Advance Care Planning
Exploratory Project

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Agenda

• Overview of the Advance Care Planning Exploration Project
• Description of Advanced Illness Care Today
• Rationale that Supports the Need for the Project
• Opportunities To Do It Better
• The Power of a Person-Centered Approach
Avera Advance Care Planning Project

- The goal for this project is to evaluate the need for and to make recommendations for a consistent approach to advance care planning (ACP) for the Avera Health system, in order to provide optimal care for our patients.

- An advance directive is a written document that provides direction regarding an individual’s medical treatment preferences and/or the designation of a stand-in decision-maker. We seek to ensure that we have a “well-designed educational and reflective process...not just for documenting patients’ values and wishes, but for facilitating meaningful dialogue about things that do matter” (Levi & Green, 2010).
Project Objectives

- Engage stakeholders and organize a project planning team
- Investigate and analyze the current practice related to the use of advance directives and advance care planning
- Evaluate current literature and evidence-based practice
- Design a project plan utilizing adaptive change principles and evidence-based practice
- Summarize and articulate to system leadership the vision for a new model for advance directives and advance care planning, and its advantages
Project Approach/Methodology

- Interdisciplinary project team/Regional representatives/Charter
- Stakeholder surveys
  - Physician/Midlevel Providers
  - Clinicians
  - Non-Clinicians
  - Attorneys
  - Patients
- Current policy, form, and process review
- Literature Review
- Consultation with other health systems
- Gap Analysis
Advanced Illness Care Trajectory Times

Adapted from Kramer, R. (2011, June 23). Aetna compassionate care lecture
2011 World Health Care Congress Leadership Summit, Chicago, IL
The Great Divide

“There is a great divide separating the kind of care Americans say they want at the end of life and what our culture currently provides. Surveys show that we want to die at home, free of pain, surrounded by the people we love. But the vast majority of us die in the hospital, alone, and experiencing unnecessary discomfort” Bill Moyers, PBS Commentator, 2000

“Spending one’s final days in an I.C.U. because of terminal illness is...a failure” for our patients and their families. Atul Gawande, MD, 2010
The health care decision-making process across key stakeholders during advanced illness is commonly non-existent, ineffective, or dysfunctional.

A Fundamental Assumption

Why This is Messy

- Physicians and Health providers
  - Not talking honestly with patients about death, yet knowing it is coming soon (McPhee et al, 2011)
  - Report feeling uncomfortable with EOL conversation (Zhou, 2010)
  - Knowingly offer aggressive treatment in advanced illness, knowing it is likely to cause even worse symptoms (Zhou, 2010)

- Patients
  - Lack knowledge about their disease
  - Patients assume that compliance is expected

- Families
  - Do not always know what their loved ones want
  - Disagreement within the family unit
Messier Yet...

- The definition of a ‘good death’ varies from person to person
- No good answer about what constitutes a good quality of life for patients while living with advanced disease
- Dynamic not a static process
- No ‘how to’ manual for patients and physicians
- Payers
  - Address issues through medical review/case management
  - Have largely ignored that patients have unexpressed quality of life preferences that favor less aggressive treatment
- State Legislation
  - Some variations of Physicians Orders for Life Sustaining Treatment (POLST) potentially controversial
Survey Approach

- Advance Directive /DNR Policies (24 policies reviewed)
- Survey Participants
  - Patients (172), Physicians (61), Clinicians (335), Non-clinicians (141)
- Attorney Survey
- Respondents
  - 4 states
  - Avera and Non-Avera entities
Types of Questions Asked

• Provider type/ Where you work/ Number of years in practice
• When you have been aware that a patient has an advance directive, how often do you and the patient discuss the specific directives in the document?
• When a patient’s health situation begins to decline, how often do you refer back to the advance directive?
• Generally speaking, do advance directives make a meaningful difference in the care of patients?
• Do you know where to find the advance directive in the EMR?
• Have you had formal education on advance care planning discussions with patients and families?
• Do you personally have a Durable Power of Attorney for Healthcare document or another end of life care directive?
**Physician / Midlevel Survey (61)**

### Specialty

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<th>Specialty</th>
<th>Frequency</th>
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<td>Family Medicine</td>
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<td>Other (please specify)</td>
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### Do you know where to find the advance directive in the EMR?

- **Yes, 14, 33%**
- **No, 29, 59%**
- **NA (do not use the EMR), 4, 8%**

59% say NO

### Have the patient's AD been a source of conflict for you and the patient?

- **Yes, 14, 28%**
- **No, 36, 72%**

28% say YES

### Comfort with end of life conversations with patients?

- **Very Comfortable 39, 78%**
- **Somewhat Comfortable 10, 20%**
- **Not comfortable 1, 2%**

78% say VERY COMFORTABLE
Clinician Survey (335)

**Provider type**

- RN: 195
- Pharmacist: 37
- Other: 36
- SW: 36
- Chaplain/Pastoral: 11
- LPN: 10
- Physical Therapist: 8
- Occupational: 2

**Department**

- Acute Care: 60%
- Emergency: 29%
- ICU: 22%
- Long Term: 21%
- Outpatient: 16%
- Home Care: 11%
- Hospice: 17%
- Palliative Care: 11%

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**Do advance directives make a meaningful difference in the care of patients?**

- Definitely Yes, 150, 41%
- Somewhat, 111, 31%
- Not sure, 32, 9%
- No, 19, 5%
- Other Responses, 51, 14%

41% say YES

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**Have you had formal education on Advance Care Planning?**

- Yes (please describe below), 38, 12%
- No, 237, 76%
- Not sure, 38, 12%

76% say NO
**Patient Survey (172)**

**Do you have an advanced directive, living will, or durable power of attorney for healthcare decisions?**
- Yes, 45, 26%
- No, 124, 72%
- I don't know, 3, 2%

72% say NO

**Have you reviewed the document with your physician?**
- Yes, 101, 68%
- No, 8, 5%
- I don't know, 40, 27%

38% of have reviewed their AD with MD

**Do you feel like your Advance Directive will be followed if you are unable to make decisions?**
- Yes, 101, 68%
- No, 8, 5%
- I don't know, 40, 27%

32% say NO or I Don’t Know
“Big misconceptions about the legal document. Patients, providers and lawyers understanding is different and thus leads to conflict about the AD”

“It is surprising how often a chronically ill patient with significant co-morbidities has never discussed end of life care with their Primary Care Provider”

“Family's often have mistaken view of what Hospice or Palliative Care is”

“Takes time to have this discussion – difficult to fit in during regular clinic day”

“Could be a meaningful roadmap if done well”

“Make it easier to find in EMR and maybe have it brought up by default like vaccines”

“Almost always, the AD is far too nonspecific. The patient rarely understands it. Most state if they are in an incurable state with no hope of recovery, do not resuscitate. It is never that simple.”

“Sometimes the DPOA is struggling emotionally and having a difficult time following the directive. Sometimes the physician has strong views about doing more aggressive care than the patient’s directive indicates and family listens to the physician.”
Examples of how other Communities/ Health Systems are approaching this?

• Gundersen’s Model – Respecting Choices
  – Life Stages approach
    • First Steps (AD document/ retrieval / storage)
    • Next Steps (Advanced disease - ACP facilitation)
    • Last Steps (End of life care plan)

• Other models
Ineffective ACP

- Only 18-36% of Americans have written AD (Wenger, 2009)
- AD written too general or too specific to help with the issue to be decided
- Requires people to ‘forward think’ to circumstances that they have never experienced
- Health care proxy somewhat effective, yet not ideal - Family members might not have a good read on what their loved one wants and may not have discussed
- Has not resulted in better care at EOL (Hammes et al, 2010)
Findings

- Less than 25% of surveyed patients had an AD and only 38% of those had reviewed it with their doctor
- 59% of providers unaware of where to locate the AD in EMR
- Less than 50% of physicians and clinicians feel that the AD makes a meaningful difference for patients
- 60-75% of physicians and clinicians report no previous training on ACP
- Wide variation AD policies/ processes
- Need for education for all stakeholders
- Promising practice at Gundersen Lutheran and other health systems
- Plan will need investment and staged approach over 2-3 years
Effective ACP

- Process of evaluation and reevaluation involving stakeholders
- Discussing and understanding what lies ahead
- Active participation by stakeholders
- Ongoing and frequent communication throughout illness
The Vision for Optimal Care

The patient and his/her family need to become active in the healthcare decision-making process so that health care decisions are consistent with life preferences, values, and priorities, ultimately increasing quality of care during advanced illness.
The Business Case

- Cost avoidance and savings
- Shortened length of stay
- Improved patient satisfaction
- Lower hospital mortality rates
“Our responsibility, in medicine, is to deal with human beings as they are. People die only once. They have no experience to draw upon. They need doctors and nurses who are willing to have the hard discussions and say what they have seen, who will help people prepare for what is to come—and to escape a warehoused oblivion that few really want.”

Dr. Atul Gawande, 2010
A Person-Centered ACP Program

Commitment to advanced illness quality of life and care

Standardized Staff Training Program

Informed consumers & Proxy Decision-Makers

Increased #’s of patients referred to hospice

Increased #’s of patients, over age 50, with AD

Trained Facilitators in EOL Conversation

Development of consistent tools & processes

Meaningful conversation about illness between physicians & patients occurring regularly

Increased #’s of patients, over age 50, with AD
References


13. United States Conference of Catholic Bishops (2009), Ethical and Religious Directives for Catholic Health Care Services, (5th ed.).
