Diversity Issues in Thanatology

Culturally Conscientious Thanatology

by Tashel Bordere, PhD, CT

“Never doubt that a small group of thoughtful committed citizens can change the world; indeed, it’s the only thing that ever has.” - Margaret Mead

In thanatology, we are no strangers to culture. Delving into the cultural phenomena of death and bereavement is our passion. It is our life’s work. Thus, the intention of this article is not to highlight deficiencies as is often the case when topics of culture and diversity arise. It is instead intended to further empower a group of dedicated and culturally conscious individuals to work towards even greater cultural conscientiousness in our work with the bereaved. Cultural consciousness entails an appreciation and awareness of diversity, a mindset that is no doubt a central part of our journey through grief with families. However, it is our cultural conscience that allows us to be industrious in carrying out the important work of meeting the diverse needs of families from varied social locations (e.g., family structure, ability, sexuality, class, nationality, ethnicity, spirituality).

As with any quest, there are barriers, whether perceived or real, conscious or unconscious, that may pose challenges in the pursuit of cultural conscientiousness. I have had the good fortune of conducting workshops and trainings across the country pertaining to cultural awareness, sensitivity, and competence. Whatever the arena, I have found the themes across the audiences to be the same. Most individuals desire to further their knowledge and skills in cultural diversity and to implement them both in practice and in their everyday lives. However, these hopes are often overtaken by feelings of inadequacy (e.g., not knowing enough), fears (of offending or being misunderstood), misconceptions about the amount of work required, and messages imprinted through socialization that matters of culture are “optional.”

It is not enough for culture to be a

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A Note From the Editor

by Kay Fowler, PhD, FT

Death is universal and loss nearly so, but the experience, the interpretation, and the expression of dying and grief are as diverse as human beings themselves. As thanatologists, we seek to understand, to celebrate, and to honor that diversity in our efforts to profoundly connect with one another. Fundamental principles of thanatology emphasize the need to listen carefully and compassionately to the values and concerns of the dying, the griever, the caregivers. They are the “professors” as Daryl Owens (p. 16 in this issue) reminds us; we, as much as we can be, are their attentive, respectful students.

We use our best judgment to decide when to simply accept and honor, and when and how to intervene. And it is in developing this judgment that the challenge lies. As infinite as we human beings are, each of us is finite in our experiences and in the people we encounter.

These shape the cultural context and the filters through which we listen and learn. Thus we are (always) ultimately, underprepared for the next encounter. Knowing this, we seek — in our personal and professional lives — to move, as Tashel Bordere says (p. 1), from cultural consciousness to cultural conscientiousness. We do this through the arts (see Fajardo, p. 11), through research (see Pearson, Kim, & Sherman, p. 7 or Walker, p. 13) through attention to sociocultural

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President’s Message: ADEC on the Forefront
by Heather Servaty-Seib, PhD

For my final President’s column, I would like to offer some of my thoughts about where ADEC is as an organization—and the ways that I see ADEC fulfilling its vision in the present and moving toward fulfillment in the near future. To begin, I include the last sentence of ADEC’s vision statement:

Therefore, the Association, ever committed to being on the forefront of thanatology (the study of death and dying), will provide a home for professionals from diverse backgrounds to advance the body of knowledge and to promote practical applications of research and theory.

ADEC’s commitment “to being on the forefront of thanatology” is evident through a number of organizational initiatives, especially the development of the Body of Knowledge matrix and the publication of the Handbook of Thanatology (Balk, Wogrin, Thornton & Meagher, 2007). These advances set the stage for ADEC to not just be on the forefront, but to authoritatively lead the charge. Efforts are also underway to build collaborations with organizations who share our vision. Such alliances will benefit ADEC members, while also moving the whole field forward through combining efforts around issues such as public education.

One of ADEC’s greatest strengths is the evolving multi-level diversity of its membership. The ADEC board itself reflects the diversity of the membership at large, drawing members from nursing, social work, education, ministry, psychology, family studies, counseling, and anthropology and working in a variety of settings such as private practice, hospice, academia, and hospitals.

ADEC is advancing the Body of Knowledge (BOK) by using the matrix as an intentional tool through which to structure organizational activities. For example, the programming for the Dallas conference (and two prior conferences) was built around the BOK matrix—in an attempt to balance content across the field as much as possible. Future themes of The Forum have been specifically selected to address areas within the matrix that have not traditionally received as much attention. This past year, much time and effort has also gone into exploring the creation of BOK-based continuing education and distance education opportunities.

Practical applications of research and theory currently exist at the annual conference, through the Bridging Research and Practice Networking Group, within the online journals Death Studies and Omega, and through Forum articles such as those included in the present issue. In addition, the ADEC board has approved the formation of a scientific advisory committee for the organization. The specifics of how this committee will function are currently under development.

I am proud to be an ADEC member and honored to have had the opportunity to serve the organization as its president. It has been a privilege to work with a productive and thoughtful board and a competent and professional management firm.

Reference:

Hospice Foundation of America 2009 National Bereavement Teleconference - Diversity and End-of-Life Care
Wednesday, April 29, 2009
http://www.hospicefoundation.org/teleconference
“consideration.” A consideration is something that is up for debate -- negotiable. To the contrary, if we are to be effective in our work with grieving individuals and families, all of our undertakings, whether in research, teaching, practice, or service must be approached from a cultural perspective. What do we mean by this idea of “cultural perspective,” a concept often tossed around and reified to the point that we could almost carry it around in our pockets? And what exactly are we committing ourselves to do? Inherent in the concept of diversity is the notion of multiple complexities, which makes addressing it seem daunting. The reality is that having a cultural outlook does not commit us to knowing everything about every group in society. In fact, such an expectation is self-defeating and often opens doors to unintentional stereotyping or generalizations. A cultural perspective, quite simply, requires that we commit ourselves to evolving knowledge of bereaved families. Below I present some practical suggestions and challenges in achieving this end, incorporating some of my own successes, struggles, and lessons learned in culture and thanatology.

**Self-Reflection:** Despite years of training, some of my most profound and affirming lessons in self-reflection as a cultural practice have come through my experiences and interactions with my grandfather in his dying process and recent death. In my grandfather’s transition to hospice, his primary nurse met with my family to discuss the type of care hospice provides. She explained that my grandfather would no longer be seeing his current doctor, but would now be cared for by the hospice team, including a new doctor. At this, my grandfather, frail and docile, hardly speaking above a whisper during the visit, began to yell out in protest: “I’m not signing NO papers!! I’m NOT signing ‘em. I want MY doctor!” Banging his hands on the arms of his leather recliner, he exclaimed, “I don’t know these people. I’m not gonna’ be laid out to dry!”

Startled by my grandfather’s reaction, the hospice nurse eased into the kitchen to make a call to the main office. In the interim, I was able to intervene as a gatekeeper, calming my grandfather and providing him the reassurance he needed to feel safe and secure in his transition to hospice. Meanwhile, I listened as the well-intentioned nurse described my otherwise sharp grandfather as “confused,” mistaking his anxiety, brought on by feelings of mistrust in the medical system, for “disorientation.” My grandfather’s fears and mistrust, like that of many African Americans, were deeply rooted in historical experiences. They were very real for him. Prior to being diagnosed with cancer, my grandfather had not seen a doctor in 30 years. In fairness, the nurse could not have known that.

The nurse did, however, know something about the value of self-reflection in connecting with families. I will always respect and appreciate her for her call the next day. Expressing concern about my grandfather’s apprehensiveness, she asked for background information so that she could develop a more holistic picture and individualized plan for him. It was her ability to engage in self-reflection and her openness to evolving knowledge that allowed her to meet my grandfather’s needs and to enter into true collaboration with him and my family.

In thanatology as a discipline and in ADEC, our commitment to self-reflective practice is evident. The commitment is reflected in ADEC’s program planning, where proposals may be submitted for practice and self-reflective reports, thus providing opportunities to reflect on our experiences in the company of supportive people who can offer validation and constructive feedback.

**Methods:** In reflecting on our methods and approaches, we should look first at our strengths. What are we already doing in the way of culture in our work with the bereaved? What is the place of culture in our work? Are we treating it as optional or are we conscientiously infusing it throughout our work? Once we have considered these questions, we can begin to set goals.

Although some researchers do specifically set out to explore certain cultural phenomena, every study should encompass a cultural component. Furthermore, we should hold ourselves responsible for identifying how we address cultural diversity in our work (e.g., in publications) so that others, like developing scholars, can benefit from our experiences. If we are to become more effective in outreach and recruitment efforts in research, as well as in teaching, we must be less concerned with separating ourselves as traditional methods would require (i.e., researcher neutrality in interviews), and more concerned with connecting. Indeed it is when my students and research participants perceive connections between their experiences and mine, that trust begins to be established and that more detailed personal disclosure can begin to follow.

Being present is not enough. Many valuable supportive services across the country go underutilized, because the support staff have the knowledge and presence but lack visibility in the community. Connecting requires outreach, particularly with underserved populations traditionally labeled as “hard to reach.” Let us continue to create new and innovative ways to reach different populations. Let us assume greater accountability and responsibility as researchers and practitioners. Regarding underserved populations, let us ask ourselves, are they “hard to reach” or have we just not found the most effective way to reach them yet? What can we do to bridge gaps and build greater trust in various communities? Let us start by connecting with the people who have been effective in reaching our populations of interest and let us continue to be the trailblazers in changing traditions that do not serve us and even more importantly, that do not allow us to serve the populations that need us most.

**Cultural Conflicts – Honoring Differences:** In attempts to connect, cultural conflicts may arise. In my grandfather’s dying process, I found myself in the midst of my own cultural dilemma, caught between respecting my family’s wishes and doing what I thought was needed based on my training. I had forgotten one of the essentials of cultural sensitivity, and that is that individuals and families know best what they need. If we listen closely, they will tell us.

Unfamiliar with hospice, my grandfather believed that the people providing his care were from home health care. My family reinforced

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his thinking by not referring to hospice by name when communicating
with him. I really struggled with this, believing that my family's failure
to name hospice would prevent both my grandfather and my family
from doing the work that is needed at the end of life. Did he realize
he was dying? Did my family really understand that he was nearing
the end of his life? In my last interaction with my grandfather, he
communicated his understanding of his impending death to me
through the language that he knew best – that of Biblical scriptures.
Knowing that he read his Bible every day prior to his decline, I asked
him if he wanted me to read it to him. To that, he said, “No, I'm a big
boy” and turned to his side. He then opened his eyes and said, “Let
me read the Bible to you!” Looking directly into my eyes, he quoted
several scriptures to me from memory, including Psalms 23: “Yea,
though I walk through the shadow of death, I will fear no evil,” and
John 14:1-3:

1. Let not your heart be troubled. You believe in God, believe
also in Me.
2. In my Father's house are many mansions; If it were not so, I
would have told you. I go to prepare a place for you
3. And if I go and prepare a place for you, I will come again and
receive you unto Myself; That where I am, there you may be
also.

In that powerful moment, with all of my theories, I had nothing
to quote back to him. We were united in silence. I was not present
when my grandfather died, but they say he died peacefully,
appearing to be restfully sleeping. If my grandfather, coming from
historical experiences of oppression and discrimination, was able
to die feeling that the service he was receiving from hospice was
related to fairness or equality in medical treatment as opposed to
being taken care of by a team of people because he was dying -- who
was I to take that away?

When I listened closely, I also better understood the unspoken
reality surrounding my grandfather's behaviors. She did not want
my grandfather to think that she was “giving up” on him. For her,
acknowledging hospice in his presence would be communicating to
him that she had.

**Thanatological Theories and Research:** We should continue
to create and explore opportunities to infuse culture into theories
within thanatology (for example, intuitive and instrumental styles
of grieving, Martin & Doka, 2000). At the same time a growing body
of qualitative research across the literature in thanatology is an
indicator of our commitment to understanding and voicing the lived
experiences of the people we serve. We should continue in our trend
towards greater qualitative research. More research is needed too
that looks at death and loss from a global perspective and examines
the diversity regarding death and loss that exists within cultures.

We need to be sure that we are exploring individuals and families
from a strengths perspective, highlighting both their challenges and
their resiliencies (see Bordere, 2009). That necessitates looking
at the types of questions we are asking in research and practice.
Do those questions lend themselves to looking at strengths within
bereaved families?

A special area for new expanded research is in the exploration of
losses which, while unrelated to death, are, nonetheless, pressing
issues in our society. There are, for example, an increasing number
of same-sex unions that include children. With few protections in
place to secure the rights of non-birth and non-adoptive parents,
many parents are faced with memorializing children who are alive
but that they have no legal rights to see (i.e., visitation). Families are
coping with financial and material losses. Those who have
experienced natural disasters, families of deployed military
personnel, and groups disenfranchised within our society all face
powerful and life-altering losses that need to be researched and
addressed.

**Pass it On:** There are many recent examples in the literature on
the “how to” of cultural infusion in teaching (e.g., Bordere, 2008;
Fowler 2008) as well as in research and practice (e.g., Barrett, 2006;
Winston, Leshner, Kramer, & Allen, 2005). Let us seek out and build
upon resources and methods that have already been shown to be
effective. In doing so, we allow others to evolve with us. Let us
continue in our journey to greater evolution!

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to access and utilization of hospice and palliative care services in African-

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It was a late night at the hospital and I was on the phone in an empty, quiet hallway explaining to a woman I had never met that her young, gay son was dying from AIDS. He had just asked me when his mom and dad were coming to see him. I decided to call, without his consent, to inform them of his impending death. I was hoping that this time they would come. She nervously rambled that they had been busy with family visiting during the holidays and they would not be able to be there. The hospital was only an hour from their small town in North Carolina. My eyes filled with tears as feelings of sadness and despair overwhelmed me. As a gay man, I deeply understood her rejection and her fear. My sadness for him turned to anger as I blurted, “he needs you now; he is dying.” Silence. In the silence, I heard her pain as well. Her voice cracked as she muffled through her tears “please, I just can’t. Tell him how much I loved him.” We both were crying as she hung up. As I walked back to his room I realized I had become his caregiver and I wondered what I could say to help him understand that his mom and dad would not be coming. This experience was the beginning of my journey in understanding the unique issues of caregiving and death with gay men and lesbians.

Researchers and clinicians have developed models in understanding how individuals experience dying, death, and grief in our Western culture (Bowlby, 1980; Kübler-Ross, 1969; Rando, 1984; Worden, 2008). While these models and others are used widely in clinical practice, they tend to be based on majority populations and may not fully reflect the experiences of minority populations. Specifically, lesbians and gay men, as compared to heterosexuals, face unique issues in coping with death, caring for a dying partner or grieving the loss of a loved one. Unfortunately, the research is limited in examining these differences (Bent & Magilvy, 2006; Hash, 2006). This brief article will discuss the distinctive concerns of lesbians and gay men on caregiving and grief and will provide some suggestions for working with these populations.

Research findings support the premise that lesbians and gay men experience some unique factors that influence caregiving for the dying. One of the challenges for lesbians and gay men is in receiving support for their role as caregivers. Fredriksen (1999) conducted a large-scale study with 1,466 lesbians and gay men who were providing care to adults and children. Of those assisting adults, 82% experienced harassment because of their sexual orientation. Harassment in this study was reported as verbal (93%), emotional (46%), physical (14%), and sexual (8%). Interestingly, of this sample, most reported being “out” to co-workers (56%) and healthcare providers (62%).

In an earlier report, Fredriksen (1996) also found that lesbian and gay male caregivers, compared to heterosexual caregivers, provided higher levels of quality care and more hours while reporting greater emotional strain about their job termination due to increased caregiving responsibilities. Cahill, South, and Spade (2000) found a similar result of increased strain with older lesbians and gay men reporting a greater burden for caring for parents due to the assumption that they are more available to provide care because they are not “married” or do not have children. Clearly, lesbians and gay men are providing quality care, but also experience greater strain as a result of a lack of sensitivity to their gay identity.

Hash (2006) conducted one of the few qualitative studies looking at caregiving and post-caregiving experiences among lesbians and gay men. Higher levels of role strain on caregivers were again reported due to issues around disclosure of relationship status, lack of sensitivity to gay relationships among healthcare providers, and policies and practices (healthcare decisions, workplace leave, end-of-life decisions) that are not supportive of gay relationships. One of the distinguishing aspects of this study was the role of formal and informal support systems. Participants discussed how informal support (family, friends, co-workers) many times revealed a lack of support for their gay relationship. Ex-spouses and adult children, in some cases, were perceived as “hostile” to the caregiving relationship of gay partners. Many mentioned having a “family of choice” as informal support rather than their biological family. Harassment by healthcare professionals (formal support) due to sexual orientation was also a theme in the interviews. This was expressed as “slighting remarks, facial expressions, rude or hostile behavior” (p. 132). While most respondents reported being treated fairly well by healthcare professionals, a majority shared a perceived stigma and apprehension of discrimination with health services, further increasing the strain experienced by lesbian and gay male caregivers.

After the death of a partner, many lesbians and gay men struggle with the ability to find supportive friends and family who can validate their special relationship and recognize their unique grieving process. Studies examining the bereavement patterns of lesbians and gay men reveal some unique factors. Hash (2006) found bereaved lesbians and gay men feeling extremely lonely and isolated, despite friends, coworkers and family concern. The experience may be worsened by others’ limited knowledge of the more “invisible” expression and understanding of love, intimacy and commitment of gay partners. Bent and Magilvy (2006), in a study of lesbian widows, found that the unpredictability of support among family and friends added significantly to the “disenfranchised grief” experienced by these women. This “unpredictability” seemed to be tempered by one’s acceptance of the women’s relationship. Lesbian widows felt more support from those who were more accepting of their relationship.

Clearly, the AIDS epidemic created a “bereavement overload” for many gay men and lesbians that seemed to be a never-ending grieving process. Oram, Fraser, and Landolt (2004), surveyed gay men to assess what was most helpful in coping with multiple AIDS-related losses. Respondents mentioned: support of friends (91%), time heals (88%), spirituality (74%), accepting the loss (87%), and...
Caregiving and Grief Among Lesbian and Gay Men

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knowledge of HIV/AIDS (93%). Formal support (counseling services and support groups) were found to be the least helpful. While family support was reported to be effective, it was rated significantly lower than the support of friends and/or partners. In grief, lesbians and gay men seem to seek help primarily from friends and family who validate their gay identity and their relationships.

A few trends emerge that can guide “best practice” for clinicians, healthcare professionals, and educators working with caregiving or grieving lesbians and gay men. Clearly, the greatest support will be to validate and recognize their gay identity and partner relationship. This will involve asking about their being gay and what that means to them as well as exploring their relationship with their partner. The challenge here is to assess, by asking, their comfort level with disclosure of their gay identity and relationship status. Do not assume that a client would prefer not to discuss such matters. In my experience, many times as the helper we fear discussing the obvious due to societal norms. Keep in mind, this conversation requires sensitivity and knowledge from the helper that may require some intentional training or life experience in gay culture.

As a professional, facilitating a safe, comfortable relationship with a lesbian and/or gay male client is essential. Explore their world by asking about their experience as a caregiver or in grieving their loss. Empowering the gay client to discuss “slighting remarks” or rude facial expressions will provide greater support and build trust. Finally, it is important to provide some practical support as well in managing the enhanced strain many caregiving and grieving lesbians and gay men experience. Assist them in identifying supportive friends, family, or co-workers. Discuss policies and practices that may hinder their ability as the caregiver or complicate their grief. Again, exploring these pragmatic concerns -- rather than providing answers for the client -- will foster a greater collaborative, trusting relationship.

As suggested by the research, these strategies or interventions may certainly assist the clinician, healthcare professional, or educator in working more compassionately and effectively with these populations. Personally, as I think back on my experience in the mid 1980’s of walking back into my friend’s hospital room, I recognize that research and prescribed interventions are only a part of “best practice” in caring for others. When I returned to the room, I smiled awkwardly at him and he knew. They were not coming. I said nothing. I simply got in the bed, held him in my arms and let him cry. Being present in the moment of someone’s grief is still the best medicine.

References

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A Note from the Editor

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history (see Menyweather-Woods, p. 9) and through theory (see Harris, p. 10). We enter, empathically and non-judgmentally, into the minds and hearts of those we wish to help. And sometimes, we find ourselves well beyond our comfort zone. This is when we place ourselves in what Lynne Despelder calls a posture of “curiosity” (p. 15) or simply say, “Tell me” as Sharon West (p. 14) so eloquently illustrates. And sometimes, as Leslie Kooyman movingly notes, all we can do is be “present in the moment of someone’s grief” (p. 5). We will sometimes fail but we will keep trying. It is exciting, daunting -- and rewarding.

This issue of The Forum is a contribution to our collective ongoing conversation about diversity in death, dying, bereavement, and caregiving. The articles point as well to a multitude of other resources to support us in our journey toward cultural competence. For some additional suggestions see the bibliographies at http://phobos.ramapo.edu/~kfowler/diversourceswebpage.html.

The conversation doesn’t end here. “Diversity Matters in Thanatology” will be a new regular Forum feature. There is so much to learn, so much work to be done, so much to celebrate and so much to share! Enjoy – and join the conversation.
Culture, Social Support, and Coping With Bereavement for Asians and Asian Americans

by Dairine M. Pearson, Heejung S. Kim, PhD, David K. Sherman, PhD

Asians and Asian Americans seek and perhaps benefit from social support less than European Americans in coping with stressful life events. In this article, we review research findings that support this statement. We apply these findings to broaden the understanding of how people from different cultures might respond to and cope with the life stressor of losing a close relationship. Grief is a human emotion found in all cultures, and bereavement is a human condition that is intuitively understood by most to be a consequence of loss and a reaction to the death of a close relationship. Although bereavement may be universal and inescapable, the cultural diversity of human life presents some obstacles to understanding and providing the most helpful services to those experiencing grief. We believe that cultural understanding is of vital importance to end-of-life clinicians, educators, and mental health professionals who seek to provide comfort and assistance to culturally diverse populations.

Working With Grief

Grief counseling varies widely and incorporates such techniques as life review, forging a new relationship with the deceased, finding meaning from the loss, and active work on expressing deep feelings concerning the loss. One active grief work model, quite prominently employed, considers unresolved grief to be almost always about undelivered communications of an emotional nature, and holds that bereaved people should learn to communicate their feelings and then say goodbye to the relationship that has ended (Friedman & James, 2002). Grief counseling generally involves the interaction of a bereaved person with a trained professional who, using psychotherapeutic techniques, aids the bereaved in understanding and coming to terms with their loss in individual, family or group counseling formats. In 2007, hospice organizations alone provided bereavement services to an estimated 2.8 million individuals, including phone calls, visits, mailings, and grief counseling (National Hospice and Palliative Care Organization, 2008).

Although the active grief work model can be an effective coping strategy, an unintended consequence of its popularity may be the mistaken belief that it is appropriate for all bereaved people. However, recent research has demonstrated that while almost all bereaved individuals experience intense initial grief reactions to a significant loss, the bereavement trajectory differs markedly between individuals. Some people experience severe reactions, or “complicated” grief, marked by a sense of disbelief about the death, intense longing for the deceased, and the presence of bitterness and anger more than six months after the death (Prigerson et al., 1995). Yet, research by Bonanno, Folkman, Moskowitz, & Papa (2005) demonstrates that as many as half of all bereaved people do not experience depressive symptoms or significant loss of functioning even when dealing with the loss of a spouse or a child. Furthermore, a minority of bereaved individuals who were suffering depressive symptoms prior to their loss actually experienced psychological improvement after their loss.

Findings demonstrating diversity in the bereavement experience call for re-examining the grief work assumption in terms of one important source of psychological diversity, culture. Is the popular grief work model, used extensively in the U.S., the best coping model for people from other cultural backgrounds? We propose an alternative approach based on research we have conducted on culture and the use of social support.

Culture and Social Support

Social support is one of the most effective strategies that people use to cope with stressful events in their daily lives (Cohen & Wills, 1985). In examining the use of social support, researchers typically focus on specific support transactions involving the seeking and receiving of help through tangible assistance, informational support, or emotional support.

While many studies rely on this definition of social support, a review of studies on culture and social support (Kim, Sherman & Taylor, 2008) points out some potential limitations to focusing on explicit transactions as the sole form of social support typically sought in a culturally diverse population. For example, Asians and Asian Americans, who are from more collectivistic cultures than European Americans, are more reluctant to explicitly ask for support from close others, because they are more concerned about potentially straining relationships, losing face, or making others overly concerned about their problems. That is, Asians and Asian Americans are more concerned about potentially negative relational consequences of seeking overt social support and consequently, are less likely to pursue it (Kim et al., 2008).

To understand social support use among Asians and Asian Americans, we expand the concept to include more implicit processes. Implicit social support is defined as the emotional comfort one can obtain from social networks without disclosing or discussing one’s problems with others individually or in groups. Empirical examinations show that Asians and Asian Americans rely on implicit support as much as or even more effective in reducing psychological and biological stress responses, and is associated with increased daily well-being (Kim et al., 2008).

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Bereavement Experiences and Practices in Different Cultures
The concept of implicit social support is a useful one to keep in mind for clinicians who work in bereavement services, especially with Asian and Asian American populations. Although our research on culture and social support has not specifically focused on grief work, there is substantial indirect evidence to show the relevance of this framework in the area.

Being with family and friends, attending church and social clubs, keeping to work schedules and responsibilities, and maintaining contact with close others all involve the use of implicit social support, and are coping mechanisms just as valid and powerful as more overt coping styles. The relative importance of explicit versus implicit support can even be seen in bereavement rituals from different cultures. For instance, in an Irish-American Catholic wake, the social support used can be seen to be explicit as both family and community gather to weep, remember, eat and drink in honor of the deceased, with more emphasis on openly expressing the loss of the loved one. By contrast, certain Chinese customs call for elaborate ceremonies with paper money burned to assuage the deities of the afterlife and to ensure a secure place for the deceased in the realm of the ancestors. Here, the practices of the group focus more on the journey and well-being of the deceased, and focus less on the emotional experience of the bereaved. Hence, the social support gained by participating in this ritual is more implicit in nature.

For people from Asian cultures restraint in expressing negative feelings or complaints is valuable both in maintaining self-esteem and group harmony (Markus & Kitayama, 1991). A study of Asian Americans who had lost a loved one in the World Trade Center attacks on 9/11 found that the bereaved family members coped by seeking the comfort and company of other relatives, but that they avoided talking about the deceased as they did not want to burden others with their feelings or problems relating to their loss (Yeh, Inman, Kim & Okubo, 2006). This notion of spending time with others without explicit emotional disclosure is consistent with the notion of implicit social support, and this study provides more direct evidence for the relevance of the findings regarding cultural differences in the way social support is used during bereavement.

Implications
While we suggest the consideration of cultural differences in social coping in grief work, we would also like to emphasize the complexity of understanding cultural influence in human psychology. We do not suggest that this cultural difference explains and predicts behavioral and psychological responses to bereavement from every member of a certain ethnic group. Nonetheless, some sources of the diversity within cultural groups can be understood. For example, acculturation adds layers of complexity to how social support is utilized. With successive generations, the behavior and psychological tendencies in immigrant families can shift towards that of the dominant culture. Thus, in the same family, different generations may view and utilize social support and, by extension, bereavement services differently. The main goal of this article is to underscore the cultural diversity that exists in the ways in which people respond to the experience of bereavement. The research we described focused primarily on cultural differences between Asian and Asian Americans and European Americans. Other ethnic and cultural groups are likely to vary significantly in how they cope with loss as well. There may also be significantly different patterns of coping that are equally effective between men and women, or old and young. Clinicians, educators, and service providers who work with diverse populations should be aware of the importance of implicit social support. With this article, we hope to encourage further consideration of different potential ways by which individuals cope with their grief.

References

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“Funeral and memorial activities validate the lives of those who are deceased and can strengthen the connection of those who survive losses.” (Walsh-Burke, 2006)

Walsh-Burke’s statement acknowledges the significance in many cultures of honoring the loss of a loved one. In Black American culture, variations in life/death ideology exist not only between groups but within groups (Churn, 2003; Collins & Doolittle, 2006). African American sociocultural history is rooted in Africa and the North American experience, separated by distinct histories and cultural experiences (Barrett & Heller, 2002; Collins & Doolittle, 2006).

How African Americans perceive or understand death in the 21st century is quite significant. Many African Americans have considered death as being a “transition,” a homegoing to a better home (Kellermen & Edwards, 2007). Barrett and Heller (2002) note that African Americans consider life and death cyclical, whereas Whites view it as linear. They observe, however, that as African Americans move up the social ladder in America, they lose their cultural interests and have a tendency to “move away” from the traditional views and practices toward a diametrically opposite value system. The Omaha experience for African Americans and their perception and understanding of death is quite representative of this changing tide.

African Americans have been referred to as “people of the Book,” “God-fearers,” “Prayer warriors.” I remember as a youth in Muskogee, Oklahoma, seeing the truth of an old axiom, “no one dies outside the Church.” Even if a person did not belong to the Church, the funeral was held at the Church which was always available to the community. This was seen as outreach, an opportunity to “win souls for Christ.” It didn’t matter whether a person had been a worker or a drunk; dignity was always priority and all were welcome. This belief was an essential part of my 30 years of Pastoral Theology. My spirituality was not given to sit in judgment but to serve as an instrument of leadership to the “more excellent way.” This position went against what many African American Churches in Omaha were teaching at the time.

It is interesting that Barrett and Heller (2002) suggest that African Americans who are Afrocentric and traditional are likely to have a profoundly spiritual approach to dying and will, consequently, choose to hold “sit-ups” or wakes. Many young African Americans no longer hold wakes, seeing them as “second” funerals. As an Afrocentric and Black Liberationist pastor/teacher, I have openly manifested my commitment to lifting others out of darkness and assisting in distinguishing between tradition and traditionalism. I attempt to explain that the wake still has significance for the grieving process, serving as a familiar comfortable environment for those who would like to honor the loved one and a more appropriate time for organizations to give their thoughts and respects.

There are real differences among African Americans in their interpretation of death and dying related to class. The affluent tend to move away from their communities of origin, and become less traditional, whereas the poor are more likely to follow traditional practices (Heller, 2003). Classism was not problematic during the early Civil Rights Movement, possibly because Malcolm X’s question “What do you call a Negro with a PhD?” was still relevant. However, that began to change following Johnson’s Civil Rights Bill (1964) and the Voting Rights Act (1965). One illustration of this shift is visible in the changing response to the question, “Who’s got the body?”—often the first question raised after someone dies within the Black community. Holloway (2003) writes that in the historical separation of Blacks and Whites in America in the early 20th century, Blacks established mortuaries separate from Whites. At that time the answer would have been the “Black funeral home.” For Blacks in Omaha, that answer changed in the mid-1900s, starting with gang members selecting White mortuaries as opposed to Black.

From slavery until the mid-1960s, our “spiritual roots” and traditions sustained African Americans and moved us “beyond suffering” (Kellemen & Edwards, 2007). The shift away from our “spiritual heritage” and traditions has resulted in the present status of the African American community. African Americans now face our gravest challenge – our spirituality has been questioned, our theology has once again been described as inauthentic, and classism is breaking up our collective spirit, i.e., the community which gathers when death breaks the ties which bind our hearts as brothers and sisters. As a community, we must face these challenges and changes to continue to address death and bereavement with courage, grace, dignity, and support for one another.

References

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Larry Menyweather-Woods, PhD, is an assistant professor in Black studies at University of Nebraska, Omaha. His research interest is developing new strategies to reduce violence in Black American communities through understanding the influence of worldview, racial socialization, and traditional Black Religion on death anxiety of Black American youth and elders. E-mail: mmmbc1887@aol.com
Gender Stereotyping and Oppression in Grief

Darcy Harris, PhD, FT

I frequently see the impact of gender socialization and stereotyping on the grief experience of the individuals who come to my office. On many occasions, I have paused to reflect upon this aspect of my clients’ experiences. Some examples:

- A female client returned to work shortly after the sudden death of her twenty-year-old daughter. She found that the routine helped her to get out of the house and to cope. However, family members chastised her for this decision, insisting that she was not grieving properly. Others asked veiled questions about her relationship with her daughter, assuming that there was a problem because the client was not overtly emotional, nor did she talk openly about what happened.

- A male client, whose wife had died 8 months prior, mentioned that when he wanted to invite a woman that he had recently met to a social function, his two grown daughters refused to speak with him. Previously, these same daughters had been so worried about his despair and social withdrawal that they had told him they would come with him to see a counselor.

- One male client stated outright that he was tired of “wallowing in self-pity,” ashamed of himself for not being able to “pull it together” after his wife of 32 years died. He was struggling with intense feelings of loneliness and despair, and felt disgusted with himself when he sensed the pity of others. The only time he felt comfortable was when he was with his wife’s friends who openly reminisced about his wife and talked about how much they missed her.

- One client was referred for counseling by his work supervisor because substance abuse was interfering with his ability to function after his brother died. He spoke of the double-bind he felt of needing to be in control, while not being able to sleep or concentrate because the events of the loss kept replaying in his mind. Substance use helped him to feel numb and more in control of his emotions.

When I look at the context of my clients’ experiences, I turn to my training in feminist theory which requires the exposure of underlying social structures and values. Specifically, feminist analysis looks at the structures and values that oppress or skew the distribution of power relevant to gender first, but also to class, race, and power as interlocking influences (Hooks, 1994).

According to Brown (1994), feminist therapy approaches the task of identifying and addressing oppression as it is manifested as distress in people’s lives. Brown defines oppression as the act of empowering and/or privileging one group at the expense of disempowering, marginalizing, silencing, and subordinating another. Oppressed people face both external barriers and internalized constraints leading to a sense of being in a double-bind, unable to move freely in any direction (Frye, 1998). Disempowerment and disenfranchisement result from such gender-based social expectations regarding grief. Looking at the client examples that I began with, we can identify how each one felt marginalized, disempowered, placed into a double-bind, or silenced by the gender-based social expectations they feel (and have internalized) in relation to their experience of grief. Each of these individuals has experienced a form of dissonance (Martin & Doka, 2000) between how they experienced their grief and how they believed they were supposed to experience it. It was this sense of dissonance that led them to seek counseling.

I have often spoken and written about the need to analyze the “work” of thanatology critically, and in this instance, using the lens of feminist theory, to expose the ways that death, dying, and grief are marginalized in the current patriarchal Western society. Feminist thinkers have suggested that the Western denial of death and the devaluing of death-related experiences occurs because death is associated with the body, which is viewed as a feminine realm (Rumsey, 1999). However, it is my thinking that when we are personally exposed to death, the soft underbelly of our attachment system is exposed in a unique way, making us highly vulnerable. The resulting inability to conform to rigid gender-based social standards, sets us apart and opens us to criticism, ostracism, and stigma at a time when we most need the healing presence of our community. I think we would all agree that human beings are far more complex than dichotomous male-female descriptors would suggest, and yet these descriptors still form the “script” from which we are to act when we face death and loss.

Much has been written about differences between men and women’s grieving patterns in specific situations (see McGoldrick, 2004, for a good review). Martin and Doka (2000) put forth the non-genderized terms of instrumental and intuitive grief to try to allow for diversity in the expression and experience of grief. A key point seems to be that if one’s experience of grief is restricted because of concern about disenfranchisement, there is the potential for harm and additional pain to someone who is already in a compromised position.

It is my belief that in experiences related to death and bereavement, both men and women can be oppressed by social expectations. Despite changes over the past 20 years, popular culture and social policies still perpetuate stereotypes for both sexes, but with an added twist. While men are still expected to project the image of the rugged individual, they are now also expected to access their emotions on cue for the women in their lives (Real, 2002). Women are still expected to remain in touch with their emotions, but are now also expected to maintain full functionality as both family caregiver and productive worker (McGoldrick, 2004).

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“Kiss the casket,” my mom instructed, “that way you won’t have ‘susto’.™ I was sixteen years old looking at my Grandpa’s body as he lay in his casket. I stared at his chest, and I swear, I could see it rise and fall. “He’s alive,” I thought, “Can’t they all see he’s alive?” I didn’t know why I needed to kiss the casket, but I followed suit and did as the others did. There were hundreds of people present, and yet the church was silent. The silence was broken by the sound of nearing footsteps. I watched a man walk down the center aisle carrying a black case. He knelt beside my grandfather’s side as he took out his accordion. He spoke not a word, and yet all in attendance knew the message of his heart as he played a familiar tune... “Te Vas, Angel Mio.” My mother once told me that the accordion can cry. That day I heard it for myself.

Te vas angel mio (You’re leaving, my angel)
Ya vas a partir (You’re ready to part)
Dejando mi alma herida (Leaving my wounded soul)
Y un corazon a sufrir (And my suffering heart)

While Latino tradition discourages the community sharing of family problems and public expression of feelings in a therapeutic setting (Falicov, 1998), such practices are celebrated when expressed through poetry, story-telling, and song. Thoughts and feelings that are found to be too difficult to articulate can be more easily conveyed and processed (implicitly or explicitly) through the arts.

Gabriel, 57, was lying in his hospital bed surrounded by people who loved him. His illness had been getting the best of him; he was weak and had little ability to speak. For days, our family stayed close providing support by bringing in food, and drinks, and a guitar. “Do you want music?” they asked. He nodded. We made a circle around his bed, and sang his favorite songs. Gabriel tapped his hands in time with the music, and nodded in acknowledgement. When we began to play “Un Dia a La Vez,” tears swarmed down his face.

Un dia a la vez, Dios mio (One day at a time, sweet Jesus)
Es lo que pido de ti (Is all I’m asking from you)
Dame la fuerza (Give me the strength)
Para seguir, amándolos (So I can continue loving you/your eyes)

“Un Dia a La Vez,” which translates to the English version of “One Day at a Time,” identifies the need for God’s help through the difficult times. Many Latinos use this song as a daily prayer and reminder that God is in control and that we need not worry.

An understanding of the Latino perspective toward death and dying may be obtained by reviewing music frequently played at Latino wakes or rituals (Fajardo, 2008). I recently conducted a survey asking Latino respondents to 1) identify songs they have heard at Latino funerals; 2) identify songs that have been helpful for their own grief process and 3) identify songs they would want played at their own funeral/memorial service. Of 50 surveys dispersed, 25 responded. Respondents were Latinos ages 18 through 65. All identified as Christians, with 22 identifying themselves specifically as Catholic. One popular response was “Las Golondrinas” (literally “the swallows”), a man’s confession to a bird that he feels lost and regrets that he cannot escape as she can. The song invokes feelings of sadness, confusion and loss. The most popular choices noted were “Te Vas, Angel mio,” “Un Dia a La Vez” and “Amor Eterno” (which received the most votes). Other songs named were “Old Mexican Canciones” (Alfredo Jimenez, Pedro Infante, Ramon Ayala) and Linda Ronstadt’s “Canciones de Mi Padre”.

“Dad, if you had to choose a song that you would want played at your funeral, what would it be?” I didn’t think he would actually answer, as these are not the kinds of conversation to which we are accustomed. My father, a 67-year-old Mexican-American cowboy seemed less than excited about my query. “I don’t know, I haven’t thought about that,” he answered. So I pushed a little further. “C’mon Dad, take a moment and think about it.” “What for?” he asked. “Well,” I said, “It’s for science...and you would be helping me with an experiment I’m conducting.” (I knew that would work!) After a moment of silence, my father responded gruffly, “Amor Eterno.” “Wow, who would have guessed?” I thought to myself. Those two words gave me such insight into my father’s belief in love and in the afterlife. He had never spoken of this to me before.

Amor eterno, (My Eternal Love)
E inolvidable (You are unforgettable)
Tarde o temprano estaré contigo (Sooner or later I will be with you)
Para seguir, amándolos (So I can continue loving you/your eyes)

“Amor Eterno” (“Eternal Love”) was written by artist Juan Gabriel and sung by Rocio Durcal in response to the death of her son who died by drowning. A man sings to his deceased loved one, professing his eternal love beyond the grave.

It should be noted that direct questioning from a practitioner about grief and loss may not be the most effective approach to bereaved Latino clients. Instead, asking them to journal and reflect about songs that have special meaning may offer a less threatening medium for fostering difficult but crucial conversations. This intervention assists clients in identifying their beliefs regarding life and death, identifying their feelings, and processing grief whether individually or in groups.

Latino social workers, therapists, psychologists, and other mental health professionals recently participated in a workshop on “Death, Dying and Bereavement,” at the Latino Behavioral Artst...
Diversity Issues in Thanatology

Gender Stereotyping and Oppression in Grief

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Thanatologists need to continue to develop awareness of the social norms that oppress the true expression of the grief experience that is congruent for any individual. The key for change starts with developing awareness of how gender stereotyping permeates our lives and perpetuates oppressive barriers, and then making conscious choices which embrace the complexity of the human experience from a multi-faceted and open-ended approach.

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Darcy Harris, PhD, FT, has been active in death education for the past 15 years. She is currently the thanatology coordinator at King’s University College. She maintains a private counseling practice with a specialization in the areas of loss and bereavement and writes and lectures on issues related to loss, change, transition, and the concerns of professional caregivers. Email: Darcy.Harris@uwo.ca.

I’m sure the examples I give are not novel. Furthermore, I recognize that for every individual, gender roles and social expectations exist within that person’s cultural framework, race, and class. My practice consists mostly of white middle- and upper-class professionals, which, I realize, may skew my clinical experience and interpretation of gender stereotyping.

Accordions Can Cry: Music as Healing for Latino Bereavement

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Health Institute Conference (Fajardo, 2008). Since that workshop, several practitioners have reported that they have introduced this intervention to their practice and have found it to be effective for individual, group, and family grief facilitation for Latino families. Music’s unique capacity to capture and convey images and themes from Latino culture provides a powerful alternative route to conventional approaches to helping the Latino bereaved.

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’Susto: a folk illness generally caused by fear

Upcoming Issues of The Forum

July 2009 — Conference Issue
October 2009 — Resilience, Coping and Meaning
January 2010 — Care of the Dying
American Indian Populations: Why Bother?

by Andrea C. Walker, PhD

Throughout my studies, my thoughts have considered the question, “Why bother?” Why study a group that represents only 1.5% of the U. S. population (Ogunwole, 2006) and has in the past seemed so wary of the education, research, healthcare, religion, and counseling offered by mainstream society? The hesitation may be partly a consequence of mainstream society’s lack of cultural awareness. As one 39-year-old Creek man explained of a research project:

Many Creek Indians might be cautious about participating in the study because the researcher is White and because the research is being written down…They don’t want to be made into a “science project” and be observed by others who don’t truly understand the spirit from which they developed (Walker & Balk, 2007, p. 650).

A major ethical principle for those in “helping” professions is beneficence. Professionals must recognize the value and wisdom that native tribal members have to offer others and amplify their voices in research and practice. In so doing, professionals “bother” about understanding American Indian populations because: (a) to do so presents a tremendous opportunity to help heal historical wounds, (b) American Indian core philosophy is valuable, especially in terms of dealing with life, death, and transition, and (c) the current tentative relationship between American Indians and other cultural groups in the U. S. harnessed potential for meaningful interchange from which all can benefit. I will address these reasons using Muscogee Creeks as an example.

The 2000 Census recorded 4.3 million American Indians and Alaskan Natives in the United States (Ogunwole, 2006), a sharp contrast with the 12 million estimated to be here in 1492. Numerous broken treaties and forced removal from familiar lands have led to many deaths. Many Creek children in particular were forced to attend boarding schools where they were taught Christianity and English, as well as to shun all things Creek. These events perpetuated a distrustful relationship between Creeks and mainstream culture. A 50-year-old Creek man commented: “The idea here was to break the spirit of the Muskogee Creek, do away with his religion, do away with his culture, do away with his traditions, and do away with his language, until he has nothing left” (Walker, 2009, p. 1). The past must be attended to, considered, and appreciated in order to understand the context in which the American Indian experience is nested and to facilitate healing.

Assimilation and intermarrying has gradually blurred cultural distinctions, though Creeks have been found to continue to hold some core values (Walker, 2008; Walker & Balk, 2007). Originally, Creek cultural underpinnings were quite dissimilar to Western values. Creek healthcare, for instance, was based on Indian Medicine, natural herbal techniques intended to restore balance and harmony within the body. Balance was also important in the Creek focus on the number four (the four phases of the moon, four primary colors, four seasons, four natural elements, etc.). These examples also describe an ongoing, cyclical trajectory of the earth in its natural form, having certain religious and spiritual implications for life, death and transition. Creek values were not only embedded in physical and spiritual health but also social health in terms of community (Chaudhuri & Chaudhuri, 2001). In every major tribal decision, all parties involved were expected to voice their opinion, but consensus stamped the final decision. It is as easy to see the relevance of such values to grief and bereavement experiences as it is to see their fundamental differences with certain common Western views, such as linearity of life and death. Certainly American Indians are no strangers to loss, and yet many, such as the Creeks, have managed to adapt and survive.

Some Creeks have learned how to interact successfully within mainstream society while adhering closely to traditional ceremonial rituals and beliefs. The majority of the tribe have found ways to successfully reconcile the differences among cultures, negotiating between extremes when necessary, and arriving at a coherent view of the world. It is this ability to adapt and change with transition that has characterized a cultural survival and resurgence of the Creeks.

All cultures are empowered, and all are necessary for learning to occur. “Help” should thus be redefined as an interchange, as bidirectional sharing of individual and cultural ideas and perspectives, not as something one imparts upon another. Researchers, educators, counselors, clergy, and healthcare workers, all “helping professions,” will enhance their success, ethical fortitude, and professionalism by learning from past mistakes, understanding and appreciating American Indian populations as experts in the field of grief and bereavement, and seizing opportunities for meaningful interchange. I challenge professionals in mainstream society to engage in the same kind of openness and reciprocity of ideas that the Creeks and other American Indians have demonstrated.

References


About the Author:

Andrea C. Walker is an associate professor of psychology at Oral Roberts University in Oklahoma and a licensed alcohol and drug counselor. Her research interests include death and dying, addictions, and multicultural issues, and she has authored several manuscripts on Muscogee Creek grief, bereavement, and spirituality. E-mail: awalker@oru.edu.
“Sharon, do you know who we are?”: Cultural Awareness in End-of-Life Nursing

by Sharon Kelly West, RN

I first met Angi, a 27-year-old African American patient diagnosed with an aggressive form of breast cancer, when I worked as an oncology nurse case manager at a local hospital. Angi’s husband, Jimmy, was not hesitant about making sure staff was aware of her preferences such as “she does not eat breakfast before 10:00 a.m.” He requested a cot to sleep in the room daily and when present at mealtimes, expected his own meal tray.

It didn’t take long for the nursing staff to size him up as intimidating, demanding, and manipulative. He dressed in “hip hop” attire and occasionally displayed seemingly “glazed” eyes. Jimmy would arrive at the hospital late at night and would sleep on the cot until 1030 or 11 a.m. His threats to the staff to not awaken “her” before 10 became a source of contention causing delays to critical treatments (hanging chemo, taking vital signs, etc.). We soon realized that time we spent placating Jimmy was taking away from our primary responsibility, Angi. Staff viewed me as the “go to” person concerning Angi and Jimmy. I needed to remind staff that “just because I am African American and they are African American does not make them trust me any more than they trust a non-African American. I must build trust as well.”

Angi shared with me the strained relationship she had with her parents because of Jimmy. She admired me for being a nurse, an ambition she had held until she met Jimmy, fell in love, and eventually dropped out of nursing school. “I had one more year to go, Sharon, and I lost sight.” Jimmy asked me: “Sharon, do you know who we are? Why are you taking so much time with us? Before she was diagnosed with cancer, we did some things that were not good. I was accused of a crime and she was taken to jail as an accessory. Sharon, I found my mother stabbed to death by my stepfather when I was 10 years old and now I am watching my wife die.” Jimmy viewed his “demanding” personality as protecting his wife in the only way he knew how. He was demanding respect yet interpreting the perceived lack of prompt responses by staff as intentional and racially motivated. As Washington (2006) notes, African American wariness of the healthcare system is neither unusual nor without basis. The Institute of Medicine recently reported:

Racial and ethnic disparities in healthcare are known to reflect access to care and other issues that arise from differing socioeconomic conditions. There is, however, increasing evidence that even after such differences are accounted for, race and ethnicity remain significant predictors of the quality of healthcare received. (Smedley & Stith, 2002).

It is important for healthcare professionals to be aware of such historical and current inequities for African Americans as they work to understand the attitudes and suspicions of their patients and families.

Staff felt it appropriate to use staff meetings with the chaplaincy service and the palliative care team to ventilate feelings about working with Angi and Jimmy. I began to share bits and pieces of information as appropriate so that we as a team could begin to break down the barriers caused by a seemingly passive patient and a seemingly aggressive spouse. We eventually uncovered a history of physical abuse prior to hospitalization. It was, of course, our preference that Angi not return to her home environment, but go to live with her parents. She was quite willing. Jimmy, however, was adamant that she return home with him.

After twenty-eight days, Angi was discharged with Home Health. She refused hospice despite our efforts to explain why hospice would be appropriate. Jimmy convinced her that accepting hospice meant “giving up.” A few days later, Home Health staff found Angi at home lying on the floor in urine and feces, “left alone — again.” Due to unbearable pain and multiple falls, Angi was readmitted for a week. Jimmy again began making demands.

Three months later, Angi presented to the emergency room due to extreme shortness of breath and non-responsiveness and died 24 hours later. Jimmy visited our floor to thank each of us for our care of Angi during her many hospitalizations. We all felt sad, helpless, and overwhelmed with internal questions; “Did we provide the support Angi needed? Did we miss something? Could we forgive Jimmy? Could Jimmy forgive himself?”

As I have written elsewhere (West, 2004), I have learned the principles of basic life support in caring for patients and their families and continue to find these principles essential in promoting culturally appropriate patient care:

Look: Ask yourself: Am I stereotyping based on what I have heard? Seen? What do I know for sure about this person? Listen: Be cautious of any pre-conceived ideas or assumptions that would limit hearing what the patient is saying. Avoid assumptions. Ask questions. Feel: Develop a relationship first; focus on the task second. Be genuine and empathetic.

Somewhere in my depths, I firmly believe that the barriers began to fall and a bridge began to be constructed on a morning a while back as I spoke with Jimmy and Angi. When Jimmy asked: “Sharon, do you know who we are?” I said, “Tell me.” They talked and I listened.

Continued research is needed on perceptions of ethnic and racial minority distrust of the healthcare system. We need more community focused listening sessions, and discussions with health staff to identify and implement culturally appropriate approaches to medical treatment. Jenko and Moffitt (2006) is an excellent place to start. Jimmy and Angi are real and so are the challenges that the healthcare system poses for them — and that they pose for the healthcare system — as we all collectively try to provide the best possible end-of-life care for everyone.

References:


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Cultural Competence: Teaching Strategies

by Lynne Ann DeSpelder, MA, FT

Over the years, I have used several techniques to help students understand how to listen and respond in discussions that could bring discomfort and even disbelief. Teaching, researching, and writing with my ADEC colleague, Ronald K. Barrett, PhD, has also provided opportunities to expand my understanding of cultural, socio-economic, religious, national, and other differences.

Ron and I have used various terms to identify the skills we want our students to develop: Cultural Sensitivity, Cultural Accommodation, Cultural Diversity, and most recently, Cultural Competence. The techniques that you will read about here are designed to give students the know-how for relating to differences. So how does that work in the classroom?

It’s the first day of your death and dying class. Depending on where you teach, you may be facing a group of students representing various cultures and socio-economic backgrounds. Or your classroom might be homogeneous with little apparent variety. If you are fortunate enough to have diversity within your student population, you will be able to draw upon their experiences. If not, you will need to have your homogeneous population understand that even if they appear to come from similar backgrounds, there are differences in attitudes and beliefs.

Discussions about material that might be uncomfortable are best facilitated when students feel that they can choose to participate or not without judgment from others. I explain that I will feel free to call on anyone at anytime for his or her experience or opinion. If the student does not wish to respond, he or she need only say, “I pass.” (This also works the other way, in that students may ask me or others anything at anytime and we have the option of “passing” as well.) I explain that “pass” takes away having to “hallucinate” whether it would be a good or bad thing to bring someone into a discussion. Students are free to discover their own boundaries and respect those of others in large and small group activities. After explaining this “rule” I also ask students to respect the privacy of others in the class by keeping disclosures confidential, thus encouraging them to learn from others in the room. I tell my death and dying students, “What happens in class stays in class.”

Building on the issues of whether something is good or bad, right or wrong, okay or not, I give a short demonstration about the distinction between judgment and curiosity. I ask students to remember a time (even if they have to go back to childhood) when they were really curious about something or someone -- curious in the sense of being interested, inquisitive, and inquiring. While they are remembering, I ask where in their body the “curious” feeling resides. Answers vary: “my gut,” “my head,” “my shoulders,” “my neck,” etc. Anchoring the fact that curiosity elicits a response such as, “That’s interesting, tell me more,” is the next step. When I am sure they grasp their internal state when curious, I have them compare that to sitting in judgment or disbelief. It quickly becomes apparent that coming to a firm conclusion about something or someone is vastly different from being curious about a person’s experience.

If this is your first class, you can make the point that “there is no way to know the similarities, and differences of the person sitting next to you without curiosity and understanding” by relating this experience of mine from a long-ago class. A student spectacularly interrupted me as I was asking students to collect jokes about death. A large young man, he stood and shouted, “There’s nothing funny about death” as he threaded his way to the door. I found him outside on the balcony sobbing. As he talked, I discovered that his father had recently disclosed to his family that he was gay and dying of AIDS. I agreed that there was nothing funny about death right now and that he was excused from the assignment.

I asked if he was willing to discuss his reaction with the class. He said that he was only comfortable saying that something personal had triggered his reaction and he would “pass” on the content. Eventually he chose to share his experience with the class. In later years, I would find jokes and cartoons slipped into my mailbox with notes about his well-being. During the course, discussions are often based on intimate experiences, and students can be reluctant to divulge personal information to a class of “strangers.” This hesitancy may come from a lack of awareness about the loss and death experiences of classmates. Students are often surprised and comforted to discover essential similarities in their attitudes and behaviors toward death and dying.

The sooner they become comfortable with each other, the easier it is to initiate meaningful class discussions. Learning that it is acceptable and routine to “pass,” understanding that privacy will be respected, and knowing that one’s experiences will be responded to with curiosity is a beginning. Another way to bring out similarities and differences is to have students anonymously fill out a three-by-five card with the following information:

- Side 1: What brings you here?
- Side 2: What would you like to take away from this course when it is over?

This strategy provides an opportunity to determine the composition of the class in terms of experience, curiosity, personal or professional needs, and so on. You can open the next class meeting by reading the cards aloud to build rapport. It is not unusual for a student to disclose additional information after the cards are read.

All three of these techniques enable students to discuss or listen to topics that might raise discomfort and even skepticism. Think for a moment about issues like cultural and socioeconomic inequities in health care or in aftercare. If skepticism arises, all I have to do is use the phrase “curiosity please” and the interaction changes.

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Clinical Chaplains: The Well of Hope Never Runs Dry

by Darryl I. Owens, MDiv, BCC, CT

As a chaplain, I sometimes face situations that drain my well of hope. One particular day, I was paged to a mom delivering her stillborn baby whose father’s funeral was the following day. Then the next morning, another set of doctors paged me to visit Ann, an oncology patient whose family had come to inform her of her sister’s death. Okay God, this is hard!

Ann and her sister were close, and both dealt with a chronic disease. How would Ann grieve her sister’s death and remain hopeful about her own health situation? Holder and Aldredge-Clanton (2004) note that death often presents nothing short of a spiritual crisis, both for the one who is dying and for the companion (p. 4). How, I wonder, would Ann participate in the crises of her sister’s death and the real possibility of her own death?

Ann’s family answered all of her questions with compassion and sensitivity. Aware of our pastoral relationship, the family asked me to spend some one-on-one time with Ann to help her process her grief. Over the next few days, we did a great deal of processing. Ann and her family also talked nightly. Still many times, families are protected from the patient’s anticipatory grief. The patients know the family will try to stop this expression because it is too painful to hear. In our conversation, I tried to open space for Ann to voice whatever feelings she wanted to express without judgment on my part.

The conversation transitioned smoothly to her recent cancer-related losses, but Ann wouldn’t stay there too long. It was painful experiencing and discussing these different types of loss. Nonetheless, I noticed throughout our conversations that Ann remained very hopeful about her cancer. This presented a real challenge for me because her physicians had recently told me that Ann’s cancer was growing again and there was nothing more they could do. They wanted to discuss hospice. My challenge was not to falsely lead her on in her hope-filled conversations, since I knew that I would be present when the doctors had “the conversation” with her.

What happens when the patient is looking to the chaplain for hope, and the chaplain struggles to be where the patient is presently? Andrew Lester (1995), observes: “Hope is rooted in reality... it provides the courage to face whatever chaos and trauma life throws at us” (p. 85). I had to keep this in mind as I tried to authentically point Ann to her reservoirs of hope, while knowing the end-of-life conversations the doctors were planning. I knew that my role as a clinical chaplain was not to dictate where I thought Ann should be in her grief or hope. My job includes many tasks like spiritual assessment: using appropriate pastoral interventions, rites, and rituals, empathic listening and offering the staff perspectives on Ann spiritually and emotionally. None of this was happening as I planned. She didn’t want to talk about these issues. Consequently, my well seemed to be emptying of hope for Ann.

As I faced my own anxiety, and realistically saw what was happening to Ann, I looked for my own reservoirs of hope for Ann. This is never a quick or easy process. I realized that things had changed. For a long time, Ann and I had discussed whatever was going on and now we couldn’t. As I processed this change in the pastoral care, I realized that this could be a, “holy place,” for her. While I may have seen processing the coming conversation as a “holy place,” I was instead invited to adjust to Ann’s perspective. Did this mean that I was not a “good” chaplain to Ann? No. It meant that I am not the expert, the patient is. I have to always remind myself to be a student of life from professors like Ann. Eventually, the doctors, Ann, and I did have “the conversation.” It went better than Ann imagined but we were never able to talk again as we had prior to the conversation. Ann had to process all of this grief in her own way.

As professionals/clinicians in thanatology, we want to do our best for those we serve. We have in mind what that “best” looks like or should look like to others and to us. Many times, when those we serve are going through the crisis of their own death or that of others, our ideal for their well-being doesn’t match their ideal for themselves. It can be at those moments that we feel our wells running dry of hope for a good death. We know there are parameters for what we all think of good deaths, but the definition of a good death can be as diverse as the people we serve. When I find myself caring for the Ann’s of this world or the parents experiencing a perinatal death and additional simultaneous deaths, I may struggle to see what is “best” for them. It is at those times, when I am being stretched in my perspective to see effective clinical chaplaincy through the eyes of those I am privileged to serve. The well of knowledge and hope never has to run dry.

References


About the Author

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International Death, Grief, and Bereavement Conference: Cross Cultural University of Wisconsin-La Crosse
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Spoken Words From the Silent Auction

by Kaori Wada, Co-chair of the Student Initiative Committee

In the last issue, the Student Initiative Committee traced the history of the Student Silent Auction—how Carla Sofka’s initiative as a graduate student led to the establishment of the auction and student scholarship fund. Continuing on the theme of the silent auction, this article explores how the auctions have served the organization and non-student members.

The silent auction usually takes place in an exhibit hall, where conference attendees gather for refreshments during breaks. With a cup of coffee and brownies in hand, unique auction items are easy conversation starters. This is what Erin Troup, the former Silent Auction Chair, enjoyed most about her role: “people meet and get to know each other, not only in the area of death and dying but also in reference to what is on the bidding table.”

Barbara Sheard, a member since 1994, has been one of the most generous supporters of the auctions. When asked about what keeps her coming back to the auctions year after year, she replied with her usual humor: “because I am a bargain hunter!” However, her real motivation lies in something more profound and personal—she knows the financial struggles of students. In her mid-thirties, Barbara was not only a graduate student but also a single parent of four children. Even if she had known about ADEC back then, she would not have been able to afford to attend the conferences. Donating and bidding at the auctions is her way of giving back to the organization and non-student members.

ADEC members have stories from silent auctions that they fondly remember and laugh about even years later. At her first silent auction, Erin remembers that there were handbags from Mexico with skeletons on them. “I thought ‘how interesting, but will people bid on these?” When people really started bidding them up I quickly realized how ‘into the cause’ of death and dying everyone was.”

Barbara also has an interesting story from the 1996 Pittsburgh conference. Someone had solicited a donation of a model trolley, autographed by Fred Rogers, from the children’s TV show “Mister Rogers’ Neighborhood.” Barbara was determined to get the trolley because she was a fan of Mister Rogers. Over the course of the bidding period, Barbara noticed that she and someone else had been bidding over each other. When Barbara went over to the auction table, she overheard a woman say, “someone overbid me again!” When she disclosed to the woman that she was the rival bidder, the lady said to Barbara, “I have a 2-year-old grandson,” implicitly asking Barbara to quit bidding. Still determined to win, Barbara replied, “I have a 2-year-old grandson, too, and he’s deaf, but he is not getting this. It’s going to live on my desk!”

Later that day, Barbara planned to attend a workshop by well-known thanatologist Judith Stillion. Barbara had never met her, or so she thought. However, when Barbara got to the workshop, she immediately realized that the presenter was the lady she had been competing with over the trolley!

So guess who won the trolley in the end? Earlier in the day, Barbara had attended another workshop given by Hedda Sharapan, a colleague of Mister Rogers. Having learned from Barbara about the competition over the trolley, Ms. Sharapan managed to get 4 more autographed trolleys. In the end, Barbara, Judith Stillion and a few lucky others, all happily brought home a Mister Rogers’ autographed trolley. To this day Barbara’s remains on Barbara’s desk!

Obituary: Florence Schorske Wald, RN, MSN, FAAN

by Stephen R. Connor, PhD

Florence Schorske Wald, RN MSN, FAAN died peacefully at her home in Connecticut on Saturday, November 8th, 2008 at the age of 91. Florence is credited with bringing hospice care to the United States. She was the dean of nursing at Yale University (1959-1968) when in 1965 she invited Dr. Cicely Saunders to serve as a visiting faculty member. Saunders’ lectures there inspired a close friendship and admiration that led Florence to spend a year in 1968 at St. Christopher’s Hospice in the UK to learn as much as possible about caring for the dying.

Florence believed that hospice care should come to the U.S. and along with a determined group of people she established the first U.S. hospice, the Connecticut Hospice, in New Haven in 1974. Mrs. Wald was married to Henry Wald who preceded her in death and she was active in the International Work Group on Death, Dying, and Bereavement (IWG) until her death. She was very active until a recent fall and I can recall only a few years ago swimming with her in the Bergen Fjord at an IWG conference.

Florence Wald was a true American pioneer and her contributions continue to improve the lives of hundreds of thousands of patients and families each year through the US hospice community. She was committed to bringing hospice care to everyone who needed it and to ensuring that people could die with dignity and compassion and that families received the support they needed. Those who knew and admired her will miss her spirit and voice.
Everything is “Up to Date” in Kansas City!

by Harold Ivan Smith, Co-Chair, ADEC 2010

“Kansas City? Why would ADEC go to Kansas City?” If I had a dollar for every time I’ve heard, “I drove through Kansas City once. Didn’t stop!” I’d be a rich man. In the words of the musical Oklahoma, “Everything’s up to date in Kansas City!” ADEC in 2010 will gather in the bull’s eye of Kansas City’s stunning renaissance. As conference co-chair and Kansas City resident for three decades, I invite you to come early, or stay after to sample our world famous barbecue and strip steak, see where “When you care enough to send the best” greeting cards are created, peer into the west where Lewis and Clark camped out or walk through the historic renovated Union Station where the troop trains stopped and where the FBI “got their man” (Pretty Boy Floyd). Kansas City is perfect for the thanatologically-inclined. Visit the nation’s most elegant World War I monument or the Union cemetery or the Arabia Queen, a steamboat long submerged in the Missouri River.

From the new football-shaped glass Sprint Center to the spiraling new opera house, there is a lot to explore.

- Crown Center - The Hyatt, part of Hallmark’s Crown Center, has places to grab a latte or perhaps a keepsake at Halls Department Store or Hallmark’s trendsetting card shop. Rent ice skates and glide away. (No CEUs for ice-skating!)
- The Negro Leagues Baseball Museum - Explore the rich heritage of African-American baseball.
- The Power and Light District - Incredible places to dine, sip local brews, and enjoy great music and art.
- The Plaza – America’s first shopping center has restaurants, shops, movie theatres, and bookstores – even carriage rides.
- The Harry S Truman Presidential Library and Museum in Independence - KC was Harry’s town and we have lots of Truman stories to tell.
- Underground Library - If you get warm, descend into Park University’s library (it’s in a cave!) It’s so cool!
- Art - One percent of the costs of all KC building projects is spent on art. You will immediately notice the four pylons in the sky over the Convention Center. Wander (and wonder) through the marvelous Nelson Art Museum and see the new stunning glass buildings. (It’s free!).

There is something infectious about Kansas City. I moved here in 1979 to stay two years, never thinking it would become home. The City of Fountains welcomes you proudly. We hope you’ll go away from our fair city humming, “Everything’s up to date” and that you will want to come back and stay a while.

NEW FROM DR. ALAN WOLFELT

The Handbook for Companioning the Mourner

Eleven Essential Principles

This inspiring handbook explores Dr. Wolfelt’s “companioning” model of grief care and contrasts it with the traditional “treatment” model. Concise and engaging, this is a primer designed to spread the companioning philosophy among everyone who walks alongside mourners—counselors, hospice caregivers, funeral home staff, friends and family members.

Caregivers are talking about the companioning model of grief care:

“Dr. Wolfelt’s companioning philosophy resonates with my spirit and makes my heart sing.”

“Finally, a model of caregiving that is inherently compassionate and heart-based, not head-based.”

“We need to advocate for this model of care throughout the world. I’m going to get these loving tenets into the hands of as many people as I possibly can.”

ISBN 978-1-879651-61-6 • 128 pages • hardcover • $15.95

To order this visit your local bookstore or call the Center for Loss & Life Transition at 970-226-6050
What’s New from ADEC Members


Building on his previous contributions on living with a life-threatening illness, Doka has provided a substantial handbook for clinicians and other caregivers who counsel individuals and their families coping with life-threatening illness. The 12 chapters explore the complexity in each of the five phases Doka has identified as common in the trajectory of life-threatening illness: prediagnostic, acute, chronic, recovery/remission and terminal phases. He provides an historic overview of the literature, many vivid case examples, a commitment to holistic care and a broad definition of what comprises a “family” system as it responds to the multi-dimensioned crisis of life-threatening illness. This book will likely become a standard text for those seeking to gain insight and skill in care of clients experiencing serious illness.


Maria Dancing Heart brings to the difficult work of ministering to the dying a joyful hopefulness that her very name suggests. A strong advocate of hospice, her resource book blends an eclectic mix of stories, poetry, scripture, prayers and guided meditations for those personally or professionally dealing with dying, death and bereavement. Its 11 chapters draw from the author's experience both as a parish-based minister and as a hospice bereavement counselor, as well as her broad appreciation of diverse spiritual traditions. This book offers new perspectives and practical guidance to help change the fact of death from a perceived tragedy to a process of deep spiritual transformation.


Gloria Horsley is an ADEC member who along with her daughter invited former National Football League Quarterback Eric Hippie to write about his experience with depression, which intensified following the tragedy of his 15-year-old son's suicide in April 2000. His story of finally overcoming his grief, loss and clinical depression is very engaging and will be especially interesting for those who are familiar with famous sports figures. The book will also educate men and boys that personal problems can be addressed and that psychopharmacological help can be effective.


Death is not new. But as Werth, his co-editor and the other 27 contributors demonstrate in this remarkable book, demographics, economics and technological medical advances have dramatically changed the process of dying in the United States. The 19 chapters of this book, ordered in four sections (I: Personal Stories; II: Overview of Major Issues; III: Aspects of End-of-Life Choices and Decision Making; IV: Psychosocial Considerations) provide helpful, thoughtful and even touching first-person accounts of the complex decision making that now so commonly surrounds the experience of dying. This book will advance the conversation and profession of counseling those in end-of-life care contexts.


Wolfelt has applied his professional insight into the processes of loss and grief that accompany the experience of divorce. Using his personal divorce experience and the understanding gained from walking the journey with many others, he offers 10 “touchstones” that present physical, emotional, cognitive, social and spiritual guidance to those sorting through a divorce. The companion Journal provides encouragement and ample space to document the always uniquely personal dynamics of a divorce. These books will provide welcome support to the high number of men and women who go through divorce each year.


Worden first published this book 25 years ago. It has been revised and expanded for this fourth edition, updating it to embrace new developments in the grief field. It continues to set the standard for those seeking to understand the mourning process and become capable of assisting others. The 10 chapters provide a comprehensive, layered and practical introduction to foundational concepts and offer the new or experienced counselor valuable insights, clear conceptualizations and practical skills for realistic helping in the grieving process. The final chapter offers 18 clinical vignettes developed by Dr. Worden to deepen the training of counselors through role-play. This book is a wonderful resource that will continue to enrich the bereavement field.

“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 an actual copy (not just an announcement) of recent materials (2006 to present) to:

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