

Dialogues in Best Practice



October 16th, 2007

How to Best Communicate End-of-Life Issues with Older Adults with End-Stage Dementia and their Families

Moderated by:

Christine Kovach, PhD, FAAN, Professor of Nursing
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Panel Members:

Vicki Chossek, Family Caregiver
Toni Kesler, MS, NP, Community Care, Inc.
Jung Kwak, MSW, PhD, UWM Center on Age & Community
Sandra Matson, RN, MA, Family Care Best Practice Team, Community Care, Inc.
Marilyn J. Sincaban, MD, Community Care, Inc.

Participant Biographies

Moderator

CHRISTINE R. KOVACH, PHD, RN, FAAN, Professor, College of Nursing, UWM, has done extensive clinical work and research with people who have Alzheimer's disease and other dementias. Her work is particularly focused on those with more advanced dementia and improving skilled nursing care. She is funded by the National Institutes for Health for her work developing and testing an intervention to improve management of pain and unmet needs of people with dementia who no longer are able to clearly or consistently verbalize their needs. She is also the Methods Core Director of the Center for the Enhancement of Self-Management in Individuals and Families, which is funded by the National Institutes for Health and housed in the College of Nursing at UWM.

Panel Members

VICKI CHOSSEK is a recent family caregiver for her father. Vicki Chosseck is a former teacher and executive director of several nonprofit organizations, and currently a patent paralegal at Master Lock Company. Ms. Chosseck is representing the caregiver's point of view on our panel. Her father, Richard, died in March after a 10-year, steady decline from Parkinson's disease and the dementia it can cause. Through the process, Ms. Chosseck worked with her family as well as various outside service providers such as Parkinson's disease research programs, in-home physical therapy programs, adult day care programs, respite services for the caregiver, rehabilitation centers, nursing homes, doctors and insurance companies. As her mother became older, Ms. Chosseck frequently played a key role in caregiving and coordinating family involvement and health care services in her father's end-of-life care. Her family was fortunate to find many helpful, caring service providers. She also shares insights on areas that left her family looking for more caregiving assistance.

TONI KESLER, MS, NP, Palliative Care Specialist, Community Care, Inc., is an advanced practice nurse. Ms. Kesler has worked with the elderly for 29 years in a variety of practice settings. She has been employed by Community Care for 15 years and developed the Palliative Care services for her agency. Her current job responsibilities include Palliative Care Specialist, Ethics Chairperson, and Quality Improvement. She received her certification in Clinical Aromatherapy in 2005. Recent publications include her article, "Assessment of Dying: A Tool to Help Providers Recognize Imminent Death," which appeared in the November, 2003 *American Journal of Nursing (AJN)*. Ms. Kesler currently serves as a board member for the End-of-Life Coalition of Southeastern Wisconsin.

JUNG KWAK, MSW, PHD is a post-doctoral fellow at the Center on Age & Community, UWM. Dr. Kwak's research focuses on cultural diversity in end-of-life decision making and health disparities in long-term and acute care services use and outcomes. Her research on these topics has been published in *The Gerontologist*, *Journal of the American Geriatrics Society*, and *Journal of Pain and Symptom Management*. Dr. Kwak is also an American Academy of Hospice and Palliative Medicine Year-Long Mentee, working with Dr. Betty Kramer at the University of Wisconsin – Madison on mixed methods research on end-of-life care.

SANDRA MATSON, RN, MA is a member of the Family Care Best Practice Team, Community Care, Inc. Ms. Matson has worked in long-term care for 27 years. She is currently a Quality Monitor at Community Care working with the Milwaukee County Family Care program. She is a member of the Community Care Ethics Committee, the Milwaukee County Department on Aging CMO Ethics Committee, and the Lakeview Specialty Hospital and Rehabilitation Ethics Committee. She is an adjunct instructor in the Bioethics Department of the Medical College of Wisconsin and was former project director for "Institutionalizing Effective Pain Management Practices in Long-Term Care Settings," a project with the Palliative Care Program at the Medical College of Wisconsin, in conjunction with Dr. David Weissman.

MARILYN J. SINCABAN, MD is Associate Medical Director, Community Care, Inc. Dr. Sincaban is an experienced geriatrician as well as a palliative care specialist. She has been with Community Care for over eight years as a physician, taking excellent care of frail older adults throughout their illness trajectories and at the end of life.

Dialogue

Anne Basting welcomes everyone and introduces Dr. Christine Kovach, a gerontological nurse and professor at UWM who is serving as the dialogue facilitator.

CHRISTINE KOVACH: I'm so happy to be here this afternoon for this very important dialogue. I will begin by reading some quotations about the aging process. T.S. Eliot wrote in his poem "East Coker,"

"Home is where one starts from. As we grow older
The world becomes stranger, the pattern more complicated
Of dead and living. Not the intense moment
Isolated, with no before and after,
But a lifetime burning in every moment
And not the lifetime of one man only
But of old stones that cannot be deciphered."

An older adult patient named Gene Higgins said,

"Suffering is everywhere, and when one has passed
through the cauldron, a sincere hand and heart are
needed. Be interested in people, their lives and their
families. It is vital that you not feel like a total patient.
Hell, we're all patients in this universe we share now."

We do death as though it is something we have to beat. We treat it as though it is something we want to get out of. But life is 100% death. Care of people with late-stage dementia is, among other things, a dramatic reminder that cultural attitudes have consequences. It is within the context of dementia care that our broader society's fear and denial of aging, illness, and death plays itself out in end-of-life care, both those afflicted and their family members. Many of you in this room have the privilege of helping people in the end of their lives. And from that perch you are able to see the wonderful humanity of the health care system, the lack of humanity and indeed, inhumanity as well.

One day, while doing a project funded by the Helen Bader Foundation to set up hospice households for people with advanced dementia, I asked a nurse on a traditional unit why it was that only the residents with late-stage dementia were still in bed dressed in nightclothes at midmorning. She replied, "Well, they're the ones who can't complain so we do them up last." Those words – "the ones who can't complain" – what a powerful testament to how much we are failing to comprehend the daily experiences of people with advanced dementia.

Families are often placed in the horrific position of making exceedingly difficult decisions without accurate information about the expected consequences of that decision on comfort, quality of life, or co-morbid problems at the end of life. Some of the most critical decisions involve whether to treat pneumonia with antibiotics, whether transfer to a hospital will yield benefit for their loved one, whether to insert a feeding tube or provide non-invasive feeding assistance—wrenching dilemmas commonly faced by families of people with advanced dementia.

Those of us in health care professions are supposed to make a positive difference in the lives of those we serve. We are supposed to help. Yet, in our quiet moments when we have time for reflection, we recognize that our knowledge base is underdeveloped, and we still struggle to understand the needs and experiences of people with dementia. We know that this human suffering is unacceptable.

Dementia really allows us the opportunity to shed the arrogance born of our hyper-cognitive and hyper-busy, self-important lives. It allows us to get more in touch with our humanness, and getting in touch with our humanness hopefully makes us more open to comprehending the experiences of others... even if that person experiences and responds to pain and joy in ways that are foreign to us. So much of the care we provide to people with dementia is helping them and their families have a journey that ultimately validates the meaningfulness of the human condition and our potential for interconnectedness. One aspect of that interconnectedness is advocating for and finding new ways to understand "the ones who can't complain."

Today's dialogue considers how to best communicate about end-of-life-issues. Anne Basting and Jeanne Prochnow are the folks that hatched the idea for this specific focus. And as the panel members and I were meeting to discuss this session, it was clear that this topic of communication interfaces well with many issues regarding care, cultural differences, and our personal biases about what constitutes a "good death." We realized that better communication along the trajectory of illness would decrease suffering for both the family and the person with dementia, and avoid a cascade of problems that often ensue when we are enmeshed in this very tough and very real stuff of living and dying with Alzheimer's disease and related disorders. So the topic is well chosen, we think, and we have gathered an esteemed panel together today, both to share their ideas with you but also to have a dialogue with you. Many of the people in the audience could well have served on this panel. We have allotted a lot of time for discussion and dialogue.

The panel will give introductory comments, and then present some questions. On the handout sheets there are three main questions, so we'll start with those and see where it takes us.

EDITOR: Dr. Kovach then introduces the panel members, each of whom provides opening remarks. (See biographical notes above.)

MARILYN SINCABAN:

Good afternoon. I'm really happy to be here. I am a physician at Community Care, so I think what I am bringing to this discussion is a physician's perspective in terms of presenting the difficult discussions related to end of life care.

To give you an idea of how I might begin the discussion with a family facing this situation, I will describe the tools that the practitioner might carry to the table during a discussion, and what I perceive to be the family's tools to navigate the situation.

The first tool the physician brings is knowledge about a disease process, which includes identifying issues, a prognosis, and what to expect as dementia progresses. The physician also presents the options that will be before the family, including available treatments, feeding issues, dispositions, where the loved one will live, and caregiver concerns.

The second tool the physician brings is to serve as a bridge between the medical system and the family. It's very hard for the family to face so many technical options and choices and not know what it's going to take to help their loved one. The physician serves as a bridge to define how to weight the benefits of the treatment decisions. A physician who is doing his or her job well also brings to the table knowledge of the patient and the family that has developed over time. If we are fortunate, our doctor will be someone who has been with us and has grown with us and will walk with us as the treatment progresses.

Another tool the physician brings to the table is his or her perspective on child and caregiver. If we are fortunate, we have the ability to understand and feel what the family is going through.

I'm not saying this is all for a doctor to bring – there is a team of services. A physician hopes that the family also brings to the table an openness about what they are going through and feeling. It is hard sometimes to only rely on the body language and not be told by the family what the issues really are. Families need to understand what the burdens and possible good outcomes of the treatment can be. Then, if problems arise, the family can say, "Mom understood this risk, and we know she would or would not want that." They understand that their role is to speak for their loved one.

TONI KESLER: I'm sort of reflecting on what Marilyn is saying. I think in a long-term care model, we get the opportunity to work with people over a long time. When we first developed palliative care services, it was somewhat controversial because we didn't think people would stay with us until they died. The fact that people in long-term care do stay there until death is, in a way, a measure of success, as well as a

paradigm shift in thinking. We have a small palliative care team that gets called in to work with our teams and families earlier, or at the end. In looking at chronic illnesses, with dementia, illness can go on a long, long time, unlike cancer where we can better know the trajectory of the illness.

I knew a family where the daughter said, "You know, Mom's been with me for so long that I didn't think she'd ever leave me." But her mother did die. Dementia can go on for so long without visible outside markers where we can see the progression.

There is no way to really identify it, which can be one of the daunting challenges of chronic illness. Families are often confused by it because we tell them to get prepared for the end, and then that time can be slow in coming.

When I have the honor to be able to be with a family, I know that this is the first time for them and it is a story about love – and sometimes we come in with our *diagnoses* as health care providers, and sometimes those things don't match. That's my point of view to start this conversation.

JUNG KWAK: I am a post-doctoral fellow at the Center on Age & Community. I'm very delighted and honored to be here with the other panel members. Sometimes we academics are sort of in our ivory towers conducting research – sometimes we can be isolated. So I always feel so humbled when I can connect with practitioners.

I am here to share a little of what the research says, and what I have been working on in the past few years. Five minutes is not enough time, so I did prepare a handout – a literature review about what we know about cultural diversity in end-of-life care.

My previous research focused on Asian Americans. Hopefully there are some practical implications for your practice. When you work with families from other cultural backgrounds, there are recommendations for practice.

When I was in a graduate school, I worked as clinical social worker in a local hospice, and I learned to do the research that matters. This goes back to why we are having this dialogue. Practitioners bring wisdom, and they deal with day to day challenges. When people come from different cultural backgrounds, these issues can be more complicated. As researchers, we want to do research that matters. This is such a great opportunity for me to learn from all of you. I am very excited to be here.

VICKI CHOSSEK: I think it's going to help you the most when you hear my comments later, to hear some insight into my family now so you can understand the context. So I'm going to share a little bit. Everyone who would talk about my family would say, "How incredible!" But I can say that I think we were incredibly dysfunctional.

There was my mom, my dad, four children, more or less actively involved in caregiving, depending on my mom. My mother is from a German work tradition. It became her calling and sainthood and maybe martyrdom to keep Dad at home. My father was dealing with Parkinson's disease plus dementia. My mom is incredibly strong-willed. She fought to remain in the driver's seat, but then complained about it. With the four children, I happen to be third one in the chronology. In our views of Mom, we differed greatly, had different expectations of the health care providers, and disagreed quite a bit.

The end was actually easier, which is not to say it was easy, but there were some things that really helped us. What you do qualifies you for sainthood. That's the context from which I will share comments from a caregiver's perspective. I did have my turns changing his diapers, the day-to-day things when mom needed a break. I considered my job taking care of my mom so she could take care of my dad. Those roles changed as the disease progressed. Within the entire family, I was the consensus builder and the one making conference calls. So it's from that framework that you'll hear my comments.

SANDRA MATSON: I've been in long-term care for 20 years and had the privilege of being at the bedside of my parents as they died. My background is in bioethics. I'm kind of at the end of the line here, things happen that were not anticipated. As the end is near, something happens. Maybe there's a change in condition that no one anticipated, something that is more than the family knows how to cope with. Sometimes someone from the medical community will recommend putting a feeding tube in your mom, and the family is horrified. On the other hand, you may have the family saying, "Our mother always wanted everything done," and the medical community is horrified. A common situation is that a daughter flies in from out of town at the last minute and she can't believe everything's not being done. Or you can have a family member who is around but is so strong that other family members are afraid to speak up.

Communication is the main topic here, and that really is what helps a lot. When the issues come up, it is sometimes too late to thoroughly ask the family what the individual would have wanted. It's important to ask a lot of questions. There will be someone around such as a nurse or patient advocate or chaplain who will be sympathetic. Find someone who's good. The other thing is, listen. We need to hear, "What is the family telling us?" There's often a good reason they are saying what they are. And families need to listen to health care providers. So, it's important to take both sides and come together.

Some common questions include: How much time do we have? When do we have to make a decision? What's the normal progression

of this disease? What is this treatment actually going to accomplish? What are the risks and benefits of this treatment? Has the individual ever talked about anyone else in a similar situation?

The most important question to ask is, "If Mom were here right now, what would she say she wants done?"

CHRISTINE KOVACH: With dialogue, I feel that it's best to keep it loose and free-form. I want to allow the panel an opportunity to respond to the questions, and I want to hear from you. What are the burning issues?

Just to get us started, I will throw out the first discussion question, which is very broad. "What are the challenges in communicating about end-of-life issues along the trajectory of Alzheimer's Disease and Related Disorders with family members, those afflicted, and health care providers?"

And because this is about best practices, we don't want to just identify problems, but talk about best practices as well and how we can reframe it and do better.

MARILYN SINCABAN: The challenge is to identify problems to the family. It is hard to communicate clearly to families about something that has no cure. Dementia cannot be seen and has such a slow progression. There is a time frame that can be four to five or eight to ten years, so it is difficult to communicate what to expect. Another challenge is to identify the critical periods where you have to re-identify what the problem is, and reset the layout again. Remind the family that this is the progression. The challenge is to remember to communicate that. For the family, this is a new thing. Every decline demands that you re-discuss health care goals.

CHRISTINE KOVACH: I'd like to talk about two things. Do family members readily accept diagnoses, or is there difficulty with that?

MARILYN SINCABAN: It depends. Some already have an inkling and you're re-affirming what they already suspected. Others are already living with a loved one, and cannot see it. You may have to coax them into seeing what everyone else sees.

TONI KESLER: Sometimes as health care providers, we're ready to get going and families need to sit with the diagnosis information for a while. Sometimes people wonder, "Why don't they get it?" Sometimes it can get to be adversarial.

CHRISTINE KOVACH: Denial is an effective psychological coping mechanism, but at a certain point there are things that need to be done.

VICKI CHOSSEK: [In my family's experience,] we had different levels of communication, but the one that sticks out for me, in part, was that my father was unable to swallow his meds anymore. Our family was actively involved with every meal, but somehow the fact that he was not taking his meds, we didn't know and no one told us, and when we figured it out, the nurse said, "We put him on comfort care." Having stopped taking meds is a significant change and it was not communicated. And when it was communicated, it was communicated badly. So that was one where they did not recognize the opportunity to say that's what was happening.

CHRISTINE KOVACH: Many years ago, I was a critical care nurse and I worked with so many people who were dying, and there's a filter that develops among family members. When you're in these crisis situations, sometimes you don't hear all of the messages. I'd have to say, "This person has *died*," because otherwise the family members wouldn't get it. But this [Vicki Chossek's story] is an example of being way too blunt and not involving the family.

I wanted to make sure we got back to your point of making adjustments to the goals of care. It is really key to knowing the trajectory of the illness.

MARILYN SINCABAN: Whenever there's a change in condition, we jump at the opportunity to have a meeting. We identify that the reason for the meeting is to [discuss progress] and reestablish the goals of the care. At first, the goal may be to keep the person at home or as active as possible, and families will opt for rather aggressive treatments. But when things move further along, you need to address swallowing and nutrition. So we sit down again and discuss how it is a progressive problem, and we say, "Let's define what the goal of care is now." Now it's, "Well, if your loved one develops pneumonia, should we treat it? How aggressively should we treat it?" If there is a problem, let's say, with the heart also, are we going to pursue procedures such as a cardiac catheterization? If someone is in advanced dementia, is it more burdensome to put them through an emergency room situation that they don't understand? If you weigh the risks and benefits, it may no longer be beneficial to pursue aggressive treatment.

AUDIENCE: When we get to that point, when do you start talking about that this is getting close to the end?

MARILYN SINCABAN: I had a patient many years ago who was losing weight and could not swallow. I knew treatments would not be beneficial. But the family insisted that they wanted a feeding tube, and it ended up that the patient went on to live many years. Now, I'm careful to no longer say, "This is the end." I frame it in terms of, "This is the trajectory, and these are the stages of dementia"

CHRISTINE KOVACH: Other thoughts and questions?

AUDIENCE: If you had an advanced directive in place, would you have the same conversation, or would things like feeding tubes be outlined already in that document? Would you still meet with the families?

TONI KESLER: We do have advanced directives, but sometimes things change and the families do not talk to the people about it. It doesn't always work out as you planned, so we sit down and talk about the parents' intentions. Sometimes people will say, "I want everything done for my loved one," and that may not always be in concert [with the advanced directive].

VICKI CHOSSEK: Along the same lines, what we found as a family was that we thought things would be black and white. My mom thought she'd be sued if she didn't pursue all of the different avenues of care for my dad. I think you should make the gray areas apparent for families. My mom didn't understand there was a gray area in between. I want to emphasize, we don't know to ask, but you know there are some gray areas in there.

AUDIENCE: Do you think society still has the view that we are supposed to do everything possible for a family member at the end of life? I happen to come from a family like yours where there are disagreements. My mother was on dialysis for her last months and I thought that was ridiculous, and my brother was a strong advocate for it. But do you think that is the prevailing view in society? How do you bridge that?

SANDRA MATSON: I don't know if that's the prevailing view but there are strong feelings, and you feel guilty. You don't want the family to disintegrate about these issues. When Mom passes, you want the family to be able to still be together. It's about always bringing up, "If Mom were here, what would she want us to do?"

AUDIENCE: Do we teach our students about that piece?

SANDRA MATSON: In the medical college there is a bioethics course where they talk about these issues. But it's only one semester and not all schools do that.

JUNG KWAK: You can look at that issue from multiple levels, including Medicare and Medicaid, look at what kinds of services get higher reimbursement. It makes it very difficult for families to make decisions about hospice if they want to be reimbursed by Medicare. It also forces the patients to choose between curative and palliative care. When the Medicare hospice benefit was created, one of the driving reasons was it would cut health care spending. The health care

industry in general tends to focus on the curative end of the spectrum. There is also the issue that we love these people and we don't want to lose them.

In a story from my own family, I told my mother that if something happens to me, I want this but I don't want that. And she didn't want to hear about it. My mom told me, "It doesn't matter, because I'm going to do everything [all of the treatments]." Despite this view, my mother did not take any dramatic approach to my grandfather's care. So I don't know, if my mom is in this situation, if she will really do everything as she said or if she will adjust and change.

TONI KESLER: I was in same situation with my mother and she had some changes in what she wanted. It made me concerned because I asked, "Do I really know what she wants?" I think as we get closer to death, we realize it and we kick it up, wanting last changes. When my mom went home, she got calls from people about devices to restart her heart, so information about technology can stir up changes in what treatments people think they want.

AUDIENCE: How ironclad are these Power of Attorney (POA) forms the family is filling out, when no one is actually sure how everything will play out and how easy is it to change and who can make the changes?

MARILYN SINCABAN: My experience is that you can change the medical treatment that the patient receives. Seeing patients in the ICU, it often clearly states "Do Not Resuscitate." But when someone is in a grave situation, the team will tend to err on the side of what they think is good. I think we need to get away from the side of thinking that being technological is aggressive care. When someone is in a grave situation, there is also aggressive comfort-based care. It can change, and that's why we have to let our families know clearly what we want.

AUDIENCE: About advanced directives, one of the things we teach is that the doctor is just the end point and the focus is really on the dialogue with the family. If made in a vacuum, the document is not useful. So when we teach, the focus should be on the dialogue, "What does quality of life mean? What's important to me?" Because the doctor can never cover every situation, the doctor needs to be consistent with your values. What's important, too, is who you pick as your agent. Who is the one that is strong enough to uphold your wishes? So that's all a really important part of that dialogue.

SANDRA MATSON: That's really true. In the old days, deciding treatment plans was more of a laundry list. What we found is, that doesn't work. So now it's more about the values. When you give an individual the right to withdraw a feeding tube, you want to make sure it's the right person. We should be honoring those and someone should be looking to say, "This doesn't seem to be what the individual would want."

ANNE BASTING, DIRECTOR, CENTER ON AGE AND COMMUNITY:

I have recently been closer to the birthing process than the dying process. There is a whole trade of doulas and midwives, who act as an interlocutor between the family and the medical. I don't know if that same sort of person exists in the dying process. One person said, they had created that person particularly because of cultural and language difficulties, testing that person as a go-between. I wonder if that actually exists?

JUNG KWAK: We are fortunate to have a variety here, because these are managed care providers, and a feature of that is care management. Their job is to make sure they coordinate the right kind of care and act as an advocate. Care managers take on a variety of these challenges.

TONI KESSLER: There's a concept in Ireland where there are some training programs to be that support person like a birth coach or a coach going through the dying process. We are a death-denying society, so I don't know if we've perfected that in America. I know from a managed-care standpoint, that is the role we embrace because we do follow people for an average of four years. At an earlier juncture, we may get to know the family and our patients a lot sooner and take that walk with them.

AUDIENCE: I'm an attorney and I teach in the department of communication and my specialty is communication and conflict. I can't think of any more important communication topic than living and dying. In an ideal world, that form of thorough communication is the ultimate. But in the real world, it doesn't always happen. We can help families through the process of saying goodbye and know that they are dealing with a long and extended grief process. Listening is very important. The fractured family can cause problems for the family itself and for caregivers. By the way, all families are dysfunctional.

The worst mediation I ever saw came out of probate court, and the elder had already died and it started with the care decisions – guilt and shame, and some family members in denial and some moving on, and then it turned into a fight over the estate. We can't deal with the substantive issues until we've dealt with the emotional ones. That's what I'd advise you to do, sit down with the family and ask what they're going through.

CHRISTINE KOVACH: One of the goals in this is to get the family to the other side in one piece. It can be a very volatile situation. The more you lay it on the table that you're in for the long trajectory here and make the commitment that you're going to get to the other side as a group, the better. In my family, we did get to the other side, but we were really different in the ways that we coped. A study used the phrase "coping with negative choices." When I use that phrase with

family members they say, “That’s it!” You keep looking for the positive one but just saying that [phrase] helps family members because they are all negative choices.

Dr. Carol Ott, in back, is doing a study like this – do you want to jump in here?

CAROL OTT, FROM AUDIENCE: I think they definitely identified all of the losses that go along with being a caregiver. Loss of that relationship, the ability to communicate with the persona that has dementia, the longing for what used to be... And also there’s a myth that people, because they have grieved so long during the illness, that once the person dies, a lot of their grief has been taken care of. For some people this is true, but not for all. Some people who were very high grievers during the illness continue to be high grievers after the death. My own mother died this past summer after dementia and I guess I was even rather surprised at my own grief, even though, at the age of 95, she has lived a long life. So that emotional aspect of things is so true. What you said, coping with negative choices, is an important concept. I met with a gentleman today who said that none of the choices make you happy.

CHRISTINE KOVACH: To give some background on question two [from the handouts], it is based on Toni’s case study of a person with dementia. When a person is on a ventilator, at the end, the case study explores, how did we get to this point? We have all these biases that they shouldn’t have gotten to that point. I want to make sure we spend a little time focusing on: What is best practice? What can people suggest?

AUDIENCE: Knowing that it’s full of surprises, and that it is important not to assume. I had a sixty-two-year-old brother with Down’s Syndrome and Alzheimer’s, and everyone assumed I knew what to do, and I don’t. Any number of attorneys don’t know what family meetings are or who to turn to for services in the county. Sometimes we get enmeshed. We shouldn’t take a lot of stuff for granted, and these experiences are full of surprises.

VICKI CHOSSEK: As families with no experience, we didn’t even know to ask. It’s so basic. We didn’t have the network, people who knew us or our family. We didn’t have a “death doula.”

CHRISTINE KOVACH: In thinking about the “death doula,” it’s unique in dementia because these people cannot communicate if they are cold or bored or lonely. They end up having decreased insight into how they are doing. Therefore, we need to get much better at knowing this person really well and observing behavior so we can tell when there is a change in how they are doing. Very often, the things you do for dementia are very aggressive but low technology. There are some

hospice organizations – I am very supportive of hospice – who know and understand dementia care better than other organizations.

AUDIENCE: The difference between hospice with cancer and hospice with dementia, is like the difference between dating and marriage. With dementia, it is more about caring for the family. Family needs a lot more care.

JUNG KWAK: There are several demonstration projects. Kaiser health programs, VA hospitals are doing programs with one year instead of 6-month progresses. The programs try to be more inclusive and extensive.

CHRISTINE KOVACH: The biggest hospice doing dementia care well is in Phoenix. What they found is they were losing lots of money on Medicare reimbursement benefits because lots of folks were living longer than six months. So they developed a new service with a different reimbursement mechanism and it’s really working well for them. So much is driven by reimbursement, but if you have the right people at the table, sometimes it turns out okay.

AUDIENCE: It is important to keep the cultural ethnicity component there. I, at times, was offended by the medical team who told me she’s [my relative has] lived a long life. In my culture we have a reverence for elders. They would say, “She’s 94, what do you expect?” – focusing on the numeric age rather than, she’s my grandmother, so *what* if she’s 94? Instead of telling me the things that I needed to hear – they were not doing that. There’s a difference with how certain cultures understand dementia. Certain ethnicities don’t have the knowledge that they should have.

CHRISTINE KOVACH: There are cultural differences, and there are individual differences, in the meaning of suffering. Be aware of, from that person’s tradition, what is the meaning of suffering? Different groups have different histories with lack of trust and the health care system. When you think of the violation of trust with the study done at Tuskegee with African Americans, there is a reason they have a lack of participation in the health care system.

We are getting to end of time, but this has been wonderful dialogue and I want to thank everyone for their participation.

ANN BASTING: I thank all of the panelists for being open and I appreciate all of the comments. You can email aging@uwm.edu. Email the website and we can create a dialogue list there and we can add the questions to the white paper that will get typed up. Keep the questions coming, come to the website, and please hand in your evaluations. Thank you all very much.