Portfolio Management and Execution

An IHI Expedition
Managing Advanced Disease and Palliative Care

Session 1
David Weissman & Kelly McCutcheon Adams

WebEx Quick Reference

- Welcome to today’s session!
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- Connect and problem-solve with like-minded colleagues from other organizations.

**Where are you joining from?**

**What is an Expedition?**

*ex·pe·di·tion (noun)*
- 1. an excursion, journey, or voyage made for some specific purpose
- 2. the group of persons engaged in such an activity
- 3. promptness or speed in accomplishing something
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Our Expedition Director

Kelly McCutcheon Adams, MSW, LICSW, is a Director at the Institute for Healthcare Improvement. She is a medical social worker with experience in hospice, nursing home, sub-acute rehabilitation, emergency department, and ICU settings.

Overall Program Aim

The aim of this Expedition, Managing Advanced Disease and Palliative Care, is to help health professionals empower patients and families to make more informed choices about the use of specific life-sustaining treatments when coping with a serious illness.

Objectives

- **Describe** the positive outcomes for all parties — patients with advanced illness, their families, health care providers, and institutions — that arise from outstanding informed consent, education, and advance care planning.
- **Assess** their current system for conducting and documenting the informed consent conversation process at critical junctures in advanced illness: initiating tube feeding, kidney dialysis, or antibiotics.
- **Identify** process steps and test improvements in the informed consent, documentation, and education processes for patients and families.
Introducing faculty

David E. Weissman, MD

— Professor Emeritus, Palliative Care Program, Medical College of Wisconsin
— Consultant, Center to Advance Palliative Care
— Founding Editor, Journal of Palliative Medicine
— Founder, EPERC and Palliative Care

Fast Facts

A common scenario

• 84 y/o man, bed bound with dementia, brought to ED for fever.
• Antibiotics started in ED; sent to ICU for possible sepsis. NG tube placed for nutrition.
• Day 3, patient becomes anuric; CVVH started.
• Day 13, informed there is nothing else to do.
• Patient dies in ICU on Day 15 from multi-organ failure.

Is there a different way?

Progressive Care Options: 2010

• Palliative care - ED integration initiative
• Palliative care - ICU integration initiative
• Improving shared decision making for all patients in all settings—incorporating palliative care principles into routine daily care

— This is the focus of this Expedition!
Stop and Reflect

• At your setting, what are the medical procedures that are commonly utilized that you believe represent “excessive” interventions for the dying?

• (Group Discussion Time)

Your list

• My guess is your list looks something like this …
  — ICU care / Mechanical Ventilation
  — Feeding tubes
  — Antibiotics
  — Chemotherapy
  — Kidney Dialysis
  — What did I miss?

This Expedition

• Certain medical interventions provide critical junctures that allow us to pause and connect with patients and their families about the goals of care. These conversations can prevent us from being in the position of providing care that is excessive in relation to patient wishes.

• A central tenet of palliative care is to match the right procedure for the right patient at the right time.
Focus

We have elected to focus on three medical interventions:
- Kidney Dialysis
- Feeding Tubes
- Antibiotics

Why these three?
- Common
- Good evidence to support alternatives
- Palliative Care teams recognize that these three interventions cause significant patient/family suffering

Session Topics and Speakers

- Today: Informed consent and goal setting
- April 28/May 12: Dialysis discussions; Dr. Alvin Moss
- May 26/June 9: Feeding tube discussions; Carol Monteleoni, MS, CCC-SLP
- June 23/July 7: Antibiotic discussions; Tammie Quest, MD
- July 21: Team reports/wrap up

Homework

- At the conclusion of each session we will provide suggested homework to help move the process forward at your institution.
- At the start of each session, you will have a chance to describe your work and reflect on the impact.
Let’s Get Started

- Background critical to this project:
  - What is Informed Consent in the setting of critical interventions?
  - What are Goals of Care and how can care processes be designed to help clinicians incorporate Goal of Care information into informed consent decisions?

Improving the Informed Consent Process

- Informed consent, using a model of Shared Decision Making, is central to Palliative Care.
- Instituting potentially life-prolonging treatments always requires an Informed Consent Discussion.
- But let’s be honest, the actual discussion and documentation is highly variable, often resulting in less than optimal decision making.

Is this informed consent?

- “Your mother will starve unless we place a feeding tube.”
- “Withholding dialysis will result in a horribly painful death”
- “Your father has pneumonia, I am starting antibiotics and fluids.”
Definition

- Informed consent is a process, not a signature, whereby a physician discloses key information to help patients make a choice among healthcare options. The Informed Consent process requires that three conditions be met:
  - the patient is able to make a voluntary choice,
  - the patient is informed
  - the patient has the capacity to make medical decisions.

Information to be provided

- The patient's diagnosis, if known
- The nature, purpose, risks and benefits of a proposed treatment or procedure
- The nature, purpose, risks and benefits of alternative treatments or procedures
- The risks and benefits of not receiving or undergoing a treatment or procedure
- A clinician's recommendation

Common Myths

- Only high-risk procedures require informed consent. — Every medical intervention requires informed consent.
- Patients brought to the ED or coming from LTC do not require informed consent discussions. — There is no implied informed consent; however there is an emergency exception.
- Documentation is only needed for high-risk procedures. — Documentation requirements are guided by local policy or in some cases fed/state law.
- Physician duty is to present options, not a recommendation. — Physician duty is to present options and make a recommendation based on medical knowledge and judgment of the individual patient situation.
Stop and Reflect

• What is happening your setting?
• Have you developed standards of care and processes to honor the spirit of true informed consent in the setting of seriously ill and dying patients?
• (Group discussion time)

Goals of Care

If you don’t know where you are going, you will end up somewhere else.

—Y Berra

How do goals get established?

• Physician directed
  — Important in life-threatening emergency situations
  — Risk of paternalism—imposition of physician values without due consideration of patient/family values
• Patient-Family directed
  — Enhances autonomy but...loses importance of physician recommendations based on knowledge/experience; may enhance family guilt when considering treatment limitation or withdrawal
• Shared decision making
  — Ideal process—physician working together with patient/family to arrive at goals based on patient values combined with physician recommendations.
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The Patient/Family Goal-Setting Conference

- Opportunity for shared-decision making process in establishing goals near the end of life
  - Patients/Surrogates want an opportunity to discuss the Big Picture
  - Can be emotionally volatile
  - Palliative Care's "procedure"

Meeting leadership

- Leading a Family Conference should be thought of as a 'team sport' to include physician, nursing, social worker, and chaplains, as dictated by the clinical situation.
- Skill set necessary for successful outcome
  - Group facilitation skills
  - Counseling/emotional reactivity skills
  - Knowledge of medical and prognostic information
  - Willingness to provide leadership in decision-making

Summary of Key Steps

1. Pre-meeting planning
2. Proper environment
3. Introductions/Build relationship
4. What does the patient/family know?
5. Medical review
6. Silence, respond to emotions
7. Present options
8. Managing conflict
9. Transform goals into a medical plan
10. Summarize and document

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1. Pre-Meeting Planning

- Review medical history/treatment options/prognostic information
- Coordinate medical opinions between consultants/primary physician
- Obtain patient/family psychosocial data from care team members
- Review Advance Care Planning Documents
- Decide what is medically appropriate

2. Environment

- Choose a Proper Environment
  - Quiet, comfortable, chairs in a circle
  - Invite participants to sit down
  - Check your personal appearance; turn off your beeper

3. Introductions - Build Relationship

- Introduce yourself, have participants identify themselves and their relationship to patient
- Identify the legal decision maker or family designated decision maker
- Review your goals; ask family if these are the same or different from their goals
- For patients, or families, ask a non-medical question:
  “I know about Mrs. Jones’ illness, but I was wondering if you can tell me something more about her as a person, what were her hobbies?”
4. **What does the patient / family know?**

   - Make no assumptions: Determine what the patient/family already knows:
     - What do you understand about your condition?
     - What have the doctors told you?
     - How do you feel things are going?

   - **Chronic Illness:** tell me how things have been going for the past 3-6 months—what changes have you noticed?

5. **Medical Review**

   - Present medical information succinctly
     - Speak slowly, deliberately, clearly
     - No medical jargon
   - Present the big picture

   Your mother’s kidneys have stopped working due to the diabetes and high blood pressure. Besides the kidney problems, your mother has many serious medical problems that we cannot fix. *(Your mother is dying)*

Stop and Reflect

- **The First 5 Steps**
  - Is this all new to you?
  - What errors do see commonly made at your institution?
6. Silence; Respond to Emotions

- Allow silence, give patient/family time to react and ask questions
- Acknowledge and validate reactions prior to any further discussion.

7. Present Broad Care Options

There are generally two broad care options:

A. Continue aggressive care aimed at restoring function or prolonging life.
   - Begin kidney dialysis and associated treatments

B. Provide supportive care geared at symptom relief and quality, but with no expectation of life prolongation.

Helping Families Decide

- To help patients and families arrive at a decision, the two most critical pieces of information are:
  - Prognostic information (time and function)
  - The clinician’s recommendation
Prognostication

• Answering “how long does she have?”
  — Confirm that information is desired:
    “is something you would like me to address?”
  — If you have a good sense of the prognosis, provide honest information using ranges.
    “In general, patients like your mother who have stopped making urine will live only 1-2 weeks; if she begins to make urine again on her own, it could be longer, on the order of a few weeks to months”
  — Address emotional reaction.

Prognostication (cont.)

• What if patients don’t ask about their prognosis?
  — It is difficult to do Goal Setting if how much time is not addressed. Patients can be prompted “has anyone talked to you about time?”
• Some patients decline to discuss.
  — No reason to force a discussion except in certain uncommon circumstances

Making recommendations

• Patients and families want their physician to help them make decisions.
• Yet, physicians are fearful of making recommendations:
  — Fear of introducing personal bias
  — Fear of bad outcome leading to malpractice claim
  — Fear of paternalism
    ➢ Distorted concept of patient autonomy
Getting at the patient’s “voice”

- When the patient is not able to participate:
  - Bring a copy of their Advance Directive to the meeting
  - Ask the family: “If your father were sitting here, what would he say?”
- Explore patient and family values behind decisions

8. Managing Conflict

- The Patient/Family
  - Lack of accurate information
  - Guilt/Fear/Anger
  - Grief—Time
  - Lack of trust
  - Cultural/Religious conflict
  - Dysfunctional family system

Other contributing causes

- The physician
  - Inaccurate information
    - Overly optimistic prognosis
  - Guilt-Anger-Fear
    - Fear of malpractice
    - Fear of unethical impropriety
    - Peer pressure (perceived or real)
    - Fear of mistakes
    - Prognostic Uncertainty
  - Cultural conflict between physician values and patient values
Moving forward when there is no consensus

- Ensure that everyone has the same medical information;
- Ensure that a relationship of trust exists between the doctor and family
- Establish a time-limited trial
- Schedule a follow up meeting
- Seek expert input
  - Palliative care or ethics consultation
  - Involvement of other mediators (e.g. personal clergy)

9. Translate goals into a plan

- Ask
  - We have discussed that time is short. Knowing that, what is important to you… What do you need/want to do in the time you have left?
- Typical responses
  - Home; Family; Comfort; Upcoming life events
- Confirm Goals
  - So what you are saying is that you want to be home, be free of pain, and would like to live beyond your next wedding anniversary in six weeks, is that correct?

Translate goals into a plan (cont.)

- Mutually decide with the patient on the steps necessary to achieve the stated goals.
- Common issues that need discussion:
  - Future hospitalizations or ICU
  - Diagnostic tests
  - DNR status
  - Artificial hydration/nutrition
  - Antibiotics or blood products
  - Home support (Home Hospice) or placement
10. Summarize and Document

- Summarize areas of consensus and disagreement
- Caution against unexpected outcomes
- Provide continuity
- Document in the medical record
  - Who was present, what was decided, what are the next steps
  - Use a standard chart template
- Discuss results w/ health professionals not present

Your Turn

- Think about your own setting.
- How often are treatment decisions in seriously ill patients framed against the background of the entire medical situation (dementia/bed bound), rather than the narrow issues at hand (anuria, pneumonia)?
- Do you have any data documenting that such discussions are not conducted?

(The Group Discussion)
AIM: What are we trying to accomplish?

- Write a clear statement of aim with numerical goals.
- Make the target for improvement unambiguous.
- Guidance
  - Include anything to keep the team focused (location, strategies, patient populations, office systems, spread plans, etc.).

Examples

- Reduce the number of feeding tubes placed in patients with dementia by 20% over the next 6 months.
- Increase by 30%, the percentage of patients offered dialysis, where there is documentation of a complete informed consent discussion in the medical record.
- Increase by 40%, the number of families of dementia patients who say they were offered the opportunity to not use antibiotics to treat aspiration pneumonia.
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MEASUREMENT: How Will We Know That a Change is an Improvement?

- Measures are used to guide improvement and test changes.
- Measures should reflect your aim statement & make it specific.
- Integrate measurement into daily routine.
- Plot data for the measures over time and annotate graph with changes.

Examples

- Number of feeding tubes placed
- Number of charts showing complete documentation of informed consent discussions
- Family satisfaction data on time spent and completeness of communication with clinician.

Changes: The PDSA Cycle

<table>
<thead>
<tr>
<th>Act</th>
<th>Plan</th>
<th>Study</th>
<th>Do</th>
</tr>
</thead>
<tbody>
<tr>
<td>- What changes are to be made? - Next cycle?</td>
<td>- Objective</td>
<td>- Complete the analysis of the data - Compare data to predictions - Summarize what was learned</td>
<td>- Carry out the plan - Document problems and unexpected observations - Begin analysis of the data</td>
</tr>
<tr>
<td>- Objective - Questions and predictions (why)</td>
<td>- Plan to carry out the cycle (who, what, where, when)</td>
<td>- Complete the analysis of the data - Compare data to predictions - Summarize what was learned</td>
<td>- Carry out the plan - Document problems and unexpected observations - Begin analysis of the data</td>
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Why Test?

• Increase belief that the change will result in improvement.
• Predict how much improvement can be expected from the change.
• Learn how to adapt the change to local conditions.
• Evaluate costs and side-effects.
• Minimize resistance upon implementation.

Accelerating Learning and Improvement

• What cycle can we complete by next Tuesday?
  • Willing to compromise on scope, size, rigor, and sophistication, but the cycle must be completed by Tuesday.

Examples

• Patient/Family education material
• Checklist of procedures to ensure robust Informed Consent Discussion/Documentation
• Standard form for Family Conference/Goal of Care Discussion
• Pocket card of Family Conference steps

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**Homework: Chart Review**

- Review 10 charts of hospitalized patients who started dialysis in the last six months
- Examine the documentation for the dialysis discussion:
  - Procedure description
  - Risks and Benefits including prognosis
  - Alternatives including no dialysis
  - Clinician Recommendation

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**Next Session**

- Review your homework
- Hear from Dr. Moss, a national expert on dialysis shared decision making process.
- Develop an Action Plan for improving the processes of kidney dialysis discussions.

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**References**

- Cohen, JJ. Moving from provider-centered toward family-centered care. Academic Medicine, 1999; 74(4) 425.
- Weissman, DE, Quill TE, and Arnold R. Family Conference Series; Fast Facts and Concepts, [www.wperc.mcw.edu](http://www.wperc.mcw.edu), # 223-227