

Faithfully Facing Dying: A Lenten Study Guide on Critical Issues and Decisions for the Members of the United Church of Christ

SESSION # 3
Hospice Care

Prayer

Compassionate God who holds us close, we come together in your presence to learn about hospice care. We know that our final months of living can be one of the richest times of our lives, both for us and for our loved ones. Increase our hope that these months might be peaceful, comfortable, free of pain and stress, and filled with time spent lovingly with those we love. Help us share openly with one another, and give us ears to hear the good news of how hospice can help make our hopes for our final days a reality. We ask these things in the name of Jesus, who removed the sting of death from our lives. Amen.

Reading Ps 139:1-18, 23-24

Hospice Care

“Dying is at once a fact of life and a profound mystery.”[1]

Only 24.9 percent of Americans die at home even though more than 70 percent say they wish to do so.[2] Approximately 2.5 million people die in the United States each year. Approximately 80% have a protracted illness before death and yet less than 20% use hospice or palliative care.[3] In the last years of life, health care costs are more profound. “One recent study found that, for those alive at age eighty-five, one-third of life-time health costs are still ahead.”[4] According to CMS (Centers for Medicare and Medicaid), about one-fourth of total Medicare spending occurs the last year of life. This share has remained generally constant for the past 20 years. The majority of Medicare end of life costs are from inpatient hospital expenditures.[5]

So, while the majority of people want to die at home, the reality is that only about 25% of people have their wish fulfilled. There are many reasons for this, not the least of which is our desire as human beings to live as long as possible. This desire often leads us to utilize the life sustaining equipment talked about in the first session. This modern technology may enable us to stay alive for longer, but it may also rob us of the chance to die at home.

Scenarios

Robin is a 46 year old woman, who has just been diagnosed with stage 4 breast cancer which had already metastasized to her bones. After extensive discussion with her doctor, who wanted her to try an aggressive drug and radiation regime, and discussions with her family, Robin decided not to pursue aggressive care, but instead to live whatever time she had left to the fullest. Her oncologist, who disagreed with her decision, suggested she talk with her personal physician about what her options might be. Her doctor recommended that she consider hospice, since it appeared that she would have about six months to live. Then the doctor called the area hospice and arranged for Robin to be seen by them. The next day, she was visited at home by a nurse who sat down with her and explained the benefits of hospice. After discussing

what her family would need to do to assist her, she agreed to hospice care and decided that she would ask her close friends and family to be her caretakers.

Hospice provided Robin and her family with nursing care, a social worker, a chaplain, home health aides, and specially trained volunteers who were able to assist her and her family every step of the way. Robin was able to be at home, among her family and friends, and was kept comfortable with pain medications while her disease followed its natural progression. Robin died 8 months later, with those who loved her surrounding her. The family received bereavement support for a year following Robin's death.

David is an active and "healthy" 54 year old. At his annual physical, he is diagnosed with advanced prostate cancer. His doctor recommends several different courses of treatment which might buy him some extra time – but there are no guarantees. David chooses one of the treatments and begins a rigorous course of chemotherapy and radiation. After several weeks, David is having negative reactions to the chemo and radiation but chooses to continue. His family is getting worried because he is not eating and is sleeping when he is not at the hospital for treatments. His weight drops dramatically and he is in a great deal of pain. Despite the pain medications, he is in constant pain but does not want to "give up" believing that he can "beat it." After a few months of treatment, David develops an infection and is admitted to the hospital. He dies in the ICU two weeks after his admission.

David's family is left wondering if he chose the best route for his care and if they had been given all of the information about the possible choices he had when first diagnosed. They also wonder if his doctors had been realistic and honest with David about his chances of survival.

Discussion

Consider these questions:

It has been said that Americans are the only individuals on earth who believe that death is negotiable.[6] What do you think? Is death negotiable?

What is "a good death" for you?

Where do you want to die?

Do you want your family members taking care of you or would you prefer "professional caregivers," such as nurses?

If you want to die at home, does your health insurance cover the associated medical costs?

If you want to die in an Assisted Living Facility, does your health insurance cover those costs?

Have you talked with your physician about whether or not you want to die at home?

What is your physician's position on hospice? Can he/she be supportive of that method of comfort care if aggressive care does not achieve what you had hoped it would achieve?

When is "enough, enough" in terms of how long you want to be sustained by technology or "one more" treatment?

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.]

As we defined it in the Introduction, Hospice provides patient-centered palliative care for people who are terminally ill. It combines emotional, spiritual and social support with expert medical and nursing care delivered by an interdisciplinary team of specially trained health professionals and volunteers. Hospice provides support for the entire family and deals with the social, emotional and spiritual issues that may arise. Hospice care is palliative care, that is, comfort care, for those who forego curative treatment and have a life expectancy that can be measured in months.

Changes in the leading causes of death among Americans have affected how people experience death. Americans are living longer with chronic conditions or degenerative diseases which will, ultimately, cause their death. In the early 20th century, the leading causes of death included pneumonia and other infectious diseases like TB. In the early 21st century, death for most Americans is characterized by a gradual onset of disease that leads to a slow decline in an individual's health and ability to maintain functional independence, resulting in a dying process that can be longer in duration and much less predictable.[7]

The setting in which people experience death often varies according to the underlying cause of death. For example, "[i]n a 2001 study of over 1.74 million non-traumatic deaths of persons age 65 and older, two-thirds of individuals whose underlying cause of death was dementia died in a nursing home (67%), compared with 21% whose underlying cause of death was cancer and 28% who had some other condition that resulted in death." [8]

So when is the “right” time to ask for a Hospice consultation?

To be eligible for the Medicare hospice benefit, beneficiaries must be certified by their attending physician, and the hospice physician, as being terminally ill with a life expectancy of six months or less if the disease follows its “normal course.”

Some believe that you should investigate hospice before you get sick so that you can know ahead of time what your options are, particularly checking your health plan to see if hospice is covered. Medicare and Medicaid do cover hospice, with at least partial payments for hospice. The best way to find out is to either contact your local hospice or ask your health insurance carrier. Many people have assumed that their medical plan includes hospice only to find out that it is not covered, or is not 100% covered.

You should consider hospice as an option when you receive a “terminal” diagnosis – that is, a diagnosis that would lead to death within about six months. If your doctor does not suggest it, it is quite appropriate for you to ask about it. Some doctors are hesitant to suggest hospice because it means that you will not receive aggressive care that seeks to “cure” your terminal illness. Some doctors may feel that they have “failed” you if they cannot cure you, and may steer you away from options other than aggressive care. But considering hospice is an individual’s choice, and a legitimate option. You should learn about ALL of your options before making any decisions about “aggressive” care or “comfort” care.

What are the benefits and burdens of Hospice?

Hospice care can be provided in a variety of settings including a private residence, a long-term care facility such as a nursing home, or a residential care facility such as an assisted living facility. Some hospice providers also operate a dedicated inpatient unit or freestanding hospice facility. According to NHPCO (the National Hospice and Palliative Care Organization), most hospice patients die in their own residence or the “place they call home.”[9] That is, an estimated three out of every four hospice patients (70.3%) died in a private residence, nursing home, or other residential care facility.

The benefit is that the hospice team works with you and your family, seeking to assure that you will have the kind of “good death” that you desire. Hospice care also provides respite care for family members, and this service provides them temporary relief from their caregiving responsibilities.

A burden of being on hospice is that it can put a lot of pressure on family members who are the basic caregivers, 24/7, unless your health insurance covers homecare services. Even with respite care, this can be a burden, albeit a loving burden, on a family. If you don’t have family members who are able or willing to take this on, there are residential hospices available in most areas of the country, where you can go and live for the rest of your life, being taken care of, as if at home, in the comfort of a place that is not a hospital and will provide on-going 24-hour care.

Another “burden” or possible drawback is that you cannot receive aggressive or curative care when you are in hospice. However, you can change your mind and withdraw from hospice and return to curative care at any time. You can receive palliative

care, such as radiation to shrink a tumor that is causing you pain, but you would not be able to continue chemotherapy. On the other hand, you could still receive dialysis since it is considered palliative treatment.

There is evidence that people find hospice helpful. For example, one research study found that less aggressive medical care and earlier hospice referrals were associated with better patient quality of life near death.[10]

What can you do as a congregation?

Isolation when one is dying can be profound. As a society, we shun those who are dying, remove ourselves from them and leave them to die without people around, other than the immediate family (sometimes). But community is at the heart of our religious beliefs. We worship together each week and come together for celebrations and for rituals. It is important that those who are dying know that they are not forgotten. While they are entitled to their privacy, it is important for the religious community to provide support in whatever ways might be acceptable to the one who is dying and to his or her family.

Even though it may be scary for you, reach out to those who are ill and those who are dying and to their families. Rather than saying, "What can I do to help?," say instead, "I am going to the grocery store today, what can I get for you?" This kind of offer is easier to hear and respond to. Ensuring that family members get a break by offering to stay with their loved one can be quite helpful. They need a break and offering to drive them somewhere or run errands for them is most appreciated. But it is also important not just to "do" for them, but to be present with them. Perhaps you can sit and have a cup of coffee – just be present – not to have the answers, but to be a listener. You can hold the hand of the person who is dying. Read psalms or the newspaper to them if that is what they want. You don't have to make small talk. Instead, try to be present with the person and talk when they want to talk and sit quietly when they don't want to talk. The most important thing to remember is that you are there to remind the family and the person who is dying that they are not alone in their time of distress or grief or illness. God is there too.[11]

Closing Prayer

God who gathers us in us as a hen gathers her brood, we rejoice in the availability of hospice services and in hospice workers who have devoted their lives to helping people with terminal illness make the most of their final days. May the time we have spent here help us better understand our desires and our options for the last months of our earthly lives, and may we feel your abiding presence every step of the way. We ask these things in the name of Jesus, our savior, shepherd, and guide. Amen.

On-line Resources:

NHPCO website www.nhpco.org

Hospice Foundation www.hospicefoundation.org

American Academy of Hospice and Palliative Medicine www.aahpm.org

Dying Well www.dyingwell.com
Growth House www.growthhouse.org
On Our Own Terms: Moyers on Dying www.pbs.org/wnet/onourown/terms

Footnotes:

[1] Institute of Medicine, *Approaching Death: Improving Care at the End of Life*, Washington, DC, National Academy Press, 1997, 1.

[2] *Means to a Better End: A Report on Dying in America Today*, November 2002.

[3] Phillip M. Kleespies, *Life and Death Decisions: Psychological and Ethical Considerations in End-Of-Life Care*, Washington, DC, American Psychological Association, 2004, 143-44.

[4] Joanne Lynn, "Living Long in Fragile Health: The new demographics shape end of life care," *Improving End of life Care: Why has it been so difficult? Hastings Center Report Special Report* 35, no 6, 2005, S15.

[5] Congressional Research Service (CRS), *End of Life Care: Services, Costs, Ethics and Quality of Care*, http://assets.opencrs.com/rpts/R40235_20090223.pdf, accessed 12/3/09.

[6] CRS, 4.

[7] *Ibid.*, 2-3.

[8] *Ibid.*, 3.

[9] NHPCO Facts and Figures, 2008.

[10] CRS 24.

[11] Martha Jacobs, *A Clergy Guide to End of Life Issues*, Cleveland: Pilgrim Press, 2010.