Advance Care Planning

Adding Value to the Role of the Chaplain

Objectives

- Discuss what advance care planning is and is not.
- Instruct chaplains how to harmonize chaplaincy with advance care planning.
- Describe the three elements of a successful advance care planning program.

Henry Ford Health System

- Henry Ford Health System, one of the largest and most comprehensive integrated U.S. health care systems, is a national leader in clinical care, research and education. The system includes the 1,200-member Henry Ford Medical Group, five hospitals, Health Alliance Plan (a health insurance and wellness company), Henry Ford Physician Network, a 150-site ambulatory network and many other health-related entities throughout southeast Michigan, providing a full continuum of care.

Advance Directive Does NOT = Advance Care Planning

Advance Directive

An **advance health care directive,** sometimes known as **living will, personal directive, advance directive,** or **advance decision,** is a legal document in which a person specifies what actions should be taken for their health if they are no longer able to make decisions for themselves because of illness or incapacity.

Advance Care Planning

Advance care planning is a person-centered, ongoing process of communication that facilitates individuals' understanding, reflection and discussion of their goals, values and preferences for future healthcare decisions.

Downside to Focusing on Advance Directives

- Too Many Scenarios
  - In filling out an Advance Directive, patients are asked to make decisions regarding the future medical care they would or would not want in the case of an event or medical condition that renders them unable to speak for themselves. The problem is that Advance Directives require patients to make broad decisions about specific medical interventions they may or may not want without identifying potential scenarios that could very well change those answers.

Advance Care Planning

- **Advance Care planning** is a method of discussing, exploring and sharing with others which care and medical treatments a person desires in light of their medical prognosis, goals of care, faith and values. The specific treatments and care that a person wants (or wants to avoid) are discussed and communicated to both physicians and to those who are their advocates (their spokesperson when the individual is unable to speak for themselves). The "fruit" of these conversations creates the foundation for the written document known as the Advance Directive.

- The process teaches people how to make medical decisions in light of their prognosis, goals of care, faith, and values. This process equips them to make medical decisions as various scenarios arise. By sharing this process with family members, advocates gain insight into the rationale behind the patient's decisions. And if the time comes that a patient can't speak for themselves, all parties involved can feel confident that the advocate is making decisions that are in line with the wishes, goals, values and faith of their loved one.

Focus of an ACP Consult

- Patient's medical understanding
  - Gaps in understanding
  - Unknown likely prognosis
- Patient's Spokesperson or "Advocate"
- Goals of Care, Influences to medical decision making, "Living Well"
  - Faith
  - Culture
  - Values

Areas Address Within a Consult

- Fears/Concerns
  - Loss
  - Loved ones
  - Finances
  - Death
- Past Experiences
  - An experience they might try to achieve
  - An experience they would like to avoid
- What does "Living Well" look like to the patient
  - Emphasis is not on end-of-life, death & Dying

Benefits to Advance Planning

- Peace of Mind for the Individual
  - Individuals are better equipped to work "with" physicians on a course of action that will help achieve their personal goals.
  - Patients, families, and care givers are all on "the same page" when it comes to what the patient wants
- Empowered Advocates
  - Caregivers relieved of the burden of trying to guess what their loved one would want.
  - Family harmony
  - Clear direction for care
- Informed Physicians
  - Physicians are better able to offer plans of care based on who the person is and what their goals of care are

Communication

- Seriously ill hospitalized patients have identified the following as most important priorities for quality improvement in end-of-life care
  - **Communication**
  - **Decision making about goals of care**

Physicians' orders for life-sustaining treatments, such as CPR were frequently inconsistent with seriously ill hospitalized patients' wishes.

Technology-laden EOL care is associated with decreased quality of life, lower satisfaction with EOL care, and increased family anxiety and depression.

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Scenario One

- (1) Mrs. J, a 78-year-old woman, experienced a massive brain hemorrhage and is comatose. A neurological consultant states that regaining consciousness in her case would be unprecedented. During the next few weeks the attending physician and the patient's husband meet regularly to discuss the prognosis and further treatment. The husband requests maximal medical care for his wife, including the placement of a permanent feeding tube and unlimited life-sustaining interventions to treat any complication. The husband expresses a hope that God will grant a miracle and that his wife will wake up. He also states that, even without a miracle, "Who are we to interfere with God's plan?"

Theological Issue

- Hope

Scenario Two

- Mr. S, an 85-year-old nursing home resident with advanced dementia, is bedridden and has limb contractures and decubitus ulcers. Sustained by gastrostomy tube feedings, he has not communicated for several years, but he moans when he is turned in bed. Mr. S develops severe pneumonia and is transferred to the hospital; he has hypoxemia and hypotension, and cries out in apparent pain when he is moved. The patient's wife requests aggressive care, including mechanical ventilation and transfer to an ICU. The wife states that according to the patient's religious belief he would have wanted life-sustaining treatment in this condition because "every day of life is a blessing." The physician asks whether this kind of life – prolonged by machines when prognosis is very poor – is what the patient had in mind. The wife replies that "God wouldn't have given you these machines if he didn't want you to use them." The physician notes the patient's suffering, and explains that intensive care will inflict further pain. The wife responds, "God sometimes wants us to suffer."

Theological Issue

- Suffering

Scenario Three

- Mr. L is an 80-year-old Orthodox Jewish gentleman who has a long medical history of progressive heart disease. A cardiac arrest some months ago resulted in anoxic brain injury. Mr. L is not brain dead, but he is minimally responsive and shows no signs of awareness of his environment. He is also ventilator-dependent, and there is very little prospect of improvement in his condition. The latest development in his deteriorating condition is progressive renal failure, so now there is question as to the appropriateness of beginning renal dialysis. Consulting nephrologists are opposed to the initiation of dialysis, citing guidelines regarding appropriate use of dialysis from the Renal Physicians Association. In their estimation, dialysis would not be beneficial because it would not provide Mr. L with any expectation of ever leaving an intensive, technology-heavy care facility (and placement of a patient in any long-term nursing facility that could provide both mechanical ventilation and dialysis would be nearly impossible), and because it would not provide Mr. L with any expectation of recovery of mentation. However, Mr. L's family members, in consultation with their long-time rabbi, insist that "Life is good, and any extension of life is a good." They reject any treatment decisions that involve judgments about "quality of life" and insist upon judgments of extension of life instead. They have accepted medical recommendation of a DNR order for Mr. L because they are convinced that CPR would likely not extend his life and may cause added suffering. They are insistent, however, that dialysis can prolong his life and should be started.

Theological Issue

- God's sovereignty

Building an ACP Program vs Doing ACP

- Leadership "Buy-in"
- ACP Champion
- Comprehensive
  - Community
  - Ambulatory
  - In-patient
    - ICU, Complex case

Lessons I've Learned

- Start smart, start small
  - Think Global, work local
- Build strategic alliances
  - Who are your natural ally's in this work?
    - FCN, Palliative, Geriatric, Specialties, Faith communities,
- Train with purpose
- Measure and report
- Celebrate every success
- Don't give up