Chapter 7: Communication & Shared Decision-Making

STEP I – CONDUCT AN AUDIT

Key Item- the questions the TOOLKIT After-death Bereaved Family Member Interview asks communication and decision-making

1. Did [PATIENT] have specific wishes or plans about the types of medical treatment (he/she) did or did not want while dying?  
   [ ] YES   [ ] NO   [ ] DON’T KNOW

2. To the best of your knowledge, did [PATIENT]’s doctor or the medical staff who cared for (him/her) while under care of the (hospital/nursing home/hospice) speak to (him/her) or you about (his/her) wishes about medical treatment?  
   [ ] YES   [ ] NO

3. Did (his/her) doctor or the medical staff who cared for (him/her) while under care of the {hospital/nursing home/hospice) speak to (him/her) or you about making sure (his/her) care was consistent with (his/her) wishes?  
   [ ] YES   [ ] NO

4. (In that last week/ While under care of the hospital/nursing home/hospice), was there any medical procedure or treatment that happened to (him/her) that was inconsistent with (his/her) previously stated wishes?  
   [ ] YES   [ ] NO

5. Did [PATIENT] have a signed Durable Power of Attorney for Health Care naming someone to make decisions about medical treatment if (he/she) could not speak for (him/her) self?  
   [ ] YES   [ ] NO   [ ] DON’T KNOW

6. Did [PATIENT] have a signed Living Will giving directions for the kind of medical treatment (he/she) would want if (he/she) could not speak for (him/her) self?  
   [ ] YES   [ ] NO   [ ] DON’T KNOW

7. Had you or [PATIENT] discussed (his/her) Living Will or Durable Power of Attorney for Health Care with a doctor caring for (him/her) while under care of the (hospital/nursing home/hospice)?  
   [ ] YES   [ ] NO
8. (In that last week/While under care of the hospital/nursing home/hospice), was there ever a decision made about (his/her) care without enough input from (him/her) or (his/her) family?
   [ ] YES  [ ] NO

9. (In the last week of [PATIENT’S] life/While [PATIENT] was under care of the hospital/nursing home/hospice), how would you rate how well those taking care of [PATIENT] provided medical care that respected (his/her) wishes?
   [ 0 1 2 3 4 5 6 7 8 9 10 ]

STEP II – ENGAGE STAKEHOLDERS & DEFINE A GOAL

7.1 Key item – the importance of focusing on communication and shared decision making

At the heart of palliative medicine is communication – many dying persons and family members want to know what to expect. Stopping or forgoing further treatment is a life-altering decision – for many patients, it means abandoning hope for a cure and now focusing on bringing their lives to closure. The key question becomes not whether the patient will die, but when.

At what point should there be a shift in the goals of care?
How can transitions be made without taking away all hope?

Communication about prognosis, preferences, care plans to honor those preferences, and what dying persons and their families can expect are important determinants of the quality end of life care.

Patient and Family Experiences

They kind of turned us over to hospice...there should have been more overlap between the health care team and hospice...I called to tell (the doctor) that (the patient) hadn’t eaten in 24 hours... And (the patient) died two hours later. The doctor said hospice was in charge of his care... the hospice people didn’t even know us... we should have had more information about what would happen when we got home, both for symptoms and medical care.
   ~ a 31 year-old mother recalls the death of her husband

Tragically, this young wife was confronted with caring for her actively dying husband at home. When he stopped eating, as many people do who are actively dying, she was frightened and uncertain about how to help him. She felt alone, abandoned and without information about what to expect from healthcare providers.
This case raises a second important point. The transition to hospice or comfort care is **NOT** the time for the patient’s physician to decrease his or her involvement. Rather, continuity and coordination of care are critical and needed.

While we tell a new mother what to expect and how to care for her newborn baby, we are ill-prepared to provide the same level of guidance to families about caring for a loved one during the dying process.

### 7.2 Key Item – expert advice about communication and decision-making

"**Every human being of adult years and sound mind has a right to determine what shall be done with his own body.**"

–Justice Benjamin N. Cardoza

The fundamental right of a person to make choices for his/her health care is often referred to as autonomy. Justice Cardoza supported the ethical principle of autonomy in his ruling regarding an individual’s right to accept or refuse treatment—specifically, whether or not to have an amputation in this case.

There is near uniform agreement regarding the right of a patient to make his/her own choices regarding their medical treatment and setting of care.

With the passage of the Patient Self-Determination Act of 1990 (PSDA), medical facilities are now required to provide patients with written notification of their right to refuse or consent to medical treatment.

While the PSDA is well intentioned, it has not promoted more effective communication between health care providers and patients. In fact, it seems to have taken autonomy to the extreme. Too often, when patients and families are at their most vulnerable, they are inundated with information from numerous sources and expected to arrive at informed decisions.

It is important to remember that autonomy is a choice, not a command. Patients and families must be able to look to their physicians and other health care providers for expert advice and guidance as they confront the myriad of decisions involved with medical treatment.
Questions that support autonomy and informed decision-making

- Do you understand the how much this patient wants to know about his/her diagnosis and prognosis?
- Do you know what level of involvement this patient wants to have in the decision-making process? Is there anyone else that the patient wants to be involved in the decision-making process?
- Have you provided the desired level of information and guidance needed to help this patient and his/her loved ones in the decision-making process?
- Have you discussed and negotiated individualized treatment goals and plans that will ensure his/her preferences will be honored?

7.3   Key item – the basics about communication and decision-making

Usually, there are three sentinel moments in end-of-life care communication and decision-making.

- **a. Breaking Bad News:** Multi-step journey for patient, family & providers
- **b. Advance Care Planning:** Treatment goals and care plan to honor goals
- **c. Anticipatory Guidance:** Information on what to expect from the illness, from healthcare providers and from patients & families can do to help.

7.3a   Breaking bad news

There is often not one, clearly defined episode of when “bad news” is broken to a patient and his/her family. Rather, there are multiple episodes of bad news— for example, bad news occurs at:

- the time of diagnosis,
- treatment failures,
- decisions to stop chemotherapy for cancer patients.
In the *Oxford Textbook of Palliative Medicine*, Robert Buckman proposes a six-step method for breaking bad news, as outlined in the following table.

<table>
<thead>
<tr>
<th><strong>Buckman’s Six Steps for Breaking Bad News</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
</tr>
<tr>
<td>Getting the context right may be difficult in the setting of urgent decision making. Whenever possible, you should introduce yourself and your role in the medical care of their loved one and sit down in a quiet setting if at all possible.</td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
</tr>
<tr>
<td>It is important first to listen to the patient and their family knowledge about their illness, especially in regards to their understanding and how they choose to frame the patients’ prognosis. Through carefully listening, you will learn how to tailor the information that you present to the special needs of this patient and their families.</td>
</tr>
<tr>
<td><strong>Step 3</strong></td>
</tr>
<tr>
<td>Even if the patient and/or family do not want information on the patients’ prognosis, you still should discuss treatment plans with them.</td>
</tr>
<tr>
<td><strong>Step 4</strong></td>
</tr>
<tr>
<td>Through actively listening to the patient, you should be able to tailor the presentation of information to the “mental model” of the patient and their family. For example, a family that speaks of probability based on medical information on the World Wide Web should have the information tailored to their needs for probabilistic information based on the scientific evidence. When there is uncertainty, openly discuss it with the patient and/or surrogate. Educating and clarifying misperceptions are often an important part of sharing information.</td>
</tr>
<tr>
<td><strong>Step 5</strong></td>
</tr>
<tr>
<td>Being empathetic is key. One must be cognizant of how far one can push a patient or family in decision making if they have fully come to terms with their emotional response to their situation.</td>
</tr>
<tr>
<td><strong>Step 6</strong></td>
</tr>
<tr>
<td>Key to closure is that you summarize the situation, state the plan, and set a time for the next meeting.</td>
</tr>
</tbody>
</table>

* as modified by Teno, reprinted from Oxford Textbook of Palliative Medicine in the ICU.
7.3b Advance care planning: more than a document

Advance care planning is a communication process that entails negotiating with a person regarding goals of and plans for future care. An advance directive is one potential outcome of the advance care planning process.

Successful advance care planning requires two important components - communicating and negotiating with patients to arrive at treatment goals and developing a plan of care that ensures those treatment goals will be honored.

There are a variety of documents that can be utilized to state preferences for future health care or to designate a proxy decision-maker who can speak for a patient if he/she is unable to do so. All 50 states and the District of Columbia have laws recognizing the use of advance directives. On the internet, you and your patients can find up to date information about your state at www.partnershipforcaring.org.

**Advance Care Planning: A Case Study**

Let’s consider a 78-year-old gentleman you’re discharging from your unit after a 35 day stay, during most of which he was in the ICU on a ventilator. You have cared for this patient during previous admissions for his COPD. You notice that he seems more frail than ever before. While you are reviewing the discharge plans with him and his wife, he tells you that he no longer wants to return to the hospital and certainly does not want to be intubated again. He explains that death is preferable to a life of distress from shortness of breath and the continued drain of every day existence. You contact the physician to discuss the patient’s preferences. The physician, who has known the patient for many years, stops in to see the patient before discharge. The discharge plan of care includes the following documentation:

- Out of Hospital Do Not Resuscitate Order – check your state’s statute as this varies from state to state.
- Updated state specific Advance Directive or Health Care Proxy.
- Telephone procedure for accessing 24/7 support of hospice or palliative care service.
- Availability of essential medications to manage severe dyspnea at home.

Without these plans to appropriately palliate the patient’s symptoms and support the caregiver, the patient will either call 911 or die gasping for breath.
7.3c **Informing dying patients and family members about what to expect**

Dying persons and their families need practical information on what to expect during those final days. Often family members are distressed by what they see when a loved one is dying. Knowing that breathing patterns change and that dying people often stop taking fluids, for example, can ease a family member’s distress.

Many family members also are concerned that they are not “doing the right thing” in how they provide medical care. Health care providers must provide both the knowledge and teach the skills that will allow a family member to care for a loved one at home with confidence.

There are several resources written for the caregiver that review signs and symptoms of approaching death. You will find many of these resources on the web, such as [Signs and Symptoms of Approaching Death](#).

7.4 **Defining an overall goal for improving communication and decision-making**

Take a look at your audit results concerning communication and shared decision-making. Remember that, when considering your results, it is useful to look at both the overall problem score for this domain and the individual question scores. The scores on the individual items can help raise awareness of specific opportunities to improve and may provide clues about processes that need improvement.

With your knowledge of the importance of and basic facts about this domain, work with the stakeholders in your institution to define an overall goal. This process should lead you to answer the fundamental guiding questions for improvement:

*What is our overall goal?*

*How will we know when this goal is achieved?*

**STEP III - DEVELOP INTERVENTIONS AND MEASURE CHANGE**

“Our goal is to improve (X) and we will know this by a change in (Y). For our first PDCA Cycle, we will improve (X) process of care by specifically addressing (Z).”

7.5 **Key Item - the kinds of interventions that are appropriate and measurable for communication and decision-making**
Corresponding to the three sentinel moments in end-of-life care communication and decision-making discussed above, there are three important components that are crucial to successful improvement in this domain.

1. making medical decisions at critical points in time
2. advance care planning
3. informing dying patients and family members about what to expect.

With these components in mind, here are some ideas for potential interventions.

**Make advance care planning part of the admitting History & Physical.** In the initial part of the AIDS epidemic, sexual histories did not become routine, until they were listed as questions on the admitting History & Physical.

**Use simulated patients for practice.** Increasingly, simulated patients have been used to provide physicians with feedback on their counseling skills around HIV, diagnosis of depression, etc. Extending this to advance care planning is a logical next step.

**Make education about what to expect part of critical pathways.** Build the education into the discharge process or the admission process to a home health agency or hospice.

When developing your interventions, remember to...

- …answer the fundamental guiding questions for each intervention.  
  *What are we trying to accomplish with this intervention?*  
  *What change can we make that will result in improvement?*  
  *How will we know that a change is an improvement?*

- …utilize the quality improvement tools to help identify and develop your interventions.  
  *Process Flow Charts*  
  *Ishikawa Cause and Effect Diagrams*  
  *Multiple PDCA Cycles*

See Chapter 6 of *this guide* for more on using the quality improvement tools.
More ideas for improving communication and shared decision-making

Find a physician champion -- Unlike other domains, it is critical to have the participation of physicians in efforts dedicated to improving communication to inform and make shared medical decisions. Educational programs through medical staff meetings or local CME events are not enough to provide the substantial change needed. Instead, find a respected physician who can model effective communication skills in end of life discussions and design forums that engages medical staff in opportunities to practice communication skills. Visit the EPEC (Education for Physicians on End of Life Care) web site for educational resources at [http://www.ama-assn.org/ethic/epec/handbook.htm](http://www.ama-assn.org/ethic/epec/handbook.htm).

Ask physicians about the barriers. Many will say they lack adequate time for in-depth conversations with patients. Some may admit to being uncomfortable with end of life discussions. Identify perceived barriers, be innovative, and respond to them.

Write and distribute a guide on what to expect while dying. There are many wonderful resources on the world wide web, but it is important that you individualize the resource to your local medical community.

Use reminder systems. Explore ways of prompting action through effective use of electronic cues or simple reminder notes in a place where the physician will see it. All unit staff, including physicians must understand its meaning and appreciate the urgency of initiating an advance care planning discussion with the patient and their family. Hold physicians accountable for documenting the patient’s goals of care and preferences in the advance care planning section of the chart.

Provide physicians with tools to trigger discussions. Simple tools may provide physicians with the cue that it is time to update patient preferences. Encourage physicians to ask themselves if they would be surprised if this patient died in the next year. Consider providing a formal mechanism that encourages prognostic discussions.

Provide anticipatory guidance. Patients and their families need to be kept aware of what to expect during the course of a life-limiting illness while being sensitive to cultural and ethnic differences that will influence how important information is delivered and to whom. Bear in mind that patients and families will be distracted by the magnitude of the news you are delivering and therefore not fully “hear” all that you are saying.
Reference List


American College of Surgeons. Principles Guiding Care at the End of Life. Web Page. Available at: www.facs.org/fellows_info/statements/.


Nebraska Nursing Ethics Committee. Care of the dying patient - guidelines for
nursing practice. *Nebraska Nurse.* 1995;34.


VANH Bioethics Committee. VA National Headquarters: National Center for Clinical Ethics; 1996.


