Adults With End-of-Life Decisions



By James L. Werth, PhD

I seem to be getting a lot of jokes about growing older and dying lately. Perhaps this is because of all the contrived controversy about the end-of-life (EOL) counseling provision in the early health care reform debate. With shrill – and demonstrably false – pronouncements about how the proposals would allow government bureaucrats to “pull the plug on granny”, I suppose it was only a matter of time for the jokes and cartoons targeting elders to follow.

On the one hand the focus on this tiny provision led to some good opportunities for education and discussion; however, it is likely that it also did at least as much, if not more, damage to the efforts of many individuals and groups who are encouraging people to have conversations about end-of-life decisions. As with the media attention surrounding the situation involving Theresa Schiavo in Florida a few years ago, there was a window of opportunity to somewhat easily incorporate end-of-life discussions into informal conversations as well as clinical interventions. I am confident that many ADEC members and Forum readers did just this, when appropriate. Depending on the cultural background and demographics of the older adult, in some cases such discussion may have been purposefully avoided altogether; in others, they may have been framed in terms of self-determination / autonomy / control, and, in still others, presented in terms of helping loved ones / interpersonal relationships.

Those professionals who did include EOL issues in sessions probably talked about wishes / desires / hopes regarding the dying process and the event of death. One of the biggest fears for many people is dying alone. It can be invaluable, therefore to help someone make plans that will reduce the likelihood that the person will find herself or himself without support. Not surprisingly, many people say they want to die quickly and painlessly in their sleep, although this is not the typical death. A question that naturally arises in this case is whether the person has said everything s/he wants to say to loved ones before going to bed. Another frequent wish is to die at home, although, in fact, most people die in institutional settings. People often don't think about how hard it can be to get appropriate care at home and how difficult it might be for loved ones to continue to live in the house where someone they lived has died.

The issue of where to die is linked to a larger issue of where to live as one grows older. There is a movement toward “aging in place” in order to allow people to continue to live in their residences. However, for many people, at some point it is not realistic or safe to live without assistance. Decisions about moving, especially to an institutional setting, can be difficult for all involved as are discussions of when to stop driving with its implication for impact on the older adult's independence and the onus it places on the caregiver. In fact, both decisions may be influenced by the older

person's concerns about loved ones and caregivers. One of the most frequently mentioned concerns is being a “burden” to others. The counselor can encourage the person to consider that caregivers may find purpose and meaning in helping.

We know that while many people support the idea behind living wills and durable powers of attorney for health care, relatively few actually have them. Some of the hesitation may be cultural, such as the legacy of the Tuskegee syphilis study for some African Americans or beliefs about the effects of talking about death for some Native Americans and Asian Americans. The professional needs to be respectful in such situations. If conversations about these documents are held, it may be important to note that living wills are not solely for limiting treatment but can also identify interventions that are wanted. Durable power of attorney decisions need to be made carefully because the best person to serve in this role may not be the individual who is emotionally closest to the dying person.

Whenever professionals are assisting clients and their loved ones with end-of-life decisions, it is important for the helpers to be aware of their own thoughts, beliefs, and feelings regarding dying and death, being cared for and being a caregiver, and about documents such as living wills / durable powers of attorney. Our own experiences with dying and death obviously may impact our work with clients, as ADEC members know. However, perhaps not as salient to professionals are their beliefs about what it is like to be elderly. We may not be aware of our ageist beliefs and how our sense of the issues and opportunities experienced by older adults may subtly (or not-so-subtly) influence our end-of-life discussions with elderly individuals. Having good consultants available can be invaluable and can reduce the chances that our own “stuff” interferes with providing good care.

I am not saying that finding a joke about older adults funny means that we cannot or will not provide good care to an elderly person. However, I suggest that we pay attention to our reactions to these jokes, stories, or phrases and consider the potential for what our reactions say about our own hopes and fears associated with growing older.

About the Author

James L. Werth, Jr., PhD, is a licensed psychologist and is the director of the Radford University Doctor of Psychology program. He serves on ADEC's Scientific Advisory Committee and has many publications on end-of-life issues.

Werth conducted an ADEC Webinar in January entitled, *Myths and Facts About Advance Care Planning: Dispelling the “Death Panel” Claim*. The Webinar is available for purchase for 1.5 CE Credits or Nursing Contact Hours. See www.adec.org for details. E-mail: jwerth@radford.edu.

Capitalizing on the Resilient Nature of Haitian Culture Through Loss



By Tashel C. Bordere, PhD, CT

We were, for awhile, showered daily with media images highlighting the mass destruction of Haiti wrought by the 7.0 earthquake that struck on the evening of January 12, 2010. As those images start to fade, and the media moves on to spotlight other hot and pressing stories, the grief experiences of the people of Haiti will not have diminished. With thousands homeless, over two hundred thousand dead and still others missing, attempts to cope with multiple and varied losses will remain.

The excessive number of deaths combined with limited options for body disposal has necessitated the use of mass gravesites containing identified and unidentified bodies, gravesites sealed by the very rubble which claimed many lives. Thus, the experience of loss among the Haitian people is compounded by the fact that many families have neither been able to identify their deceased loved ones (necessary for spiritual connectedness) nor participate in one of the culture's most important transitional rituals, that of a dignified funeral and burial (See Colin, 2010).

Despite unfathomable circumstances and the initially stalled recovery efforts, the people of Haiti have remained hopeful and prayerful and have persisted in their attempts to move forward in rebuilding their lives. In our work with grieving individuals and families, it is important that we capitalize on the hopeful nature of the Haitian culture through their experiences of loss.

Implications for Thanatologists from a Cultural Perspective

Due to the increasing number of unprecedented natural disasters striking across the world, cultures that have in many ways been thanatophobic are now faced with losses so profound that death-denial is less of a possibility. Thus, now more than ever, it seems paramount that we, as thanatologists, come to the forefront, making resources and supportive services more visible and available through outreach efforts across communities.

We can support Haitian families through the development and implementation of rituals that allow them to feel that their loved ones have been memorialized in a way that is both respectful and dignified. Further, given the significance of spiritual connectedness among the deceased and the living for many within Haitian culture, it is paramount that we facilitate a process whereby Haitian individuals are able to find ways to maintain their spiritual connections to their deceased loved ones. Health and mental health professionals need to educate themselves on Haitian culture as they reach out to support survivors. (For some useful background on health and mental health care for Haitians and Haitian immigrants, see Colin & Paperwall, 2003; Desrosiers & St. Fleurose, 2002; Menos, 2005; Nicolas et al, 2007; Nicolas, DeSilva, Grey & Gonzales-Eastep, 2006; and The New York State Psychological Association, 2010).

As a consequence of the changes wrought by natural disaster, there are two lives that survivors will know: life as they knew it before the disaster (e.g., teacher) and the life that they will come to lead and know as they rebuild their lives following the disaster

(e.g., retired teacher now office professional). As thanatologists, our task will be to help individuals and families incorporate their losses in ways that allow them to see their strengths in transitioning from their past to their present lives.

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About the Author:

Tashel C. Bordere, PhD, CT, assistant editor of *The Forum* and member of the ADEC Board of Directors, is an assistant professor of child and family development at the University of Central Missouri in Warrensburg. Her research focuses on diversity and resilience through grief. Her most recent publication, "To look at death another way: Black teenage males' perspectives on second-lines and regular funerals in New Orleans" appeared in *Omega: Journal of Death and Dying*. E-mail tbordere@ucmo.edu.

ONLINE RESOURCES ON HAITI EARTHQUAKE RELIEF CAN BE FOUND AT

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Psychology beyond borders:
<http://www.psychologybeyondborders.org/>

U. S. Aid: <http://www.usaid.gov/helphaiti/>

The White House: <http://www.whitehouse.gov/HaitiEarthquake>

Student Initiative Committee Program Profile: Southwestern College

By Cher de Rossiter, Co-Chair, Student Initiative Committee

Students are important to ADEC, and we want ADEC to be important to its student members. Those of us who are students know that the costs associated with attending the annual conference are often beyond our budget, but scholarships to the conference make attendance possible. The Student Committee tries to alleviate the burden a little further by providing a contribution to travel expenses.

Coming to the conference is one of the real benefits that membership in ADEC brings students, especially as they begin to get involved in the organization and meet people they have only known through journals or books. For some of us the conference is our introduction to the "home" that ADEC offers to those who work in the field of death and dying. It's a chance to network, but it's also a chance to feel like you belong. (After all, outside the organization, we are often thought just a little strange for the field we are interested in).

To continue to provide travel money for students coming to the conference, we need to raise money through the silent auction, and to do that we need members to help us by donating items to put in the auction. If you are reading this, please bring something wonderful to the conference for the auction, or come to the auction and bid generously. You can just go the auction area and drop off items when you arrive. The participation of students at the conference and in the silent auction

helps get the next generation of ADEC leaders involved in the work of the organization and familiar with its values. Additionally, it helps expose them to a large number of leaders and practitioners in the field.

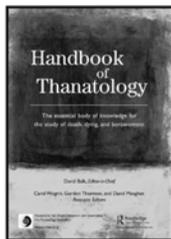
There is another way that you can help both ADEC and students. If you are an educator who has contact with students whose interests coincide with those of ADEC, please encourage them to join the organization and to participate in its activities. My professors did encourage me to join professional organizations where I could develop a professional identity that was consistent with the work I would be doing and where I could find a supportive culture for my interests, but none of them knew about ADEC. It took me a while to find my "home." You could make it a lot easier and help the next generation find us.

If you don't have regular contact with students, you can still add your support by making sure that you talk to the student members who are at the conference, help them feel comfortable and make connections they can take away from the meeting.

This will be my last "conversation" with you as student chair. I've learned a lot in the past year and am grateful for the opportunity. ADEC is a valuable resource for me, as it is for other students, and as my last task I'd like to ask you to support the silent auction, encourage students to participate in ADEC and welcome those who do. E-mail: cher.derossiter@walden.edu.

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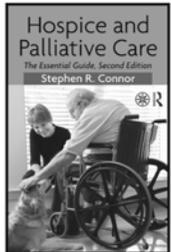
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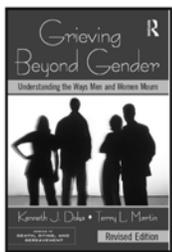
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What's New From ADEC Members



By the Rev. Paul A. Metzler, DMin

Berger, Susan A. *The Five Ways We Grieve*. Boston, MA: Trumpeter Books, 2009. ISBN: 978-1-59030-697-0. Hardcover, 223 pages.

Berger offers a typology of 5-types of personal healing trajectories after loss based on her doctoral studies and qualitative research with over 60 survivors of significant loss. Her interview subjects ranged in age from 24 to 65, with a variety of types of loss (parent, spouse, anticipated, sudden, etc.) ranging from 5 to 20 years prior to the interviews. Her interviewees were admittedly well-educated, Caucasian and middle aged and therefore not a scientific sample, but an interesting and insightful group who exemplify Berger's 5-types: Nomads, Memorialists, Normalizers, Activists, and Seekers. Her book concludes with a useful appendix of "Resources for Self-Help." Many grievers will be able to gain helpful insights into their own experience from this book.

Jeffers, Steven L. and Harold Ivan Smith. *Finding A Sacred Oasis In Grief: A Resource Manual for Pastoral Care Givers*. Oxford, England: Radcliffe Publications, 2007. ISBN: 1-84619-181-5. Softcover, 188 pages.

In this thoughtful and helpful book, Jeffers and Smith offer 15 chapters to inform and guide a deep level of pastoral care. This book will be helpful in seminary classrooms but also in congregations trying to equip both clergy and lay caregivers for ongoing care of the dying and bereaved. A chapter that reviews the diversity of beliefs among 7 of the largest religious traditions (Baha'I, Buddhism, Christianity, Hinduism, Islam, Judaism and Native American) is especially appropriate in the diverse world in which most pastoral care is delivered. The Appendices ("Suggestions to Those Who Plan My Funeral" and "Where to Find Help") and annotated "Recommended Reading" list are all particularly rich and useful.

Lee, Marlene and Lil Ingram. *That's My Hope*. Boyds, Maryland: Early Light Press, 2008. Hardcover, 41 pages.

Lee and her co-author have written a read-aloud book that tells the story of a young girl, Hope, whose father is deployed with his military unit but soon is hurt in "an accident" and must have a leg amputated. The 7 brief chapters take the readers through Hope's first reaction to the news, her visit to a CHILL Unit (Children's Interactive Learning Laboratory) at the hospital that teaches children about their parents' injuries and her reunion with her dad as he learns to walk again with the aid of a prosthesis. This book graced with art from many children will provide a wonderful entrée to conversations with the thousands of children who have been impacted in recent years by their parents' military service and the high incidence of major injuries. The book provides guidance for parents about to interact with children when reading the book and concludes with a list of Resources focused on both military and general amputee organizations.

Neimeyer, Robert. *The Art of Longing. Selected Poems*. Bookserge Publishing, 2009. ISBN: 1-4392-2611-3. Softcover, 66 pages.

Neimeyer is well known as a thanatologist and prolific author of professional bereavement literature. His contributions as a free verse poet are newer, but continuous with his longing to search for meaning-making insights, language and images that can open for the reader new glimpses of the reality of life and loss. This collection of 27 poems is joined with 29 images from an international group of 7 artists whose paintings, photos, collages and sculpture foster yet further meaning to these poignant poems. Neimeyer is to be admired for his deep insights, verbal gifts, and reach beyond the confines of academic writing to embrace the poetic and visual arts.

Showalter, Sherry E. *Healing Heartaches. Stories of Loss and Life*. West Conshohocken, PA: Infinity Publishing.Com, 2009. ISBN: 0-7414-5692-3. Softcover, 233 pages.

Showalter is an active hospice professional and drew from that experience to write 17 chapters that share stories of loss and grief but also of hope, humor and healing. With her strong Native American spirituality, she lifts up the stories of many diverse individuals and families to foster mind-body-spirit healing and embrace the connection of all human experience and stories. Many will be touched by and identify with these stories.

Tarr, Teddy. *Job's Gifts. Lessons From a Righteous Mourner for the Bereaved and Those Who Co-Journey With Them*. Miami: FL: Griefworksinc.com, 2009. Self-published 3-ring loose-leaf binder. ISBN: none. Irregular pagination.

Tarr offers a comparison and contrast between the experience of the biblical Job's responses to his losses and topics in modern bereavement literature. She seeks to differentiate what is helpful and unhelpful in support of the bereaved and to enable contemporary helpers of the bereaved to honor the individual uniqueness of each experience of loss.

Wolfelt, Alan D. *Understanding Your Suicide Grief. Ten Essential Touchstones for Finding Hope and Healing in Your Heart*. Ft. Collins, CO: Companion Press, 2009. ISBN: 978-1-879651-58-6. Softcover, 227 pages.

Wolfelt uses his signature concept of "touchstones" to present 10 important emotional, conceptual, spiritual and self-care concepts to support and heal those shattered by suicide grief. He writes not only from professional knowledge, but from the personal grief he experienced following his friend's suicide death. Wolfelt is gifted in his ability to offer compassionate and comprehensive guidance in a very personal voice to the many who will be helped in reaching this book.

"What's New" is a listing of educational materials written or produced by ADEC members. Each listing is run once and is intended to showcase contributions of our membership to the field of death, dying, and bereavement. Send a review copy (not just an announcement) of recent material (2008 to present) to:

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ADEC and *The Forum* congratulate and thank Paul Metzler for more than twelve years of conscientious and excellent contributions to *The Forum* in his quarterly "What's New" column. Paul Metzler will be honored at the 2010 ADEC Conference.



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