

Death, Dying, Grieving, and End of Life Care: Understanding Personal Meanings of Aboriginal Friends

Angelina Baydala
Department of Psychology
University of Regina

Mary Hampton
Luther College
University of Regina

Lionel Kinunwa
Lakota Nation

Germaine Kinunwa
Lakota Nation

Leon Kinunwa Sr.
Lakota Nation

In health care settings, personal meanings of death, dying, grieving, and care at end of life tend to be eclipsed by technical and rational biomedical frameworks of understanding. We propose that by narrating personal meanings, multivocal significance can be restored within worlds of care. In this article, we illustrate a relationship-based approach to the construction of meaning. We convey messages of personal meaning as they emerge in the relationship of the researchers with traditionally minded Aboriginal friends asked to consider personal meanings of death, dying, grief, and end-of-life care. Recognizing that there are many different Aboriginal cultures unique to different Aboriginal peoples, the messages conveyed here are grounded in a unique personal perspective that is part of a diverse circle of cultural relations.

The present medical culture of dying is affected by the values of Western society, science, trade, and industry. Persons experiencing death, dying, grieving, and end-of-life care in hospital are subject to standardized medical practices that subordinate the importance of personal and cultural meanings. Benoliel and Degner (1995) observe that, "Under the influence of industrialization, dying has changed from a tribal or familial ritual to an organizational procedure governed by bureaucratic rules and dominated by the influence of health care providers" (p. 134). Control over the act of dying has shifted from the family to the experts to the physician and hospital team, who follow a model of work historically influenced by assembly-line production that fragments tasks and creates a bureaucratized and depersonalized experience. The biomedical model treats the diseased body as a broken machine, and hospitals become industries to control death and fix the body. This is not because health care professionals lack basic humanity, but the medical model prioritizes cure over care and leaves little room in health care settings of curricula for attention to personal meanings of death, dying, and grieving (Wass, 2004).

In accord with the new wave of grief theory focusing on personal, cultural, and community practices dealing with loss (R. A. Neimeyer, 2001), we focus here on personally negotiated meanings of death, dying, grief, and end-of-life care. Our research shifts the locus of meaning from objective decontextualized knowledge to an ethically constituted set of social engagements. We assume that personal meaning is constructed and reconstructed within social, familial, and cultural circles of influence. Thus, fundamentally, the process of making sense of experience is not private and cognitive but a social practice.

Narrative hermeneutic research is often long on theory and short on example (Baydala, 2003). The research presented in this article is short on theory and long on example in an effort to bridge conventional and Aboriginal approaches to social science (Colorado, 1988). We are emphasizing inner psychological worlds of meaning instead of either theoretical abstractions or impersonal determinate realities. We provide a counterpoint to the hegemony of Western objectivity, knowledge divorced from the personal, reified as universal (Ermine, 1995). Our research process includes relations, feelings, and an awareness of history, observing a holistic process of gathering knowledge. We do not formulate meanings of death, dying, grief, or care detached from family, community, culture, or ceremony. The meanings represented here emerged in dialogue through trusting personal relationships grounded in a larger circle of ancestral traditions, family relations, and friendships. We use narrative research because it is suitable for documenting socially positioned meaning (Clandinin & Connelly, 2000; Emerson & Frosh, 2004; Hoshmand, 2005). This approach is respectful of Aboriginal epistemology, which makes space for a heterogeneity of voices and recognizes that one can only speak from personal experience and not on behalf of another (Smith, 1999).

In this article, we invite humanistic educators and health care providers to hear and reflect on meanings of dying, death, grief, and care in an effort to highlight

how meaning can impact the way one lives (Rowe, 1983). Fear of death can negatively affect the care that health care workers are psychologically able to provide (G. J. Neimeyer, Behnke, & Reiss, 1984; G. J. Neimeyer & Van Brunt, 1995). Facing fear of death and reflecting on personal meanings of death and dying may foster psychological growth, alleviate dysfunctional anxiety, and help one to live with greater integrity (Moraglia, 2004). Personal engagement with issues of death, loss, and grief is an important part of education for health care providers (Wass, 2004). If health care providers do not face these questions of meaning, then they risk succumbing to a flurry of activity that may be distracting and deeply extraneous to the meaning of one's life and the care of another (Becker, 1973).

We share here narratives for personal reflection from our friends—one woman, Mato Wi (Bear Woman), a Lakota Elder, and her son, Mato Maza (Iron Bear)—who have listened and tried to follow the ways of their Elders. There are ethical and hermeneutic issues that arise when attempting to understand personal meanings that emerge between cultures (Ermine, Sinclair, & Jeffery, 2004). Mary Hampton and I (Angelina Baydala) come to this research as nonaboriginal, Euro-North American educators and mental health care providers engaged in inquiry with Aboriginal Elders and families in First Nations communities. We research by entering into relationships with Mato Wi and Mato Maza as they relate their world to our own history of experience. By virtue of being in a committed relationship with Mato Wi and Mato Maza, recognizing them as friends, and Mary Hampton having been adopted by them as family, we find that misunderstandings and disagreements generate fruitful new insights through ongoing communication and the giving and receiving of meaning.

This work intends to demonstrate a respectful effort to understand personal and cultural meanings that come to bear when caring for people and their loved ones at end of life. As this work moves through moments in the storyline of the dying person toward the moment of death, meanings of health and harm are conveyed in the telling of personal stories. Being open to hearing these stories, even when they clash with one's own personal meanings, can broaden one's understanding in an ongoing process of emerging meaning (Ricoeur, 1981). However, one's understanding can do violence to the heterogeneity of meaning when generalized into an expectation.

This work is hermeneutic and does not intend to reliably predict meaning, but to deeply understand possibilities and thereby open existing meaning to a world of potential actions (Gadamer, 1998; Ricoeur, 1981). It is our view that by hearing and understanding the traditions of one family, end-of-life educators and health care providers may be in a better position to reclaim a more meaningful and personal dimension in a world of techno-rational modern health care. Yet, it is important to address the question of how this research is useful if it does not claim to be generalizable. What knowledge claims can be made when considering the opinions of one family? Taking generalizability as a criterion for knowledge, however,

can be thought of as a social construction (Mishler, 1990). Alternatively, knowledge might be considered valid, not because it is generalizable across persons and contexts, but because it is a trustworthy representation of an actual life situation. In this case, knowledge is valid insofar as it is constructed through personally responsible actions, communications, and relations. This position is in accord with the emerging literature on Aboriginal epistemology and ethical research involving indigenous peoples (Colorado, 1988; Ermine, 1995; Ermine, Sinclair, & Jeffery, 2004; Smith, 1999). Such research proceeds in a collaborative relationship-based manner and challenges the authority of the traditional scientific insistence on reliability, falsifiability, and objectivity. As narrative researchers, we do not claim abstract unitary findings, but, rather, we seek to provide trustworthy interpretations and to found sense-making in ethical personal relationships. As an approach to research, narrative inquiry gains validity insofar as we, the researchers, are personally—not just professionally—invested in understanding with Mato Maza and Mato Wi. We recognize the consequences that their stories have for their lives, for our relations with them, and for the possible relations of those who read their stories.

THE WAY OF THE PIPE

Mato Wi and Mato Maza honor the traditional ways by sharing knowledge about the metaphysics of death and dying. Our friends have received traditional Lakota (Sioux) knowledge about caring for the dying. We experience Mato Wi as living according to the teachings of the pipe and as holder of the sacred pipe. Historically, and to the present, the tobacco pipe is used in ceremony to teach a sacred way of life. Accounts of ceremonies associated with the sacred pipe form an important tradition for the Lakota. Descriptions of pipe ceremonies first appeared in the writing of Neihardt (1932) and later of Brown (1953):

This account of the sacred pipe and the rites of the Oglala Sioux was handed down orally to three men by the former Keeper of the Sacred Pipe, Elk Head (*Hehaka Pa*). Of these three, Black Elk was the only one still living at the time this history was written When Elk Head gave this account to Black Elk, he told him that it must be handed down—that their people will live for as long as the rites are known and the pipe is used, but as soon as the sacred pipe is forgotten, the people will be without a center and they will perish. (Brown, 1953, p. xvii)

Teachings of the pipe are handed down through generations and involve listening to the ways of the grandmothers and grandfathers, ceremonial prayer for the good of all nations, and efforts to live in a good way. When one faces the experience of death, either one's own or the death of those for whom one cares, the experience of

loss can be positively transformed by following the traditional ways. The way of the pipe provides space for making meaning and for restoring harmony, balance, and peace. This represents life on the sacred path.

We experience our friends as living such a life, honoring the way of the pipe, and respecting the traditional ceremonies. Mary Hampton was honored to be present with them and respectfully learn from them, at a time of great pain for her family. When her sister's husband died, she became part of the traditional ceremonies that honored his passing. She relates how these ceremonies supported her experience of metaphysical transformation as the soul of her nephew's father made the journey from human physical form to spiritual being. Through ceremonies, the grieving process was facilitated, and the family's pain was transformed into something more meaningful. Following traditional spiritual practices, Mary witnessed her family's conscious care for the spirit crossing over.

THE MESSAGE AND THE MEANING

Quick, foreseen, violent, peaceful, alone or together, at one's own hand or at the hand of another, shrouded in mystery or shouted from the roof tops, how can one make sense of death, dying, and grief experienced with the loss of a loved one? What do these understandings mean for how we care for each other? For our friends who answered, there is a formal process of asking—an exchange of gifts, a demonstration of respect—that raises awareness and values the sacredness of this knowledge. Anyone properly asked cannot be refused. Our younger friend, Mato Maza, explains,

If you, my friend, ask, I must answer. That's part of our duty, it is to share, teach, and speak with anyone because all these things belong to everybody. If anybody shows interest, wants to ask, and their intent and their questions are sincere, and we have a connection, then it doesn't matter the relationship or how long we've known each other. It's our duty to offer these things.

As researchers, we inquire by asking for understanding, not just for our own sake, but to foster respectful ways of understanding between health care providers and Aboriginal individuals, families, and communities. Given the kinds of misunderstandings that have happened between Euro-North Americans and Aboriginal peoples, this research is also sensitive to the limits of how much *can* be understood about what is being *said* about Aboriginal ways at end of life.

There are two ways our friends conveyed that misunderstandings happen: generalizations and embellishments. Before beginning to communicate the meaning

of death, dying, and grief, our younger Lakota friend speaks to the limited meaning of his statements. Mato Maza says,

I want to preface this by saying that any of my responses are mine alone. They're not reflective of the whole. So when somebody hears this, they shouldn't say he speaks for the whole. I speak from what I've learned, what I've encountered, what I've been taught, from my experience. I can't represent or be an authority in that position. People shouldn't hear this and go, "Oh, so this is how all Lakotas think or this is how men of that age think." This is just me talking, one guy. Anybody who hears this can take the words as only that. At the end they cannot attach a footnote saying that he represents such and such. That's got to be very clear. I trust you to convey that to anybody you share this with.

In speaking of the meanings of dying and death, he relates his own meanings and not the meanings of another. His statements are not to be generalized; he is not to be considered a representative or spokesperson for others. He asks that we who receive the message do not seek to understand by generalizing the meaning of his statements. For example, our understanding of our friends respecting the way of the pipe is our experience and not something that they claim for themselves. Mato Maza explains,

Being identified as a pipe keeper or carrier, with all due respect, that's something for someone else to claim, there are many guys out there who would be identified as such, but I am not one of them. Too many would put things attached where they don't belong if they read that. I would rather be identified as "Wichasha." Wichasha means man. That is what I am after all, just a simple man living in a simple manner, trying to be just a man as best as I can in each moment. I was and am blessed to be raised by two traditional people, both along the way teaching and showing me how to live a good way, to be a good person, no more, no less. For some who would read this paper and see me identified as a pipe carrier, just because of that label or title, some may put things into what I said that don't belong. I don't know anything more or anything less than anyone else, I know what I am supposed to know, that may or may not make any sense, but it is the best way I can explain it.

This request to respect the personal significance of his statements and not to conflate his meaning with anyone else's has implication for hermeneutics in general. When we receive the message of another, we may seek to understand by exploring our own experience and our own preconceptions in the light of what we hear. New meaning may then be generated. What our friends mean and my and your personal understandings are interpretations, and the difference must be respected.

Ricoeur (1981) explains the understanding of another as, in part, an act of appropriation. When we listen to another's message, we must recognize there is a

world from which that message comes. Ultimately, if I understand the message of another, then that understanding must be respected as my *own* understanding, an understanding of the other appropriated into my own world. Although we may meaningfully share a lived world, insofar as we each stand at the center of a world, we are each responsible for our own understanding. Our work as humanistic therapists, educators, and researchers involves respecting the message of another while seeking to find ways to responsibly participate in communication and the generation of shared meaning. We respect the integrity of a message by protecting space for messages to stand as text on their own. Each reader can then take responsibility for his or her own understanding and attempt at shared meaning. Mato Wi, our Elder Lakota friend, explains,

I think this issue of cultural appropriation is *really* important because if the message isn't put out there and if it isn't understood in a proper sort of way, it's like the university books. People write so much as a matter of interpretation instead of listening to *the* message and not adding on to it. Don't try to embellish the message because you want to make it better or more romantic sounding. When you look at Aboriginal people, if we don't stay to the *simple* form of the cycle of life, then our transition is also going to be complex and that's not allowed. We always have to respect the next part of the circle. We don't want them to have to spend time trying to clean us up as we transition over there. So just keep it simple. Some researchers are excellent, others are romantics, and others are just trying to get their paper completed. It would be unfair to label everybody in the same category. It's a matter of taking care, but researchers appropriate and exploit when they embellish.

As researchers, paraphrasing, text reduction, and interpretations are inevitable. Yet, we own these as our interpretations while also carrying these messages to caregivers to *hear*. Understanding can arise at the confluence of personal meanings forged in relationships, but no one can hear for another. To use Gadamer's (1998) metaphor, each stands within his or her own horizon of meaning.

The Message and the Meaning of Dying

Dying. So what messages did our friends convey about the meaning of death and dying? Regarding death, Mato Maza said,

My answer is simple. It's that each individual has a journey and whatever their relationship is to that process, that is what death is to them. For me personally, death is part of a whole process. It's a circle. You're born, you reach certain markers in your life, and death is a period at the end of a sentence. But one sentence doesn't make a whole paragraph or a whole article. It's just one sentence. Amongst it there are commas, semicolons, all those different grammatical markers, but death is just the period

saying, “We have finished this. I have finished this, and now it’s time to start a new sentence.”

When asked the meaning of dying, he replied,

In its simplest form, it’s the process of being born in reverse. You’re conceived through an act of love between your mother and father and their relationship with the creator. They conceive you through that emotion and action—a force of nature happens. You start growing, developing from a single cell into more cells, attaching yourself more to the universe. The meaning of dying is just shedding those cells. You’re just giving them back, you’re going back to that final period, when your soul leaves and goes out, you leave those cells here to stay, to mean whatever they mean to those left here. You, and that life force, which the creator and your mother and father got together with, created and you return back. Dying is just a 180-degree spin on how you were created from one force.

Mato Wi also spoke of the cyclical nature of death. She said,

Death is an English term that is so final that I think when you begin to acclimatize too far over to this term, then death becomes fearful and you no longer recognize the continuance, compared to just saying, “Okay, it’s the end of just *this* part of the circle.” “Death” is such a final, harsh reality in this society. “Crossing over” is a much nicer term because then you recognize the transition, even “transitioning to another part of the circle” sounds so much nicer than “death.” Because you really don’t die from here as long as some of us are still here to keep you alive.

And when asked about the meaning of dying, she replied,

Dying is like your preparation for the end of the cycle. Again the word “dying,” like death, is rather harsh. If you look at a flower in terms of, “Oh my gosh, it’s starting to die,” that’s a real visual. When you see somebody becoming old there’s the visual of starting to die. But doesn’t that sound awful rather than they’re preparing for the transition of crossing over?

The words used are not just labels for events. Words bring forth a world; they bring specific meanings to light while precluding others. Words have power—the vibrations created when words are spoken create an emotional resonance in our being. Is it end of life or re-death? Is it being brain dead or passing away?

Dying well. Not having died, what could we know of dying well? All we know are the deaths of others, unless we consider the deaths that we live each day, the ordinary endings of things: the end of a conversation, the finish of a day, the completion of a project, the attainment of a goal, the passing of a phase of life,

shifting to a new role. These are deaths undergone so many times in this life. Dying well is intimately related to living well. How we live determines how we will be remembered. Longevity can be measured by how long we remember into the past and how long we are remembered in the future (Holden, 2002, p. 23). When asked of the relationship between living and dying, our younger friend, Mato Maza, said,

You want to live each moment in the best way it can be lived so that you don't end up leaving with undone, unsaid things, unspoken things, and regrets. You want to hug everybody everyday, acknowledge everybody everyday, and give thanks and respect to everything around you, so that when you go that energy is returned to you. In its most simple form, living well and dying well means you're going to leave good memories behind. It means anybody who knew you has nothing bad to say about you. Any reputation, honor, or dignity you had as you were *living*, can never be any worse in your passing. Nobody can make stuff up about you if you've lived well and you've died well. If anything, you become elevated a little bit and mythologized, which isn't a bad thing as long as the memories continue. We want to be remembered because that is how we continue to live in *this* world. If my grandchildren, though they never met me, *remember* me, that speaks directly to that, because that means they must have had contact with people in their area who *knew* of me or *knew* me and still spoke well enough of me for them to say, "You know, I never knew my Grandpa but I heard he was a really good guy." Living well and dying well leads to exactly that.

Mato Wi spoke of the importance of taking care of oneself so one can live and die well. She said,

Your first responsibility is to self, once the tribe has given you the tools to take care of self, as long as you continue to take care of self, then the confidence is in you to give everything you have to give along the way. So when it is your time you can look back and say "Yep, good day to die. It's *all* I have left." So when you transition to the other side you actually go there with a smile because you've left nothing. You've done everything that you were supposed to do while you were here.

We can prepare for death and practice dying well in every moment of life, respecting and honoring everything, saying thank you, thank you, and thank you.

Lingering at the Crossroads

Grieving. If death is not an end but a transition, a crossing over, and dying is the completion of a circle as natural as a period at the end of a sentence, then what is the sadness about? When asked about the meaning of grieving, Mato Maza said,

Grief is for an individual to comprehend and deal with the moment, the loss. We can say we grieve for others, we actually grieve for ourselves to help us cope and deal

with being left behind and missing that person, missing that thing. We can even grieve events; we grieve anniversaries, birthdays, vacations, which are initiated by scents, smells, touches, sights, and sounds. There is grief on different levels. But if you're attaching grief to death, then, in my understanding, grief is so you can cope with being left behind and survive in this moment without that person, that *one*. You can even grieve your own death before it happens. Your death attaches with regrets and what is undone, unsaid, unspoken, things that you feel are unfulfilled and unfinished in your process and your journey. You would grieve not having tried harder to recognize that you didn't *live* to the fullest potential. That's what grief is, as far as I'm concerned.

Whereas Mato Wi explained,

Grief is very individual, I think. The meaning of grief to me is not being able to physically have coffee with him anymore. Not being able to get in the car and take a ride and have that chitchat along the way. Those are the things that are grieved. It's no different than if I lost something that I needed. I would grieve that loss. You would never replace it. You might figure out a way of living without it. But it's a process of getting used to the transition, I think. Some people take a long time to get used to the change in their life. Others, they've prepared so well that they kind of carry on in a proper sort of way, but you don't really know what goes on inside them, only if they're willing to put it out there for others to know. Sometimes it's so private you don't talk about it. It's a spiritual thing but again it's a transition. Their life changed, my life is changing, and I'm grieving what I've been. That's my definition of it. Grief lets you know that you're still alive and that you still have an appreciation for the trail wherever it's going to lead you. It's kind of a lonely place because what you're grieving or moving away from is something that you had great appreciation for. Otherwise you wouldn't grieve it.

Taboos. When someone is grieving, there is sometimes an awkwardness in not knowing how to be with, or respond to, such sadness. It may be uncomfortable to communicate with someone who has lost a loved one. Perhaps openly speaking of death and dying feels impolite because the very words conjure aversion and a deep inner recoiling that implores "not me, not my loved ones." Why bring this dark, fearful topic to the forefront? Why bring forward this hidden background that forms the subtext of life? Death is in life, but we do not see it. You may have been taught to always be positive, happy, and pleasing, to avoid that which is unsavory. This may have led to careful tiptoeing around such weighty topics as dying and death, perhaps out of fear of being sucked into darkness there. Fear may keep you from recognizing the death that is inevitable for everything that is born. For one who grieves, however, avoiding speaking of death, perhaps in an attempt to forbid death itself, can be frustrating and exhausting. Mato Wi put it this way:

It's a natural process and people act like all of a sudden you have been overcome by this terrible disease. You're grieving, you're grieving very hard, but you're working

so hard to put them at ease. If they would just say, “I really don’t know what to say but I just wanted to be here with you in spirit, mind, and body.” Then you can say, “Thank you.” Taboos prevent immersing yourself in things, respecting yourself, and being in the moment. That’s a really hard one—verbal taboos. When I experienced it, I really felt like a lot of people just heard I had cancer, AIDS, or something, and they didn’t know how to deal with me. Instead of saying, “I’m really sorry he passed, I know you’re going to miss him.” That’s all I would have needed to hear. Even just to say, “I just wanted you to know I’m here for you. You don’t have to talk about him, what happened, or describe the last few hours.” You’re in such a fog anyway you don’t really understand what happened.

Without acknowledging death as part of the process of life, without accepting it, one refuses to accept life in death. Speaking of death and dying reclaims a place for death in life and life in death. The taboo of grieving is born in the assumption that one needs to heal from grief. Elder Mato Wi disagrees. To assume that one heals from grieving, she says,

insinuates that grief is like the end of some sort of disease or something. And to me, grieving is a part of life. It’s a part of the cycle. If you don’t understand grief and have a grieving process, then you don’t recognize loss, anything new, or transitions in other parts of your life. I think you would be kind of stuck in a groove and never move forward. I think we’re always grieving something. To heal from it? I don’t know if you need to heal from grief. I think grief is an indicator of the transition. When you get there you’re not grieving that part anymore. Again it’s kind of like the period to the end of that part.

Grieving too hard. Although grieving is natural, grieving too hard and too long prevents life for the living and delays transition for those passing. Without a life of one’s own, one may purely exist for the love and the life of another. This is a sacrifice of death to life, but death has the greater patience, and eventually life must be sacrificed to death. Whether death approaches violently or gently, albeit painfully, it comes in its own time but only enters when allowed; the will must comply or be suspended in animation. Mato Maza conveys the importance of grieving and letting go for the ones who remain:

To grieve is just about saying, “Okay, I understand I just lost this person, and man, life is going to be hard and it’s going to be tough. But because of what they gave me and what my ancestors gave them, I’m still connected to all of that so I just have to get on with it, I have to continue, carry on and do things as I have been blessed to do.” Grieving is okay emotionally for a little bit, but then there comes a time when there’re too many tears and you get out of balance.

He also spoke to the importance of letting go of someone who is dying. He said,

You can trap their memory, their energy in a place in time, and potentially prohibit their journey, stopping them in the process from doing that journey. It's unhealthy for you as well because you're trapping yourself in a moment in time. It's important for the ones left behind because, above all else, they've got to continue to live. They have to continue to move forward. Because one person dies doesn't mean the universe stops. Time doesn't stop. What it is about is living in an honorable way, in a way that honors them, what they were to you, what they may have imparted into you, and taught you. So that when your time comes, however that may happen, you meet up again in the spirit way. Both have vision, one saw it from above, one saw it from below, and they get there and they talk and they say, "Thank you for honoring me by living a good life."

Mato Wi related the need to let go in these terms:

When that Elder has prepared for that journey, it's like if you were preparing for a journey to Hawaii, you're all excited about it and all of a sudden the kids start crying and it's hard for you to go, "Do I go? Do I stay? Do I go? Do I stay?"

With some phase of life complete, another life waits there at the end, beckoning to begin again. At those moments in life when something is complete and something else is about to begin, there is sometimes a desire to die alongside that wish to bear a new life. If there is a sense of death, as re-death, then life must be forfeited to death for re-birth. If death is for the sake of life, then it is important that one let there be ends—ends to friendships, works, relations, and life. How can you truly love and embrace what life there is if one does not, or cannot, accept the death that makes space for life's possibility? Yet, it is in the nature of love to want more, to choose in ways that extend what is loved, and everywhere you see around you the effort to preserve life. Rarely is the art of ending acknowledged and practiced. Without reverence for limitations of being, ends are not ends in love but ends in fear, hatred, anger, and sorrow. The ending of being is welcome when there is a sense of those who came before and those who come after you, and a sense of one's goal having being engaged. Then the difficult art of dying at the right time is made easier.

The Art of Caring at End of Life

Ceremonies. In traditional cultures not dominated by technology and rationalism, caring for the dead is considered one of the highest honors. Ceremonies and rituals form the art of caring at end of life. Our friend Mato Maza explains their importance:

It's important not so much for the one who is dying as it is for those in the circle around them so that they can begin, continue, or complete their own process in the

grieving stages. We have that connection innately, it's in our DNA, these are the things we are born into, into a ritual, into a ceremony. We were named in a ritual, in a ceremony. We progress through childhood into teenage years and we have a ritual and a ceremony. We come to adulthood and we have a ritual and ceremony. We get married and we have rituals and ceremonies. We have rituals and ceremonies our whole life so it is only appropriate that we have them as we die.

For example, the washing of the body is a form of care at end of life and a symbolic burial ritual in many cultures (What, 2002, p. 15). This washing is present at the beginning and at the end of life, as explained by Elder Mato Wi:

When a baby is born, the first thing you do is clean that baby. So it comes into this part of the circle nice and clean from the residue of the other part of the circle. On their way out, after they've transitioned over, you have to prepare them to be met on the other side symbolically. In my culture, you clean the feet so their first steps are pure then we just work up the body. They never bring anything from here over there.

She explained other important rituals in this way:

The strength of the eagle, the wisdom of that white eagle, it's a power symbol and sometimes when we're in a weakened state, you give a stone or a feather or something and all of a sudden that energy starts to flow a lot quicker. If it's in the midst of transition, they need to have those symbols with them and sometimes hospitals won't allow them.

A ritual, unlike a routine, makes space to reflect on the meaning of what is happening. Meaning requires a space for the rituals of dying and death. There is no formula that can be followed that will ensure meaningful end of life. What (2002) writes of her experience as part of a burial society: "There is no typical scenario ... The prescribed rituals do not translate into a routine. Each time we are hesitant before beginning, in awe of the importance of the task ahead of us" (p. 15). Those honored with the responsibility of these rituals often speak of how being intimate with death brings great gifts and that the horizon of death brings forth our own authenticity.

It is important to recognize that the meaning of rituals is highly personal. Mato Maza said,

Yes, there are rituals to it, and they'll mean nothing to anybody who is untrained or uneducated or unknowing. So even by asking about them, you're kind of asking something that really doesn't apply because the ritual is between the one who is dying and the family themselves. *They* light the sage, *they* light the tobacco, *they* do the laying out of colors and stones and feathers and whatever else they may use in that ritual. The doctor, the nurse, or the health care provider can observe from a distance but

they really have no position within that moment. They shouldn't be involved unless personally invited by that family. Even then, they really have no role. They simply have to allow the process to happen. They have to, no matter what they may be feeling inside about how wrong this is or how silly it appears. If this helps all progress, then that's what needs to be allowed to happen.

Storytelling. Storytelling is another form of meaningful caring at end of life. Most cultures value storytelling at the time of death to heal the living and honor the dead. There is a sense of immortality created by the human story (Holden, 2002, p. 26). The central role of storytelling in the lives of our friends is made clear in the following:

Storytelling is there from the beginning, even before we're born, as we're in the womb we hear our mothers speaking and our fathers speaking and our relatives speaking, and those are stories to us. When we're born, we go through the same thing, we get *bone* talk, they talk to us, and they become stories. As you're dying it's the same thing. As you're laying there in whatever state you're in, you're hearing them speak, and your son or somebody says, "Oh, remember when Grandpa fell off the roof," and they go into this long story and it's totally inappropriate, it's as you would say, "taboo" to talk about the old man falling off the roof, but it's funny because that's who he was and it's *healing* because you're living the life again quickly in a mini-movie. It helps the one lying there because he goes, "Oh, they remembered that! Oh, that was bad, ooo! But, you know, that's who I was, that's who I am, and the fact that they have that memory means I have impact in their life, and so that's *good*." They don't leave feeling they were forgotten.

What meaning is given to death depends entirely on what meaning is given to life. Stories tell which death, whose death, whose life. Stories transform the finality of death and generate meaningful existence. These stories can be redemptive and heal the trauma of loss that could otherwise be passed from generation to generation. Gadamer (1996) writes about the unspoken understanding not to speak poorly of those who have passed. He argues that an idealized version of the person is remembered and serves as a model in the lives of those that remain. Telling the stories of loved ones that have passed motivates us to live our lives in ways that honor our relationship to them. When asked about the importance of storytelling at end of life, our friend and Elder Mato Wi said,

I think storytelling is really important because it's like reliving. It's like bringing them back into your heart, you remember your favorite story and you want to share it. I had this with him, we had this, and this happened. But in a sense it's kind of more like becoming a part of them. You have your story. You have your story. You have your story. I also have one. So it's kind of reaffirming and confirming the goodness of

that person. I wanted to be a part of it. Him and I had something together. This is *our* story. I think it's important.

FINAL THOUGHTS

These messages are not about *the* definitive meaning of death, dying, grief, and care, but strive to be truthful and respectful communications, conveying multivocal meaning, difference, diversity, and space for the possibility of generating further understanding. Personal meanings of death, dying, and grief are included and transcended in the moment that one person understands another. What you, the reader, make of these messages is your claim and does not remain the same indefinitely across time and contexts. Victor Frankl (1985) writes of the superabundance of meaning, explaining that one cannot presume to know the complete meaning of anything because meaning arises in relationship and the significance of things is forever unfolding in light of new relations. Between teller, messenger, and listener, there is an interdependent relationship that brings forth meanings. The emergent meanings represent the experience of the teller, but also reflect the nature of the relationships that exist between the messenger, the listener, and the teller. Respect for the separateness of the other is the condition for the possibility of shared meaning. It seems contradictory, but inescapably true, that teller, messenger, and listener have their own personal understandings, and a gulf of being separates each from the world of the other while minds meet and understanding is shared.

When there is a history of cultural exploitation, is the appropriation of meaning and possible generation of shared understanding worth the risk of continued abuse? Mato Maza explained that, when he is asked, he must share his knowledge because this knowledge belongs to everyone. Yet, with a history of White researchers entering Aboriginal communities and taking knowledge to complete theses, research papers, and degrees, why continue to gather stories of Aboriginal peoples and convey their messages outside of their communities? With nothing to offer but what comes from our world, and when that world is what dispossessed the Aboriginal peoples of their traditional ways of being, how can White Western researchers presume to understand their Aboriginal friends without participating in a history of abuse?

There are several reasons that we take the risk to try to understand each other. This work, first of all, intends to bridge the world of conventional health care practices with the world of traditional Aboriginal ways of caring. By making space for this communication, we hope that psychologists, social workers, and educators may discover, for themselves, personal ways to provide Aboriginal peoples with meaningful care. Second, by documenting messages of Aboriginal individuals and families, we contribute to the preservation and promotion of traditional values and ways of caring in techno–rationally dominated institutions of care. In working to

promote the availability of culturally appropriate care, Aboriginal individuals and families may experience greater respect and make greater use of public resources. Third, this research may help caregivers to acknowledge and promote diversity in our societies. We do not intend to romanticize another culture as having a “better way,” but make space for diverse meanings to temper the trend toward homogenizing practices. Our intention is not to preserve a dying culture, to box it for viewing possibilities of existence, but to foster cross-cultural dialogue within our institutions.

Perhaps through this dialogue, the humanist will have gained a greater sense of possibilities for addressing psychospiritual care at end of life. Although techno–rationally based medicine can excel at addressing biophysiological needs, it seems that human *care* at end of life requires a more ordinary way of being with another. End of life can be healing when mental, physical, social, cultural, and historical realms of meaning are integrated by respecting community traditions. If one is unsure of what to do or say to another who is losing a loved one, or to another who is passing, perhaps appealing to expertise or valid protocol is unnecessary. Instead, it seems, one’s humanity may be enough to listen and understand, thereby making space not for management, but for care.

ACKNOWLEDGMENTS

This paper is based on a presentation given at the second biannual meeting of the International Network for Personal Meaning in Vancouver, Canada, in July 2002. We extend our sincere thanks to two anonymous reviewers and to Editor Larry M. Leitner for helpful comments on earlier drafts of this manuscript.

REFERENCES

- Baydala, A. (2003). Ricoeurian hermeneutics of time and grounds for creative psychotherapeutic discourse. In N. Stephenson, H. L. Radtke, R. J. Jorna, & H. J. Stam (Eds.), *Theoretical psychology: Critical contributions* (pp. 244–250). Concord, Ontario, Canada: Captus.
- Becker, E. (1973). *The denial of death*. New York: Free Press.
- Benoliel, J. Q., & Degner, L. F. (1995). Institutional dying: A convergence of cultural values, technology, and social organization. In H. Wass & R. A. Neimeyer (Eds.), *Dying: Facing the facts* (pp. 117–141). Washington, DC: Taylor & Francis.
- Brown, J. E. (Ed.). (1953). *The sacred pipe: Black Elk’s account of the seven rites of the Oglala Sioux*. Norman: University of Oklahoma Press.
- Clandinin, D. J., & Connelly, M. F. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco: Jossey-Bass.
- Colorado, P. (1988). Bridging Western and Native science. *Convergence*, XXI(2/3), 49–68.
- Emerson, P., & Frosh, S. (2004). *Critical narrative analysis in psychology: A guide to practice*. New York: Palgrave Macmillan.

- Ermine, W. (1995). Aboriginal epistemology. In M. Battiste & J. Barman (Eds.), *First Nations education in Canada: The circle unfolds* (pp. 101–112). Vancouver, British Columbia, Canada: UBC Press.
- Ermine, W., Sinclair, R., & Jeffery, B. (2004). *The ethics of research involving indigenous peoples: Report of the indigenous peoples' health research centre to the interagency advisory panel on research ethics*. Saskatoon, Saskatchewan, Canada: Indigenous Peoples' Health Research Centre, CIHR.
- Frankl, V. (1985). *Man's search for meaning*. New York: Washington Square Press.
- Gadamer, H.-G. (1996). *The enigma of health: The art of healing in a scientific age*. Stanford, CA: Stanford University Press.
- Gadamer, H.-G. (1998). *Truth and method*. New York: Continuum.
- Holden, M. (2002). Godfather death: Storytelling lights the transition. *Parabola*, 27(2), 20–28.
- Hoshmand, L. T. (2005). Narratology, cultural psychology, and counseling research. *Journal of Counseling Psychology*, 52, 178–186.
- Mishler, E. G. (1990). Validation in inquiry-guided research: The role of exemplars in narrative studies. *Harvard Educational Review*, 60, 415–442.
- Moraglia, G. (2004). On facing death: Views of some prominent psychologists. *Journal of Humanistic Psychology*, 44, 337–357.
- Neihardt, J. G. (Ed.). (1932). *Black Elk speaks: Being the life story of a holy man of the Oglala Sioux*. Lincoln: University of Nebraska Press.
- Neimeyer, G. J., Behnke, M., & Reiss, J. (1984). Constructs and coping: Physicians' responses to patient death. In F. R. Epting & R. A. Neimeyer (Eds.), *Personal meanings of death: Applications of personal construct theory to clinical practice* (pp. 159–178). Toronto, Ontario, Canada: McGraw-Hill.
- Neimeyer, R. A. (Ed.). (2001). *Meaning reconstruction and the experience of loss*. Washington, DC: American Psychological Association.
- Neimeyer, R. A., & Van Brunt, D. (1995). Death anxiety. In H. Wess & R. A. Neimeyer (Eds.), *Dying: Facing the facts* (pp. 49–88). Washington, DC: Taylor & Francis.
- Ricoeur, P. (1981). *Paul Ricoeur hermeneutics and the human sciences: Essays on language, action and interpretation* (J. B. Thompson, Ed. & Trans.). Cambridge, MA: Cambridge University Press.
- Rowe, D. (1983). Constructing life and death. *Death Education*, 7(2–3), 97–113.
- Smith, L. T. (1999). *Decolonizing methodologies: Research and indigenous peoples*. London: Zed Books.
- Wass, H. (2004). A perspective on the current state of death education. *Death Studies*, 28, 29–308.
- What, J. (2002). Why we wash the dead: Caring for what remains. *Parabola*, 27(2), 13–19.

AUTHOR NOTE

Angelina Baydala, PhD, is an Assistant Professor and registered clinical psychologist in the Department of Psychology at the University of Regina. She was educated in philosophy at the University of Toronto and clinical and theoretical psychology at the University of Calgary. Her research focuses on understanding cultures and theories of psychospiritual health and healing, developing paths of community-based narrative research, and communicating the breadth of psychological belief systems. She regularly teaches undergraduate courses on the history of psychology, systems of psychology, theories of personality, and yoga psychology, as well as a graduate course on theories and practices of psychotherapy.

Mary Hampton holds an EdD in counseling and consulting psychology from Harvard University and an EdM in counseling psychology from Boston University. She is a registered clinical psychologist and a Professor of psychology at Luther College at the University of Regina. She has published in the areas of youth sexual health, women's reproductive health, cross-cultural psychology, and community development. Her research interests include violence against women, women's health, death and dying, and cross-cultural healing. She teaches courses in psychology of women, humanistic psychology, ethics, developmental psychology, and abnormal psychology.

Lionel Kinunwa described himself to many groups as just a common, ordinary man. He enjoyed simplicity and lived accordingly. He greeted each new day with anticipation and excitement. He lived each day as if it would be his last day on this part of the circle. Lionel's every breath was to honor his Grandfather Kinunwa, who fought so hard so that his grandchildren could become common, ordinary men and women who would continue teaching the rules of living a good life. He is husband to Mato Wi and father to Mato Maza. In this article, he is an author because he speaks through Mato Wi and Mato Maza as they have listened to him.

Germaine Kinunwa is a traditional Elder, a woman who appreciates each step she takes toward the next circle. In every day, she is preparing for her last day on this part of our circle. In following the rituals and ceremonies of the Sacred Pipe, she finds that she is reminded to create joy in her life and others. Those days when grief seems to overtake happiness, she tries to stay in the moment and learn from the spirit of those emotions. As the sun connects her spirit to her past and the stars connect her spirit to her future, she lives in the present and tries to be in the moment. She is just a common, ordinary woman. She is Mato Wi (Bear Woman).

Leon H. Kinunwa, Sr., was born of the seventh generation removed from the last of the free thinkers, the free ones who did not live on reservations, who lived as free people. He is Mato Maza (Iron Bear) Leon H. Kinunwa, Sr. Raised by traditional parents and traveling as a family, he witnessed his parents live on the Red Road, living the Pipe Way, being Lakota among all peoples. Understanding that we have come through four distinct ages of time—Water/Fire/Stone/Pipe—he has become, as his parents wished, a simple man living in a simple way, living in the moment and being thankful for everything and everyone in his world. His education has been simple, and his classroom has been Mother Earth; her lessons of natural law and energy, watching his parents help others, be with others, and sacrifice so much for others have taught him to likewise make the offering when called. He is a proud son of proud people and prays his son, Hante Ska Mato (White Cedar Bear), Leon H. Kinunwa, Jr., continues the traditional journey as the first-born Kinunwa, free and proud and strong, Lakota.