Communication and End of Life Workshop

SYLLABUS

Communication & EOL Workshop Agenda

Time	Module	Faculty
9:00 AM – 9:15 AM	Welcome, Overview of Workshop and Introductions	Haley Buller
9:15 AM – 10:15 AM	Communication Skills for Physical Aspects of Care	Betty Ferrell
10:15 AM – 10:25AM	Stretch Break	
10:20 AM – 11:00 AM	Communication Skills for Social Aspects	Haley Buller
11:00 AM – 11:05 AM	Stretch Break	
11:05 AM – 11:55 PM	Communication for Spiritual Aspects of Care	Betty Ferrell
11:55 AM – 12:00PM	Wrap-up	Betty Ferrell

Faculty Biographies

Haley Buller, MSHSC is the Administrative Program Manager and the Project Director of Interprofessional Communication (ICC) and ELNEC Communication Projects in the Division of Nursing Research and Education at City of Hope in Duarte, CA. She holds a master's degree in Health and Strategic Communication with an emphasis in Patient-Provider Communication from Chapman University in Orange, CA. She was an Adjunct Faculty member in the School of Communication and the Crean College of Health and Behavioral Sciences at Chapman University. She has taught several courses to premed and pre-pharmacy students on interpersonal communication, patient-provider communication, and team communication. Working alongside Dr. Betty Ferrell, she has co-authored several publications in peer-reviewed journals on palliative care communication.

Betty Ferrell, RN, PhD, MA, FAAN, FPCN, CHPN, has been in nursing for 40 years and has focused her clinical expertise and research in pain management, quality of life, and palliative care. Dr. Ferrell is the Director of Nursing Research & Education and a Professor at the City of Hope Medical Center in Duarte, California. She is a Fellow of the American Academy of Nursing and she has over 400 publications in peer-reviewed journals and texts. She is Principal Investigator of a Research Project funded by the National Cancer Institute on "Palliative Care for Patients with Solid Tumors on Phase 1 Clinical Trials" and Principal Investigator of the "End-of-Life Nursing Education Consortium (ELNEC)" project. She directs several other funded projects related to palliative care in cancer centers and quality of life issues. Dr. Ferrell is Co-Chairperson of the National Consensus Project for Quality Palliative Care. Dr. Ferrell completed a master's degree in Theology, Ethics, and Culture from Claremont Graduate University in 2007. She has authored eleven books including the Oxford Textbook of Palliative Nursing published by Oxford University Press (4th edition published in 2015). She is coauthor of the text, The Nature of Suffering and the Goals of Nursing published in 2008 by Oxford University Press and Making Health Care Whole: Integrating Spirituality into Patient Care (Templeton Press, 2010). In 2013 Dr. Ferrell was named one of the 30 Visionaries in the field by the American Academy of Hospice and Palliative Medicine.

Faculty Bios 3

Communication and End of Life Workshop

Welcome and Overview

Welcome and Overview: Communication Workshop

Haley Buller, MSHSC

ICC Project Director City of Hope Duarte, CA

Disclosure

The faculty for this workshop have nothing to disclose.



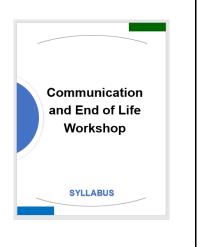
Workshop Objectives

- 1. Apply principles of communication to components of physical, social, and spiritual aspects of care in their clinical practice.
- 2. Practice communication skills to enhance physical, social, and spiritual aspects of care in their clinical practice.

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Overview

- Workshop agenda
- Materials includes:
 - Lecture slides
 - References
 - Supplemental materials
 - Lab sessions
 - Vignettes



NCP Guidelines as a Framework

- Domain 2: Physical Aspects of Care
- Domain 4: Social Aspects of Care
- Domain 5: Spiritual, Religious, and Existential Aspects of Care



Integration of Communication Principles Across Domains

- Linking communication to overall goals of palliative care.
- Palliative care applies to all stages of cancer
- Beyond "Breaking Bad News"



Introductions

- 1) Name, role, and institution
- 2) What is your current greatest communication challenge?

Communication and End of Life Workshop

Physical Aspects of Care

Communication Skills for Physical Aspects of Care

Betty Ferrell PhD, FPCN, FAAN, CHPN

Director and Professor City of Hope Duarte, CA

Objectives

- 1. Apply principles of communication to the domain of "Physical Aspects of Care"
- 2. Identify strategies for teaching communication to enhance "Physical Aspects of Care"

Pain

- Pain is an unpleasant sensory and emotional experience, associated with actual or potential tissue damage.
- Pain is whatever the patient says is occurring, when they say it does.



Merskey, 1979; Pasero & McCaffery, 2011

Assessing the Whole Person

- "Before we start, tell me a little about yourself..."
 - · Goal:
 - To learn about their values, what gives them meaning and strength
 - To help them feel valued, heard, and respected

Assessment History Questions

- Acute vs. chronic
- Location(s)
- Intensity
- Quality
- Pattern
- Aggravating, alleviating factors

- Past and present medication use
 - Efficacy and adverse effects
- Emotions/suffering
- Meaning of the pain



Gawande, 2014

Verifying

- "Can I summarize what I heard I want to be sure I heard everything correctly?"
- "I heard you have constant low back pain that is throbbing and severe, that sometimes there is an electric shock that goes down your left leg, and that the oxycodone 5 mg reduces the pain about 50% and that it does not make you feel sleepy or fuzzy.
- "I also heard you are having a hard bowel movement every 4 days or so and it takes a lot of work to get the stool out."

Lovell & Boyle, 2017

- "And you are having a very dry mouth that makes it hard to eat some foods."
- "Did I get it right? Did I miss anything?"

Health Literacy Universal Precautions

- Listen carefully
- Use plain, nonmedical language
- Use patient's words
- Slow down
- Limit and repeat content
- Be specific and concrete

- Show graphics
- Demonstrate
- Encourage questions
- "What questions do you have?"
- "We discussed a lot today, what can we review again?"
- Apply teach back

AHRQ Health Literacy Universal Precautions Toolkit, 2017

NURSE – Addressing Emotions

- Naming -normalizing
 - "Pain can make us feel anxious or worried and this is normal."
- Understand validating their emotions
 - "Pain can be overwhelming and even frightening."
- Respect recognizing their effort
 - "This is not easy and you are working really hard."
- Support they are not alone
 - "We are here to help you this is a team effort."
- Explore examine strengths
 - "You have managed your pain in the past. What was helpful then?"

(Adapted from Back et al 2005: Back et al 2013: Back et al 2014)

Communication Skills for Symptom Management





https://player.vimeo.com/video/433754515

Summary

- Physical comfort is an essential component of compassionate care across all stages of cancer.
- Expert pain and symptom management promotes psychological, social, and spiritual quality of life.
- Clear, ongoing, and empathic communication is fundamental to skilled oncology care.

References

- Agency for Healthcare Research and Quality. (2017, May). AHRQ Health Literacy Universal Precautions Toolkit.http://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/index.html
- Back, A.L., Arnold, R.M., Baile, W.F., Tulskey J.A., & Fryer-Edwards, K. (2005). Approaching difficult communication tasks in oncology. A Cancer Journal for Clinicians, 55(3),164-77. https://doi.org/10.3322/canjclin.55.3.164
- Back A.L., & Arnold, R.M. (2013). "Isn't there anything more you can do?": When empathic statements work, and when they don't. Journal of Palliative Medicine, 16(11), 1429-32. https://doi.org/10.1089/jpm.2013.0193
- Back, A.L. & Arnold, R.M. (2014). "Yes it's sad, but what should I do?" Moving from empathy to action in discussing goals of care. Journal of Palliative Medicine, 17(2), 141-44. https://doi.org/10.1089/jpm.2013.0197
- Gawande, A. (2014). Being mortal: Medicine and what matters in the end. Metropolitan Books.
- Lovell, M., & Boyle, F. (2017). Communication strategies and skills for optimum pain control. In: D.W. Kissane, B.D. Bultz, P.N.Butow, C.L. Bylund, S. Noble & S. Wilkinson (Eds.), Oxford textbook of communication in oncology and palliative care. Oxford University Press
- Merskey, H., & Watson, G.D. (1979). The lateralization of pain. Pain, 7(3), 271-80. https://doi.org/10.1016/0304-3959(79)90084-8
- Pasero, C., & McCaffery, M. (2011). Pain assessment and pharmacological management. Mosby Elsevier.

Lab Session

Contents:

1. Role Play Sessions

Lab Session

Role Play Sessions – (5-10 minutes each in small groups)

Pain/Symptom Assessment (2 participants)

- One member of team conducts pain assessment; other person relays information as a patient: (describe a painful experience you once had or consider a painful description provided by a recent patient)
- Discuss strengths, weaknesses of the experience

Educate a Patient and Family Regimen to Prevent/Manage Constipation (3-4 participants)

- Mr. Garcia is a 66-year-old man with stage IV NSCLC and poorly controlled diabetes; he
 now has a bone metastasis at right femur that has been surgically stabilized and
 radiated. Pain is well-managed with long-acting morphine 30 mg q 8 and morphine ir 15
 mg q 4 prn (he takes approximately 3 per day). His last bowel movement was 5 days
 ago and he is feeling nauseated.
- One member of the team communicates a regimen to prevent and manage constipation to Mr. Garcia, his wife, and his adult daughter
- Discuss strengths, weaknesses of the experience
- What might have been improved?

Communicate with a Colleague about a Patient with Nausea & Vomiting (2 participants)

- Consider a patient you have cared for recently with significant nausea; communicate Situation, Background, Assessment, and Recommendation
- Discuss strengths, weaknesses of the experience
- What was the experience from speaker's and recipient's perspective?
- What might have been improved?

Debrief as Large Group (5-10 minutes)

Communication and End of Life Workshop

Social Aspects of Care

Communication Skills for Social Aspects of Care

Haley Buller, MSHSC

ICC Project Director
City of Hope
Duarte, CA

Objectives

- 1. Apply principles of communication to the domain of "Social Aspects of Care"
- 2. Identify strategies for teaching communication to enhance "Social Aspects of Care"

The Importance of Family Meetings

- Opportunity to share information
- Identify needs and fears
- · Set realistic goals
- Important forum for discussions regarding:
 - Patient's condition
 - Prognosis
 - · Care preferences
 - · Listening to the family's concerns
 - Decision-making about appropriate goals of treatment

Douglas et al, 2018; Lamore et al 2017; Stajduhar & Dionne-Odom, 2019

Why Family Meetings Go Wrong...

- One study that reviewed recordings of family conferences found that clinicians tended to dominate the conversations.
- Led to missed opportunities to help family members in three important ways:
 - · Failure to listen
 - Failure to acknowledge emotions
 - Failure to explain the principles of palliative care

Douglas et al, 2018; Lamore et al, 2017; Sanderson et al, 2018

Structured Family Meeting

- Preparation
 - · Agenda and goals
 - · Who should attend?
 - · Meet briefly prior with staff who will attend
- Introduction of participants and overview of purpose and process of the meeting
- Assess the family's understanding of the patient's cancer prognosis

Gentry, 2016; Kissane & Hempton, 2017; Singer et al, 2016

Structured Family Meeting

- Summarize and educate
- Explore what it is like currently for the patient
- Explore family's views about what the patient would want under these circumstances
- Frame recommendations
- Facilitate grieving
- Plan for follow-up
- Discuss, debrief, and document

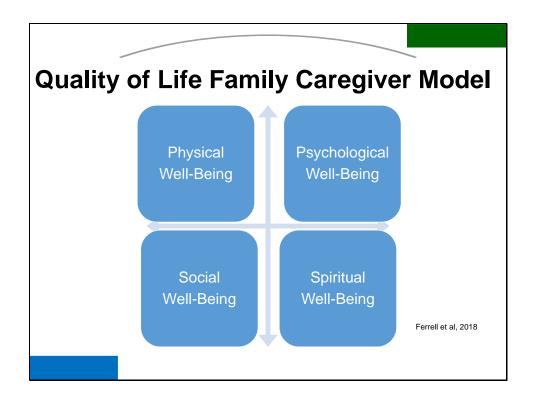
Gentry, 2016; Kissane & Hempton, 2017; Singer et al, 2016

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"VALUE": Five Objectives of the Proactive Family Conference

- V <u>Value</u> and appreciate what family members say
- A <u>Acknowledge</u> the family members' emotions
- L Listen to their concerns
- U <u>Understand</u> who the patient was in active life by asking questions
- \bullet **E** <u>Elicit</u> questions from the family members

Curtis & White, 2008



Communication of Goals of Care in a Family Meeting Vignette





https://player.vimeo.com/video/433990270

<u>Vignette Description</u>: A family meeting is held with the interdisciplinary team and the patient's wife and his brother. The patient has end stage renal cancer with renal failure and has been on dialysis for years. He has recently had several complications and has requested to stop dialysis. The meeting is much longer than showed, but this vignette demonstrates the portion of the meeting that discusses and focuses on helping the family understand the patient's goals of care while also responding to their emotions.

Vignette Debrief

- 1) The family is struggling to accept that stopping dialysis is the right thing to do at this moment. How does the interdisciplinary team communicate with the family to help them understand the severity of the patient's condition?
- 2) The patient's wife states that she understands that stopping dialysis will lead to his death. How does the interdisciplinary team handle her revelation and help her understand that this is what he wants?
- 3) What would you have done differently in this segment of a family meeting? How would you have communicated with the patient's wife or brother?

Summary

- Advanced communication skills and preplanning are necessary in order to conduct effective family meetings.
- Eliciting the family's opinions and goals is an important step to exceptional palliative care.
- Addressing social needs of the patient and family requires assessing the whole person.

References

- Curtis, J.R., & White, D.B. (2008). Practical guidance for evidenced based ICU family conferences. Chest, 134(4), 835-43. https://doi.org/10.1378/chest.08-0235
- Douglas, S.L., Lipson, A.R., & Daly, B.J. (2018). Analyzing goals of care in advanced cancer patients and their family caregivers: Evidence-based research. POJ Nursing Practice & Research, 2(1), 1-7. https://doi.org/1032648/2577-9516/2/1/003
- Ferrell, B., Kravitz, K., Borneman, T., & Friedmann, E. (2018). Family caregivers: A qualitative study to better understand the quality-of-life concerns and needs of this population. Clinical Journal of Oncology Nursing, 22(3), 286-94.
- Gentry, J. (2016). Family meetings. In: C. Dahlin, P.J. Coyne, & B.R. Ferrell (Eds.), Advanced practice
 palliative nursing. Oxford University Press.
- Kissane, D.W., & Hempton, C. (2017). Conducting a family meeting. In: D.W. Kissane, B.D. Bultz, P.N.Butow, C.L. Bylund, S. Noble & S. Wilkinson (Eds.), Oxford textbook of communication in oncology and palliative care. Oxford University Press.
- Lamore, K., Montalescot, L., & Untas, A. (2017). Treatment decision-making in chronic diseases: What are the family members' roles, needs and attitudes? A systematic review. Patient Education Counseling, 100(12), 2172-81. https://doi.org/10.1016/j.pec.2017.08.003
- Sanderson, C.R., Cahil, P.J., Phillips, J.L., Johnson, A., & Lobb, E.A. (2018). Patient-centered family meetings in palliative care: A quality improvement project to explore a new model of family meetings with patients and families at the end of life. Annals of Palliative Medicine, 6(2), 195-205. https://doi.org/10.21037/apm.2017.08.11
- Singer, A., Ash, T., Ochotorena, C., Lorenz, K.A., Chong, K., Shreve, S.T., & Ahluwalia, S.C. (2016). A
 systematic review of family meeting tools in palliative and intensive care settings. American Journal of
 Hospice and Palliative Care, 33(8), 797-806. https://doi.org/10.1177/1049909115594353
- Stajduhar, K.I., & Dionne-Odom, J.N. (2019). Supporting families and family caregivers in palliative care. In: B.R. Ferrell & J. Paice (Eds.), Oxford textbook of palliative nursing. Oxford University Press.

Contents:

1. Recommendations for Conducting a Family Meeting

Recommendations for Conducting a Family Meeting

Prepare for the Meeting

- Review medical issues and history.
- Coordinate healthcare team.
- Discuss goals of meeting with team.
- Identify a meeting leader among the health-care team.
- Discuss which family members will be present.
- Arrange a private, quiet location with seating for all.
- Try to minimize distractions: arrange adequate time and seating, turn off pagers and/or phones, if possible.

Open the Meeting

- Introduce all in attendance.
- Review the medical situation.
- Establish the overall goal of the meeting by saying something like: "Today, I'd like to make sure everyone understands how [the patient] is doing and answer all the questions that you have," or "We wanted to meet today to discuss how [the patient] will be cared for at home."
- Be prepared for the goals of the meeting to change based on the family's desires.

Elicit Family Understanding

- Ask family members questions such as "What have you been told about [the patient's] condition?"
- After hearing from the family, a helpful follow-up question is "Is there anything that isn't clear that we can help to explain?"

Elicit Patient and Family Values and Goals

- Elicit goals of all those present, especially if multiple perspectives are held.
- Begin with an open-ended question such as, "Given what's gone on, what are your hopes for [the patient]?" This may be followed by more specific suggestions for the family: "Sometimes getting home is an important goal for a patient. Sometimes seeing a certain family member or friend is an important goal: are there things like this that you imagine are important for [the patient]?"
- Understand ethnic and cultural influences on communication styles, family relationships, medical treatments, and end-of-life care by asking: "Can you please help me understand what I need to know about [the patient's] beliefs and practices to take the best care of [the patient]?"
- Maintain focus on the patient's perspectives. Often this can help to relieve guilt that family members may feel over making decisions. Such questions could include: "What do you imagine [the patient] would have done or wanted in this situation?" or "Our goal is not so much to think about what you would want or not want but to use your knowledge of [the patient] to understand what he or she would want in this situation."

Deal With Decisions That Need to Be Made

- Achieve a common understanding of the issues.
- Find out if the patient had made his or her wishes about the decision known by asking, "Has [the patient] ever discussed what he would want or not want in this kind of a situation?"
- Reassure family members that they are making a decision about what is in the best interests of the patient, not necessarily what is in their own best interests.
- Begin with open-ended assessments and then turn to specific interventions, if necessary.
- Offer clear recommendations based on patient and family goals, by suggesting, for example, "Given our understanding of the medical situation and what you've told us about [the patient's] goals, I would recommend not pursuing dialysis."
- Seek consensus whenever possible, agreeing on the decision or on the need for more information.
- Use summary statements, such as, "It sounds like we are coming to an understanding that [the patient] would not want to continue on the ventilator. Is that how everyone understands [the patient's] wishes?"
- Consider the possibilities of seeing the decision as a "therapeutic trial" or as a healthcare team recommendation that requires only family assent.
- Check for understanding of the decisions made by saying something like, "I want to make sure everyone understands that we've decided to ..."

Close the Meeting

- Offer a brief summary of what was discussed.
- Ask for any final questions.
- Offer a statement of appreciation and respect for the family: "I appreciate how
 difficult this must be, but I respect everyone for trying so hard to do right by [the
 patient]," or "I want to thank everyone for being here and for helping to make the
 difficult decisions."
- Make a clear follow-up plan, including plans for the next family meeting and how to contact the health-care team.

Follow-up on the Meeting

- Document the meeting in the chart.
- Follow-up with any information or reassessment agreed upon during the meeting by saying, "When we last met, you were going to talk with your brother about our meeting. How did that go?"

Source:

Rabow, M.W., Hauser, J.M., & Adams, J. (2004). Supporting family caregivers at the end of life: "They don't know what they don't know." Journal of the American Medical Association, 291(4), 487. Reprinted with permission.

Lab Session

Contents:

1. Case Study Activity

Lab Session

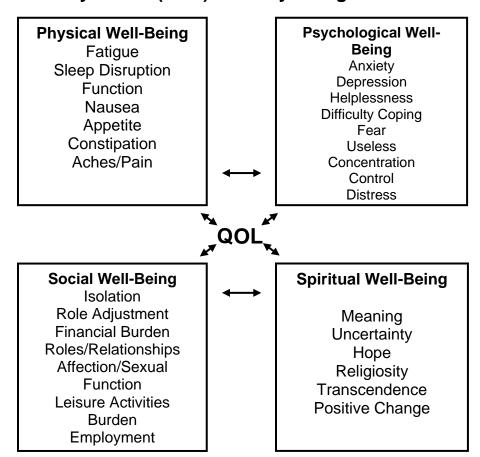
Case Study Activity

Case: Mr. Jones, age 54, has stage IV prostate cancer. He and his family (wife and 3 children—ages 9, 16, 19), who are confused and anxious, listen to you as you describe what they should expect from the hospice experience. The family does not seem to understand why you are discussing end-of-life issues with them. You call Mr. Jones' family physician who tells you that the patient assured him that he talked to his family about his prognosis. You determine that Mr. Jones has, in fact, not told his family. You talk with Mr. Jones who admits that he has told his family he is very stable and expected to have many years of life remaining. He asks you to help him break the reality of his poor prognosis to his family. A family meeting was held with Mr. Jones, his wife, and his brother. The interdisciplinary team helped Mr. Jones share the news about his prognosis with his wife and brother and to also help them plan how they will share the information with the children.

Today, you have planned a follow-up meeting with Mrs. Jones in order to get to know her alone a little more and to offer support.

<u>Instructions:</u> Use the QOL model as a conversation guide with Mrs. Jones and to asses her QOL needs for support.

Quality of Life (QOL) – Family Caregiver Model



Communication and End of Life Workshop

Spiritual Aspects of Care

Communication Skills for Spiritual Aspects of Care

Betty Ferrell PhD, FPCN, FAAN, CHPN

Director and Professor City of Hope Duarte, CA

Objectives

- 1. Apply principles of communication to the domain of "Spiritual, Religious and Existential Aspects of Care"
- 2. Identify strategies for teaching communication to enhance "Spiritual, Religious and Existential Aspects of Care"

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Need for Effective Communication in this Domain

- Communication of spirituality in all aspects of faith, meaning, and purpose
- Recognition of spiritual distress

Sinclair, 2015

Need for Effective Communication in this Domain

- Assessment of diverse religious beliefs and practices
- Life reviews, legacy, and life completion tasks
- Identification of spiritual strengths

Sinclair, 2015

Spirituality May Be Linked to Religion ~ *Or It May Not*

"Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience connectedness to the moment, to self, to others, to nature, and to the significant or sacred."

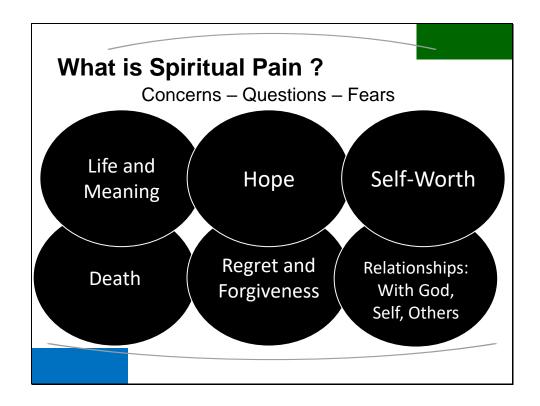
Puchalski, 2009

Communication Related to Religious Beliefs Vignette





https://player.vimeo.com/video/433998425



Living With Questions...

Is God punishing me?

Did I do **something** to deserve thi/?

Why is this happening

to me?

Will I suffer? What is the meaning of

life?

...it's Not Your Job to Have Answers

Living With Questions... ...an Invitation to Go Deeper

"Tell me more about that..."

"That must be difficult for you..."

"I wonder what that is like for you?"

•	

FICA Spiritual Assessment

• F – Faith, Belief, Meaning

Is spirituality or faith important in your life? If so, how? If not, what gives your life purpose and meaning? For example, family, work, relationships, nature, the arts, ethics...?

• I - Importance and Influence

How does your faith or spirituality influence your life? Do your beliefs help you cope with stress? Is there anything you want us to know about how your faith or religion might influence your healthcare decisions?

Puchalski & Romer, 2000

FICA Spiritual Assessment

• C – Community

Are you part of a spiritual or religious community? If so, is this community a support to you and how? If not, is there a group of people who are important to you for nurture and support?

• A – Address/Action in Care

What do you want us to keep in mind regarding your beliefs as we provide healthcare and support to you and your family? We have a chaplain who I think you would enjoy meeting. May I ask her/him to stop by?

Puchalski & Romer, 2000

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Referring Someone to a Chaplain is Like Introducing them to a Friend

"You mentioned that you haven't gone to church in years. Many people find themselves grappling with spiritual issues when they are ill. We have a wonderful chaplain who, I think, could be a good person for you to talk with. May I ask him to stop by?"

"You said you are not religious, and I want to honor that. I've found that a lot of patients, like you, aren't interested in religious conversation but do want to talk about issues of life and meaning when they are ill. We have a chaplain who provides spiritual care in a variety of ways. I think you would really like her. I'd like to ask her to stop by your room just so she can introduce herself to you.

Would that be okay?"

Rosa, 2019

Summary

- Clinicians should be prepared to provide spiritual care to patients and families.
- Open-ended questions and exploration are important for learning more about a patient's spirituality.
- Addressing spiritual needs of the patient and family requires asking questions related to existential themes and spiritual pain.

References

- Puchalski, C., & Romer, A.L. (2000). Taking a spiritual history allows clinicians to understand patients more fully. *Journal of Palliative Medicine*, 3(1), 129-37. https://doi.org/10.1089/jpm.2000.3.129
- Puchalski, C., Ferrell, B., Virani, R., et al. (2009). Improving the quality of spiritual care as a dimension of palliative care: The report of the consensus conference. Journal of Palliative Medicine, 12(10), 885-904. https://doi.org/10.1089/jpm.2009.0142
- Rosa, W. (2019). Spiritual care intervention. In B.R. Ferrell, N. Coyle, J.A. Paice (Eds.), Oxford textbook of palliative nursing. Oxford University Press.
- Sinclair, S. (2015). Spiritual communication. In: E. Wittenberg, B. Ferrell, J. Goldsmith, T. Smith, S. Ragan, M. Glajchen, & G. Handzo (Eds.), Textbook of palliative care communication. Oxford University Press.

Contents:

- 1. Take Home Exercise for Mindfulness
- 2. Spiritual Care Questions from Clinician to Patient
- 3. CASH Assessment Questions with Associated Existential Themes
- 4. Spiritual Health Assessment

Take Home Exercise for Mindfulness

Explore your own beliefs and values before you talk to others.

To support others spiritually, it's important to understand your own spiritual beliefs about illness. Think of a time when you faced a major life transition, change, or loss.

.

- How did it affect you spiritually?
- How did your spirituality affect the experience?
- Did you discover spiritual strength during that time?
- Did you ever question your faith?
- How did you want to be supported spiritually?

If you have never been diagnosed with a serious illness yourself, exploring these questions will help you understand your spirituality when facing life-changing situations. Even within families, among friends, and in faith communities, people's spiritual beliefs and experiences may be very different. Be clear that the beliefs and values you express reflect your own beliefs and yours alone. Just as you would want another person to listen to you with respect and understanding, your family member or friend wants you to listen to them with respect and understanding as well.

Understand the kinds of spiritual questions people with a serious illness may ask. People who are very ill often draw on their spiritual beliefs and experiences as sources of strength. However, facing illness may also bring up a wide range of thoughts, feelings, and questions. Here are some questions people may ask:

- Who am I now?
- What gives my life meaning?
- What am I thankful for?
- What is my relationship with family and friends?
- What is my relationship with God?
- How has my illness affected my relationships?
- Is there anything I want to change in my relationships?
- Are there ways I need to ask for forgiveness?
- What do I regret?
- What do I fear?
- What makes me sad about my illness?
- What makes me angry?
- Are there ways I feel alone or abandoned?
- What is my source of strength?
- When do I feel spiritually alive?
- How do I want my family and friends to support me spiritually?
- How do I want my clergy, chaplain, or spiritual leader to support me?
- Are there sacraments or rituals that are meaningful to me?
- What books, music, prayers, readings, or art are meaningful to me?

It is common for people living with serious illness to ask themselves these types of questions. As a "spiritual companion", you can best support others by helping them explore these questions rather than providing the answers. Be aware of spiritual pain and suffering. Spiritual pain and suffering is as real and powerful as physical or emotional pain.

From "Offering Spiritual Support for Family or Friends" http://www.caringinfo.org/UserFiles/File/faith_brochure.pdf

Box 1 Spiritual Care Questions from Clinician to Patient

- How is your spirit doing today?
- Are you scared?
- What are you most afraid of?
- What makes life worth living?
- Is there anything you haven't done that you need to do?
- What do you hope for?
- What is your deeper hope?
- Is there anything worse than death?
- What are you most proud of in your life?
- Do you have regrets?
- Do you need to forgive anyone?
- Do you need to ask forgiveness from anyone?
- What will your legacy be?
- What do you love most about your life?
- Are you at peace?

Adapted from Baird P. Spiritual care intervention. In: Ferrell BR, Coyle N, Paice JA, eds. Oxford Textbook of Palliative Nursing. 4th ed. New York, NY: Oxford University Press; 2015: 546-553.

Table 1. CASH Assessment Questions with Associated Existential Themes						
Mnemonic	Question	Existential themes				
C <u>C</u> are	What do I need to know about you to take better care of you?	Meaning, identity, autonomy, dignity				
A <u>A</u> ssistance/help	What has <u>helped</u> you most during the course of your illness?	Support, connectedness, relationships				
S <u>S</u> tress	What are the biggest stressors in your life now?	Stress, anxiety, guilt, isolation				
H <u>H</u> opes/fears	What is your biggest fear? What are you <u>hoping</u> for?	Hope, fear, anxiety, isolation				

Alesi, E., Ford, T., Chen, C., Fletcher, D., Morel, T., Bobb, B., Lyckholm, L. (2015) Development of the CASH assessment tool to address existential concerns in patients with serious illness. Journal of Palliative Medicine, 18(1) 71-75. doi:10.1089/jpm.2014.0053

Higgins, E., Coyne, H.L., Rogers, C.K.M., Infanzon, J., Velez, N., & Coyne, P. (2021) The CASH assessment tool: A window into existential suffering, *Journal of Health Care Chaplaincy*, DOI: 10.1080/08854726.2021.1922980

NAME/CARE RECEIVER ____

SPIRITUAL HEALTH ASSESSMENT Healing through Awareness

_CARE GIVER [optional] _____



Based on "Healing the Four Dimensions of Spiritual Pain" in the classical Sacred Art of Living and Dying tradition

DATE	_TIME	LOCATION		
INSTRUCTIONS • Quiet yourself and take a				
•		w you are within yourself" today.		
Use the optional questio				
		lar intervals in order to discover patte ds healing. Instead of trying to fix spir		
		MEANING		
1	2	3	4	5
Life is filled with		I feel generally		Life has become
purpose and meaning		motivated		meaningless
Who or what keeps me from	m being fully alive	·		
		FORGIVENESS		
1	2	3	4	5
I feel a deep sense of		There are no		I feel a strong sense
reconciliation towards		outstanding issues		of un-forgiveness
myself and others		that are calling for		towards myself others
Who or what do I need to fo	orgive?	forgiveness in my life		and/or another
From whom do I need seek				
		RELATEDNESS		
1	2	3	4	5
I feel a strong sense		Most important areas		I feel seriously
of connection with the		of my life seem		alienated from
persons and things		balanced		someone/thing that
that matter most to me	•			is important to me
Who are you and whose a Who or what do I fear losin				
		HOPE		
1	2	3	1	5
I feel hope-filled and	۷	ا I generally trust what	4	
optimistic		the future holds for me		I am experiencing deep depression and hopelessness
What dreams keep me aliv	e?			Пореневаннева
Why might I feel depressed	d or hopeless?			
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Lab Session

Contents:

1. Spiritual Health Assessment Activity and FICA Interviews

Lab Session

Spiritual Assessment Activity and FICA Interviews

<u>Instructions</u>: Complete the Spiritual Health Assessment individually. Then as a group, discuss the benefits of completing the Spiritual Health Assessment as a clinician.

<u>Instructions</u>: In dyads, take turns practicing FICA (pg. 47-48) interviews on one another. For the person being interviewed, think back to a recent patient situation involving spiritual care. Think of this activity as loose role playing. After 5 minutes, please discuss your experiences.

Resources

American College of Physicians – Health Literacy

- http://www.youtube.com/watch?v=ImnlptxIMXs
- An example of the barriers patients may face to optimal health outcomes because of lowered health literacy

American Medical Association Foundation - Health Literacy and Patient Safety

- http://www.youtube.com/watch?v=cGtTZ_vxjyA
- A discussion of health literacy problems in everyday healthcare practice, including patient examples

California Healthcare Foundation - Palliative Care Training for Interpreters

- http://www.chcf.org/publications/2012/08/language-lessons-palliative-care
- http://www.chcf.org/publications/2011/11/interpreting-palliative-care-curriculum
- Palliative Care Training for Interpreters-Slides
- http://www.calhospice.org/included/docs/education/5B_Interpretation_and_Palliative_
 Care_in_Public_Hospital_Setting-B&W.pdf
- Interpreting in Palliative Care
- http://learn.hcin.org/login/index.php

Centers for Disease Control – Health Literacy

- http://www.cdc.gov/healthliteracy/index.html
- Listings of health literacy organizations by state and tools to design and implement health literacy interventions

Center to Advance Palliative Care (CAPC) at Mt. Sinai Hospital, NY

- http://www.capc.org/
- the IPAL Project (Improving Palliative Care)
 - o http://www.capc.org/ipal/ipal-op
- for patients
 - o http://www.getpalliativecare.org

City of Hope Pain and Palliative Care Resource Center (COHPPRC)

- http://prc.coh.org
- Email: prc@coh.org
- The COHPPRC, established in 1995, is a central source for collecting a variety of materials including pain assessment tools, patient education materials, quality assurance materials, end of life resources, research instruments and other resources
- Bookmark/COHPPRC index included in blue folder as part of course materials

Coalition for Compassionate Care of California

http://coalitionccc.org/

The Cochrane Pain, Palliative Care and Supportive Care (PaPaS) Collaborative Review Group

Resources

http://papas.cochrane.org/

The Conversation Project

• <u>www.theconversationproject.org</u>

Department of Pain Medicine and Palliative Care. Beth Israel Hospital, New York

http://www.stoppain.org/caregivers/index.html

Dying in America, Nurses lead the conversation

www.dyinginamerica.org

End-of-Life Nursing Education Consortium (ELNEC) Project. Advancing End-of-Life Nursing Care. American Association of Colleges of Nursing.

http://www.aacnnursing.org/elnec

Geriatrics and Palliative Care blog

http://www.geripal.org/

Go Wish – A conversation game to discuss end of life care preferences

www.gowish.org

Growthhouse: Guide to death, dying, grief, bereavement and end-of-life resources

http://www.growthhouse.org

Health Literacy INDEX

- Assessment tool to evaluate the health literacy demands of patient education materials
- Kaphingst, K. A., Kreuter, M.W., Casey, C., Leme, L., Thompson, T., Cheng, M.R., Lapka, C. (2012). Health Literacy INDEX: development, reliability, and validity of a new tool for evaluating the health literacy demands of health information materials. J Health Communication, 17 (Suppl 3), 203-221. doi: 10.1080/10810730.2012.712612

Hospice and Palliative Nurses Association

http://www.hpna.org

The Joint Commission

http://www.jointcommission.org/certification/palliative_care.aspx

National Alliance for Caregiving (NAC)

• http://www.caregiving.org/resources

National Coalition for Hospice and Palliative Care

https://www.nationalcoalitionhpc.org/ncp/

Resources

NCI - Loss, Grief, and Bereavement

- www.cancer.gov/cancertopics/cancerlibrary/epeco/selfstudy/module-4
- Doctor demonstrates knowledge and care of patient beyond disease develops resources to help patient

NINR Pediatric Palliative Care

www.ninr.nih.gov/conversationsmatter/families

On Being Present, Not Perfect

- https://www.youtube.com/watch?v=phUUjk btiY
- In her TEDx talk, Dr. Elaine Meyer draws on both professional and personal experience (including her own miscarriage) to illustrate the profound gaps in healthcare communication and how to close them. As an educational leader, she brings diverse healthcare professionals together with patients and families in a "one room schoolhouse" approach. Using the Wizard of Oz as a clever metaphor, she coaxes healthcare providers and patients to hold honest, direct, genuine conversations.

Palliative Care Fast Facts and Concepts

http://www.mypcnow.org/#!fast-facts/c6xb

Patient-generated websites

- http://getyourshittogether.org/
- https://www.deathwise.org/

Project on Death in America

• http://www.opensocietyfoundations.org/publications/transforming-culture-dying-project-death-america-1994-2003

Promoting excellence in end-of-life care

http://www.promotingexcellence.org

Using Health Literacy to Improve Patient Health and Outcomes

- Health literacy is an approach that helps physicians empower patients to better understand their health and navigate the health care system
- http://www.youtube.com/watch?v=x-bg70l44pw

ICC Project Website: www.cityofhope.org/ICC

ICC Project: ICC@coh.org