

SESSION # 2

Palliative Care, Suffering and Pain Control

Prayer

Light in our darkness, tonight we come together in your presence to discuss pain and the care that can overcome it. Help us to learn how we can address physical pain in our own lives and in the lives of those we love. Help us learn to see pain relief as an issue of justice, and keep us mindful that you do not intend for anyone to suffer. We ask these things in the name of Jesus, who came to share our suffering with us. Amen.

Reading – Ps 139:1-18, 23-24

Palliative Care

Palliative Care is a medical specialty that is both a philosophy of care and a process for delivering care. The term “palliative” means to “relieve or lessen without curing; mitigate; alleviate.” Palliative care focuses on relieving suffering and reducing the severity of disease symptoms for persons with serious illness as well as improving the quality of life for patients and their families. While the purpose of palliative care is not to halt or delay disease progression or cure illness, it can be delivered along with curative treatment at any time during the course of a person’s illness.

Scenario

In the following real-life example, an interviewer asks a pastor about her experience visiting church members in pain.[1]

Rev. Johnson: I have one in particular. I have a 90-or-so-year-old woman, who, you know, they wanted her to get out of bed. They didn’t want her to just lie in bed because she might get bedsores and things. And, they sat her in the chair. And she said, “Oh, it hurts so much.” And the nurse had been there, and she told the nurse, and the nurse, “Oh, we have given you this medicine and it will probably take effect soon.” And I remember asking her, “What, on a scale of one to ten, how is your pain?” “It’s a twelve,” she said. It was just heart-breaking, and I felt helpless, and I prayed, and I felt like *this* isn’t going to do any good! [laughs] I mean, there’s the faith and hope! [laughs]

Interviewer: [laughs with her]

Rev. Johnson: It was just . . . and she was frail, and I could just . . . I could imagine those bones rubbing together, and, you know, a back that's starting to collapse. And she died about a week or two after that.

Interviewer: Oh, my!

Rev. Johnson: Yeah. She just . . . she just fell apart. She just said, "I can't live anymore." And I think she really just gave up.

Interviewer: Mm-m.

Rev. Johnson: And I don't know if medically they *could* have managed that pain better. I don't remember. I just remember that helpless[ness] and her saying, "It's a twelve!" But go! At least she *said* it!

Discussion

What did the nurse do that provided good palliative care to the patient? What did she fail to do?

What did she do that did not provide such good care?

Did the patient speak up about her pain?

Did it make any difference?

What did the visitor do to support the patient?

What could she have done differently?

What would you have done as the visitor?

Information

[This section is being provided so that the group leaders can use it during the discussion. Once people have spent about half of the session talking about the above questions, you can begin to provide this information. It

may be helpful to have this information copied and distributed to the attendees so that they have it for future reference.]

In order to address the complex needs of seriously ill patients and their families, palliative care is generally delivered through an interdisciplinary team of health care professionals. This can occur in hospitals, and it can also occur in nursing homes and private homes. The best palliative care in nursing homes and private homes is provided by hospice.[2] This team includes professionals from medicine (the primary physician), nursing, pharmacy, pastoral care, bereavement and social work, as well as volunteers; sometimes, depending upon the needs of patients, professionals from occupational therapy, physical therapy and speech pathology may be included.[3]

Palliative care involves attention to, assessment of, and attempts to relieve patient symptoms of nausea, vomiting, fatigue, dizziness, shortness of breath, dry mouth, itching, constipation, delirium, and pain. Some of these symptoms are results of the injury or disease process; others are results of the medical treatments, themselves. Professionals' ability to treat these symptoms depends upon an understanding of the relationality of suffering and upon obtaining diagnostic and treatment competence.[4] The ability of a patient to communicate the suffering of any symptom depends on the willingness and skills of the listeners, the witnesses; likewise, the possibility of relief or prevention of any of these symptoms depends upon the willingness and ability of the witness or witnesses to advocate for the sufferer.[5] Because "human life is profoundly relational,"[6] relief of suffering is a matter of justice.

Pain Control, Suffering and Justice

Zechariah 7:8-9

⁸ And the word of the LORD came again to Zechariah: ⁹ "This is what the LORD Almighty says: 'Administer true justice; show mercy and compassion to one another.'

Matthew 4:23-24

²³ Jesus went throughout Galilee, teaching in their synagogues, preaching the good news of the kingdom, and healing every disease and sickness among the people. ²⁴ News about him spread all over Syria, and people brought to him all

who were ill with various diseases, those suffering severe pain, the demon-possessed, those having seizures, and the paralyzed, and he healed them.

“Ethics has a bias toward care for the helpless and vulnerable.”[6] Those suffering at the end-of-life are especially vulnerable, so caring for them is a matter as justice, as it is with any vulnerable or oppressed group.[7,8] Another way of looking at justice is a matter of fairness. This, too, is a problem in the arena of pain control. Groups may be discriminated against because of age, gender, race, or socioeconomic status. [8-11]

Is there something good and holy about enduring severe pain? Margaret Mohrmann discusses this issue in her book *Medicine as Ministry: Reflections on Suffering*. She says that the old idea that pain strengthens character has been generally misused. When there were no medicines that could be safely used to reduce or prevent pain, and, if the pain was unavoidable, or the situation that created the pain was unavoidable, if persons were to keep their integrity, persons would have an opportunity to grow in character by developing endurance. However, in the context of healthcare in this age, especially care at the end-of-life, when effective pain control is usually possible, it is wrong to use the suffering of heroes in the Bible to justify one’s own or another’s suffering from injury or disease. Mohrmann says, “Although Jesus asked some interesting questions of his patients, he never suggested to them that they would be better off just bearing their pain. Jesus’ consistent willingness to relieve physical suffering adds a necessary qualifier and counterbalance to any discussion of the glorious endurance that suffering can produce.”[12] When caregivers neglect good treatment of symptoms, patients and families may have the impression that moderate to severe pain is inevitable. Professional caregivers who have not learned about the latest methods of pain assessment and treatment may believe that pain is inevitable. However, most of the time, it is not inevitable. [8,13,14] Pain can be safely managed in most cases, even in the emergency room [10] or the intensive care unit.[15]

Over the last 20 years, a great deal of research has been done on the pain mechanisms in the body, as well as medicines and other kinds of pain relievers. An article in the *Journal of the American Medical Association* found that coming to peace with God was as important to patients as pain control[16] Patients should be able to have both.. The stress of pain negatively impacts major systems in the body such as the immune system, the cardiovascular system, the digestive system, and so on[17] In addition, unmanaged pain interferes with a patient’s ability to address spiritual concerns, deal with unfinished business and be present with family and friends. Hospice has the best understanding of how to deal with pain, since that is their primary focus. Many

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doctors and nurses do not have the same familiarity with pain medications. Studies have shown that some of them have fears or concerns that are unfounded. For a long time, part of the culture of medicine included the acceptability of pain. Lack of knowledge, these fears, and the culture of neglect of pain can result in systematic undertreatment of pain. Consequently, patients may be reluctant to complain about pain.[17-19] However, no patients should remain in moderate to severe pain. At times it falls upon the family, friend, or clergyperson to push the medical team to provide adequate pain control. If one of your congregants is in pain, the family has the right to demand better pain control. The Joint Commission for Accreditation of Healthcare Organizations (JCAHO) requires that the hospital system be set up to make pain care effective and timely. Several years ago, (JCAHO) added pain control as a “vital sign.” That means whenever blood pressure, temperature, etc., are taken, patients are to be asked about their level of pain. The patient has the right to pain relief.[21]

In our society, there are cultural mores that tell some that the expression of pain is not appropriate; they are used to suffering in silence. However, they need not suffer in silence. It is rare that physical pain cannot be reduced to acceptable levels. Spiritual and emotional pain, if present, need to be discussed and not ignored, unless the patient does not want to deal with it. Ultimately, it is the patient’s decision, or in some cases the health care proxy’s decision about what measures to take. However, patients and families need to have complete information. For example, when pain is carefully assessed and morphine seems to be the most appropriate and effective medicine to use; and when physicians very gradually increase the morphine until relief is attained, there is little danger of depression of the respiratory system.[15,22] Therefore, if patients and families are told that using morphine up to the point of relief involves a high risk of unintended death, then these patients and families cannot give true informed consent because the options are not being presented completely or fairly.

In rare cases, when pain is intolerable and refractory to treatment, imminently dying patients may be offered the option of palliative sedation, which may mean that they are sedated somewhere on a continuum between light sedation and sedation to unconsciousness, depending on the extent of their suffering. According to a recent study, palliative sedation does not hasten death.[23,24]

Discussion

How were you taught to deal with pain? Were you ever expected to “suck it up?”

Have you ever thought about pain relief as a justice issue?

Do you think seeing it as a justice issue is helpful?

Do you think you could advocate for pain relief for yourself or someone else?

Are you afraid of being in pain at the end of your life?

Has our discussion helped reassure you that you can be treated adequately for pain through good palliative care?

Closing Prayer

Weaver of all our days, we are so blessed to be surrounded by your love and care. We thank you for the opportunity to learn about treating pain at the end-of-life. We are grateful for nurses and doctors who specialize in palliative care and for their efforts to address suffering. Help us recall what we have learned tonight, should the need arise, and keep us focused in the coming weeks, as we continue to consider issues and concerns related to the end of our earthly lives. We ask these things in the name of Jesus, who always healed people's pain. Amen.

Footnotes:

[1] Nance Cunningham, "Clergypersons' Experience of Visiting Church members in Pain: An Analysis in Terms of the Relational Theory of Pain and Implications for Pain Education and the UCC," unpublished dissertation (completed 2009).

[2] Congressional Research Service, *End of Life Care: Services, Costs, Ethics, and Quality of Care*, www.crs.gov, accessed 12/2/09, 5-6.

[3] Lisa M. Krammer, Jeanne Martinez, Eileen A. Ring, Mary Beth Williams, and Mary Jo Jacobs, "The Nurse's Role as a Member of the Interdisciplinary Palliative Care Team," in *Pain: Clinical Manual*, eds. Margo McCaffery and Chris Pasero (St. Louis, 1999), pp. 16-34.

[4] Steffen T. Simon, Christina Ramsenthaler, Claudia Bausewein, Norbert Krischke, and Gerlinde Geiss, "Core Attitudes of Professionals in Palliative Care: A Qualitative Study," *International Journal of Palliative Nursing* 15, no. 8 (2009): 405-411.

- [5] Nance Cunningham, "Primary Requirements for an Ethical Definition of Pain," *Pain Forum* 8, no. 2 (1999): 93-99.
- [6] Bruce Epperly and John Mills, *A Word to the Church on End of Life Care: Theological, Spiritual, and Ethical Reflections* The United Church of Christ Science and Technology Taskforce, 2009 [cited 4/13/2008. Available from <http://www.ucc.org/science/pdf/microsoft-word-end-of-life-care-with-theological-ethicsl-spiritual-resources.pdf>].
- [7] Frank Brennan, Daniel B. Carr, and Michael Cousins, "Pain Management: A Fundamental Human Right," *Anesthesia and Analgesia* 105, no. 1 (2007): 205-21.
- [8] Allyn L. Taylor, Lawrence O. Gostin, and Katrina A. Pagonis, "Ensuring Effective Pain Treatment: A National and Global Perspective," *JAMA* 299, no. 1 (2008): 89-91.
- [9] Carmen Green, Knox H. Todd, Allen Lebovits, Michael Francis, and Ethics American Academy of Pain Medicine Council on, "Disparities in Pain: Ethical Issues," *Pain Medicine* 7, no. 6 (2006): 530-3.
- [10] Timothy Rupp, and Kathleen A. Delaney, "Inadequate Analgesia in Emergency Medicine," *Annals of Emergency Medicine* 43, no. 4 (2004): 494-503.
- [11] Betty R. Ferrell, "Managing Pain in the Elderly," *Journal of Pain and Symptom Management* 25, no. 3 (2003): 292-93.
- [12] Margaret E. Mohrmann, *Medicine as Ministry: Reflections on Suffering, Ethics, and Hope* (Cleveland OH, 1995).
- [13] Betty Ferrell, Michael H. Levy, and Judith Paice, "Managing Pain from Advanced Cancer in the Palliative Care Setting," *Clinical Journal of Oncology Nursing* 12, no. 4 (2008): 575-81.
- [14] Nessa Coyle, and Mary Layman-Goldstein, "Pain Assessment and Pharmacological Interventions," in *Palliative Care Nursing: Quality Care to the End of Life*, eds. Marianne LaPorte Matzo and Deborah Witt Sherman (New York NY, 2006), pp. 345-405.

- [15] Richard A. Mularski, Kathleen Puntillo, Basil Varkey, Brian L. Erstad, Mary Jo Grap, Hugh C. Gilbert, Denise Li, Justine Medina, Chris Pasero, and Curtis N. Sessler, "Pain Management within the Palliative and End-of-Life Care Experience in the ICU." *Chest* 135, no. 5 (2009): 1360-9.
- [16] KE Steinhauser et al. "Factors considered important at the end of life by patients, family, physicians and other care providers," " *Journal of the American Medical Association*, November, 2000, Vol. 284, No 19, 2476-2482.
- [17] Chris Pasero, Judith A. Paice, and Margo McCaffery, "Basic Mechanisms Underlying the Causes and Effects of Pain," in *Pain: Clinical Manual*, eds. Margo McCaffery and Chris Pasero (St. Louis, 1999), pp. 16-34.
- [18] Edwin L. Lisson, "Ethical Issues Related to Pain Control," *Nursing Clinics of North America* 22, no. 3 (1987): 649-59.
- [19] Mellar P. Davis, and Declan Walsh, "Epidemiology of Cancer Pain and Factors Influencing Poor Pain Control," *American Journal of Hospice and Palliative Medicine* 21, no. 2 (2004): 137-42.
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- [21] Joint Commission on the Accreditation of Healthcare Organizations, *Pain Assessment and Management: An Organizational Approach* (Oakbrook Terrace IL, 2000).
- [22] Margaret L. Campbell, "Treating Distress at the End of Life: The Principle of Double Effect," *AACN Advanced Critical Care* 19, no. 3 (2008): 340-4.
- [23] M. Maltoni, C. Pittureri, E. Scarpi, L. Piccinini, F. Martini, P. Turci, L. Montanari, O. Nanni, and D. Amadori, "Palliative Sedation Therapy Does Not Hasten Death: Results from a Prospective Multicenter Study.[See Comment]," *Annals of Oncology* 20, no. 7 (2009): 1163-9.
- [24] N. Cherny, "The Use of Sedation to Relieve Cancer Patients' Suffering at the End of Life: Addressing Critical Issues.[Comment]," *Annals of Oncology* 20, no. 7 (2009): 1153-5.