PALLIATIVE CARE NETWORK OF WISCONSIN

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New Fast Fact Released: #364 The Role of Palliative Rehabilitation in Serious Illness

Fast Fact #364 has been released: The Role of Palliative Rehabilitation in Serious Illness.

Thanks to the authors, Noelle AppJavier and Marcos Montagnini, MD, FACP, for this new addition to the fast fact library.

Hear ye, hear ye. A new Fast Fact is available on palliative rehabilitation. This Fast Fact aims to be a concise resource for clinicians to glean a better understanding of what palliative rehabilitation is and how it can help patients with serious illness, even patients with a limited prognosis and comfort goals of care. This Fast Fact also addresses some of the common challenges in providing palliative rehabilitation in various end-of-life care settings.

PALLIATIVE CARE NETWORK OF WISCONSIN

Integrating Spirituality in Palliative Care Goals of Care Conversations

Written by
Denise Hess, MDiv
Executive Director, Supportive Care Coalition

What do we mean when we say palliative care is care for the whole person? Our usual answer is palliative care attends to the body, mind, spirit, emotions, social setting, network of relationships, and other aspects of a patient's "whole person." Described this way, providing whole person care may sound like an overwhelming task for a solo palliative care clinician. Palliative care requires an interdisciplinary team or, in words attributed to Balfour Mount, "Whole person care requires a whole person. Until one comes along—use your team."

The interdisciplinary team is absolutely central to the delivery of palliative care where each dimension of the patient is addressed discipline by discipline. The medical team members provide the diagnosis, prognosis, and interventions to ease pain and other symptoms. The social worker provides psychosocial care ranging from helping a patient find affordable in-home caregiving, to facilitating resolution of a long-standing family conflict, to "just" listening while the patient shares their fears, hopes, or

sorrows. The chaplain provides spiritual care including everything from offering a prayer or religious ritual, to addressing a patient's sources of suffering, to connecting a patient with their own sources of meaning, comfort, and hope. All together, each discipline contributing their part provides care for the whole person.

But is this truly whole person care? While each individual member of the palliative care team may be able to provide parts of the "palette of care,"[1] patients rarely present in their component parts. Instead, during a pain and symptom follow-up visit, a patient tells the palliative care physician that she was physically abused by her caregiver. The chaplain or social worker visits a patient for an initial assessment only to find that the patient has developed severe dyspnea. How to respond? A high functioning palliative care team will train and empower each team member to be a specialist in their discipline and generalist in the bio-psychosocial-spiritual care of human persons living with serious illness. However, for reasons well beyond the scope of this article, this specialist-generalist model of team functioning seems to be most challenged when addressing the overlap between the medical and spiritual aspects of care. To illustrate, consider just a few of these cross-discipline patient statements:

"Doctor, I know you told me to take the pain medicine, but my soul is being purified to meet God by the pain I am enduring."

A patient and retired priest to the nurse: "I want all the

treatments you can possibly give me, I don't believe in God anymore, I believe in science."

Are these statements expressing medical issues, spiritual issues or both? And, if both, might statements like the above be pointing to a deeper tension intrinsic to the challenge of providing whole person care?

In the book Whole Person Care: A New Paradigm for the 21st Century, edited by Tom Hutchinson, Dr. Hutchinson states that palliative care clinicians have "two jobs that need to be carried out simultaneously: curing is an activity carried out by a healthcare practitioner to eradicate disease or fix a problem; healing is a process leading to a greater sense of integrity and wholeness in response to an injury or disease that occurs within the patient, which can be facilitated by the healthcare practitioner. And the difficulty is that the roles of both the patient and the healthcare practitioner in curing versus healing are not just different, they are diametrically opposed."[2]

A second look at the patient statements above illustrates a similar tension. The patient forgoing pain medication and "enduring" her pain so that her soul will be made ready to meet God is prioritizing her healing over a cure for her physical pain. The retired priest is expressing his hope for a cure, possibly after becoming disillusioned with God in the absence of healing from illness. Holding this tension between curing and healing is the essence of whole person care.

Reframed in this way, the role of the whole person care provider is to facilitate a shift away from disintegration, disconnection, and suffering whether expressed as physical, mental, emotional, spiritual, or relational distress, and toward a sense of integration, wholeness, and well-being.

It is often said as a scalpel is to a surgeon, so the goals of care conversation is to the palliative care clinician. As it has been well documented, an expertly facilitated patient or family meeting can reduce unwanted medical care and increase the chances that a person will receive care that aligns with their values, goals, and preferences, among many other benefits. Expertly crafted tools such as Ariadne Lab's Serious Illness Conversation Guide[3] and Weissman's et al. steps for conducting a family meeting,[4] outline the necessary elements of an effective goals of care conversation. These include opening introductions, exploration of the patient/family's understanding, sharing diagnostic and prognostic information, addressing patient emotions, discussing options for care, and then translating the entire discussion into an agreed upon plan of care. However, considering the patient statements above, it is not immediately apparent how a conversation guided by these steps might open the way for healing, or even more, how they might "prepare and hold the space where the miraculous may happen."[5]

Seeking to address this gap and hold the tension between the dual obligations to cure when possible and heal always, the Supportive Care Coalition with palliative care physician Dr. Woodruff English created and piloted a goals of care

conversation protocol. The protocol was designed to open the way for existential, spiritual, and psychosocial sources of patient and family suffering to emerge, be expressed, and addressed. For the sake of comparison, Weissman's 10-step and the 10-stage models are outlined below:

David Weissman's 10 steps for conducting a family goal-setting conference	Supportive Care Coalition's 10 stages for goals-of-care conversations
Establish proper setting	Planning and the first encounter
Introductions	Briefing and intentional spiritual grounding
Assess patient/family understanding	Introductions/build relationship
Medical review/summary	What does the patient/family know?
Silence/reactions	What have the patient/family been told to expect?
Discuss prognosis	Medical review and prognosis
Assess patient/family goals	Be present for lamentation and suffering
Present broad care options	Offer options and recommendations
Translate goals into care plan	Summarize, express gratitude and hope, plan next steps
Document and discuss	Debrief and document

Adapted from: Weissman, D. E., "Conducting a Family Goal Setting Conference" pocket card; Palliative Care Center, Medical College of Wisconsin, Milwaukee, 2010.

Table 1: From English W, Picchi T. "Spiritual wisdom, a component of care." Health Progress. Jan-Feb 2014, 50-54.

At first glance, much of the two models appear to be the same. They both emphasize that first impressions matter. Careful planning of the initial patient/family meeting along with attention to important details such as introductions to establish rapport make a difference in the quality of what comes next. They both emphasize the importance of good communication. Sharing diagnostic and prognostic information in non-technical language is as essential as arriving at an agreed upon plan of care. Yet, in the midst of these and other similarities, there are several key differences:

- **Stages instead of steps**: The "10-stage" instead of "10-step" designation is intended to evoke the image of acts in a play, movements in a dance, or scenes in an improv routine. While steps tend to occur in a prescribed order, stages will occur as the team follows the lead of the patient and family. Some of the stages, such as the briefing/spiritual grounding, introductions, and debriefing/documenting, will happen at the opening and closing of the encounter, while the order of the remaining stages is determined by what arises as the team listens deeply to the spoken and unspoken communications of the patient and family.
- **Briefing and intentional spiritual grounding**: The 10-stage model assumes that multiple members of a palliative care team will not only be present at the family meeting but also that the team will gather for their own pre-meeting. During this time they will share relevant clinical information and engage in some form of centering or grounding practice. The model does not dictate what this grounding practice might look like, but instead suggests that the team find practices that assist them in setting aside their own non-relevant concerns or personal agendas so that they might be more fully present to the patient and family. Possible grounding practices can include pausing together for several moments of silence, reading a short poem aloud, or sharing a brief period of mindfulness meditation.
- **Introductions/build relationships**: In addition to sharing names and their relationship to the patient, at appropriate moments during the conversations, meeting participants are invited to enter into deeper conversation through questions such as:

    - "What do we need to know about you/your loved one to give you the best care possible?"[6]
    - "Can you tell me about (patient), what kind of person is he/she?"
    - "Where are you finding strength to get through this?"
    - "What are you hoping for?"
    - "Given all that is happening, what is most important right now?"
- **Be present for lamentation and suffering**: The discussion of the patient's diagnosis and prognosis can precipitate profound spiritual and emotional distress. Rather than attempt to dismiss, brush past, offer platitudes expressions of suffering, this conversation model encourages the palliative care team members to simply be compassionately present, grounded, attentive, and aware. Suffering, unlike physical pain, is often best honored with attuned silence, straightforward validation, and empathic acknowledgement. Pausing the conversation to recognize and name the suffering is much more important than trying to bypass or fix it.
- **Express gratitude**: While this may be the palliative care team's fourth or fifth family meeting of the day, this is likely the first time the patient/family have spoken to medical professionals in this way. Expressing genuine gratitude for the patient/family's willingness to participate, be open, and candid is an important way to acknowledge the courage and vulnerability shown during the conversation.
- **Debrief and document**: Each family meeting is an opportunity for the team to increase their skill level through a regular practice of giving and receiving

feedback. Additionally, in this model, each family meeting is an opportunity to foster greater team member self-reflection and self-awareness by briefly exploring their thoughts, feelings, reactions, and behaviors in a post-family meeting debrief. During the debrief the team regularly asks and answers questions such as:

- What did we learn about the patient/family?
- How did we feel the meeting went?
- What did we learn about ourselves, as individuals, and as a team?
- How satisfied are we that as a team we listened intently for the patient/family's spiritual concerns, beliefs, and values and integrated these into the discussion?

Over the span of three years, this 10-stage model was piloted with 20 palliative care teams from hospitals across the US. All of the teams were trained to use the model and record self-evaluation data on their effectiveness in integrating these new behaviors and principles into goals of care conversations. Participants consistently reported greater attunement to patient/family suffering, increased confidence in exploring patient and family existential and spiritual issues, and increased commitment to team self-care activities such as pre-meeting spiritual grounding and post-meeting debriefing.

As providers of whole person care, palliative care team members are uniquely positioned to attend to the physical, mental, emotional, spiritual, and relational aspects of human

persons, as well facilitate healing when a cure is not possible. This opportunity may be lost when the most important palliative care intervention, the family meeting, is approached from a “tick off the list” point of view. Pain and symptoms discussed? Check. Diagnosis and prognosis? Check. Psychosocial and Spiritual concerns? Check. Instead, this 10-stage model invites palliative care practitioners to approach the family meeting as an “I-Thou” encounter,[7] as a liminal or safe space where the “shy soul”[8] can appear. It is in this approach that the team becomes like an alchemist’s vessel[9] – a vas bene clausum – a container for the patient/family’s suffering, fears, and longings, and a place where healing can happen. If you are interested in learning more about the work of the Supportive Care Coalition and our spirituality toolkit, please visit our website: https://www.supportivecarecoalition.org

References:

[1] See Akron Children’s Pediatric Palliative Care website for background on this very apropos nickname for the palliative care team. https://www.akronchildrens.org/cms/sharing_blog/53994c22a59bb57c/index.html

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[3] https://www.ariadnelabs.org/areas-of-work/serious-illness-care/resources/#Downloads& Tools

[4] See Fast Facts 222-227 at https://www.mypcnow.org/fast-facts

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New Fast Fact Released: #363 Opioids for Neuropathic Pain

Fast Fact #363 has been relased: Opioids for Neuropathic Pain.

Thanks to our authors, Linda Huang, Dilafruz Khakimova, and Jennifer Pruskowski for this new addition to the Fast Fact Library.

Clinicians who care for dying patients with neuropathic pain

may struggle in deciding whether it's best to initiate or dose-escalate opioids vs a non-opioid adjuvant analgesic for the neuropathic pain. This Fast Fact provides a clinically relevant review of the evidence on opioids for neuropathic pain.

New Fast Fact Released: #362 Parkinson's Disease: Part 2 Palliation For Common Non-Motor Symptoms

Fast Fact Released: #362 Parkinson's Disease: Part 2 Palliation For Common Non-Motor Symptoms.
Thanks to the authors, Danny Estupinan, MD, Alva Roche'-Green, MD, Maisha Robinson, MD, and Robert P. Shannon, MD for this new addition to the Fast Fact Library.

My dedication to this growing specialty remains strong and this conference helped to remind me of why

Well the first day of the 7th annual Regional Palliative Care Conference was a success, for me, Connie Basina SSM health Palliative Care RN embedded in the oncology clinic. I have not been in my role an entire year yet so I am quite a newbie at this work and wholeheartedly embraced a chance to learn more.

This conference is the first one I have been able to attend, I am so very pleased I made it with the help of the David Weissman scholarship. Without their support I would only be hearing about it from others. So let me say, please PCNOW, continue to offer this generous leg up for folks like me that otherwise would not have made it. That being said, I was asked to share a few bullet points about what I have learned from the conference. I was able to attend both days and have Thursday under my belt. I always learn so much from Toby Campbell. For anyone that has not heard him present, I highly recommend him, his skill in Palliative interactions seems legendary to me, wow, he makes the skills look incredibly easy but I am not that naive. An NP I worked with once said, it is simple but NOT easy, isnt that the truth.

So, I guess the first thing I learned is this truly is a skill. It must be developed, practiced and honed. This is only done by practice and allowing yourself to make mistakes, not beating yourself up if you make a misstep or don't come across as therapeutic as you had hoped. The patient will help you to know if you are on the right track. Also don't avoid role playing, as it is a great way to learn. The other "simple" skill is listening, but actively, it is an art, that of listening, I mean really listening. Once you master this skill and get comfortable with silence many other things are much easier.

I also learned a simple statement that might help me open the door for someone, " Would you like to talk about what this means?" That is powerful, and gentle and shows we aren't going to shy away from the tough discussions that some patients are needing. That is quite a privilege for me to be a part of that. I also enjoyed the session about mental health in the Palliative setting. I learned about the prevalence of depression and grief in the terminally ill population, and they are not one in the same. I also learned that acceptance is not necessarily the end result of our talks with patients. That may never be and that is okay.

Well, as you could guess, I could go on and on, but I better wrap this up, I need to get to the Friday sessions that start in about an hour. Thanks for listening about my journey!

*********Day 2*********

The final day of the Conference was just as invigorating as the first. We again had amazing speakers and I was surrounded by some of the best practitioners I have ever met. I certainly realize that no matter how long you have been at this type of care we never want to stop learning how to best deliver it!

I learned about the big picture benefits when Palliative care is implemented early from improved symptom management to decreased hospital costs to decreasing hospitalizations all together. Despite how amazing and rewarding Palliative Care is as a specialty there are limited staff resources.

The program also requires care and encouragement to grow. We can as a whole, improve the awareness of Palliative Care through advocacy, cultivating the workforce and engaging in research. We can all foster growth by doing even the smallest things, such as offer for shadowing opportunities to staff interested in how Palliative Care can dove tail with their work and help their patients.

I was also encouraged to hear that Wisconsin gets an “A” for its availability and accessibility to Palliative Care, compared to other states in the Union. My dedication to this growing specialty remains strong and this conference helped to remind me of why.

I have enjoyed the topics offered and feel that what I have learned here will enrich the work I am carrying out here at

SSM Oncology. Thanks to PCNOW for making this opportunity happen for me. Hope to see you next year!

Are you living the life that you want?

I'd like to start by thanking PCNOW for allowing me to participate in this year's conference through the David Weissman scholarship. What a wonderful opportunity to continue my learning and network with others providing Palliative Care services to patients and their families.

When you are reading this, I will be on vacation with my family viewing the beautiful landscape and waters in the great state of Alaska. Family is one of the most cherished blessings I have in my life. Working in the palliative care field has taught me to take time with those you love.

Like most other conference participants, I worked part of the day on Thursday and then drove down to Lake Geneva. It was wonderful being able to gather and meet other members of our systems' Palliative Care team as well as other conference attendees over snacks and dinner. The ability to network with others doing similar work is so valuable as it reminds me that

we are part of a group of people working to improve the quality of life with those facing chronic and life ending illnesses. We don't work in isolation, but rather as a team to support one another.

There were a couple of themes that I'd like to share as a framework that fit in with the name of our organization, PCNOW: Passion, Compassion, Now, Opportunity and Wisdom.

Passion is a word that came to mind when listening to a case study about a medical student that was diagnosed with a serious illness and was faced with now being patient vs the doctor that he was training to become. I left that session being reminded to live my life with passion. Live each day fully. Be present in the moment. We don't know what life has in store for us, just as that young medical student didn't, so whatever is most important, pursue it with passion.

Compassion is a word that was used by one of the speakers in regard to how we approach our work with patients. Compassion for others is a critical attribute to possess. When plans change, tapping into our compassion helps us to ease some of the stress and sometimes frustration that arises for staff in needing to make adjustments to the changes. Sometimes I struggle to show compassion for myself. I hope to have the words to make a difference in very difficult circumstances, but the truth is sometimes there are no right words, but just being present with compassion in what is most important. The journey we are on with our patients is a sacred journey and

they need to figure it out at their pace and in their own way.

Now is the time for doing what's most important. Life is a precious gift. We don't have a crystal ball and don't know what our future may bring, so taking each day and making the most of our time is important. Focusing in on what is the most important things to do can be hard when there are many "distractions" competing for our attention. Do we get caught up in these distractions or do we stay focused on what's most important to do now? I know this can be a challenge in the midst of hectic days and competing priorities. The "someday" may never happen so living an authentic life. I have learned that living an authentic life can help do what's most important now.

Opportunity knocks in a variety of ways. When standing at a crossroads, how do you assess that? In Palliative Care we talk about quality of life with our patients. What is important for them and how do they want to spend their time? They have an opportunity to make decisions between treatment options and sometimes are expected to make decisions very quickly when presented with what can be an overload of information during a very emotionally difficult time for them. How do we assist them in thinking through their options for care? How do we provide a sense of support when they choose a plan that is different than what staff and others see as the better options? There is much thought I've done about this since length of stays in hospitals are shorter and patients are faced with making difficult decisions. I continue to believe there is great opportunity for Palliative Care to be

integrated into primary care and community settings. This provides more time for conversations with people as they journey through managing their health issues and helps to prepare them for decisions they may need to make ahead.

Wisdom is the last word that I have been pondering since being at the conference. I am struck with the amount of wisdom and experience that presenters possess. They share their wisdom in a topic area so we as participants can learn and increase our knowledge. Honestly, there are times that I feel a bit overwhelmed with the information shared as I have so much yet to learn. Each session attended provided me with more medical information and understanding that impacts my work as a Social Worker.

Periodically, something happens that triggers my thoughts back to the conference. The other day I was watching a tv program, “The Talk” while sewing. Oprah Winfrey was talking about the question she asks herself when there is negativity or an issue she’s dealing with. The question was “Are you living the life that you want?” It struck me that this fits right in to the discussions I heard in sessions at the Palliative Care conference.

For me, living an authentic life with a grateful heart helps me to continue to focus on the things that are most important. It brings meaning to what I do. Each day is a new beginning. Living life fully means taking one day at a time and being present in the moment. I tend to be a planner, so this can be

a challenge for me.

I thank you for the opportunity to step out of the usual daily routine, meet with colleagues, feel refreshed and help me re-commit to living fully each day.

Passion
Compassion
Now
Opportunity
Wisdom

With gratitude and appreciation,
Susan Scheller Kirby, MSW CSW

A Thank you to Barbara Bush: How her end-of-life could pave the way for Palliative Medicine

No matter what your politics are in the world today, we can all recognize that the Universe has lost a graceful, honest

and strong woman this month of April, 2018. Barbara Bush not only left a long legacy of being the First Lady, mother of a president, advocating for improved childhood and adult literacy but her last act may have a long lasting impact on how people choose to not only live their lives but also how they die. Mrs. Bush chose a dignified, comfortable death on her own terms without aggressive measures during her last stage of life. Mrs. Bush chose comfort measures rather than another hospitalization or ICU admission. Comfort measures, what does this mean? Comfort measures is an approach to patient care which focuses on symptom management while avoiding aggressive, disease specific treatment. The goal of comfort care is to allow the patient to have a better quality end of life with a natural death not prolonged by artificial means.

When a person is nearing the end of their life, they, as well as their care team and family, may be struggling with that most difficult question, “when is enough, enough?” This is where open and honest discussions that are ongoing from diagnosis throughout treatment can make all the difference. Discussing all options, True Consent, needs to be a conversation that specialists and primary care providers have at every visit with their patients diagnosed with life-limiting illness. These discussions may initially be difficult but if you start early in the diagnosis, these conversations can become welcoming, empowering and natural.

How do you start these conversations? An excellent start is asking your patient who was just told that they have a likely

terminal illness, “what is your greatest fear?” They may tell you that death is their greatest fear but much of the time, this is not what I hear. The more common responses are fears of pain, nausea, not being able to eat and most commonly is the fear of leaving loved ones, what will be missed, that wedding or baby being born or that graduation. Opening the door to discussing these fears which started the moment you delivered the bad news allows that person to work through the emotions which could plague their treatments. If you do not address these fears early on, they can transform into anxiety, depression, uncontrollable pain and “non-compliance.” Allowing the patient and their family to address these fears early and often can make the journey moving forward a rewarding and beneficial partnership not only for the patient and family but also for the clinicians. Allowing people to face these fears gives them permission to make those difficult decisions early, plan for the end of their life, adjust family events and bucket lists and start to develop goals of care.

Once goal setting happens, the patient-family team feels empowered and have more energy to focus on healing and living. The providers and treatment team, surprisingly, also benefit from this care planning and goal setting because it takes failure out of the discussion and rather allows the focus of treatment to be on allowing the patient and family to work toward life goals and to face these fears together. Sharing some of these fears together in an open and honest communication freeway (the provider worries they may not be able to treat this disease to the point of cure or that the treatment might cause more harm than good) opens up new doors to a partnership in the treatment plan moving forward; the

gift of “True Consent.” By having true consent, there are no longer winners and losers, failures and successes but rather moments which will come and be dealt with on a day by day basis. Taking each day as they come with a plan in mind of the worst and best case scenarios already considered allows for relief, oscillating goals and planning for the future. Instead of focusing on the 1-2% chance of cure, you can focus on the goal of quality for as long as possible and prognosis becomes a time range rather than trying to come up with a specific time (using weeks to months or months to years rather than saying, “on average people live 6 months with this diagnosis.”)

I do understand that the hospice and palliative community would have preferred that hospice be involved in Mrs. Bush’s end-of-life plan but none of us were there at her goal setting and plans of care. It may be that she had hired private hospice caregivers to allow her to have comfort measures on her own terms or she may have had a personal desire to die with specific people present with whom she had worked for many years. It is really none of our business what decisions she made. She chose to allow the information about her decision on comfort measures to be shared with the world. None of us were there for that discussion but we can all appreciate the fact that she made it very clear she was going live the end of her life the way that she lived all of her life, independently, on her own terms and with great strength and grace.

We all need to thank Barbara Bush for what she has done for palliative medicine. Her graceful death, while choosing

comfort measures, will have a positive impact on health care and all of our lives for years to come and may help us reframe the conversations we all have or need to have with our patients.

The "101" Palliative Care Encounter: What is It?

Copious well-designed studies have confirmed the value of palliative care consultations for seriously ill inpatients and outpatients with a wide variety of cancer and non-cancer diseases. This has led to Palliative Care trigger projects and other integrated, system-based practice approaches to foster broader and more reliable access to palliative care consult teams earlier in an illness trajectory. But what does a palliative care consultation entail? Is it uniformly performed across all palliative care clinicians? Institutions? If you randomly plucked a palliative care clinician from a random institution in the US, would he or she be able to reproduce the palliative care interventions that were proven to be effective for metastatic non-small cell lung cancer patients in the often-referred to Temel study? For many referring clinicians, a palliative care consultation is imagined as a "black box" from which patients often emerge with new direction in care and a new symptom management plan. I worry that this creates a mystified sense of the work we do. After

introducing yourself as a palliative care clinician, have you ever had a clinician say to you: “you must be such a special person to do what you do. I don’t know how you do it.”

I’ve heard such a phrase multiple times in the 10 years or so I’ve been practicing palliative care. Initially, I guess it made me feel a little warm and fuzzy inside. But after the honeymoon wore off, I now find myself bristling a bit if I hear comments such as this regarding palliative care work. Although I’m 100% convinced the work we do is needed, I am not 100% convinced our work is truly “special”. In fact, often I feel amazed that I get paid to offer what are often common-sense, big-picture assessments and recommendations to experienced clinicians, even specialists of patients with, yes serious, but also common-place medical problems. But more so, it is the last sentence of a comment such as this, that I find myself ruminating over in a very literal fashion. I think I’ve been misinterpreting the most plainly stated portion of a comment such as this: many clinicians aren’t marveling at our emotional stamina to the work in palliative care or marveling at our empathetic reserves, they really want to know, what do we do in a palliative care encounter.

I think there could be great benefit to our patients, clinicians, and the larger health care system if we can demystify our work. One step toward making our work more reproducible and understandable, would be to articulate what a “101” or basic Palliative Care Consultation should entail. Perhaps by doing so:

- Referring clinicians and patients would have a better anticipation of the systematic process involved when palliative care teams make independent assessments and recommendations to address unmet palliative care needs.
- Less experienced clinicians and clinicians-in-training may have better confidence and direction in performing palliative care interventions when rotating or onboarding on palliative care consultative teams.Documentation of palliative care consultations could be better standardized.

What do you think? Do you feel there is a need for our field to develop a more broadly referenced, agreed upon, and reliable guideline on how to do a Basic “101” Palliative Care Encounter or Palliative Care Consultation? Is such a goal achievable? If so, what do you feel should be essential components in a basic “101” Palliative Care Consultation?

Marla shares her experience after a loss of a loved one

This past summer my mother-in-law died after a long illness. At the end the family gathered to keep vigil, sharing memories and talking quietly to Mom to let her know how much she was loved. Although as a caregiver I have held the hands of many

dying patients, this was different; this time I felt out of place, as if I had forgotten something important. Yes, I was sad, but why was I so…edgy?

As a nurse, I was accustomed to caring for the dying patient and their family. There was always a task to do…wetting dry lips, locating a box of tissues, praying with a patient or holding the hand of a grieving spouse. What does a caregiver do when someone else is doing those tasks? When there is nothing left to be "done"?

On reflection, I discovered that it is OK to simply "be" at the bedside. That just my quiet presence is enough to honor and respect the one I love. I have learned that it is important to take care of me…that it is necessary to grieve for the loss of that person's presence in my life. And I have discovered that accepting the care offered by others helps them to cope with the pain that they feel, and helps me to heal as well.

Mom taught me much in life. As she died, she taught me to remember that it's OK to step out of the professional role and simply be a family member. It's not easy, mind…but it's a necessary part of the grief process.

Blessed Be,
Marla