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Best Practices for End-of-Life (EOL) Communication

Presented by Heidi Randen* 42 minute webinar * 03-22-2012

Janelle Shearer: I would like to begin our educational session today, named Best Practices for End-of-Life Communication. Our presenter today is Heidi Randen, who received a degree in Journalism from Northwestern University in 1990 and is a second career nurse, having worked for nearly 20 years in marketing and communications promotion for profit and non-profit organizations.

She has worked as a volunteer for the Minnesota AIDS Project and her personal experiences with hospice have inspired her to seek out a new career in nursing. She recently received a degree in nursing from the University of Minnesota’s School of Nursing December 2011 and hopes to eventually specialize in palliative care.

Heidi, thank you for presenting to us today.

Heidi Randen: Thank you so much. Good morning. I’m here this morning with some evidence-based best practices for end-of-life communication. I hope you have your handout. The opening quote is from the novel Cutting for Stone by Abraham Verghese, an Internist and Professor at the Stanford School of Medicine. I think the advice here is given by a doctor who trains medical students in his novel and it sums up the essence of providing a therapeutic presence for patients when they’re in distressing situations.

This presentation was developed for new nurses and not as healthcare workers. As a new nurse myself, I’m not sure if I have anything to offer seasoned professionals, I’m not sure if I have anything to offer seasoned professionals such as yourselves, but I hope I can show what people starting out in healthcare really need to understand about end-of-life communication and how it relates to palliative care in Hospice.

This presentation is designed to help novice healthcare providers learn about end-of-life communication in the following ways:

→ Understanding the fundamentals of good end-of-life communications
→ Practicing applying these fundamentals in hypothetical situations
→ Integrating the fundamentals into their practice
→ Reflecting on their own experiences of what they bring to end-of-life communication
→ Developing a greater appreciation for the benefits of good end-of-life communication
→ Opening to the possibility of continuing to developing these skills

My presentation today will have three sections. We’ll discuss some background on good end-of-life communications and then I’ve grouped best practices according to the stage of your relationship with a patient. Finally, we’ll have a section on advanced care directives.
We’ll start with some background on end-of-life communication, why it’s good to develop these skills and why it may be challenging to develop these skills, what good end-of-life communication entails and how these skills may develop as you become more experienced in your practice.

The basic benefit of end-of-life communication is that it helps to make death less frightening. Death is always scary but doesn’t have to be frightening. Patients are able to retain more control to make better choices about their care. In a study done by Wright and El Jawari, patients who had end-of-life discussions with their physicians had lower rates of mechanical ventilation, resuscitation and admission to the ICU.

In a study by Chang, healthcare costs in the final week of life were 35% lower for patients who reported having end-of-life discussions with their physicians. In the same setting, higher costs were correlated with greater physical distress during the final week of life and a worse quality of death as reported by caregivers.

Good end-of-life communication can be of benefit to healthcare workers as well. A qualitative study of Hospice nurses found that they listed many personal benefits to working with dying patients which included– personal growth, opportunities to confront ones own death, increased sales knowledge and deep and personal faith, transcendent experiences and more realistic expectations about life.

Here is my favorite new concept– compassion satisfaction– we’ve heard so much about compassion fatigue but now they’re actually doing studies on compassion satisfaction. A study by Caspian/Clopper, two nursing researchers from South Africa, define compassion satisfaction as “the invigoration and inspiration that a nurse receives from connecting with and sharing in a patient’s suffering, with the main focus being to relieve and alleviate the patient’s pain through the selfless use of one’s self and one’s skills and available resources.”

They write that the ultimate reward of this compassionate and competent care is the opportunity to see patients suffer less and change for the better, which in turn allows nurses to feel a sense of joy and fulfillment that energizes them and leads to retaining a high morale, to thriving in the workplace and to enthusiastically meet patient’s needs regardless of circumstances.

There are some barriers to good end-of-life communication. Our culture as a whole has difficulty dealing with death it’s viewed more as a failure rather than a natural part of life. A social worker quoted in a qualitative study by Stein Houser says “When it comes to death, you carry all your own baggage with you. You may think you’re meeting the patient where they are, but you’re also meeting the patient where you are. It’s hard to navigate your own stuff while trying to help someone else.”

In addition to our personal feelings and experiences with death and dying, there are elements inherent in the structure of healthcare delivery that can make it difficult to provide good end-of-life communication. These elements have been explored and some qualitative phenomenal logical studies by Lea Shanko and Stein Houser. Healthcare workers struggle with workload and prioritizing tasks in a limited amount of time. They may also be working with a team of other healthcare workers who aren’t all on the same page about a patient’s prognosis.

It’s easier to engage in end-of-life communication when there is consensus that that a patient is at end-of-life. Healthcare workers are also constrained by limited experience with the patient’s and their families. If you haven’t had the opportunity to provide care over a long period of time it can be difficult to establish the rapport necessary to discuss end-of-life issues during a single encounter as a provider or a single shift as a nurse.
Patients tell us that good end-of-life communication really helps them and the ways we can do this is by being available in the therapeutic process. Listening may be as or more important than speaking. Being available includes being present, talking and answering questions, sharing similar experiences, always telling the truth and using humor.

Nurses tell us that good end-of-life communication involves helping disheveled patients and families through the experience of taking in medical information, making sense of it and processing it emotionally. Helping patients and families to move through their reactions and emotions, helps them make the best decisions for end-of-life. Nurses in the Lea Shanko study, referred to this as helping with the big picture. This includes coordinating and interpreting information for families, listening to families to build trust and attempting to create an individualized culturally appropriate environment for end-of-life care.

Cathy Lee & Perrin differentiate between basic and advanced end-of-life communication and it can be helpful for novice healthcare workers to understand that these skills develop over time. Basic skills include acting as an advocate and intermediary for patients and families, which can include interpreting bad news, listening to discussions and being present with a patient as family member when death is expected.

As we grow in our practice more advanced skills involve initiating discussions related to end-of-life care, actually delivering the bad news, offering end-of-life treatment options, discussing organ donations and helping families when death is unexpected.

Perrin stages end-of-life communication into three stages that she says are parallel to the dying trajectory.

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<th>Introductory</th>
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<th>Terminal</th>
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The introductory stage includes getting to know the patient and defining their problems and their relationship with you. Perrin stresses the importance of conveying respect and using therapeutic communication techniques. The introductory stage may not be the right time to discuss end-of-life unless a patient brings it up.

As you’re getting to know a patient it’s important to know about individual preferences to ascertain any cultural considerations. Personal autonomy is not valued in all cultures or family systems. This question is recommended by researchers when doing cultural assessments. Some patients want to know everything about their condition, whereas others prefer that we speak with their families.

**How would you like to get information?**

Here’s our first case study to help get novices thinking about their end-of-life communication skills. Delia is a 90-year old woman with osteoporosis and mild heart failure. She’s had a fall and hip replacement surgery. She has completed an advanced care directive and chosen to allow natural death. She’s also developed complications following hip replacement surgery.

What questions would you ask in getting to know Delia? Some healthcare workers to abort older adults may interpret this situation as the beginning of the end for Delia, but Delia may not perceive that she is at the end of her life and it would be very disrespectful to treat her that way. It’s best to start by getting to know Delia and her story.
As we get to know her as a whole person and ask about what gives her comfort and support, we can then begin to go forward with what she needs. Once you know a patient and have built up a level of trust you can enter into the working stage of communication. Perrin recommends that you make communication as patient-centered as possible to explore the patient’s perspective about their goal and their feelings about death and dying.

When patients with advanced cancer were interviewed they identified the following preferences... making good use of time when communicating, not acting rushed, making eye contact and engaging in active listening. It’s always important to sit at eye level and use touch as appropriate to help people understand that their healthcare provider is an ally. It’s also important to acknowledge and validate the patient’s response to their situation. This helps them to feel less alone. Mentioning options, even when they are palliative rather than curative helps patients to feel supported rather than abandoned.

At this point we’ve gotten to know Delia rather well. She’s lived independently up to this point but she understands that her hip incision is not healing and IV and antibiotics have not wiped out the infection in her hip. When she’s conscious it’s hard for her to grasp where she is and what’s happening and she appears to be bringing up the subject of death. Even though we hope for the best, now may be the appropriate time to find out how Delia and her daughter perceive the situation and discuss what Delia’s care plan should be if it appears that she won’t recover from the hip replacement surgery.

The Spikes Pneumonic protocol was developed by an oncologist based on his own experiences as well as review of literature. The usefulness of the techniques suggested by this pneumonic have been confirmed by other studies. Robert Buckman, the developer of the Spikes Pneumonic Protocol, offered this quote from a colleague on delivering bad news to patients. “Doing this job badly will never be forgiven. Doing it well will never be forgotten.”

How you deliver bad news is important. Doing it in a way that acknowledges the significance of the person receiving the news and the reaction to the news helps to prevent causing emotional injury beyond the content of the news. Here is the Spikes Pneumonic in a nutshell...

S – creating an appropriate setting
P – assessing patient’s perception of the situation
I – seeking an invitation from the patient to deliver information
K – providing the knowledge
E – exposing emotions and responding in an empathetic manner
S – partnering with those patients to create a summary and strategy

→ When creating an appropriate setting, don’t initiate conversations unless you are able to spend some time engaged in active listening.
→ Find a private space for you and the patient to talk.
→ If the patient has had an exam than give them a chance to get dressed.
→ Try to sit or be at eye level with the patient to reduce the power differential.
→ Remove physical barriers like, not sitting behind a desk, try to move the patient’s tray table off to the side and minimize distracting noise.
→ Ask that the television be turned off while you talk.
→ Be sure to re-introduce yourself to remind the patient who you are and how you provide care.
→ Finally, make sure there is a box of tissues within reach.

Begin asking the patient what they know so far about their current medical situation and what they’re thinking or feeling.
Be sure to note any disconnection between the patient’s perception of the situation and the information in their medical records. Asking about their perception helps you to gauge the patient’s comprehension of what is going on, as well as their level of medical knowledge. This will help to tailor your responses to their questions.

It’s also important to ask for an invitation from the patient to deliver bad news. Just as you want to make sure that you have time to be engaged in active listening, make sure the patient has time to be engaged in active listening as well. One way to do this is simply to ask, shall I go on and give you all the details of the most recent tests and what we recommend? Be sure to respect the right of the patient to decline this information or to choose to receive such information in the presence of a family member or support person or to have this information passed on to a representative.

Once the patient has invited you to share this information, explain the information gradually. Be sure to use the same level of language as the patient. Take breaks to respond to the patient’s reaction and confirm that they understand each piece. Respond to any denial with empathy rather than judgment. Acknowledge this must be hard to take in. Finally, allow for periods of silence, which allows patient’s to understand new information, form a reaction and respond with questions. Also note that as a patient’s anxiety level increases, their ability to take in new information decreases.

This is the part that stumped me a little when I was reading the Spikes pneumonic. Dr. Buckman explains how to be empathetic, like he’s dealing with Vulcan’s from Star Trek or people with sever Asperger’s, but here is empathy 101 according to Dr. Buckman.

1. Name the emotion the patient is experiencing.
2. Name what is causing the emotion.
3. Show that you can connect the cause to the emotion.

When I gave this presentation to some oncology nurses, they very diplomatically noted that instead of using Buckman’s empathy 101, it might be better just to check with the patient and clarify what they’re feeling. Someone may look very sad to you but then tell you no, I feel mad as hell right now. One of the oncology nurses often tells people, it looks like you’re having a lot of different emotions right now.

As you close the discussion you want to end with a summary to make sure people understand what you’ve said and set up a strategy so they don’t feel left alone with what you’ve shared with them. It shows that you care what happens to them. You can do this again by clarifying the patient’s understanding and working with them to create a detailed plan to provide support. This provides support for the patient as well as support for realistic expectations.

Here is a case study to help novices think about how they might want to imagine delivering bad news. The Spikes Pneumonic can be used, not only to deliver bad news to patients but also when passing bad news along to people who are close to the patient.

In this case, Darren is a 44-year old man with advanced pancreatic cancer. He is in the hospital and right now he’s in too much pain to talk with his mother, but he asks you to tell her that he has cancer. How would you use the Spikes Pneumonic to deliver this information to Darren’s mother? You first want to find a private place in order to speak with Darren’s mother. You want to ask for an invitation and as you go forward you want to make sure she feels supported and she’s on board with how you’re going to be providing care for Darren.

As you’re helping a patient or family with the big picture, here are some things you can say during the working stage. I notice the advanced practitioners were talking to you, what did she say? Many people have questions about what this means for them. What questions do you have?
Never ever say there is nothing more we can do, even when nothing more can be done for curative care, phrasing the information this way will make them feel abandoned. It is better to offer palliative options and options for comfort care and reinforce that healthcare providers will continue to be on the patient’s team.

Perrin recommends initiating conversation about the patient’s emotional experience. Questions such as these let a patient know that it’s okay to talk about their feelings and that you care about providing them with resources so that they feel emotionally supported. If you get the feeling that a patient needs to talk about their feelings, just ask.

Spirituality and religion can offer comfort and support when people feel overwhelmed. Spiritual care has been identified as an essential component of palliative care by the National Consensus Project for Quality Palliative Care NCPs. Keep in mind that spirituality can include anything that gives meaning to someone’s life such as relationships, art, music, hobbies and pets. Always remember that a person’s spirituality is part of their deepest sense of being. Be respectful at all times and never use this as an opportunity to impose your own beliefs.

The following questions are recommended by Christine Pulski and Betty Farrow from the NCP.

What brings meaning and comfort to you?
How are you doing with all of this?
What role, if any, does spirituality or religion play in your life?

Making efforts to improve communication via interventions such as family conferences may not decrease lengths of stay or improve patient satisfaction, but they may improve long-term mental health of patients and family. Family meetings are a key component of helping with the big picture.

Assessing the patient and family’s understanding of life prolonging care and comfort care, and providing them with information as they need it can help to establish their preferences for life prolonging care vs. comfort care. Videos have shown to be an effective tool in helping patients gain a realistic understanding of life prolonging measures.

The terminal stage of communication often involves goals of helping the patient gain a sense of completion and helping the patient’s and their family say goodbye to each other, and explaining the changes observed in the dying process.

When dying patients and their families were surveyed by Pulski, many rated gaining a sense of completion to be as important as pain control and symptom management at end-of-life. Here are some questions to let a patient know that it’s okay to talk about these matters.

If you were to die soon, what would be left undone?
Is there an event that would add great meaning to your life?
What can we do to have that take place?

Here we return to the case study where novices can consider talking with patients during the terminal stage of communication.

Darren has opted to forego chemotherapy and instead is pursuing a palliative surgery that may help to reduce the pain he experiences as he dies. He has no way of knowing how long he will live, but statistics show that it’s not likely to be more than 12 months. Darren has two school-age daughters and has been a source of emotional and financial support for his family and he needs to close his business.
At this point Darren may be as concerned about emotional and financial matters as he is about medical matters. Identifying these concerns will help to find appropriate resources for Darren and his family. Hospice is an interdisciplinary approach to sick care that can assist Darren and his family with many of their immediate needs.

Palliative care physician Ira Biock has written extensively about this experience with patients who have died. He believes that expressions of love and forgiveness at end-of-life are crucial to help people die peacefully and to ease bereavement for survivors. These expressions can be summarized in four simple phrases.

Please forgive me  
I forgive you  
Thank you  
I love you

The most unsettling changes observed during the act of dying process may include the chain stokes respiration, changes in inaudible and skin temperature, and family members need to be reassured that these changes are normal, part of the dying process and do not mean that the dying person is experiencing pain.

People who are actively dying may also use symbolic language such as talking about preparing for a trip and seeing other friends and family members who have died. Try to encourage family members to go with this instead of contradicting the dying person.

This question can be helpful to open a discussion about changes observed during the dying process. When a person is close to dying, their breathing and appearance may change but it doesn’t mean they’re in pain. It would be helpful for me to explain these changes so you might know to expect.

After death, after IVs, tubing and equipment have been removed according to your organizations protocol, ask the family if they want to help wash and dress the body. This can be a very meaningful way to show care to someone they love and help to facilitate grief. Let them know that it’s okay to touch the body when they say goodbye. Also offer support to the family for any questions they may need to ask about autopsies and/or burials. Work as an ally with families to allow them to perform any rituals or practices that bring comfort and meaning to them during this time.

It’s also important for healthcare workers to maintain contact with the patient and family during end-of-life care. It provides closure to the therapeutic relationship and a sense of completion that eases the bereavement process. This contact can be as simple as a phone call or note. When a patient dies it can be helpful to both the family and healthcare workers to have everyone on the unit or homecare department to sign a sympathy card.

This last section is on advanced care directives, which are a crucial part of good end-of-life communication and really sets the stage for good end-of-life communication. Back in 2000, a longitudinal inaudible study of more than 9000 people with life-threatening conditions found that having an advanced care directive improved healthcare providers understanding of patient preferences, no better than chance.

We certainly hope that in the last 12 years, changes in the delivery of healthcare and improvements in communication by healthcare workers have improved, but the discussions between patients and their families and between patients and their providers are as important as the actual advanced care document, to make sure that family members and healthcare workers have a clear understanding of what a patient wants.
It's never too early to have an advanced care directive and there are opportunities to bring up the subject with patients at every stage of life. Don’t be afraid to bring up advanced care directives during routine visits. Research indicates that patients expressed greater satisfaction with their visits to physicians after receiving counseling for drafting a healthcare directive.

Find your own way of bringing up advanced care directives with patients. Let me provide you with two suggestions. Encourage new nurses and novice healthcare providers to draft their own advanced care directives. In addition to making sure everybody has one it helps them to approach the subject with greater empathy towards patients.

Here’s a case study to help a novice healthcare worker to find a way to bring up an advanced care directive…

Velma is a 74-year old African American woman with COPD. She is visiting her provider with her daughter for her annual influenza vaccination and to refill prescriptions. How might they ask Velma if she would like to discuss setting up an advanced care directive? Of course, you want to find out more about Velma’s story and her relationship with her daughter.

It would be good to gently ask Velma and her daughter if they’ve ever discussed who would speak for Velma if she were ever unable to do so for herself. Having a brochure with talking points may also be helpful for Velma to take away for her and her daughter to take home and discuss.

Research indicates that patients will volunteer preferences about CPR and intubation if healthcare personnel ask about these preferences early in their hospitalization. Asking about these preferences can help to increase the rate of advanced care documents during hospitalization.

End-of-life and advanced care directive discussions are correlated with lower rates of aggressive treatments and earlier referrals to Hospice care. Again, having an advanced care directive doesn’t necessarily mean that a family understands a person’s choices. Encouraging communication will help to improve the understanding.

Here are two resources, the first is HonoringChoices.org and you may have seen some pieces for this on public television recently. They have an excellent website and they’re set up to find appropriate ways for people from all different backgrounds to approach these discussions with their family. The step program is also something that can be integrated into other healthcare programs and it encourages end-of-life discussions between patients and their healthcare proxy.

We also need to ask and listen about cultural considerations about end-of-life care. Valuing individual autonomy over end-of-life decisions is common with European-American culture but may not apply to other cultures where decisions are made as a family or group. It’s also important to consider a person’s background, to not really have any judgment about the choices they make.

African-Americans and Hispanics make less use of Hospice services and opt for more aggressive end-of-life treatments than Caucasians, particularly in large urban areas. This disparity is not accounted for by cause of death, but appears to correlate more to socioeconomic status and access to healthcare throughout the life span.

Finally, patient preferences can change over time and over the course of an illness, so it’s important to keep asking and listening. Check in with patients to clarify their wishes as their situation changes.
That's the end of my presentation. I’d be happy to answer any questions you may have and I also welcome any suggestions or additions you may have.

Guest: That was an excellent presentation, thank you.

Diane Rothford: Hi, I’m with First Light.

You made reference to video to provide information for end-of-life care; do you have a name on that video or any special titles that come to mine?

Heidi Randen: They were recommending that individual facilities set up their own videos, but there are some on YouTube that are helpful and might give you an idea or that you can refer patients to. The study was done by Al Jawari which are listed in the references at the end of the presentation. They simply used video to facilitate end-of-life discussions.

Diane Rothford: Thank you very much.

Heidi Randen: You’re welcome.

Janelle Shearer: So you’ve seen the YouTube videos?

Heidi Randen: I’ve seen some of them yes and they’re very helpful for people to understand exactly what happens during a code and that it’s not like they would see on TV, which can help people make a better decision so they understand that even if they survive the code they may end up with brain damage, defibrillator burns…it’s not graphic but helps things to be a bit more concrete for people to understand.

Janelle Shearer: Could you find those links and email them to me so I can then forward them on to the group, because it might be useful to use for staff education and such. YouTube is great. Are there any other questions?

Guest: We pretty much align our palliative care services with our Hospice services, so families get a phone call followed by monthly newsletters and additional phone calls throughout that 13 months after death. We have great support groups, a children’s camp and we do speaking throughout the community and those kinds of things.

Janelle Shearer: So if a patient dies as a palliative care patient they are included in your program, okay.

In thinking about working with people from different cultures, and like you said not every culture values autonomy like the Western culture does, so I’m curious about experiences of working with folks that have that different viewpoint and how that’s worked out or how you’ve handled it?

Heidi Randen: I have another really good video that I can send just showing the right ways to talk about this and explain that if the patient does request information, even if the family has requested you not tell them anything that by law you need to share information with them, but to do it in a very respectful way. I’ll send you that link.

Janelle Shearer: Does anyone have personal experiences with other cultures in this way?
Guest: We’ve had some challenging experiences with some Southeast Asian families. I think it's hard as a Western-minded nurse to see the end of physical life coming soon and not seeing the patient or family aware of that or being prepared for it. We honor that they choose to do things their way, but it makes it difficult. We learn and work within the context.

We have to do staff support after that as well, because in our minds things could happen so much more smoothly, nicer or more peacefully, from our perspective so we have to deal with our grief over a non-ideal situation.

Janelle Shearer: Are there any other questions or comments?

Heidi Randen: I’d also like to offer a brochure and if you think of anyone on your staff that might benefit from that, feel free to make copies and get it out. It’s meant to be out there, so if it can be of benefit to new nurses and other novice healthcare providers that’d be great.

Janelle Shearer: You shared a lot of great tips and information, like the verbiage that’s best used for a variety of situations.

This presentation will be posted on the Stratis Health Palliative Care web page and I can send everyone the link as well as the audio, so you can use it as an in-service for staff you can.

Other items we want to discuss before we close out this session is that we have the next meeting lined up and held Wednesday, June 27 and I’d like to thank Mercy Hospital and Moose Lake for being willing to host us. That will be from 10:00 to 12:00 and you should be receiving information about it in the near future. The educational topic will be Caring for Patients with Deliria; we’ve had a lot of requests for talking about that.

These meetings are generally held quarterly so following that, the next meeting will be about providing palliative care in the homecare setting.

Thank you everyone for participating today. You will receive an email from me in the next day or two with a link to the evaluation because we’d like your feedback on this session and then suggestions and/or ideas for future sessions, educational topics or questions you may want to post for the group next time.

There will also be a certificate of participation for one hour of education which you can apply to your credits. Feel free to make copies and pass that out to the folks who participated at your site.

Have a good rest of the day.

If you have questions, please contact Stratis Health, at info@stratishealth.org.

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