Toolkit of Instruments to Measure End of Life Care (TIME)

Resource Guide:

Achieving Quality of Care at Life’s End

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# Table of Contents

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Author(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td><strong>Steps on a Journey</strong></td>
<td>Written by Joan M. Teno</td>
</tr>
<tr>
<td>Chapter 1</td>
<td><strong>About the Toolkit Project</strong></td>
<td>Written by Joan M. Teno</td>
</tr>
<tr>
<td>Chapter 2</td>
<td><strong>What is Patient Focused, Family Centered Medical Care?</strong></td>
<td>Written by Joan M. Teno</td>
</tr>
<tr>
<td>Chapter 3</td>
<td><strong>Conducting an Audit</strong></td>
<td>Written by Virginia Casey &amp; Lisa C. Welch</td>
</tr>
<tr>
<td>Chapter 4</td>
<td><strong>Preparing &amp; Analyzing the Data</strong></td>
<td>Written by Lisa C. Welch &amp; Virginia Casey</td>
</tr>
<tr>
<td>Chapter 5</td>
<td><strong>Engaging Stakeholders &amp; Defining a Goal</strong></td>
<td>Written by Virginia Casey, Joan M. Teno, &amp; Lisa C. Welch</td>
</tr>
<tr>
<td>Chapter 6</td>
<td><strong>Physical Comfort</strong></td>
<td>Written by Sally Neylan Okun &amp; Joan M. Teno</td>
</tr>
<tr>
<td>Chapter 7</td>
<td><strong>Communication &amp; Shared Decision-Making</strong></td>
<td>Written by Joan M. Teno &amp; Sally Neylan Okun</td>
</tr>
<tr>
<td>Chapter 8</td>
<td><strong>Promoting Self-Efficacy of Family Caregivers</strong></td>
<td>Written by Therese Rochon</td>
</tr>
<tr>
<td>Chapter 9</td>
<td><strong>Attending to Family Members’ Emotional &amp; Spiritual Needs</strong></td>
<td>Written by Sally Neylan Okun</td>
</tr>
</tbody>
</table>

## Acknowledgements
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Using this Guide:  **Steps on a Journey**

By choosing to read this guide, you have embarked on a journey that requires you to ask key questions about your health care institution with the ultimate goal of improving the quality of end of life care provided to patients and their families. This Resource Guide will lead you through a model for improvement based on three steps: 1) conduct an audit, 2) engage stakeholders and define a goal, and 3) develop interventions for change and measure change.

**STEP I** asks you and your colleagues to identify opportunities for improvement in the quality of your institution’s current end of life care. Identifying opportunities to improve requires that you conduct an audit of the care delivered. This Resource Guide takes you through the process of conducting this audit, from choosing an instrument to analyzing the data gathered.

**STEP II** involves presenting the information you obtain from the audit in an actionable manner. That is, the task of this step is to communicate the results of the audit in a way that both engages key players in your institution and facilitates the definition of a shared goal to address the results of the audit. The results of the audit may be surprising to some of your colleagues. Some of the results may not be as favorable as you would like or expect. Often, your colleagues will not want to hear any “bad” news. It is essential that key players in your institution “get on board” and participate in addressing two fundamental guiding questions for improvement: What is our overall quality improvement goal? How will we know when we’ve achieved it?

**STEP III** employs Plan-Do-Check-Act (PDCA) cycles to implement small interventions and measure improvement. Your quality improvement team will base intervention decisions on three fundamental guiding questions for improvement: 1) What are we trying to accomplish with this intervention? 2) What change can we make that will result in improvement? 3) How will we know that a change is an improvement? These small interventions work together toward reaching the overall quality improvement goal.
Visual depiction of quality improvement model

CONDUCT AN AUDIT

ENGAGE STAKEHOLDERS & DEFINE GOAL

1. What is overall goal?
2. How will we know when it is achieved?

PLAN

1. What are we trying to accomplish with this intervention?
2. What change can we make that will result in improvement?
3. How will we know that a change is an improvement?

DO

ACT

CHECK
Organization of this Guide

Chapter 1 provides background information about the Toolkit Project. Chapter 2 discusses patient focused, family centered medical care and the Toolkit instruments’ methods for measuring it.

Chapter 3 leads you through the steps for conducting an audit, including choosing a survey tool, selecting a sample, making initial contact, informing & protecting respondents, and training the interviewers. Chapter 4 covers issues involved in preparing and analyzing the information you collect.

Chapter 5 offers suggestions for presenting your results in a format that is actionable, i.e. engaging key players with the quality improvement model and specifying an overall improvement goal.

Chapter 6 accomplishes two tasks. First, it introduces quality improvement tools that will help you develop small interventions and measure change. Specifically, it explores PDCA cycles, process flow charts, and Ishikawa diagrams. Second, Chapter 6 addresses issues specific to the domain of physical comfort (pain and dyspnea), particularly in the context of how to implement the quality improvement model and use the quality improvement tools.

The remaining chapters follow the format of Chapter 6 by discussing issues specific to three other domains of care: shared decision-making (Chapter 7), informing and educating to promote self-efficacy (Chapter 8), and attending to the emotional and spiritual needs of the patient and family (Chapter 9).

Chapters 6-9 are organized around key items that provide necessary information for implementing the improvement model. These items are:

- **Step I** questions the audit instrument asks in this domain;
- **Step II** the importance of this domain of care,
  - expert advice on this domain of care,
  - the basics about quality care in this domain;
- **Step III** the kinds of interventions that are appropriate and measurable for this domain.
Chapter 1: About the Toolkit Project

“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.”

- Mrs. M. (a 31 year old wife), recalls with pain the dying experience of her husband who died from an infection following his third bone marrow transplant.

Dying, and the death of a family member or close friend, represent a sentinel time--one that truly tests a health care system’s ability to provide compassionate and coordinated medical care. Nearly a year after her husband’s death, Mrs. M. recalls with great sadness that she was abandoned by the health care system that had seen her husband and her family through two successful and one final yet failed bone marrow transplant. Her husband had stopped eating and drinking fluids – quite common in a dying person. Coordination of care, early referral to hospice, and education for Mrs. M. regarding what to expect while her husband was dying would have lessened the her burden. Her hope was to have made a “terrible time, tolerable.”

Dying has profoundly changed over the past century. The vast majority of persons now die of progressive chronic illness – i.e., heart disease, cancer, strokes, chronic obstructive lung disease, and other such illnesses. As in the case of Mrs. M.’s husband, each of these diseases involves a journey in which the patient either dies on active treatment or decides to stop treatment. Decisions about ending treatment arise when burdens of treatment outweigh the benefits, the patients’ quality of life is at an unacceptable level, and no further treatment options remain.

Although the proportion of people who die may seem small relative to all persons who receive medical care, the patients who die often are those with the most needs and who incur the highest costs. Key to quality medical care for the dying, for example, is shared decision-making. That is, medical decisions need to reflect the informed preferences of the patient and his/her family, if the patient chooses to involve them in decision making. In addition,
while the health care system is organized around episodes of care, the dying and seriously ill persons need competent, compassionate, and coordinated care across the nursing home, home care, and acute care hospital settings. A seriously ill person truly challenges a health care system to provide such health care.

We must be concerned with the quality of care for all patients, from the person undergoing a routine cholecystectomy to the person that dies in an acute care hospital. The assumption that the person undergoing cholecystectomy wants to maximize function is certainly correct nearly 100% of the time. Indeed, that person's health related quality of life is defined by the same construct of maximizing function. For the dying, this focus on maximizing function does not hold true. While one is dying, things once ignored -- such as spirituality and life closure -- often become more important. Consequently, a statement that health related quality of life is defined by preserving or enhancing function may not hold for the dying person. Goals of care should be individualized for all patients, and this is especially true for the dying person.

A second essential difference is that the family and those who care for the patients assume an even more important role. The World Health Organization recognizes this in its definition of the goals of palliative care as providing the best quality of life possible for dying persons and their families. Indeed, an often neglected aspect of care is attending to the needs of the family after the death of the person. Increasingly, health care systems have embraced patient centered medical care. For the dying, we believe that this construct must be expanded to encompass the important role of family – that medical care for the dying must be patient focused and family centered. Patient focused care recognizes that the main emphasis of care must be on meeting the patient's needs and expectations, while family centered care recognizes the important role of the family in the dying person's life as well as the important needs of family members, including help in adjusting to life after the death of a loved one.
Overview of the TOOLKIT Project

The Toolkit of Instruments to Measure End of Life Care (i.e., the TOOLKIT project) is a research effort with the overarching goal of creating measurement tools to allow health care institutions to evaluate whether care is patient focused, family centered. The TOOLKIT includes both a prospective and retrospective interview tool which relies on both the dying person's and family's perspectives to examine the quality of care that health care providers and institutions provide. For each interview, separate domains and modules allow you to tailor the instrument to your needs.

Our fundamental premise is best stated by Demings: “If you don’t measure it, you won’t improve it.” Too often, health care institutions have not focused on the unique needs of the dying. This initial TOOLKIT will hopefully provide you, the reader, with the measurement tools, the knowledge, and the skills to apply the principles of quality improvement in order to change key processes of care so that medical care for dying persons is truly patient focused and family centered.

Despite the universality of death, much research has not focused on the unique needs of dying persons and their families. Those of us who care for and study the dying are often facing uncharted waters. As noted by Dame Cicely Saunders, we must be committed to sharing knowledge, open to challenging fundamental assumptions, and willing to recognize that the key to quality of medical care for the dying is the dying person's and his/her family's “own view on what they need.”

In the spirit of words of Dame Cicely Saunders, we are providing the measurement tools and resource guide on the World Wide Web free of charge. The instruments are copyrighted only to keep the instrument in the domain of the public. These instruments would not exist without the generous support of the Robert Wood Johnson Foundation. We are especially thankful for the guidance of Dr. Seth Emont, Rosemary Gibson, and Victoria Weisfeld, as well as the attendees of three conferences on measuring the quality of end-of-life care. These conferences were held in Woods Hole, Massachusetts and focused on developing research agendas for measuring the quality of care and quality of life of dying persons and their families.
We hope that this is not a final version of the TOOLKIT. Rather, we encourage feedback from you, the reader, in the spirit of sharing your knowledge and the results that you were able to achieve in your institutions. Given that this document will live on the World Wide Web, we plan on updating it. Our first efforts at updating will focus on providing the reader with results from diverse health care institutions in order to provide more of an authoritative benchmark on which to judge the results from your institution.

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Reference List


Chapter 2: **What is Patient Focused, Family Centered Medical Care?**

With (NAME), I felt a strong sense of advocacy for her, and no, I'm not a medical person. Again, I have some common sense, and I do have a heart. Some of my questions used to be somewhat like well if you don't do that, what does that mean. I would make them answer... You need to because sometimes they would act hurried, and they would act rushed, and they would look at their watch. I made a conscientious decision that I don't really care what you have to do. It really is not my problem, and I'm sympathetic to everyone in this hospital, but my concern right now is this patient here in this bed, and I would make them answer questions. I would call them, and I would ask for pager numbers, and I would ask how I could reach somebody. Sometimes it used to annoy me if I went to the nurse's station and they were busy, and they wouldn't even look up, but I would say excuse me, excuse me, I have a question, or I need some help with something.

We have created a health care system that too often is organized around the needs of the institution, and we lose site of what is important — providing competent, coordinated, and compassionate care. Increasingly, a patient and his or her family are faced with navigating their way through a health care system that is not responsive to their needs. Simple courtesies are lost, sad to say. Donabedian noted that “achieving and producing health and satisfaction, as defined for its individual members by a particular society or subculture, is the ultimate validator of the quality of care.” ¹ Similarly, the Institute of Medicine defined quality of health care as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.”² Central to both of these definitions is a consumer perspective and medical care that is consistent with current professional knowledge.

In the development of the dying patient and after-death bereaved family surveys, we have relied on both input from dying persons and their families regarding what they believe is important to defining high quality medical care and a review of existing professional guidelines. First, we conducted an extensive review of existing guidelines that examined the domains and key processes of care that were judged by experts and consumer organizations as important to high quality medical care. Second, focus groups and in-depth interviews were conducted with bereaved family...
members and dying persons. This latter research effort focused on capturing what was important from the patients’ and families’ perspectives. Throughout this resource guide, we have used these interviews and family members’ stories to provide important insights into what we see as the key to the quality of medical care for dying persons and their families – patient focused, family centered medical care.

2.1 Components of Patient Focused, Family Centered Medical Care

Four key elements constitute patient focused, family centered medical care. Health care providers and institutions must:

1. provide the desired physical comfort and emotional support,
2. promote shared medical decision-making,
3. treat each person as an individual by understanding their needs and expectations,
4. attend to the needs of those who care for and love the dying person.

As shown in the above diagram, there are two key care processes that are cross-cutting and important for achieving patient focused, family centered medical care. First, patients and family members must be informed and educated to the extent that they desire. As one of the bereaved family members stated, “you know what to expect, how you can help, and what you
can expect.” The key is that dying persons and their families need to understand the disease and its future trajectory, their role in living with that disease, and most importantly what they can expect from you as their health care provider.

The second important care process is coordination and continuity of care. Too often, dying persons and families reported that they felt abandoned at their time of greatest need. In the last month of life, dying persons and their family usually receive medical care from a home care agency, acute care hospital, hospice and/or a nursing home. Key to high quality end-of-life care is coordination of care across these diverse health care settings. For these dying patients and their families, there is not a series of discrete episodes. This experience structures their lives and their struggles with their illnesses.

Patient focused, family centered medical care cannot be achieved without attention to the coordination and continuity of care. It seems bizarre that an acute care hospital can spend thousands of dollars and weeks of effort on a seriously ill, dying patient and all the next set of health care providers get is one piece of paper that lists medications and treatments. There needs to be better “hand off” of seriously ill persons. The receiving health care providers must know what to expect, what to monitor, and, especially, who this person is.

2.2 Identifying Opportunities to Improve

Listening to what dying persons and their loved ones say is key to examining whether your institutions provide patient focused, family centered medical care. The survey tools included in the Toolkit provide your institution with measurement tools to capture their perspectives. Previous satisfaction surveys have relied solely on rankings of the quality of care (i.e., Thinking about your medical care, how would you rate the explanation of medical tests? Would you say: Excellent, Very Good, Good, Fair or Poor?). To answer this question, the dying person or their family member will have to perform a mental calculation that involves asking several issues – Did that patient have any medical tests? Did someone explain those tests to them?
What was their expectation regarding that explanation? Finally, how would they rank that institution using the scale that was provided to them?

A key problem with using typical satisfaction scores is that patient expectations are low and persons are reluctant to criticize health care providers resulting in the skewed distribution (i.e., everyone says either “excellent” or “very good”). In response to this concern, the Picker Institute has developed new measurement tools to measure the patient's experience called “Patient Centered Reports.” A Patient Centered Report (PCR) asks a question about a specific process of care in such a way that patient expectations or social acquiescence does not confound the answers. For example, a PCR asks “Did the staff explain the medicine that you are taking for pain in a way that you can understand?” In contrast to a ranking of “very good”, a PCR provides you with information to guide quality improvement efforts.

PCRs are summarized into problem scores. Each of the major domains (as shown in the above figure) have at least two problem scores that define that domain. A problem score is the count of the number of responses that indicate an opportunity to improve. For example, consider the following question from the retrospective after death interview.

While [PATIENT] was at [LAST PLACE], how often were you or other family members kept informed about [PATIENT’S] condition - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

Any response other than “always” is considered a problem or an opportunity to improve. A problem score counts the number of opportunities to improve in each of the problem score proposed for each of the four essential domains. Table 1 lists each of the problem scores or scales and states the objective for that sub-domain.

![PCRs identify a specific area or process that can be targeted for improvement.]

![The challenging nature of quality end-of-life care means that all institutions and providers have opportunities to improve.]

Table 1. 
*Domains and Problem Scores for the After-death Bereaved Family Member Interview*

<table>
<thead>
<tr>
<th>Domain</th>
<th>Problem Score</th>
<th>Objective</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Comfort</strong></td>
<td>Physical Comfort</td>
<td>The dying persons discomfort is recognized and they receive their desired level of comfort</td>
</tr>
<tr>
<td></td>
<td>Emotional Support</td>
<td>Same</td>
</tr>
<tr>
<td><strong>Shared Decision Making</strong></td>
<td>Advance Care Planning</td>
<td>Health care providers communicate and negotiate with the patient regarding goals of care and formulate plans, including contingency plans, so that their preferences are honored</td>
</tr>
<tr>
<td></td>
<td>Informing and Making Decisions</td>
<td>Patients and their families are informed about their illness, its disease trajectory and prognosis. Medical decisions should reflect the patients’ desired involvement and informed preferences.</td>
</tr>
<tr>
<td><strong>Focus on the Individual</strong></td>
<td>Respect, Dignity, and Kindness</td>
<td>The dying person is treated with respect and dignity. This includes helping the patient achieve their desired level of control over their functioning and daily activities.</td>
</tr>
<tr>
<td></td>
<td>Achieving Closure</td>
<td>The dying person and family are able to achieve desired closure in personal relationships and transcendence.</td>
</tr>
<tr>
<td><strong>Attend to the Caregivers</strong></td>
<td>Emotional Support including both prior and after the patient’s death</td>
<td>The family receives the desired support at time prior to and after the patient’s death, including appropriate referral for bereavement services.</td>
</tr>
<tr>
<td></td>
<td>Self-efficacy in providing hands on care</td>
<td>Family caregivers have the confidence in their ability to help the dying person in management of their medical care.</td>
</tr>
</tbody>
</table>
The dying are a small, yet vulnerable population that provides a true test of whether health care organizations provide competent, coordinated, and compassionate health. Patient focused, family centered medical care recognizes the important role that family and friends play in caring for persons dying of serious and progressive illnesses. The focus of medical care must be on the dying person; yet, key to the well being of the dying person is the support provided to family prior to and after his death. The Toolkit of Instruments to Measure End of Life Care has a survey tool for both the dying person and the bereaved family member following that person’s death. In the bereaved family member interview, we ask the respondent to report on his/her observations as an expert witness and on his/her own perceptions of interactions with the health care team. In the next chapter, we will walk you through using either of these instruments to conduct an audit – a small study to identify opportunities to improve and enhance the quality of care.
Reference List


Chapter 3: Conducting an Audit

Conducting an audit is an umbrella term that encompasses several smaller elements of the survey process. This chapter covers the nuts and bolts of administering a survey. [Chapter 4] focuses on preparing and analyzing the data that you collect.

Checklist for administering a survey

- Choose a survey tool
- Select a sample
- Make initial contact
- Train the interviewers
- Inform & protect respondents

3.1 Choose a survey tool

The Toolkit of Instruments for End of Life Care contains two survey tools: the Prospective Patient Interview and the After-death Bereaved Family Member Interview.

3.1a Purpose of the interview tools

The Prospective Patient Interview was designed to obtain feedback from a patient as he/she is receiving medical care for a life-threatening illness. Two important advantages of a prospective survey are that the data collected can be used to shape the care of the particular patient who responded to the survey and that patient preferences can become the reference point for evaluating the appropriateness of care (Fowler et al 1999).

This instrument has a set of core questions that pertain to all patients, regardless of the setting of care. In addition, there are modules that have been designed to address “new admission” issues and the special circumstances of home care, long-term care, and hospice settings.
The **After-death Bereaved Family Member Interview** was designed to gather retrospective data on the care that a patient received at the end of life. That is, we are asking the family members for his/her perception of the patient’s end-of-life medical care after the patient has died. Given that it is difficult to accurately identify patients who are in the last month/week of life and that many patients are unable to be interviewed, family members can often provide important information about the quality of medical care at the end of life. Although family members cannot know exactly what a patient was feeling or thinking, they can report on what they were told, their own observations, their perceptions of the patient’s dying experience, and their own experience with health care providers (Fowler et al 1999).

The After-death Interview includes several domains of care (e.g., physical comfort, self-efficacy of the family). You can choose to include all of these domains or to focus on only a few of them. We have prepared versions of the After-death Interview that are specific to nursing home, hospice, and hospital settings. In addition, questions specific to the last month of life are available in a module.

### 3.1b Issues to consider when choosing a tool

As these brief descriptions suggest, every survey tool has its own advantages. The tool you choose will depend on several factors, some of which are likely to be specific to your institution. Two issues to consider are the kind and time frame of the data you want to gather.

- **The kind of information you want to gather**. Do you want to gather information that will guide the care of current patients? Do you want to learn more about the extent to which family members were prepared for and supported in their loved ones’ dying process as well as their perspective on the patient’s care?

- **The time frame of the data**. Do you want information about quality of care of current patients, regardless of how long they will continue to live? Do you want to know more about quality of care in the last month or week of a patient’s life – data that may be difficult to obtain from a critically ill patient?
**Prospective Patient Survey** | **After-Death Family Member Survey**
---|---
Guidance for care of *that* patient | Family member experiences and perspectives on patient care that provide information to guide the quality of care of future patients

<table>
<thead>
<tr>
<th>Current patients</th>
<th>Past patients</th>
</tr>
</thead>
</table>
| No specific period in illness progression or life course | Data about a defined period (e.g., last week of life)

Given the difficulties of surveying patients who are close to death, the After-death Bereaved Family Member Interview is generally easier to administer than the Prospective Patient Interview. With an interviewer who is trained and sensitive to bereavement issues, family members are usually very willing to participate in this type of survey.

### 3.2 Select a sample

Your sample consists of those people who respond to your survey. When selecting your sample, it is important to consider both the make-up and size of the sample.

### 3.2a Make-up of the sample

A crucial step in administering a survey is to identify who is going to be in your sample. Some general guidelines apply to both the Prospective Patient Interview and the After-death Bereaved Family Member Interview. That is, the Toolkit surveys were not developed to address the special issues associated with the death of a child or with death by trauma or suicide. Also, children should not be asked to be respondents to this survey. Therefore, we recommend that you do not include the following people in your sample:

- patients under 18 years of age,
- family members under 18 years of age,
- patients or family members of patients who died as a result of trauma or suicide.
In addition to these general guidelines, special considerations arise for each of the two Toolkit interview tools.

- **Prospective Patient Interview** - In a survey of dying people, two key decisions are choosing which patients to include in the sample and identifying the point in the course of a patient’s disease at which data are to be collected (Fowler et al 1999). Many patients are too ill to be interviewed in the last week of life. Furthermore, identifying who is in the last week of life is a difficult task (Teno & Coppola 1999). Given these difficulties, the table on the following page identifies several alternative trigger points for identifying potential patients to include in your sample.

  Certain triggers may be more useful for specific types of institutions. For example, hospice or palliative care organizations may find entry into a service program to be the most useful trigger. On the other hand, hospitals may look to life-limiting diagnoses to identify patients who are eligible for the survey. Nursing homes may find that guidelines based on expected behaviors near the end of life are the most useful trigger for identifying a sample of patients. Regardless of the trigger you choose, it is important that your criteria for including patients in the sample be reliable on an ongoing basis so that the same trigger can be used to identify the entire sample.

- **After-death Bereaved Family Member Interview** - Selecting family members as potential respondents raises an important issue—**who is the best family member to act as a proxy for a patient’s quality of care?** The best proxy respondent is the person who was most fully involved with all phases of the patient’s dying experience and who can answer the most questions as an informed person (Fowler et al 1999). As one might expect, the person identified in the discharge records as the family members may or may not be the best proxy respondent for the deceased. We have chosen to use existing data sources to help identify the potential family member to complete the survey. For example, we suggest contacting the person listed as the informant or contact person on the hospital admission paper work. Then, ask that person: **Would you say you are one of the people who knows the most about how [PATIENT] was doing during (his/her) last few weeks of life?**
<table>
<thead>
<tr>
<th>Trigger Point</th>
<th>Advantage</th>
<th>Disadvantage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prognosis</strong></td>
<td>Can search computer database using DRG as key word</td>
<td>Not helpful criteria for certain diseases (e.g., COPD)</td>
</tr>
<tr>
<td>- Diagnosis that implies life-limiting prognosis (e.g., pancreatic cancer, metastatic colon cancer)</td>
<td>Can search computer database</td>
<td>Utilization data reflect practice patterns. Best suited for managed care in which all health events are captured</td>
</tr>
<tr>
<td>- Diagnosis with utilization data (e.g., CHF patient with 2 or more admissions)</td>
<td>Prognostication systems already in use by many institutions</td>
<td>Uncertainty in prognosis for non-cancer and ICU illnesses</td>
</tr>
<tr>
<td>- Computerized model (e.g., APACHE III with cutoff MDS/RAI)</td>
<td>HCFA uses these guidelines</td>
<td>Uncertainty in prognosis</td>
</tr>
<tr>
<td>- NHO “prognostic” guidelines</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Guidelines</strong></td>
<td>Guidelines can be developed locally</td>
<td>Variation in guidelines limits ability to compare data</td>
</tr>
<tr>
<td>- Define behaviors which should occur with limited life expectancy</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Discrete event/circumstance</strong></td>
<td>Yields actionable information about an important event; survey can be modified for a sentinel time period</td>
<td>Some questions are linked to prognosis; some questions may not be appropriate after hospital discharge</td>
</tr>
<tr>
<td>- Entry to service program (e.g., 72 hours after hospice admission)</td>
<td></td>
<td>Not cost effective; some questions may not distinguish between those with or without an event</td>
</tr>
<tr>
<td>- Occurrence of a concern or event with a particular patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Physician</strong></td>
<td>Simple</td>
<td>Linked to physician behavior; Sensitivity and specificity of question is unknown</td>
</tr>
<tr>
<td>- Use of an IHI Team question from breakthrough series “Would you be surprised if your patient died in the next year?”</td>
<td></td>
<td>Linked to physician behavior; extensive research shows concern with this trigger</td>
</tr>
<tr>
<td>- MD identification of people with six month prognoses</td>
<td></td>
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</tbody>
</table>

**Chapter 3 • Page 5**
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3.2b Size of the sample

A small amount of data collected on a regular basis can provide invaluable information. For the purpose of quality improvement, as few as 20 or 30 interviews can provide you with enough information for a baseline assessment. Research projects supported by grant funding, though, will often require larger sample sizes and more extensive planning.

Regardless of the type of project, it is important to consider that the sample you start out with will be different from your final sample because some people you ask to participate will not be able to do so or will choose not to participate. It is important that you track the number of people that agree and don’t agree to participate in the survey so that you can calculate a response rate (see Chapter 4 of this Guide).

3.3 Make initial contact

The manner in which you establish initial contact with patients or bereaved family members has a profound impact on the respondents’ right to privacy. Once you have identified patients or family members as potential respondents, we recommend sending them a letter that introduces your project. This letter should identify who is conducting the study, explain the purpose of the study and what respondents will be asked to do, and give potential respondents the opportunity to refuse all further contact from the study team. Providing potential respondents with the opportunity to refuse further contact from the study team is part of protecting their rights (see below) and sometimes is done by supplying a toll-free telephone number they can call to notify the study team of their wishes. Examples of initial contact letters for patients and family members are included on the following pages.

When is the best time to contact family members? Rarely does a family member, friend, or professional caregiver become uncomfortable in remembering the circumstance of the death of someone close (Lynn et al 1997). We recommend that you contact family members anywhere from three to six months after the patient’s death. It has been our experience that
family members will tell you if they are not ready to talk about the death of their family member.

Sample initial contact letter for Prospective Patient Interview

Dear Mr. Gonzalez,

I am writing on behalf of XXX nursing home. Currently, we are working on a project intended to promote the best quality of care for patients and their family members. We are doing this by speaking with residents, such as yourself, who can provide important information about your experience with the medical care received at our facility.

Specifically, we are asking you to participate in our project by agreeing to be interviewed over the telephone. If you decide to agree to an interview, everything that you tell us will be held in the strictest confidence. Some information you provide will be included in your medical chart and will be used to guide your care in the future; however, we will not identify you or describe you in a way that anyone else could identify you in any general reports that may result from this project.

One of our interviewers will phone you in the next few weeks. If you prefer not to participate in this project, you can call us at 1-800-555-xxxx to notify us of your wishes. Upon receiving a call from you, no one from our study team will contact you further about this project.

We are confident that this project will enable us to promote the highest-level quality of care both for you in particular and for other residents more generally. With this goal in mind, we very much hope that you will agree to participate in a telephone interview.

We look forward to talking with you.

Sincerely,

[Study Team Leader]
Sample initial contact letter for *After-death Bereaved Family Member Interview*

Dear Mrs. Smith,

I am writing on behalf of XXX Hospital. We are saddened by the loss of [patient’s name] and hope that you have been doing as well as possible during this difficult time.

Currently, we are working on a project intended to promote the best quality of care for seriously ill patients and their family members. We are doing this by speaking with people, such as yourself, who can provide important information about a loved one’s medical care at the end of life. We would like to learn about your perspective on the experience of [patient’s name] at our hospital and your own experience during that time.

Specifically, we are asking you to participate in this project by agreeing to be interviewed over the telephone. If you decide to agree to an interview, everything that you tell us will be held in strictest confidence. We will not identify you or [patient’s name] in any reports that result from this project.

One of our interviewers will phone you in the next few weeks. If you prefer not to participate in this project, you can call us at 1-800-555-xxxx to notify us of your wishes. Upon receiving a call from you, no one from our study team will contact you further about this project.

We are confident that this project will enable us to continue to promote the highest-level quality of care for seriously ill patients and their family members. With this goal in mind, we very much hope that you will agree to participate in a telephone interview.

We look forward to talking with you.

Sincerely,

[StudyTeam Leader]
3.4 Inform and Protect Respondents

Each respondent has the right to grant informed consent, to refuse participation, as well as to privacy and confidentiality.

3.4a Informed consent. Although the specific procedure for informed consent varies by institution, all informed consent procedures should include at least these three components.

**Purpose of study.** Always tell the potential respondent the purpose for conducting the survey.

**Procedures, risks, and benefits.** Each potential respondent must be informed of the procedures that will be followed and any discomforts, risks, or benefits associated with participation.

**Contact information.** Potential respondents must also know how to contact someone other than the interviewer who can provide additional information about the study.

An informed consent statement should be included at the beginning of each interview. Such a statement is included in each of the Toolkit instruments [link to informed consent statement in Afterdeath interview].

3.4b Refuse participation. Just as potential respondents have the right to know about the nature of a study, they also have the right to refuse to participate without fear of intimidation or negative consequences. In addition, they have the right to refuse to answer any question on the survey and may end the interview at any time. It should be clearly stated to every potential respondent that no aspect of his/her medical care will be impacted by a refusal to participate in this study.

3.4c Privacy and confidentiality. Respondents need to be assured that their records and responses will remain confidential. They have the right to know how their responses will be presented (e.g., as part of an overall group result with no personal identifiers). In addition, need to know that all identifying information will be kept under lock and key during the analysis of the data, and that it eventually will be destroyed.
At this point in time, many health care settings do not require that quality improvement projects seek approval of an institutional review board (IRB). An IRB typically is associated with a research institution and has the responsibility of ensuring that the process of gathering data will not harm the participants in any way. Projects that will be published in a scientific journal or that are being supported by a grant typically need to apply for approval by an IRB. Regardless of the type of project or whether IRB approval is required, it is important to remember that all respondents have rights!

3.5 Train the interviewer(s)

The Toolkit instruments are standardized survey interviews. This means that the instruments use a pre-defined question-and-answer format to gather information. The questions are carefully prepared in advance, and the answers are mainly closed-ended (i.e., the tool provides a set of possible responses from which respondents must choose). Given this, the role of the interviewer is to read the prepared questions word-for-word to the respondent, and the role of the respondent is to choose an answer from the set of responses offered by the interviewer.

This sounds simple, but there are many opportunities for confusion and “messy” data that is difficult to analyze.

Since the Toolkit surveys have been designed to be administered by an interviewer, it is important for the quality of your study that all interviewers follow the same general guidelines for conducting standardized survey interviews. The survey tools themselves include instructions for how to proceed with the interview, but the guidelines below will help interviewers put on the “interviewer hat.”
3.5a Set the stage for a successful interview

Setting up the interview interaction is crucial for the success of the interview. To set the stage effectively, the interviewer needs to explain the purpose of the interview, foster a conducive relationship, and set the standard.

i. Explain the purpose of the interview to the respondent before beginning to ask the survey questions. It is important that the respondent understand the reason that he/she should care about the interview. Even though the respondent received an initial contact letter, it is useful to tell the respondent again which institution is conducting the research and that the goal of the project is to promote the highest quality of care for seriously ill patients and their family members.

ii. Foster a conducive relationship between the respondent and the interviewer. In general, the relationship should be warm and professional. The respondent needs to be able to respect the interviewer and know that he/she can be trusted to be accepting and nonjudgmental. This may require some practice, especially if the interviews are being conducted over the telephone.

iii. Set the standard for the respondent and the interviewer. Many respondents may not have been interviewed before, which may make them uncomfortable about the process. Consequently, it is important to tell the respondent what he/she can expect from the interviewer and how it is appropriate for her/him to respond. For example, an interviewer using a Toolkit survey may want to begin by saying that the type of survey being administered requires that the interviewer read each question verbatim and that the respondent choose one of the responses offered by the interviewer.
3.5b Strive for neutrality

One of the interviewer’s goals is to avoid influencing the answers chosen by the respondents. Two rules of thumb for remaining neutral are to avoid volunteering personal information and to avoid value judgments.

i. Interviewers should avoid volunteering personal information to the respondent. Personal information about the interviewer can sway the respondent’s view of what answers the interviewer might consider appropriate or “correct”. The goal of the interview is to learn the respondent’s views, not what the respondent thinks that the interviewer wants to hear. If a respondent asks the interviewer for his/her opinion during the interview, the interviewer can tell the respondent that the goal is to learn what the respondent thinks about certain issues and that they can talk about the interviewer’s opinions after the interview.

ii. Interviewers should avoid value judgments regarding the respondent’s answers. It may be tempting for an interviewer to encourage the respondent by agreeing with or complementing him/her as a form of feedback to a response. This kind of value judgment should be avoided since it may bias further responses. For example, a patient reports that his/her pain was alleviated within the first 48 hours of admission to hospice. In an attempt to encourage the respondent, the interviewer comments “that’s good”. Even though alleviation of pain may be a “good” outcome, the patient may now feel pressure to avoid the appearance of contradiction by painting a positive picture of his/her experience with hospice during the remainder of the interview. The goal is to obtain an accurate response to each question from the perspective of the respondent.

3.5c Probe for an appropriate response

At times, the meaning of a question or an answer may need to be clarified. When this occurs, it is very
important that the interviewer probe in such a way as to avoid influencing or suggesting an answer. Interviewers should follow the “three Rs” below to ensure that they do not influence the respondents’ answers.

i. If a respondent asks the interviewer to clarify the question, the interviewer should re-read the question and possible responses in full. If the respondent needs further clarification, the interviewer should instruct him/her to choose an answer based on his/her best judgment about the meaning of the question. The interviewer should not interpret the question for the respondent.

   Re-read

ii. If the interviewer needs clarification about the respondent’s answer, the interviewer should explain to the respondent that the way to answer is to choose one of responses listed and then should re-read the entire list of possible responses. The interviewer should require that the respondent choose one of the listed responses. Some interviewer’s may be tempted to interpret the respondent’s words, saying “I think you mean X, is that right?” Such interpretation should be avoided, since this may influence the respondent’s actual answer.

   Repeat

iii. If a respondent is unsure which response to choose even after the interviewer has repeated the question and possible responses, the interviewer should record verbatim all relevant information given by the respondent. The decision as to which response this information points to will be made during the analysis process—not during the interview.

   Record

The main idea regarding probing for an appropriate response when conducting a standardized survey is to stick to the script! The interviewer can repeat questions and answer categories and can explain to the respondent the need to choose an answer category; however, the interviewer should NOT interpret a respondent’s words or assume the meaning of a respondent’s words.
3.5d Attain consistency across interviewers

Most standardized survey interview projects entail more than one interviewer. Since the goal of the project often is to compare respondents’ answers, standardization of responses is crucial. Attaining this standardization requires that interviewers are consistent in how they approach the interview and handle unexpected problems. Two tips for attaining consistency across interviewers are to utilize a common introduction and to practice with each other.

i. A common introduction to and explanation of the interview process can go a long way in attaining consistency across interviews. Standardizing the words the interviewers use to “set the stage” (see above) helps to ensure that each respondent approaches the interview with the same understanding and expectations of the interaction.

ii. Practice, practice, practice with each other! Mock interviews between interviewers not only offer practice for each interviewer but also develop common approaches to the interviewing process. Interviewers can learn from each other the most effective ways to strive for neutrality and to probe for an appropriate response (see above). In addition, interviewers who play the role of respondents can help to anticipate potential questions and problems that may arise. Videotaping and reviewing mock interviews can be a useful learning tool as well.

Interviewing seriously ill patients and bereaved family members presents specific challenges for interviewers. Both the health and emotional status of the respondent need to be considered. Undoubtedly, interviewers will encounter different degrees of acceptance and/or grief among patients and family members. Mock interviews can prepare interviewers to approach respondents with compassion while still meeting the objectives of the survey.
3.5e Pay attention to respondents’ stories

As this chapter emphasizes, the Toolkit instruments are survey instruments that require interviewers to collect precise, accurate answers to specific questions. Following the above guidelines is the primary task of the interviewer. Since interviewers do administer the instrument, though, the possibility arises that respondents may begin to expand on their specific answers with stories or examples that help to fill-in the picture of their experiences. In addition, the open-ended questions at the end of the toolkit interviews offer the opportunity for respondents to elaborate on or add to the issues addressed in the structured interview.

Even though the primary goal of the interview is to obtain specific responses to pre-defined questions, respondents’ stories can be quite useful when presenting the results of your project. People’s stories can foster a powerful and contagious excitement about the need for changes in care practices. For this reason, interviewers should pay attention to respondents’ stories. If an interviewer finds a story particularly enlightening or compelling, he/she should record that story in the following manner:

i. **Wait until the interview is over before asking the respondent to elaborate on the story!** During the standardized survey interview, the interviewer should be sure to stick to the script.

ii. It may be helpful for the interviewer to make a note on the coversheet or interview guide as a reminder to go back to the respondent’s story after the standardized interview is complete.

iii. After the standardized interview, the interviewer should tell the respondent that he/she is particularly interested in the story about “X” and ask the respondent for his/her permission to record that story.

iv. If the respondent agrees, then the interviewer should ask the respondent to repeat the details and record the story verbatim (as much as possible).

v. If the respondent does not agree to have his/her story recorded, then the interviewer should move on and not press the issue.
vi. Informing and protecting respondents’ rights applies to their stories just as much as it does to their answers to survey questions.

vii. When presenting a story as part of your results, never attach a respondent’s name to a story or describe a respondent in such a way that anyone would be able to guess whose story you are telling.

3.5f Revisit the interview process throughout the project

Although following the guidelines for conducting a standardized survey interview is crucial for ensuring the quality of the information you gather, no set of guidelines can prepare an interviewer for all possible interview situations. Given this, it is useful to gather the interviewers involved in your project at least once after the interviewing portion of your project has begun. During these sessions, the interviewers can exchange stories about interview situations (protecting the confidentiality of the individual respondents, of course) and share successful techniques. This also presents an opportunity for interviewers to check that their techniques and approaches to the interview are consistent. These sessions are very helpful for encouraging interviewers to continue to wear the “interviewer hat.”

(citation for section 3.5: Fowler & Mangione 1990)

Frequently Asked Questions

Why are the Toolkit surveys designed to be administered by an interviewer over the telephone?

As part of the work in creating the survey, we asked focus group participants about the mode of administration. Bereaved family members felt that the survey should not just be mailed out to them, but rather they wanted a person who could speak to them and refer them to bereavement services if needed. However, the majority of hospices in the United States use a self-administered survey. Future work shall modify the survey for self-administration.
Can we conduct our own telephone interviews?

To avoid the biases inherent in conducting interviews with patients in your own institution or with family members of patients who died in your institution, it is always recommended that a person not directly involved in the care of the patient conduct the interview.

What are the other modes of data collection?

In addition to being administered by an interviewer over the telephone, surveys can be: 1) administered by an interviewer in-person; 2) self-administered and returned to the study team; or 3) administered via a computer program. Sometimes people use a mixture of these modes to minimize the percentage of people who refuse to participate in the survey.

Can you use the same instrument with all modes of administration?

No. Each mode of administration requires an instrument tailored to that mode. It is possible, though, to write questions so that the results can be compared across modes of administration. We will be producing a self-administered version of the Toolkit instruments, which will be comparable to the interviewer-administered version.

Will this survey be translated into other languages?

Yes, future work will translate the survey into Spanish.
Reference List

Field Interviewer’s Manual, Center for Survey Research, University of Massachusetts 1993.


Teno JM & Coppola KM. For every numerator, you need a denominator: a simple statement but key to measuring the quality of care of the "dying". Journal of Pain and Symptom Management. 1999 (Feb); 17, 2: 109-13
Now that you have completed surveys on hand, the task becomes transforming the information you’ve gathered (i.e., the data) into results that can inform your institution’s dialogue about how to improve end-of-life care. This task includes:

1. **preparing the data** for analysis, and
2. **analyzing the data** according to the concerns of your institution.

### 4.1 Preparing the data

#### 4.1a Deciding which completed questionnaires can be utilized for analysis

One of the advantages of standardized survey interviews (such as the Toolkit instruments) is that the data included in each completed questionnaire should be clear and straightforward. That is, respondents should choose one of a list of available responses for each survey question. Some cases though, may not be so straightforward and may even be ineligible for analysis. Ineligible questionnaires are those that do not include data either for enough or for the key questions necessary for the analysis.

Questionnaires that do not include clear answers for one or more items have “missing data.” When the number of pieces of missing data exceeds a predetermined limit as set by the analyst (i.e., you!), then the questionnaire cannot be analyzed meaningfully. For the Toolkit, a good rule of thumb is to consider a questionnaire ineligible for analysis if it is missing data for more than one (1) of the key questions for a particular problem score. Since this rule is not set in stone, you may want to increase this number to two (2) missing items for a problem score with more key questions (e.g., Inform and promote shared decision-making).

A questionnaire may also become ineligible if it is missing data for one of the items that your institution finds particularly important. For example, your
institution may be conducting an audit to determine if patients’ pain levels are being relieved within 48 hours of report of pain. If a patient answers all questions except the one about whether his/her pain was relieved within 48 hours, then that respondent’s questionnaire would be ineligible for inclusion in your audit of pain relief.

4.1b Coding and entering the data

For a standardized survey, coding the data means assigning a number to each possible answer. The number assigned to the answer chosen by a respondent, then, is entered into a computer database. It is much simpler for a computer to recognize and analyze numbers (i.e., codes) than words.

The Toolkit instruments include the code for each possible answer in brackets [ ] behind the answer. Note that the same pattern for assigning codes is used with similarly structured questions (e.g., “yes”=1, “no”=5). The computer will keep track of the responses according to both the question number and the code of the answer to that question that is chosen by the respondent.

If you are using information from the coversheet, medical records, or some other source, you will need to assign a number to each possible answer (i.e., code the data). In some instances, it may be useful to group possible answers. For example, an institution may want to include in the analysis whether or not a patient currently has a spouse. The coversheet offers 4 categories for marital status, but for the purposes of this analysis “widowed”, “divorced”, and “single” all mean that no spouse is present. Consequently, “married” could be coded as “1” while “widowed”, “divorced”, and “single” could all be coded as “0”.

If you are including questionnaires that have some pieces of missing data, you will need to assign a code that represents missing data in order to tell the computer that it is missing. The code for missing data must be different from all other codes. For example, the number “99” may identify missing data if and only if no other possible answer has the code “99”.

As indicated in the “Instructions for the Interviewer” section of the Toolkit instruments, it is sometimes logical to skip questions for some respondents. For example, a patient who reports no pain should not then be asked about
pain severity. In these cases, a “skip pattern” is appropriate for that respondent. When a question is skipped, the lack of information on that question is not actually “missing data” because the information was not supposed to be supplied in the first place. Consequently, you will need to assign a different code for skip patterns. For example, the number “8” may represent a skip pattern as long as “8” does not represent any of the possible responses or missing data.

Once each of the possible responses, missing data, and skipped questions has been assigned a number as its code, then the data is ready to be entered into a computer database. Since the Toolkit Scoring Packet provides a ready-to-use Excel Worksheet and Guide for data entry and analysis (see the Registration Form), we recommend that you use Microsoft Excel as your data entry program. However, you may use other spreadsheet applications or other statistical programs (such as SAS). If you use a program other than Excel, you will need to write the necessary formulas or program coding in the language of the program you choose in order to complete the analysis.

4.1c Cleaning the data

Cleaning the data means verifying that the data has been entered correctly. The accuracy of the data entry process is essential for the quality of your results. To clean the data, remember the following checks:

✓ Check for out-of-range values. Some data entry packages can be programmed to warn the person entering the data if an out-of-range value has been entered. If your data entry package does not do this, you should check the data for numbers (i.e., codes) that are not possible given coding schemes you have assigned to the potential answers, missing data, and skipped questions.

✓ Check for skip pattern problems. Look for the code you’ve assigned to skip patterns and check to make sure that skipping that question was appropriate for that case.

✓ Check for duplicates. The number of records in the data file (e.g., lines on a data entry spreadsheet) should match the number of cases in your final sample of respondents.
4.2 Analyzing the data

**HAPPLY**, the computer will “crunch the numbers” for you! In addition, if you are using Microsoft Excel as your data management and analysis program, we will provide you with a pre-formatted Excel Worksheet that will calculate your problem, domain, and scale scores (see the Toolkit Registration Form).

Even though the computer will do the computational work, it is a good idea for you to understand how the problem scores and scale scores are calculated in order to be able to interpret them correctly. Moreover, in addition to computational issues, two questions remain: do the scores accurately reflect the quality of care in your institution, and how does an institution decide whether a problem or scale score needs to be addressed? As a result, this section will address the following:

- a. calculating problem and scale scores,
- b. interpreting the scores,
- c. prioritizing your results.

### 4.2a Calculating problem and scale scores

**Problem scores.** The majority of Toolkit survey results will be presented in terms of problem scores. As noted in the “Instructions for Scoring” section included with the instruments, problem scores are a summary of all responses in a specific domain that indicate a less than optimal experience or an opportunity to improve. Any answer that indicates an opportunity to improve is treated as a problem. For example, both a response that a patient received “less than the amount of care needed” and a response that a patient received “more than the amount of care needed” are treated as problems because both responses indicate an opportunity to improve.

A *problem score* summarizes the number of opportunities to improve within a specific domain. For example, for a particular problem score that includes 5 questions, your score could vary between 0 and 5. In this example, a score of 0 indicates that respondents reported no opportunities to...
improve and that your institution is doing very well, while a score of 5 indicates that respondents reported an opportunity to improve on all items.

A **domain score** is the average problem score across the questions included in that score. A domain score is calculated by dividing the problem score by the number of survey questions used to calculate that problem score. Following the above example, a score of 1 in a problem score comprised of 5 questions corresponds to a domain score of 0.20 (1/5=0.20). This domain score of 0.20 means that respondents identified an opportunity to improve on one out of five questions.

**Scale scores.** Unlike problem scores, scale scores do not correspond directly with an opportunity to improve. Instead, scale scores reflect the average answer to survey questions whose response categories range from a low response to a high response (e.g., ratings on a scale from “0” to “10” or responses ranging from “not at all” to “very much so”). For example, consider the domain called “Encourage the self-efficacy of the family” in the Toolkit After-death Bereaved Family Interview. The scale score will reflect whether the **average** bereaved family member felt “very confident”, “fairly confident”, or “not confident” about knowing what to expect or do while their loved one was dying.

### 4.2b Interpreting your scores

Often, the results of the survey both will confirm some of what you expected and provide surprises. Once you see the results of your audit, an important question arises. How can you be sure that the numbers accurately reflect the quality of care in your institution?

The work you’ve done up to this point is one assurance that the numbers reflect the quality of care in your institution. (See Chapter 3 of this Guide regarding using the Toolkit instruments and previous sections of this chapter for coding and entering data accurately.) Assuming the nuts and bolts of surveying and computing have been completed carefully, it remains true that **numbers (including your problem and scale scores) need to be interpreted** in the context of both possible sources of **data bias** and the **commonly held views** about your institution.
4.2b.i **Data bias** means that the data gathered reflect only part of the total picture. This can happen when one group of potential respondents is not included in the questionnaires that are eligible for analysis or when one group’s views are more pronounced than others’ in the eligible questionnaires. Every survey carries potential for data bias. Some sources of bias are eliminated by carefully following the accepted procedures for conducting the survey and computing the scores. Other sources of bias cannot be controlled by the researcher—e.g., the types of potential respondents who refuse to participate in the survey or the types of questions that respondents do not answer. It is important to identify potential sources of bias in your data (even if you could not control them) in order to be able to interpret your results appropriately.

Check the following characteristics of your data to help determine if your data are biased.

✔ **Completion and response rates.**

A completion rate is the number of questionnaires you included in your analysis out of the total number of potential questionnaires. In other words, it is the number of questionnaires your team completed divided by the number of people that theoretically could have been included. A response rate is the number of questionnaires you included in your analysis out of the number of people you planned to interview. In other words, a response rate is the number of questionnaires your team completed divided by the number of people you attempted to contact—whether or not they agreed to participate.

For example, consider the scenario in which your goal is to interview bereaved family members. A total of 100 people died in your institution. Of those 100 patients, 80 had family members that you know of. You attempt to contact those 80 family members. Of the 80 family members, you were able to interview 75. In this scenario, the completion rate is 75% (75/100), and the response rate is 93.75% (75/80).
In general, the lower your completion and/or response rates, the more likely it is that your survey has missed the perspective of one or more groups. In the above example, you don’t have information on the quality of care of those persons who did not have a family member available to be interviewed. It is quite possible that the quality of care for those patients was different than the care of those patients who had a family member to report on their experience. There is no way to know for sure.

Again from the above example, only a small number of persons refused to participate in the survey. This is one piece of evidence that your survey does reflect the experiences of all groups in your institution. If a large number of people had refused to participate, though, you would need to ask yourself if there was a reason for their refusals? Did they refuse to participate because they were particularly unsatisfied with their loved one’s medical care or traumatized by the experience? Again, there is no way to know for sure. In short, the possibility of having missed the perspective of a group of people grows with the number of people who cannot be contacted or who refuse to participate.

Possible reasons for refusals to participate (i.e., non-response bias).

Although you cannot know for sure how people who refused to participate would have answered the questions, it is useful to know who those people are. In other words, you can use the information you have about the people who refused to participate in order to identify those people who are not represented in your data. For example, you may find that those who did not or could not participate were patients within 24 hours of death at the time of contact, patients with a specific illness, patients or family members of a specific racial group, family members who were not also primary caregivers of the patient, family members of patients who were transferred to your institution within 72 hours of death, etc. Regardless of what category the non-responders may fit into, it is very useful for interpreting your scores to know whose perspectives are not reflected in those scores.
Reasons for missing data.

If a high percentage of respondents did not answer a specific question, it is useful to consider why this occurred. Was the question confusing? Did the interviewer encounter a problem reading that question? Was it particularly emotional for respondents? The interviewers may be able to shed light on possible reasons for the missing data. Exploring potential reasons behind missing data informs your interpretation of your scores by identifying what elements of the domains of care are not included in the scores because that data is missing.

4.2b.ii Identifying commonly held views about your institution is important in the process of quality improvement. Audit results may confirm or contradict the common beliefs about quality of care in an institution. If the problem and scale scores contradict commonly held beliefs about your institution, then two possibilities arise.

1. The numbers are biased in some way and, therefore, do not reflect the complete picture. In this case, you should explore the sources of bias discussed above. If you feel the results are biased, repeat the survey on another sample.

2. Second, the scores are accurate. In this case, it is possible that the commonly held views reflect bits and pieces of anecdotal evidence whereas the audit scores reflect a more complete picture. Alternatively, it is possible that expectations for end-of-life care among patients, family members, and/or care providers are somewhat different than the standard of care proposed by the survey.

Regardless of the reason, if commonly held views contradict the audit results, the reasons behind this should be explored in order to understand the meaning of the audit results in the context of your institution.
4.2c Prioritizing your results for action

Patient and family member surveys can raise many compelling and important issues. How do you decide which issues to address or to focus on first? As the central person(s) conducting and summarizing the results of the audit, you will need to choose which areas you believe should be your initial focus for quality improvement. The following suggestions can help you with these decisions.

- **Ranking problems by magnitude.** The most straightforward method of prioritizing is to rank issues in order of the size of the problem and to focus first on those that are the greatest.

- **Comparing results against outside norms or benchmarks.** A common method of prioritizing is to select issues that compare unfavorably with national, regional, or local norms or with benchmark institutions. This allows you to focus on areas of comparative weakness. Currently, we are conducting surveys that will establish national benchmarks based on the Toolkit instruments.

- **Comparing of results within your organization.** Comparison within organizations facilitates networking among units or departments and sharing of information about effective practices. Internal competitiveness may also fuel improvement efforts.

- **Ease of action.** Many organizations focus initially on the issues that most easily present solutions. By demonstrating successful interventions, this prioritization method can rally support for more difficult improvement efforts later to come.

- **Comparing results over time.** Comparing survey results over time provides a powerful analytic tool for prioritizing because it identifies trends. Following trends allows you to focus on correcting aspects of performance that are slipping over time. To determine accurate trends, though, sample sizes for each survey period must be large enough to achieve stable results.
Comparing results with predefined goals. One way to rationalize priorities is to set threshold or target goals prior to the survey. You would then focus on issues where performance does not meet these goals. This method is particularly effective when there is clear consensus on what those goals should be.

Correlating specific and overall measures. In some organizations, it is clear which overall summary measures are most important. For example, an overall rating of the quality of care that is delivered might be the most important indicator of quality for a hospital. Correlating patient responses to specific questions with the overall rating of the quality of care helps to focus attention on a specific issue that, in turn, can improve the overall measure.

Correlating results with other problems. Some problems may be “markers” for a constellation of other problems. Analyzing how problems relate to one another (i.e., correlate with each other) can help to identify and focus attention on these marker problems and possibly identify the source of the broader issues that need to be addressed.

Maintaining areas of excellence. An organization may also want to maintain excellence in areas where it is already perceived to be doing well. This approach can provide a clear and positive focus for clinical and administrative staff.

Now that you have completed Step I (conducting the survey, analyzing the data, and choosing your priority areas for improvement), it is essential that members of senior management and other colleagues “get on board”. You’ve already done a significant amount of work to identify an opportunity to improve; applying the principles and tools of quality improvement requires a facility-wide commitment. Chapter 5 will walk you through Step II of the Quality Improvement Model—Engage Stakeholders and Define a Goal.
Reference List


Chapter 5:  

**Engaging Stakeholders**  
& **Defining a Goal**

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Change is most likely to occur when there is a sense of urgency that the current practices are no longer acceptable. Transforming this sense of urgency into change requires two crucial elements:

1. engaging stakeholders in the conviction that change is necessary, and
2. working with stakeholders to define a goal for improvement.

Without these two elements in place, changing care practices will be difficult to achieve.

### 5.1 Engaging stakeholders

Engaging stakeholders means bringing senior leadership in your facility "on board" the quality improvement train. You have two important sources of information to assist you in this task. First, the *results of your audit* provide you with information specific to your health care institution that can raise awareness regarding real opportunities to improve the quality of care. Second, your *knowledge about specific domains of care*—i.e., the importance of that domain, expert advice regarding care in that domain, and the basics of care in that domain—will ensure an informed discussion with stakeholders. The *manner* in which this information is presented and the *approach* taken for discussing possible improvement efforts are crucial for bringing stakeholders "on board".

Keep in mind that no one comes to work every day believing that they are doing less than a good job. We all believe that we are doing the best that we can. Information to the contrary is often met with skepticism and resistance.

- **Our patients are sicker than patients at that other facility.**

- **Your survey must be wrong. I know it.**

- **Family members don’t understand what’s happening to their loved one. Only I know what’s really going on.**

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See Chapters 6-9 of this Guide for key informational items about specific domains of care.

Critical reflection requires a safe environment.
As a result, it is important to foster a safe, productive environment that allows critical reflection on the quality of care in your institution. You can promote an environment that will allow stakeholders to acknowledge a need to improve by

a. identifying your audience and considering its needs,
b. utilizing effective presentation techniques, and
c. listening to your audience.

5.1a Identify your audience and consider its needs

Before presenting the results of your audit, it is important to identify the stakeholders in your facility. For many health care institutions, the stakeholders include executives (e.g., Chief Executive Officer, Chief Financial Officer), physicians, nurses, and/or managers (e.g., nursing unit managers). The stakeholders in your institution may include representatives from some or all of these categories as well as others.

Once you have identified your key audience(s), ask yourself some questions to help specify their characteristics and information needs.

? What do they already know about quality end of life care?
? What information can best help educate and inform them about it?
? For what purpose will they use this information?
? What other sources of information do they trust and/or use now?
? What types of presentations or reports can best reach them?
? How many of the results are they willing or able to consider at once?

Your answers to these questions will help you determine the content and format of your presentation or reports.

Another significant clue as to how to organize your presentation is to understand the “mindset” or “mental models” of your audience. For example, administrators are often only concerned with the financial bottom line. Even though you may not consider this the most important issue, your presentation must take their concern into account. One way to do this is to approach quality improvement from the stance that improving consumer satisfaction also improves the financial bottom line. You can remind your audience that
dissatisfied customers will not refer their friends and colleagues to your health care institution. You can also remind your audience that preliminary research shows that quality improvement efforts can actually improve patient outcomes and reduce the costs of care. In short, as this example demonstrates, the concerns and mindset of your audience should shape the way you present your audit results.

5.1b Utilizing effective presentation techniques

User-friendly reports and presentations that enable readers to understand and begin to take action on key issues are critical to the success of any audit. Two possible types of results can come from a TOOLKIT audit. First, every audit will produce survey results in the form of problem scores and scale scores that measure the quality of care in your institution. Second, some interviewers may also have recorded respondents' stories in response to open questions at the end of the standardized survey interview or after a respondent has completed the interview.

People’s stories bring life to the numbers that constitute your survey results. These stories can foster an excitement about the need for changes in care practices in ways that numbers may not be able to do. While these stories can be powerful, it is important to remember that they complement your problem and scale scores. Since the Toolkit instruments are designed to produce problem scores and scale scores that summarize responses from your entire sample, one respondent’s story cannot replace or refute the survey results. Instead, a story may be used to support your survey results, or it may illustrate an experience that is not average for your institution.

A person’s experience that does not go along with the average experience as reported in your survey results is very important and should be heard. At the same time, though, that one experience does not invalidate the overall results of your survey. That person’s experience may help you and your institution’s stakeholders understand why some people report different quality of care than others, but the average report as reflected in the survey results continues to be important as well.
Tips for presenting survey results

- Gear the format to the audience. Use brief, succinct summaries for executive audiences. Use comprehensive summaries for those who will implement improvements.

- Use graphics. Data that are displayed visually are easier to interpret. Display trends or comparisons in bar charts, pie charts, or line charts.

- Keep the format succinct and consistent. Graphics, bullets, tables, and other visuals help guide the reader. Choose a few of these elements and use them consistently. Be consistent with the use and appearance of headers, fonts, graphic styles and placement of information.

- Emphasize priorities clearly. Emphasize the highest priority items for commendation in executive summaries and major findings. Highlight the most important items – for example, use **bold** or *italicized* type.

Tips for presenting respondents’ stories

- Give a pseudonym, or false name, to the person whose story you are telling. This will personalize the story without compromising your promise of confidentiality to the respondent.

- Along with a table or graph summarizing survey results, include a particularly poignant quote on the same page or handout.

- Choose the stories of one or two respondents to weave throughout your presentation.

- Emphasize the part of the story that makes your point or best illustrates the survey results. Include other information as background or only when needed to strengthen your point.

**IMPORTANT !!**

When presenting a story as part of your results, it is essential to protect the respondent’s right to confidentiality.

- Never attach a respondent’s name to a story or describe a respondent in such a way that anyone listening would be able to guess whose story you are telling.

See [Chapter 4](#) for more information on respondents’ rights.
5.1c Listening to your audience

Often, the results of an audit are met with disbelief. Rather than discount questions and skepticism, listen to stakeholders and be sensitive to their questions and concerns. Encourage them to talk about what information they would like to see to increase their understanding of the current quality of care, and then provide that information. Your goal is to engage stakeholders in a discussion that eventually will convince them that current practices no longer are adequate.

For example, nurse managers at one hospice believed that family members who were reporting distressing dyspnea in the last days of patients’ lives were misperceiving normal physiological changes of dying as distressing to the patient. The nurse asked for a separate small study that examined the nurse’s perceptions of dyspnea among patients. Much to their surprise, the results were similar to the family members’ perceptions—i.e., that patients often were in severe distress in the last days of life. A small degree of extra data collection in this situation resulted in the management staff recognizing the importance of an improvement project focusing on dyspnea.

Staff members also may voice concerns about the results of the audit. In this case, collecting data from medical records regarding processes of care can be very helpful for demonstrating the need to improve. For example, the hospice team members that examined dyspnea among terminally ill patients asked the staff members to outline the steps that should occur in the management of dyspnea for a 79 year-old white male with lung cancer. After the staff outlined each step, the evidence of what actually happened with this patient was presented from his medical record. This proved to be a powerful illustration of the need to improve current practices.

Listening to your audience and responding to their concerns encourages them to take ownership of the problem. Remember that your goal is to engage stakeholders in a discussion that eventually will convince them that there is an urgent need to improve current practices. You may have an idea of what your improvement goal should be, but your broader
purpose is to engage your audience in the discussion and to convince them that something must be done. At this stage in the improvement model, allowing and encouraging others in your institution take ownership of the problem is a crucial element for implementing change. Change will not occur until key stakeholders say “Aha! We must change our current way of doing things.”

5.2 Defining a goal

As with the task of engaging stakeholders, you bring two important sources of information to the task of defining an overall goal—your audit results and your knowledge of quality care in specific domains. With this information in hand, work with your team of stakeholders to answer the two fundamental guiding questions for quality improvement:

- What is our overall goal?
- How will we know when this goal is achieved?

Answering these questions will guide your team to define a goal that is both clear and actionable.

What is our overall goal? Stating a clear goal is essential so that everyone in the unit knows the objective of the quality improvement effort. When defining your overall goal, keep in mind three criteria for creating overall goals. That is, define a goal that is of interest to the team members, that is feasible, and that focuses on a prevalent care issue. The prevalence of the care issue being addressed is important because the initial enthusiasm and momentum for quality improvement can be lost if the team must wait a long time before being able to begin. Another way to think about a goal is to consider what you want to promise yourselves and your patients about your chosen domain of care.
NOTE: Remember to allow your quality improvement team and staff members sufficient time to learn and become comfortable with applying quality improvement techniques. If this will be one of the first CQI efforts on this floor or at this institution, we recommend that you start with something “easy”—such as pain management. The reason for this is that the quality improvement team can focus most of its energies on educating itself and other staff members about quality improvement techniques rather than the need for quality pain management.

How will we know when this goal is achieved? Setting up a specific target for care allows everyone involved to know—and to celebrate—when success has been achieved. In other words, answering this question specifies the means by which change will be measured. One way to measure change is to re-administer that part of the Toolkit audit that addresses your chosen domain of interest.

5.2a Writing a goal statement

After answering these two fundamental guiding questions, you will be ready to write a goal statement that includes both your objective for change and the means by which this change will be measured.

“Our goal is to improve (X) and we will know this by a change in (Y).”

For example, let’s say that your institution’s stakeholders choose pain management as its quality improvement topic. After a meeting reviewing your audit results and current knowledge about quality care regarding pain management, your quality improvement team circulates the following goal statement:

Our goal is that dying patients will receive their desired level of pain control. We will know we’ve achieved this goal when our scores from the bereaved family member survey change from our current audit results to scores showing that all dying patients received their desired level of pain control.
5.2b Bringing staff members “on board”

In the process of engaging stakeholders and defining your goal, it is likely that you already have included some staff members in your quality improvement effort. Once you have arrived at an overall goal, it is important to speak with all the staff members on the unit where small changes in the process of care will be tested. Staff members need to know why it is important for them to change their care processes and behaviors.

Again, your two sources of information come in to play. That is, we recommend that you 1) present to staff members the results of your audit in your chosen area of improvement, and 2) discuss with staff members current knowledge about the chosen domain of care. For the above pain management goal statement, for example, staff members should know their facility’s or unit’s problem score for dying patients’ pain and they should be well versed current knowledge regarding effective pain management.

In short, just as you engaged stakeholders in the quality improvement process, staff members need to be brought “on board” with your overall goal for quality improvement. As with stakeholders, it is important to be patient, to listen to staff members’ comments, and to be responsive to their concerns. Letting those who need to change their behaviors take ownership of the goal and the improvement process is important for ensuring that change will occur and be sustained.

In **Step II**, you have accomplished two very important tasks. First, you have engaged the key players in your institution in order to bring them “on board” the quality improvement process. Second, you have defined an overall goal for the entire quality improvement project. **Step III** involves putting your plans into action. Chapter 6 uses the domain of physical comfort to introduce the quality improvement tools that you will use to reach your overall goal.

As you read Chapter 6, keep in mind that most quality improvement goals require multiple small interventions to be achieved. Just like the overall goal, each small intervention requires its own goal statement so that everyone knows the objective of the intervention and the means by which this change will be measured. Following the above example, you’ve stated that
your overall goal is for dying patients to receive their desired level of pain management. Your first intervention might set a goal of 90% of nurses documenting pain as “fifth vital sign.” You will know if this goal is achieved by following chart reviews over time. In short, while reading the following domain-specific chapters, remember that your change process will pursue multiple small changes that will accumulate over time to achieve your overall goal.
Reference List


Chapter 6: **Physical Comfort**

The goal of the chapter is to apply the quality improvement model to the specific domain of physical comfort. Along the way, we will describe in more depth three useful quality improvement tools: PDCA cycles, process flow charts, and Ishikawa diagrams. To accomplish these tasks, we divide the chapter into two sections.

**SECTION A** focuses on pain management, with particular attention to the knowledge necessary to convince stakeholders of a need for change and to define an overall goal.

**SECTION B** follows the experience of an inpatient hospice unit as it implements the quality improvement model and uses quality improvement tools to ameliorate dyspnea among persons dying on the unit.

**SECTION A -- PAIN MANAGEMENT**

**STEP I -- CONDUCT AN AUDIT**

1. (In that last week/While under care of the hospital/hospice/nursing home), was [PATIENT] on medicines to treat (his/her) pain?
   [ ] YES  [ ] NO  [ ] DON'T KNOW

2. (In that last week/While under care of the hospital/hospice/nursing home), did (his/her) doctor or the medical staff who cared for (him/her) tell you about how (his/her) pain would be treated, in a way that you could understand?
   [ ] YES  [ ] NO

3. (In that last week/While under care of the hospital/hospice/nursing home), did [PATIENT] receive too much, too little, or just the right amount of medication for (his/her) pain?
   [ ] TOO MUCH  [ ] TOO LITTLE  [ ] RIGHT AMOUNT

4. (In that last week/While under care of the hospital/hospice/nursing home), was there ever a time when one doctor or nurse said one thing about treatment of (his/her) pain and another said something else?
   [ ] YES  [ ] NO

5. (In the last week of [PATIENT'S] life/While [PATIENT] was under care of the hospital/hospice/nursing home), how well did those taking care of [PATIENT] make sure (his/her) symptoms were controlled to a degree that was acceptable to (him/her)?
   [ 0 1 2 3 4 5 6 7 8 9 10 ]
STEP II -- ENGAGE STAKEHOLDERS & DEFINE A GOAL

6A.1 Key Item – the importance of focusing on pain

The importance of the adequate treatment of pain and other symptoms such as dyspnea is central to the management of the physical and psychological well-being of all patients. Adequate pain and symptom control translates to increased personal control.

6A.1a The Experience of Pain

Pain is a symptom most expected and most feared by terminally ill patients. Unrelieved pain is a major source of distress that can have enormous physiological and psychological effects on both the patient and their loved ones. Poorly controlled pain can become a person’s sole focus as it appears unending and steadily worsening. The distraction of pain can expand to occupy a patient’s whole attention, isolating him/her from the world around allowing little opportunity to attend to relationships and emotional/spiritual closure. Pain negatively affects the quality of life by impairing daily functions, social relationships, sleep, and/or self worth.

Total Pain:
The complex and interrelated dimensions of pain

SOURCE: Adapted from UNIPAC THREE: Assessment and Treatment of Pain in the Terminally Ill, 1996
6A.1b Patient and Family Experience of Total Pain

Pain is what the patient says it is. Pain is not what the clinician expects it to be or thinks it ought to be. Clinicians must learn to appreciate the complexities of the total pain experience.

Pain is an experience that is highly individualized and multidimensional. For this reason it is impossible for clinicians to see the patient's suffering or to directly measure it. The Total Pain diagram provides a useful construct for appreciating the complexity of the pain experience. Despite these complexities, pain management can be simplified using clinical skills and tools.

Most importantly, the patient’s and family’s account of their pain experience is the most valuable tool available to the clinician. Time spent listening to the patient and family permits them to express feelings that may range from frustration, fear, anger, and guilt to stoicism, hopelessness and even acceptance. Avoid assumptions – not all patients want to be completely pain free. Listen carefully for clues about the meaning of pain and suffering, observe for emotional responses as they tell you about their experiences.

Involving the patient and family in the development of the pain and symptom management plan allows them to regain a sense of control at a time when so much seems out of their control. Pain and other distressing symptoms are very distracting and can keep patients and families from attending to important life closure issues. Too often, unrelieved pain leaves families permanently scarred with distressing memories of a loved one’s final days.

6A.1c Remember P-A-I-N

Remember that the experience of pain is multidimensional. Each dimension contributes to the individual’s perception and response to pain. Keep this helpful pneumonic in mind:

<table>
<thead>
<tr>
<th>Physical</th>
<th>Anxiety</th>
<th>Interpersonal</th>
<th>Non-acceptance</th>
</tr>
</thead>
<tbody>
<tr>
<td>problems, often multiple, must be specifically diagnosed and treated.</td>
<td>anger, and depression are critical components of pain that must be addressed by the clinician in conjunction with other health care professionals.</td>
<td>problems, including loneliness, financial stress, and family tensions, are interwoven in the fabric of a patient’s symptoms.</td>
<td>of approaching death, a sense of hopelessness, and a desperate search for meaning in life can cause severe suffering unrelieved by medications.</td>
</tr>
</tbody>
</table>

SOURCE: UNIPAC THREE: Assessment and Treatment of Pain in the Terminally Ill, 1996

Pain impacts the entire family.
6A.2 Key Item - expert advice about pain management

Experts agree that effective treatments are available to manage pain for the majority of patients. Unfortunately, pain is frequently not recognized and therefore it is under-treated.

Achieving excellent practice in pain and symptom management requires an interdisciplinary and collaborative approach that is patient-family centered. It is important to identify basic principles that can be used to guide practice in your clinical setting. These principles form the foundation from which to build your team’s best practice. Here are some key principles to consider:

6A.2a Principles of Pain Management

- **Keep the patient in control.** The patient is the authority about his/her pain experience.
- **Focus on the patient and his/her loved ones.** Pain disrupts the entire family. It is important to keep this in mind when assessing relationship issues and dynamics.
- **Utilize a team approach.** The complexity of pain demands a team approach. The patient and caregivers, as the core of this team, will require the assistance of physicians, nurses and other professionals.
- **Assess patients in the context of their Total Pain experience.** Physical, emotional, social and spiritual domains must be considered.
- **Employ multiple methods appropriate for the patient.** Modify disease (palliative surgery, radiation, hormonal or chemotherapy); modify pain perception (drugs, education, psychological support, relaxation); interrupt pain transmission (nerve blocks, TENS, acupuncture); modify lifestyle (physiotherapy aids, homemaking services, meditation)
- **Treat other symptoms and side effects.** Pain and its treatment are associated with a variety of other symptoms which may increase the perception of pain. Pain relief must include measures to control other sources of discomfort, such as nausea, vomiting, constipation, anorexia, dyspnea, weakness.
- **Never use placebos.** Placebos should never be used in this patient population. It is illogical and unethical.
- **Reassess, reassess and reassess again!** Pain is a dynamic condition that requires meticulous monitoring. The presence of pain should always be considered an emergency requiring immediate attention and relief.
6A.2b Pain Management Guidelines, Standards and Position Statements

There are numerous guidelines available from organizations dedicated to improving the management of pain. Most of these guidelines have elements that are fundamental to any pain management program regardless of care setting. A comprehensive listing of resources, guidelines, standards and position papers is available at PainLink and Talaria.

A NEW PATIENT ARRIVES ON THE UNIT FOR ADMISSION

Gloria arrived on the oncology unit with her daughter at 11:30 am. Gloria’s doctor decided to admit her from the clinic following the discovery of a breast lesion along an old mastectomy suture line. The skin is reddened and warm to touch. Gloria is also complaining of pain in the lower lumbar region for which she is taking Percocet “once in a while”. Gloria has been taking 30 mg of MS Contin BID for about 3 months. She doesn’t remember if she took her dose this morning. Gloria’s daughter seems anxious and often answers for her mother. When asked about how she would rate her pain now, Gloria responds “Well, it’s been worse but I try not to complain too much – I hate to worry my family. Anyway, I suppose I should expect some arthritis at my age.” Her daughter adds, “Mom is pretty strong. She doesn’t like to depend on pain killers. She still lives by herself and believes that God helps her get by each day.”

6A.3 Key Item – the basics about pain management

Knowledge alone does not improve practice… Knowledge in the presence of clinical wisdom and experience improves practice!

KNOW YOUR ABC’s

Ask about and Assess physical comfort regularly.
Believe the patient and family in their reports of pain and what relieves it.
Choose pain control options appropriate for the patient, family and setting.
Deliver interventions in a timely, logical, and coordinated fashion.
Empower patients and their families. Enable them as much control as possible.
### Key Elements of Pain History

<table>
<thead>
<tr>
<th>Key Elements of Pain History</th>
<th>Suggested Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site(s) and Radiation</td>
<td>Where is it? Does it spread anywhere?</td>
</tr>
<tr>
<td>Timing</td>
<td>How long have you had it? Does it come and go or is it always there? How long does it last?</td>
</tr>
<tr>
<td>Quality</td>
<td>Describe the pain in your own words (e.g., dull, sharp, ache, throbbing, burning, stabbing)</td>
</tr>
<tr>
<td>Severity</td>
<td>How severe is the pain?</td>
</tr>
<tr>
<td>Aggravating Factors</td>
<td>What brings on the pain or makes it worse? (e.g., posture, movement, eating, time of day)</td>
</tr>
<tr>
<td>Relieving Factors</td>
<td>What makes the pain better? (e.g., medication, positioning, massage, music, prayer)</td>
</tr>
<tr>
<td>Impact of Pain on Daily Life</td>
<td>▪ on sleep: Does pain disturb your sleep?</td>
</tr>
<tr>
<td></td>
<td>▪ on mood: Does the pain cause you to be depressed, angry, discouraged?</td>
</tr>
<tr>
<td></td>
<td>▪ on activity: How has pain affected your activities (e.g., job, work in house, social life, relationships, hobbies)</td>
</tr>
<tr>
<td>Previous Therapy</td>
<td>Which drugs or other therapies have helped?</td>
</tr>
<tr>
<td></td>
<td>Which ones have failed to relieve the pain?</td>
</tr>
</tbody>
</table>

**SOURCE:** Adapted from *A Monograph on the Management of Cancer Pain, Health & Welfare Canada, 1984*

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**Assessing Physical Comfort in the Cognitively Impaired Patient** – Behavior has meaning and may be clues to assessing pain in a patient with cognitive impairment and/or dementia. Look for:

- change in activity level or functioning; changes in sleep patterns;
- tense body language, fidgeting, rubbing of body part, wringing of hands;
- sad or frightened facial expression;
- vocalizations may range from being hushed and negative to mournful and groaning;
- breathing that is audible or appears labored or exaggerated.

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**Assessing Physical Comfort in a non-English speaking patient** – Culture and ethnicity may influence perception and reporting of pain and other symptoms. Medical interpreters, when available, should be used to assist non-English speaking patients and caregivers through the pain assessment. Medical terms and phrases may have very different meanings when literally translated and may need to be put into cultural context for the patient and caregiver. Visual Analog Scales and Faces of Pain Scales may be helpful after they are explained to the patient in their first language.
**Reviewing and Reassessing** – Pain is seldom static. Frequent reassessment and explanation to the patient and family must be done regularly.

**Listening for Clues to Pain Type** – Listen carefully to how the patient or family describes the pain. Certain words can give you important information.

<table>
<thead>
<tr>
<th>Description and Clues</th>
<th>Types of Pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I ache all the time”</td>
<td>Visceral Pain – usually localized to the site of injury/tumor. Pain can be referred to the somatic area supplied by the same nerve root.</td>
</tr>
<tr>
<td>“I’m sore &amp; stiff” “It feels like a charley-horse”</td>
<td>Muscle Pain – sometimes difficult to isolate as it may be due to an underlying disorder, a systemic or metabolic cause.</td>
</tr>
<tr>
<td>“It hurts when I move” “It aches at night”</td>
<td>Bone Pain – local bone pain can range from dull ache to deep, intense pain. Usually well localized and worse on movement and weight-bearing, it may be worse at night. Bone pain can be masked by muscle pain arising from involuntary, protective spasm of the surrounding muscles.</td>
</tr>
<tr>
<td>“It feels like my skin is burning” “It feels like someone stabbed me” “It is a shooting pain”</td>
<td>Neuropathic Pain – Constant, superficial burning pain is usually caused by actual damage to peripheral nerve, plexus, root or spinal cord. When a specific nerve is involved, pain is in a relatively constant area of the body surface (dermatome) but may also be referred to the somatic area supplied by the nerve. The degree of nerve pain will be effected by the degree of nerve compression or infiltration.</td>
</tr>
<tr>
<td>“Its worse when I breathe in”</td>
<td>Pleuritic Pain – patient may complain of pain on inspiration or may present with guarded, shallow breathing.</td>
</tr>
<tr>
<td>“Comes &amp; goes like cramps”</td>
<td>Colic Pain – partial or complete obstruction of a hollow viscus can result in intermittent cramps.</td>
</tr>
</tbody>
</table>


**6A.3b Treatments for Pain**

**Pharmacological and Non-pharmacological Interventions**

Pain management is best accomplished through a combination of pharmacological and non-pharmacological techniques. Each intervention must be considered in the context of the patient’s total pain experience, taking into account their individualized pain assessment and the patient’s personal preferences.

![Diagram of Treatments for Pain](image)

The complexity of the pain experience requires multiple treatment methods.
Keep it Simple: The WHO “Analgesic Ladder”

- **WHO STEP 1** - Patients with mild to moderate pain should be treated with nonopioid analgesic, which should be combined with adjuvant drugs if indication for one exists.

- **WHO STEP 2** - Patients who have limited opioid exposure and present with moderate to severe pain or who fail to achieve adequate relief after a trial of a nonopioid analgesic should be treated with an opioid conventionally used for moderate pain.

- **WHO STEP 3** - Patients who present with severe pain or who fail to achieve adequate relief following appropriate administration of drugs on the second step of the analgesic ladder should receive an opioid conventionally used for severe pain.

**Step 1:** Non-narcotic – “around the clock”
- Acetaminophen 650mg q4h or
- ASA 650mg q4h or
- Ibuprofen 400mg q4h or
- Choline magnesium trisalicylate 1500mg bid or
- other NSAIDs

**Step 2:** Add Opioid for Moderate Pain – “around the clock”
- Acetaminophen 325mg + codeine 30mg q4h (Tylenol #3) or
- Acetaminophen 325mg + codeine 60mg q4h (Tylenol #4) or
- Acetaminophen 325/500mg + oxycodone 5mg q4h (Percocet/Roxicet)

Note: Consider stronger opioid if pain not controlled by these combinations at a total daily dose if 400mg/day of codeine or 80mg/day of oxycodone

**Step 3:** Start strong oral opioid – “around the clock”
- Morphine 15-30mg q4h titrate to pain
- Dilaudid 2-4 mg q4h titrate to pain
- MS-Contin or other long acting 30-60mg q8-12 h

Notes: Use short acting prep of same medication for breakthrough pain. Consider lower dose in opioid naïve and elderly patients.

**RED FLAGS:**
Unrelieved pain should raise a red flag that attracts clinicians’ attention.
2:30 PM – The admission paperwork is complete but the process was quite rushed. Two other admissions arrived at 12:45 PM, just I was getting to the pain assessment of Gloria. Well, I’ll tell evenings can get back to the assessment later. Gloria looks like she is sleeping now anyway, and isn’t due for her MS Contin until bedtime.

3:15pm – Gloria’s daughter asks for a hot water bottle for her mother’s back, saying that it’s probably the hospital bed. I bring in the warm pad and help Gloria turn to her side. She grimaces and pulls her right leg up – she is clearly uncomfortable. I ease her over and suggest we complete her admission pain assessment. While we talk I can see that she is a little confused about time. She tells me she always takes “those purple pills” after breakfast and then at bedtime. Gloria tells me that she fell asleep after supper last night and never got back to the kitchen where she keeps her “purple pills”. She said she took some Tylenol when she got up to use the bathroom later in the night. Gloria says she left the house so early this morning to get to the doctors on time that she never even had breakfast never mind those “pain killers”. So it appears that Gloria has not had any morphine in more than 24 hours.

Gloria isn’t sure exactly how many Percocets she takes a day but knows she takes “two at a time and usually I take them around mealtime” I explain the Visual Analog Scale and ask Gloria to rate her current pain with a number from 1 to 10, with 1 being no pain at all and 10 being the worst pain she ever had. She tells me that her worst pain ever had to be the abscessed tooth she had a few years ago and although her current back pain isn’t as bad as that, it aches and throbs “just like that awful toothache.” Her other pain is related to the chest wall lesion that she describes as being “sore and hot” now. Gloria is having trouble putting a number to her discomfort. Gloria’s daughter reports that she just refilled her mother’s Percocet two days ago. The bottle originally contained 30 pills. There are now 20 pills in the bottle.

Let's review what we know about Gloria and her pain:

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Pain Site #1 – Lower Back</th>
<th>Pain Site #2 – Chest Wall</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Timing and quality of pain</strong></td>
<td>2 months duration; “it comes and goes but when it comes it lasts a few days”</td>
<td>10 days duration; “started out just sore but now it’s on fire”</td>
</tr>
<tr>
<td><strong>Severity</strong></td>
<td>“It is very distracting. I have trouble concentrating when it is acting up.”</td>
<td>“The burning right now is very bad. Worse than usual.”</td>
</tr>
<tr>
<td><strong>Aggravating Factors</strong></td>
<td>“I went to the mall last week with my grandchildren and all that walking put me in bed for the whole next day. I told them not to come by the other day.”</td>
<td>“It is hard to dress in the morning without aggravating it. I need to wear very loose clothes, and I can’t wear my bra at all anymore.”</td>
</tr>
<tr>
<td><strong>Relieving Factors</strong></td>
<td>“Hot water bottle feels good especially when I take two of the white pills at the same time.”</td>
<td>“I put a cool wash cloth on during my bath.”</td>
</tr>
</tbody>
</table>
What else do we know?

- Gloria lives alone and has been managing her own medications. Her daughter describes her as stoic and thinks she may be underreporting the impact of the pain on her sleep and daily activities. She thinks Gloria looks very tired and sometimes seems more forgetful than usual.
- God is an important part of Gloria’s belief system.
- Gloria’s pain is not well controlled on her current regimen of MS Contin 30 mg BID and Percocet 1-2 tabs Q 4-6 hours as needed.

It is helpful at this point to convert Gloria’s total dose of analgesic to the oral morphine equivalent. This conversion will provide a starting point from which to compare relative potencies of medication needed to effectively control Gloria’s escalating pain.

Talaria, a resource for health care professionals, addresses the management of pain and offers providers several tools to assist with patient care. The equianalgesic drug conversion calculator allows you to enter multiple drugs and dosages and obtain the proper dosage when converting to a different drug. Please note that while these tools were developed and tested by experienced medical practitioners, they are intended as aids only and not as authoritative resources.

### Oral Morphine Equivalents

<table>
<thead>
<tr>
<th>Oral Equivalent</th>
<th>Morphine Equivalent</th>
<th>Opioid</th>
<th>Other Preparations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 – 2 mg</td>
<td>codeine 30 mg</td>
<td>acetaminophen (APAP)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>oxycodone 1 mg</td>
<td>Hycodan 5 mg (hydrocodone)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>morphine immediate release 1-2 mg</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 mg</td>
<td>oxycodone 5 mg</td>
<td>Percocet (oxycodone 5 mg plus APAP 325 mg)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>morphine immediate release 5 mg</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 mg</td>
<td>hydromorphone (Dilaudid) 2.5 mg</td>
<td>morphine – Slow Release 30 mg q 12 hours</td>
<td></td>
</tr>
<tr>
<td></td>
<td>morphine immediate release 10 mg</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15 mg (= 5 mg parenteral)</td>
<td>morphine immediate release 15 mg</td>
<td>morphine – Slow Release 30 mg q 8 hours</td>
<td></td>
</tr>
<tr>
<td>20 mg</td>
<td>Hydromorphone (Dilaudid) 5 mg</td>
<td>Consider higher concentration preparation of morphine (20mg=1cc)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Morphine immediate release 20 mg</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30 mg (= 10 mg parenteral)</td>
<td>Morphine immediate release 30 mg</td>
<td>Morphine – slow release 60 mg q 8 hours</td>
<td></td>
</tr>
</tbody>
</table>

Based on Gloria’s assessment and her daughter accounting of the Percocet, let’s convert Gloria’s current medication use to the Oral Morphine Equivalent for a twenty four hour period.

MS Contin 30 mg BID = 60 mg / day of slow release morphine
Percocet – about 6 tabs per day = 6 x 5 mg of oral morphine equivalent = 30 mg / day

Therefore, Gloria is using the equivalent of 90 mg of oral morphine per day but her pain is not well controlled. If we were to dose Gloria with immediate release oral morphine we would need to administer a minimum of 15 mg.
every four hours based on the duration of effect for oral morphine. Every four-hour dosing is useful during the titration phase while Gloria is hospitalized but the team needs to work towards a practical dosing schedule for Gloria to use when she goes home. The team might want to consider long acting sustained release products or possibly a transdermal fentanyl patch.

Another important consideration in developing Gloria’s analgesic plan is to have an as needed order for breakthrough pain. Generally, the breakthrough dose is ½ of the usual q 4 hour dose. Breakthrough doses should be monitored carefully during the titration phase. If a patient is requiring 4 or more breakthrough doses during a 24 hour period their regular four hour dose needs to titrated upward to reflect the total oral morphine equivalent the patient is taking in both her routine dose and her breakthrough doses.

Now, back to Gloria.

Since she is not pain free on her current regimen of 90 mg of oral morphine equivalent per day it is reasonable to increase her total daily dose. A starting point might be an increase of 25% to 30%, which would bring her to about 110 to 120 mg per day of oral morphine equivalent.

But first, let’s consider the type of pain Gloria is experiencing. The pain in Gloria’s lower back sounds like it is bone pain. This is confirmed when a bone scan reveals metastasis to the right pelvis and hip region. The chest wall pain involves soft tissue but nerve involvement is suspected given the proximity to the brachial plexus and her description of burning pain.

The team might consider a titration plan as follows:

- Morphine Sulfate Immediate Release (MSIR) 20 mg q 4 hours around the clock
- Morphine Sulfate Immediate Release 5 – 10 mg q 4 hours as needed for breakthrough pain.
- Ibuprophen 400 mg QID for bone pain
- Amitriptyline 25 mg q hs for nerve pain
- Colace 1-2 tabs QD
- Senna 1-2 tabs BID

During the next two days, Gloria’s pain, mental status and other symptoms must be reassessed frequently. The goal of converting Gloria’s oral morphine equivalent to a more convenient delivery method should begin before discharge to assure a smooth transition. At the end of day two, Gloria had received 20 mg of oral morphine every four hours and 3 breakthrough doses of 10 mg each in the previous 24 hours. This is equivalent to 150 mg of oral morphine per day (6 doses of 20 mg and 3 doses of 10 mg). The breakthrough doses were associated with procedures and transferring to & from stretchers.
Let’s convert this to a slow release morphine dosing schedule with an appropriate breakthrough dose. The dose works out to be 50 mg every 12 hours or 75 mg every 8 hours. MS Contin is available in 15, 30, 60 and 75 mg tabs. The team might decide to use 45 mg every 12 hours as a starting point with immediate release morphine (MSIR) 10 – 20 mg q 4 hours as needed for breakthrough pain.

There may be times when a patient’s situation does not allow for oral dosing. Converting morphine from the oral route to the parenteral route is done by taking the total 24 hour oral dose and dividing by three, then convert that 24 hour parenteral dose into an hourly amount by dividing it by 24. For more information, see The Narcotic Equivalency Guidelines and the equianalgesic drug conversion calculator.

Let’s use Gloria’s case again as an example. Take her daily dose of 150 mg of oral morphine and divide by 3, which equals 50 mg of parenteral morphine per day. Now divide 50 mg of parenteral morphine by 24 to get the hourly amount of parenteral morphine needed to equal Gloria’s daily dose of oral morphine. The hourly amount is about 2 mg per hour.

**Important Pain Management Messages to Remember**

- Keep the patient in control.
- Focus on both the patient and their loved ones.
- Always attempt to prevent pain.
- Use the oral route whenever possible.
- Use ‘around the clock’ dosing with appropriate short acting breakthrough medication prn.
- Titrate dose individually – as pain changes dosage must be adjusted to match pain intensity. [The Narcotic Equivalency Guidelines](#)
- Consider adjuvant medications as appropriate to pain assessment
- Always implement a bowel regimen when opioids are initiated – as in pain management, the aim of bowel care should be to prevent rather than to treat the problem.
- Assess for other unwanted side effects, especially when opioids are initiated. Nausea, vomiting, drowsiness, confusion, urinary retention.
- Use co-analgesics, when appropriate (e.g. corticosteroids, anti-emetics, anti-psychotics, anti-depressants)
- Use complementary therapies as appropriate (e.g. massage, TENS, imagery)
STEP III - DEVELOP INTERVENTIONS AND MEASURE CHANGE

"Never doubt that a small group of thoughtful, committed citizens can change the world: indeed, it’s the only thing that ever does."
~Margaret Mead

Interventions are small changes in the care process that are intended to contribute to an overall goal and that can be measured. The interventions you choose to implement will depend on the results of your audit and the goal developed by the quality improvement team.

Returning to the visual depiction of the improvement model, each intervention is developed with three fundamental questions in mind:

1. What are we trying to accomplish with this intervention?
2. What change can we make that will result in improvement?
3. How will we know that a change is an improvement?

Key Item - the kinds of interventions that are appropriate and measurable for pain management

Gloria’s experience of pain and her pain treatment plan (discussed in the case study above) can offer useful suggestions for interventions. Two other examples of interventions appropriate for pain management are to make pain the fifth vital sign in your facility and to conduct a patient/family education session regarding managing pain.

In clinical settings, a patient flow sheet is maintained to regularly record blood pressure, temperature, pulse and respiration. For the dying person, pain and/or other bothersome symptoms are the most important “vital symptoms” to be monitored on a routine basis. Just as marked changes in vital signs signify an emergency, severe distressing pain is always an emergency.

Clinicians appreciate and understand the common language associated with vital signs. Measurements outside of accepted norms trigger appropriate action steps. Adding pain as the fifth vital sign provides clinicians an opportunity to develop a common “pain language” that can be equally appreciated and understood. Routinely measuring pain intensity and level of distress allows clinicians to communicate specific pain related information that the patient is experiencing, along with other indicators of the patient’s well-being.

Another example of a potential intervention is to conduct a pain education session with patients and families. Patients and their loved ones must understand their role in pain management if the goals of treatment are to be achieved. Most patients and their caregivers have questions and concerns about pain and its management. A patient and family education session could teach...
patients and caregivers to assess pain, to monitor the effectiveness of the medicine, and what to do if the medicine does not work.

How does a health care facility or institution decide that making pain the fifth vital sign or starting an education program will accomplish its pain management goal?

How does a facility go about implementing such an intervention?

What are the best ways to measure any changes in pain management that occur?

These questions must be answered before any intervention begins, and Section B of this chapter will discuss the quality improvement tools that help in answering them.

More ideas for improving pain management

Identify Leverage Points – Look for appropriate leverage points within your system to garner the support needed to advance an important and creative initiative. Take advantage of other initiatives within your system that may share some common objectives. For example, bring the newly released JCAHO pain standards.

Maximize Information Technology - Using data can be very effective in motivating change and can also uncover areas where a change in thinking is warranted. Look for ways to maximize the capabilities of your system's information technology to gather, record and disseminate important facts about pain management practice and to identify learning needs.

Get the Community Interested – Survey consumers about their beliefs and knowledge about effective pain management. Audiences can be found through senior centers, malls, and various group and organizational meetings. Consumers often have many questions, such as “Should I only take medicine or other treatments when I have pain? Will I become hooked or addicted to pain medication? If I take too much medicine, will it stop working? If I complain too much, am I not being a good patient?”
SECTION B – DYSPNEA AMELIORATION

In this section, we follow the experience of an inpatient hospice unit as it implements the quality improvement model and utilizes the quality improvement tools to ameliorate dyspnea among persons dying in its inpatient unit.

STEP I - CONDUCT AN AUDIT

Key Item - questions the TOOLKIT After-death Bereaved Family Member Interview asks about dyspnea

1. (In that last week/ While under care of the hospital/hospice/nursing home), did (he/she) have trouble breathing?
   [ ] YES [ ] NO [ ] DON'T KNOW

2. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed, or about the right amount?
   [ ] LESS THAN WAS NEEDED [ ] RIGHT AMOUNT

3. (In the last week of [PATIENT’S] life/ While [PATIENT] was under care of the hospital/hospice/nursing home), how well did those taking care of [PATIENT] make sure (his/her) symptoms were controlled to a degree that was acceptable to (him/her)?
   [ 0 1 2 3 4 5 6 7 8 9 10 ]

Audit Results

Overall, the unit's scores look good, but they are concerned about this finding:

24% of patient's family members felt that their loved ones received less help than was needed in dealing with dyspnea.

With this finding, the unit has identified an important opportunity to improve its care for dying patients.

OPPORTUNITY TO IMPROVE  →  UNRELIEVED DYSPNEA
STEP II - ENGAGE STAKEHOLDERS & DEFINE A GOAL

Once the audit has identified an opportunity to improve, it is time to engage the key players in the hospice unit and to set an overall goal of improvement.

6B.1 Engaging Stakeholders

In order to engage stakeholders, members of the hospice unit draw on two skill areas: current knowledge about quality care for dyspnea and effective presentation techniques.

To organize their knowledge about caring for dyspnea, they address three key items.

6B.1a Key Item – the importance of dyspnea management

“...[Dyspnea] is a subjective sensation of difficulty in breathing, not necessarily related to exertion, that compels the individual to increase his ventilation or reduce his activity. Although subjective, its effect on function and other activities of living may be objectively observable.”

~ The Oxford Textbook of Palliative Medicine

Like pain, dyspnea is a subjective experience that should trigger an immediate response from the clinical team. Breathlessness can be an all consuming and terrifying experience that should be considered an end of life ‘medical emergency’ needing prompt assessment, intervention and follow up.

It is important to consider dyspnea and other distressing symptoms in the context of the Total Pain model described earlier in this chapter. As with pain, dyspnea impacts the psychological, physical and emotional well-being of individuals. The impact extends to the family as well. Dyspnea is especially disturbing for loved ones, who are often overwhelmed by feelings of panic and helplessness.

The prevalence of dyspnea is quite variable, but patients with lung cancer, chronic obstructive pulmonary disease, and end stage congestive heart failure often experience it.

6B.1b Key Item – expert advice about dyspnea management

As with pain, the causes of dyspnea are numerous and may not always be obvious to the health care provider. Therefore, it is important to complete a thorough assessment to identify the most likely cause and establish appropriate interventions.
Assessing dyspnea
Your assessment should consider:

✔ severity of the dyspnea;

✔ presence of any pre-existing conditions—such as COPD, lung cancer and CHF;

✔ exacerbating factors such as anemia, ascites, severe anxiety; and

✔ confounding factors such as infection, pleural effusion, pulmonary emboli.

As with pain, it is important to develop consistent and effective tools to measure dyspnea. You might want to consider adding an assessment scale to the vital sign sheet that records not only the number of respirations per minute but also the patient’s rating of their respiratory effort or his/her level of respiratory distress.

Remember the possible causes of dyspnea

- Bronchospasm (B)
- Atelectasis (A)
- Pleural effusion (E)
- Airway obstruction (A)
- Mucus secretions (T)
- Anemia (H)
- Anxiety (N)
- Interpersonal issues (I)
- Religious concerns (R)

Guiding principles for treatment of dyspnea

✔ Determine underlying cause and treat as appropriate for the patient’s condition.

✔ Weigh the benefits and burdens of the intervention as it relates to the patient’s overall quality of living both prior to and after the intervention. For example, a patient needs to fully appreciate the possible outcomes of tapping a pleural effusion, the potential for recurrence, and the discomfort associated with the procedure.

✔ Maintain a calming atmosphere during the management of a respiratory distress.
6B.1c Key Item – the basics of dyspnea management

Descriptions & clues
As with pain, patients describe dyspnea in many different ways. It is important to listen carefully to clues given by patients and families. Some common ways that patients describe dyspnea include the following:

- I can't catch my breath.
- I feel like I am suffocating.
- The room is closing in on me.
- It feels like someone is sitting on my chest.

These descriptions reinforce the urgency for seeking relief.

Important Dyspnea Management Messages to Remember

- Reassure the patient and their loved ones that you will treat the breathlessness seriously and seek to relieve it as quickly as possible.
- Utilize appropriate pharmacological intervention.
- Provide appropriate explanations about what is happening and how you will be treating it.
- Increase the circulation of air in the room with a fan or by opening a window. This is a very effective measure.
- Apply a cool cloth to the brow and the back of the neck.
- Reposition the patient to maximize lung capacity.
- Reduce activity in room and consider quiet music, relaxation or other techniques to distract the patient from their focus on breathing.
- Assist patient and family in identifying the interventions that are most effective. Review and rehearse these interventions as part of a contingency plan for relief of future episodes.
- Have contingency plans in place for patients at home, including appropriate medications and instructions on use.
- Encourage opportunities to discuss interpersonal issues that might contribute to distress.
- Reassess, reassess, and reassess again! The experience of dyspnea can be so frightening that it is often the reason patients return to the hospital, often in the middle of the night and/or after calling 911.

Dyspnea impacts the family, too.
Pharmacological interventions
Pharmacological interventions may be appropriate to augment the interventions listed above or when no treatable cause has been determined. Opioids are very effective in relieving the feeling of breathlessness.

The American Academy of Hospice & Palliative Medicine (AAHPM) guidelines for opioid therapy are below.

**IMPORTANT:** These are guidelines only! Each patient's medical condition must be evaluated by his/her physician.

...to treat dyspnea, order the same opioids on the same schedule as those prescribed for pain and increase the dose by 30-50% every 4-12 hours until the patient is comfortable.

**Mild dyspnea**- For mild dyspnea in patients taking no pain medications, begin with low doses of an opioid such as one of the following:

<table>
<thead>
<tr>
<th>Drug</th>
<th>Dose</th>
<th>Frequency</th>
<th>Breakthrough</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hydrocodone (Hycodan or Lortab)</td>
<td>5 mg</td>
<td>Q 4 hours</td>
<td>5 mg q 2 hours</td>
</tr>
<tr>
<td>Acetaminophen with codeine (Tylenol #3)</td>
<td>30 mg</td>
<td>Q 4 hours</td>
<td>30 mg q 2 hours</td>
</tr>
</tbody>
</table>

**Severe dyspnea or dyspnea being treated with weak opioids**- For patients with severe dyspnea who are taking no pain medication or for patients who are taking weak opioids such as codeine, hydrocodone, or propoxyphene, consider switching to a strong oral opioid such as one of those below:

<table>
<thead>
<tr>
<th>Drug</th>
<th>Dose</th>
<th>Frequency</th>
<th>Breakthrough</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oxycodeone</td>
<td>3 – 10 mg</td>
<td>Q 4 hours</td>
<td>and prn</td>
</tr>
<tr>
<td>Morphine syrup</td>
<td>3 – 10 mg</td>
<td>Q 4 hours</td>
<td>and prn</td>
</tr>
<tr>
<td>Hydromorphone (Dilaudid)</td>
<td>0.5 – 2 mg</td>
<td>Q 4 hours</td>
<td>and prn</td>
</tr>
</tbody>
</table>

**Severe dyspnea being treated with strong opioids**- For patients already taking strong opioids and for those with dyspnea and high levels of anxiety, try increasing the above doses by 50% every 4-12 hours until the patient experiences relief.

Patients and families often place importance on the use of oxygen for breathlessness. In fact, opioids are quite effective as a first line intervention—so effective that oxygen may not be needed. If used, oxygen should be delivered via nasal prongs instead of a facemask, which can feel confining and smothering.
6B.1d Presenting the Data

In addition to the general guidelines for presentation discussed in Chapter 5 of this Guide, consider these tips—along with your own brainstorming!

- Increase awareness about the opportunity to improve how dyspnea is currently assessed and managed by creating a safe environment to examine your own practice.

- Use both qualitative and quantitative data. Numbers are essential but can be rather bland; words and stories can be very motivating.

- Compare what you know about successful dyspnea management with a real patient scenario—an enlightening exercise that can have surprising results.

- Do additional data collection and analysis to add to your evidence base. For example, gather baseline data to determine the current number of episodes of severe dyspnea that last longer than 4 hours.

6B.2 Defining an Overall Goal

Once stakeholders are “on board” with the need for a quality improvement effort, the quality improvement team turns its attention to two fundamental guiding questions.

What is our overall goal? It is essential to clearly state an overall goal so that everyone in the unit knows the purpose of the interventions.

“Our goal is to ameliorate dyspnea in persons dying at our inpatient hospice unit.”

How will we know when this goal is achieved? Defining a specific target allows everyone in the unit to know when success has been achieved.

“We will know this by examining the last 48 hours of life of 5 patients/week in regards to the number of episodes of severe dyspnea (i.e. >4 on scale of 10) and whether they had episodes that lasted longer than 4 hours.”
As with defining an overall goal, it is essential to the success of each small intervention to keep in mind the fundamental guiding questions for improvement.

What are we trying to accomplish with this intervention?

How will we know that a change is an improvement?

What change(s) can be made that will result in improvement?

6B.3  Using the Tools of Quality Improvement

The quality improvement team decides to utilize various quality improvement tools to assist in developing their first intervention and answering these fundamental guiding questions.

6B.3a  Examining the care process and influential factors

The quality improvement team realizes that, in order to identify a change that will make an improvement, they must understand

- the unit’s current care process for treating dyspnea (Process Flow Chart), and
- the factors that influence dyspnea management (Ishikawa Cause and Effect Diagram).
**Process Flow Chart** – This tool shows the main steps and eventual outputs of a process. Involve other people who are familiar with the process. Look for steps that are inefficient or unnecessary. Refrain from trying to change or fix a piece of the process until it is fully diagrammed and analyzed.

Pt develops severe dyspnea

- **NO**
  - Pt waits
  - Reported to RN

- **YES**
  - RN recognizes

  - RN calls MD
  - MD returns call

  - MD decides on treatment

  - Pt improves or does not

  - RN assessment determines intervention

  - Appropriate orders on chart
    - Choices: Ativan, MS and/or O₂

  - Pt improves or does not

  - Reassess patient
With the insights gained from the Process Flow Chart and the Ishikawa Cause and Effect Diagram, the quality improvement team plans the first improvement cycle based on the guiding questions for improvement.

**What are we trying to accomplish with this cycle?**

“We’ll implement ‘dyspnea as a fifth vital sign’ and it will be completed every shift on 90% of the patients.”

**How will we know that a change is an improvement?**

“An increasing number of patient charts will include standardized dyspnea assessment data.”

**What change(s) can be made that will result in improvement?**

“We’ll create a uniform dyspnea assessment form for staff to use.”

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**Ishikawa Cause and Effect Diagram – aka The Fishbone Diagram** – This diagram is named for the founding father of quality management, Karou Ishikawa. It is an aid to identify factors that contribute to a particular outcome. Be sure to define the desired outcome first. Then, identify the main factors affecting the outcome and show these as the main branches of the diagram. List specific factors under each branch until all relevant factors are included.

- Pt / Family
  - Non-compliance
  - Misperception
  - Financial Barrier
  - Does not want to report
  - Afraid of opiates

- Dyspnea
  - Acute Medical Event
  - Chronic Medical Event
  - Biology

- Nurse
  - Does not recognize
  - Staffing
  - Does not see as urgent issue
  - Does not follow up

- Treatment
  - Incorrect Treatment, Dose, Route
  - Standing Orders
  - Equip failure/ unavailable
  - Unable to reach MD for orders

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Satisfactory Control
6B.3b Documenting Activities and Tracking Progress

The PDCA Worksheet is a way to document the activities within the cycle and show progression from one cycle to the next. Tracking your progress helps to build organization support and acknowledgment of your improvement accomplishments.

PDCA CYCLE WORKSHEET       Date begun:  January 1, 2000       Date finished:

PLAN: Objective of cycle, questions and predictions, details of process, data collection

- Baseline Data – In January the QI Team examines charts of all patients on the unit to determine the number of episodes of severe dyspnea that were not relieved by the end of an 8 hour shift.

  Run Chart - January
  Episodes of Severe Dyspnea

- Stating The Aim - “What do we want to promise our patients and their families about dyspnea management?” Remember the overall aim of the QI Team is to ameliorate dyspnea in persons dying on their inpatient unit. The above Run Chart indicates that 50% of the episodes of severe dyspnea that occurred in January were unrelieved at the end of an 8 hour shift.

  “We’ll implement ‘dyspnea as a fifth vital sign’ & it will be completed every shift on 90% of the patients.”

DO: Transforming Learning into Action

- Uniform Dyspnea Assessment Form - The QI Team uses the knowledge gained from brainstorming sessions, process flow and Ishikawa diagrams and the above baseline data analysis to create a uniform dyspnea assessment form that will be completed on every shift.

- Instruct Staff and Document Utilization of Form – Be sure staff have knowledge and skills needed to understand how to use new form and conduct periodic chart audits to monitor utilization patterns, document and respond to issues quickly.

CHECK: Monitor the intervention

- Use Run Charts as visual displays of utilization patterns.

ACT: What changes or adjustments need to be made. What is the next cycle to consider?

The QI Team sees a positive trend in correct utilization of the dyspnea assessment form but will continue to monitor. In the meantime, the QI Team decides to do a small scale study comparing the family’s assessment of the severity of their loved one’s dyspnea.
6B.4 Using Concurrent PDCA Cycles

CQI is a long-term process that must include a commitment to rapid-cycle interventions that your team can implement, measure and celebrate by “next Tuesday”.

It is unlikely that one intervention alone will be successful in reaching the overall improvement goal. This is why the “Act” portion of the PDCA cycle asks the quality improvement team to suggest next cycles to consider.

As part of their first PDCA cycle, the hospice unit’s quality improvement team creates a list of additional ideas to improve the management of dyspnea on the inpatient unit.

- “We need to improve the dyspnea assessment form.”
- “We need standards of care for dyspnea management and education on using them.”
- “Standing orders and clinical protocols for dyspnea management would help.”
- “Use Run Charts to plot ongoing observations of episodes of severe dyspnea over time.”

The QI Team decides to establish task forces that will dedicate their time to a specific intervention and the associated PDCA Cycles needed to reach the overall goal of ameliorating dyspnea in persons dying on the inpatient hospice unit.

**TASK FORCES FOR PLANNED INTERVENTIONS**

- **Dyspnea Assessment Tool** – Uniform assessment of all patients utilizing Dyspnea Self Assessment Tool and Dyspnea Assessment Tool for persons unable to rate their own dyspnea. Assessment will be charted on daily flow sheet with other vital signs.

- **Principles of Dyspnea Management & Staff Education** – Develop principles and standards of care for the management of dyspnea as medical emergency in dying patients. Establish methods for educating staff and monitoring competencies.


- **Data Management** – Establish to monitor the collection, analysis and presentation of data associated with the overall target of improvement to ameliorate dyspnea on the inpatient hospice unit.

Often no one change or sequence of changes is responsible for the overall improvement. In general, increased frequency and number of cycles results in increased improvement.
The QI Team completes a number of sequential small scale, rapid PDCA Cycles during which they developed, tested and implemented changes. Throughout each cycle data was collected and analyzed. Data collection continues over time.

Let's look at the progression of data collected over time that measures the number of episodes of severe dyspnea that go unrelieved in an 8 hour shift.

Measuring Change  The QI Team is thrilled to share the May data with the staff. They have achieved the goal of their first PDCA Cycle to measure respiratory comfort as a 5th vital sign. In so doing, the frequency of episodes of severe dyspnea in an 8 hour period went from 50% in January to zero in May!

![Image of a bar graph showing the change in episodes of severe dyspnea from January to May.]

**Before CQI intervention:**
In January 50% of the episodes of severe dyspnea were not relieved by the end of an 8 hour shift.

**Goal after intervention:**
By the end of May there are no episodes of dyspnea that go unrelieved by the end of an 8 hour shift.

**ONGOING ROUTINE CHART AUDIT** now examines the last 48 hours of life of 5 patients each week in regards to the number of episodes of severe dyspnea (i.e. greater than 4 on a scale of 10) and whether they had severe dyspnea that lasted longer than 4 hours.
6B.5 Sustaining Change

Effective and sustained improvement requires:
- creatively developed, tested and implemented changes,
- establishing a system of improvement that provides a framework for leading change as a high priority, and
- continued cycles of measuring and monitoring.

Multiple Measures – It is possible that a combination of interventions will influence the improvement results for ameliorating dyspnea on the hospice inpatient unit. Therefore it is important to simultaneously monitor all the interventions in order to assess their impact on the identified change. For this reason it is helpful not to have too many interventions at one time!

Examples of additional measurements include:
- Education Intervention – conduct pre and post tests
- Nursing Competencies – incorporate the competency standards into existing job performance measurement tool
- Standing Orders – Measure physician compliance with instituting standing orders
- Dyspnea Assessment – Conduct periodic measurement of patient/surrogate report and compare to actual assessed report completed by staff

Tips for Managing Improvement Efforts

1. Stay with project until concept for change is established.
2. Test changes on a scale small enough to minimize the risk of developing and implementing interventions that foster innovation.
3. Stay aware of the detail work that is needed to make sure the gains and improvements are held.
4. Ensure that resources needed to sustain the change are given the appropriate priority and attention.
5. Study the changes to learn about the fundamental causes of problems in the system or organization.

Key activities for leading sustained change

Establish and communicate the purpose of the organization.

View the organization as a system.

Design and manage a system for gathering information for improvement.
Reference List


Storey P, Knight CF. UNIPAC Four: Management of Selected Nonpain Symptoms in the Terminally Ill. American Academy of Hospice and Palliative Medicine, 1996
Chapter 6 Appendix A

Pain Assessment Tools

Initial Pain Assessment Tool

Date: __________________

Patient’s name: _________________________ Age: ______
Room: ________

Diagnosis: ____________________________ Physician: _________ Nurse: ________

I. Location: Patient or nurse marks drawing

II. Intensity: Patient rates the pain. Scale used: __________
  Present: ____________________________________________
  Worst pain gets: ____________________________________
  Best pain gets: ____________________________________
  Acceptable level of pain: ____________________________

III. Quality: (Use patient’s own words, e.g., prick, ache, burn, throb, pull, sharp)
  ____________________________________________________

IV. Onset, duration, variations, rhythms: _________________________________
V. **Manner of expressing pain:**

VI. **What relieves the pain?**

VII. **What causes or increases the pain?**

VIII. **Effects of pain:** (Note decreased function, decreased quality of life.)

   Accompanying symptoms (e.g., nausea)

   Sleep

   Appetite

   Physical activity

   Relationship with others (e.g., irritability)

   Emotions (e.g., anger, suicidal, crying)

   Concentration

   Other

IX. **Other comments:**

X. **Plan:**

*Note:* May be duplicated and used in clinical practice

*Source:* [McCaffery and Beebe, 1989](#) Used with permission.
Pain Scales

Simple Descriptive Pain Distress Scale [1]
None       Annoying     Uncomfortable     Dreadful     Horrible     Agonizing

0-10 Numeric Pain Distress Scale [1]
No pain                                 Distressing pain                                 Unbearable pain

Visual Analog Scale (VAS) [2]
No distress                                 Unbearable distress

[1] If used as a graphic rating scale, a 10 cm baseline is recommended
[2] A 10-cm baseline is recommended for BAS scales.

Memorial Pain Assessment Card

Note: Card is folded along broken line so that each measure is presented to the patient separately in the numbered order.

Faces Pain Scale

The Cancer Pain Algorithm Flow Sheet

<table>
<thead>
<tr>
<th>Pain Character - Key Words</th>
<th>Mixed</th>
<th>Pain Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nociceptive</td>
<td></td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>Aching</td>
<td></td>
<td>No Pain</td>
</tr>
<tr>
<td>Tender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Throbbing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neuropathic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shooting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stabbing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Burning/Electrical</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Date
Location
1. 
2. new site?
Character
Noci-Neuro-Mixed
Score (0-10)
worst usual

Side Effects
Y = yes
N = no
N/V
Constipation
Sedation
NSAID GI Distress
Delirium
Mydriasis
Dry Mouth

Reassessment Due
Plan:

This tool is part of the Cancer Pain Algorithm, Copyright ©1999 Du Pen, Inc. Published here with permission.
**Patient Self-Assessment Pain management log**

Pain management log for:

Please use this pain assessment scale to fill out your pain control log.

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>How severe is the pain?</th>
<th>Medicine or non-drug pain control method</th>
<th>How severe is pain after one hour?</th>
<th>Activity at time of pain</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
## Chapter 6 Appendix B

### Narcotic Equivalency Guidelines

<table>
<thead>
<tr>
<th>Drug</th>
<th>Equianalgesic dose (mg)</th>
<th>Relative potency vs parenteral morphine</th>
<th>Approximate duration of action (hrs)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morphine</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parenteral</td>
<td>10 mg</td>
<td>1.00</td>
<td>4 hours</td>
</tr>
<tr>
<td>Oral</td>
<td>30 mg*</td>
<td>0.33*</td>
<td>4 hours</td>
</tr>
<tr>
<td>Hydromorphone</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parenteral</td>
<td>1.5 mg</td>
<td>6.67</td>
<td>4 hours</td>
</tr>
<tr>
<td>Oral</td>
<td>7.5 mg</td>
<td>1.33</td>
<td>4 hours</td>
</tr>
<tr>
<td>Codeine</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parenteral</td>
<td>130 mg</td>
<td>0.08</td>
<td>4 hours</td>
</tr>
<tr>
<td>Oral</td>
<td>200 mg</td>
<td>0.05</td>
<td>4 hours</td>
</tr>
<tr>
<td>Oxycodone</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oral</td>
<td>30 mg</td>
<td>0.33</td>
<td>4 hours</td>
</tr>
<tr>
<td>Levorphanol</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parenteral</td>
<td>2 mg</td>
<td>5.00</td>
<td>5 hours</td>
</tr>
<tr>
<td>Oral</td>
<td>4 mg</td>
<td>2.50</td>
<td>5 hours</td>
</tr>
<tr>
<td>Meperidin</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parenteral</td>
<td>75 mg</td>
<td>0.13</td>
<td>3 hours</td>
</tr>
<tr>
<td>Oral</td>
<td>300 mg</td>
<td>0.03</td>
<td>4 hours</td>
</tr>
<tr>
<td>Methadone</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parenteral</td>
<td>10 mg</td>
<td>1.00</td>
<td>5.5 hours</td>
</tr>
<tr>
<td>Oral</td>
<td>20 mg</td>
<td>0.50</td>
<td>5.5 hours</td>
</tr>
</tbody>
</table>

*Single dose studies suggest the equianalgesic dose for oral to parenteral morphine is 60:10, but clinical experience has shown that when administered chronically, a 2 or 3:1 ratio is more applicable. SOURCE: Patt, R.B. Cancer Pain, 1993, p. 567

Adapted from Grossman, S.A. & Sheidler, V.R. World Health forum, 8(525-529), 1987
### 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**

<table>
<thead>
<tr>
<th>Step</th>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Don't Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Did [PATIENT] have specific wishes or plans about the types of medical treatment (he/she) did or did not want while dying?</td>
<td>[ ]</td>
<td></td>
<td>[ ]</td>
</tr>
<tr>
<td>2</td>
<td>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?</td>
<td>[ ]</td>
<td></td>
<td>[ ]</td>
</tr>
<tr>
<td>3</td>
<td>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?</td>
<td>[ ]</td>
<td></td>
<td>[ ]</td>
</tr>
<tr>
<td>4</td>
<td>(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?</td>
<td>[ ]</td>
<td></td>
<td>[ ]</td>
</tr>
<tr>
<td>5</td>
<td>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?</td>
<td>[ ]</td>
<td></td>
<td>[ ]</td>
</tr>
<tr>
<td>6</td>
<td>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?</td>
<td>[ ]</td>
<td></td>
<td>[ ]</td>
</tr>
<tr>
<td>7</td>
<td>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)?</td>
<td>[ ]</td>
<td></td>
<td>[ ]</td>
</tr>
</tbody>
</table>
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.

**Buckman’s Six Steps for Breaking Bad News***

<table>
<thead>
<tr>
<th>Step 1</th>
<th>Getting the physical context right</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<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>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Step 2</th>
<th>Finding out how much information the patient and/or family knows</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<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>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Step 3</th>
<th>Finding out how much information the patient and/or family wants to know</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<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>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Step 4</th>
<th>Sharing information (aligning and educating)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<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>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Step 5</th>
<th>Responding to the patient’s and/or family’s feelings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<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>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Step 6</th>
<th>Planning and following through</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<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.
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Chapter 8: Promoting Self-Efficacy of Family Caregivers

STEP I - CONDUCT AN AUDIT

Key item - the questions the TOOLKIT After-death Bereaved Family Member Interview asks about supporting the self-efficacy of the family

1. How confident were you that you knew what to expect while [PATIENT] was dying - very confident, fairly confidently, or not confident?
   [ ] VERY CONFIDENT
   [ ] FAIRLY CONFIDENT
   [ ] NOT CONFIDENT

2. How confident were you that you knew what to do at the time of death - very confident, fairly confidently, or not confident?
   [ ] VERY CONFIDENT
   [ ] FAIRLY CONFIDENT
   [ ] NOT CONFIDENT

3. How confident were you that you understood about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms - very confident, fairly confidently, or not confident?
   [ ] VERY CONFIDENT
   [ ] FAIRLY CONFIDENT
   [ ] NOT CONFIDENT

4. How confident did you feel about taking care of [PATIENT] at home - very confident, fairly confidently, or not confident?
   [ ] VERY CONFIDENT
   [ ] FAIRLY CONFIDENT
   [ ] NOT CONFIDENT

STEP II - ENGAGE STAKEHOLDERS & DEFINE A GOAL

8.1 Key item - the importance of focusing on promoting self-efficacy

Providing information and educating caregivers will contribute to improved care.
~Ferrell 1998
Along with informing and educating patients and families, promoting self-efficacy among family caregivers is a key process for achieving patient-focused, family-centered medical care. In fact, promoting the self-efficacy of family caregivers has a direct impact on patient care outcomes. As a result, promoting self-efficacy is an effective strategy for working with family members of patients who are dying.

Family members often feel stressed and overwhelmed by the experience of caregiving, and they often express feelings of powerlessness. They may never have cared for someone who was sick or dying. They may never even have been in the presence of one who was dying. Increasing their confidence in their ability to know what to do and how to provide care can go a long way in reducing their stress.

Self-efficacy refers to a person's confidence in how well s/he can accomplish a task or group of tasks. In the context of end-of-life care, self-efficacy is the confidence that a caregiver has in her/his ability to meet the needs of the one that is dying. Family caregivers take responsibility for or help with a variety of tasks, for many of which they have little or no experience and training. Over time, family members can gain a sense of control over the events of the dying process by mastering certain tasks in the face of difficult situations.

Health care providers play a key role in enhancing caregiver confidence in that they know what to do at crucial times of caring for a person dying at home and can share that information with the caregiver. Whatever obstacles a family caregiver may face, the health care provider can influence how the caregiver utilizes information about providing care, therefore increasing the caregiver's confidence in his/her ability to successfully undertake the task.

I want to know how to provide the care when it is needed and to be sure that I am doing the right thing.

~Family member

Self-efficacy is a process. Family caregivers often provide the hands-on care that supports a seriously ill person’s ability to remain at home. Caregivers assume responsibility for pain relief and need to understand the basic pain management principles. They may need to learn new skills in assisting someone with ambulation, comfort care, and end-of-life care. The performance of each of these skills changes with the phase of the illness.

Family caregiving has an emotional impact that can be profound. When the caregiver’s needs are identified, validated and supported, to the extent possible, and when the caregiver feels confident and prepared for the eventualities of the dying process, the experience can be quite meaningful and valuable for all involved. Conversely, when the caregiver feels alone and uncertain, exhausted and anxious, the caregiving experience can leave everyone involved with a sense of abandonment, inadequacy, resentment and anger.
Mary, Gloria’s Caregiver

As Gloria’s condition begins to worsen, Mary wonders if she will know what to do for her mother as she gets closer to death. Gloria has gotten weaker and needs more help to get around. Her doctor said that she would become so weak that she will not be able to get out of bed and eventually would become unresponsive. Mary has never cared for someone so sick. She is not at all confident that she will be able to give adequate care for someone that is on bed rest and who needs help with all aspects of care. The prospect of feeding her mother or changing the bed sheets, although seemingly simple, causes her to doubt her ability to provide the care her mother may need. She feels even less confident that she will know what to do as death gets very close.

While talking with an old friend, Mary worries aloud: "I want to give the right medications and keep her comfortable, but it all is so foreign to me. I just don't know that I can do it, but I've promised Mom that I'll take care of her at home." Her friend asks if Mary has considered hospice services. Mary responds, “Oh, I don’t think we’re at that point yet, do you?” After some discussion, Mary decides to call the Hospice House palliative care nurse whom she had met earlier through the hospital discharge planner.

When Mary calls Hospice House, the nurse offers to come to her home and talk with Mary and Gloria. During the visit, the nurse talks about the options and how hospice can be of help, even at this stage in the disease. They all discuss the care that can be provided at home and the support that hospice can provide so that Mary can effectively and adequately provide for her mother’s needs. After this meeting, Mary feels more motivated to continue as her mother’s caregiver since she knows that there is some backup to guide her through each step.

Self-efficacy: Beyond Informing & Educating

Informing and educating are important parts of promoting self-efficacy. Caregivers have reported that communication with health care providers is helpful, and a lack of knowledge can result in decreased caregiver confidence. Clear, honest information regarding medications, symptoms, disease progression, comfort, and what to do in the event of a change in condition or at the time of death is essential for supporting self-efficacy.

The provision of information prepares caregivers to support the patient, reinforces the treatment goals, and assists in managing side effects of medication and disease.

~Tringali (1986)

Although very important, informing and educating family caregivers cannot fully promote self-efficacy. Beyond informing and educating, health care providers need to:

- **model** tasks for caregivers,
- **encourage** caregivers as they carry out care tasks, and
- **support** caregiver needs.
8.2  **Key item - expert advice about promoting self efficacy**

8.2a  The theory behind promoting self-efficacy

According to Albert Bandura (1997), self-efficacy involves three important components:

- a person's estimate of her/his own level of capability to perform in the particular environment,
- a person's feelings of increased confidence in accomplishing a particular task, and
- a person's belief system that allows an individual to have control over her/his thoughts, feelings and actions.

Defined in this way, enhancing self-efficacy can:

- explain many health and self-care behaviors;
- affect the amount of effort a person will expend in developing or learning new behaviors;
- reflect a person's belief in her/his ability to persevere as well as influence the choices that are made;
- influence preventive efforts to reduce illness risks and mortality; and
- predict change in many types of learning and behaviors, including health-related behaviors.

A person's *confidence* in her/his own ability to accomplish a task is primary. Knowledge and skills are not the only things that determine if a task can be performed. Rather, how much confidence a person has in performing a task will strongly influence how the person will behave. In other words, if a person feels comfortable with a given activity, the person is more likely to take part in it. People tend to stay away from activities that make them feel uncomfortable.

Furthermore, *motivation* has been directly linked to how capable a person feels. A very confident person will be more motivated and have a better outcome than a less confident person. The less confident person will be more easily frustrated when he/she encounters difficult changes. A challenge may be perceived as a personal threat.

8.2b  Self-efficacy in practice

**Pain.** Patients in pain are often fearful because others have the power to control the pain medication. This can increase their fear and result in depression. If the caregiver is able to recognize a change in the person's level of pain and has information on how this can be treated, then both patient and caregiver have a sense of control and increased confidence that there is always something that can be done. The patient's and the caregiver's belief that they are able to effectively manage pain will ultimately result in more successful pain relief. They can begin to realize that a certain pain rating implies an intervention that will result in pain relief.
End-of-life care. A health care provider wants a confident caregiver for the dying patient. Although a caregiver may be intelligent, she/he often is anxious about her/his ability to provide the basics of personal care. By promoting the caregiver’s self-efficacy, the health care provider knows that the caregiver will become more competent in providing care for the patient and will feel satisfied that she/he was able to perform all the care necessary despite the grief and difficulty that accompanies the situation.

8.2c How to promote self-efficacy

Bandura identifies four ways to develop self-efficacy:

♦ Skills mastery
  ♦ Modeling
    ♦ Verbal persuasion
    ♦ Reducing aversive physiological signs and symptoms

♦ Skills mastery
Skills mastery is learning and practicing appropriate behaviors. The caregiver needs to have a sense of what the tasks will be. Even though the trajectory is not clear, some idea about the course of the illness can be outlined. If the caregiver knows what needs to be done for a person who is dying, she/he will feel more confident. Give the caregiver the information that is needed to perform each task.

[www.Caregiver.com](http://www.Caregiver.com) - This web site offers information on a variety of diseases, Fact Sheets, and resource links.

[www.stoppain.org](http://www.stoppain.org) - This is a resource guide intended to help caregivers feel less alone and overwhelmed. It offers resources, facts, and advice about caring for a loved one at end of life.

♦ Modeling
Modeling means observing others who have mastered a behavior and copying that behavior. Since, it can be difficult to visualize how a task will be accomplished in a particular situation, observing how the task is performed can be quite useful. For example, a caregiver may know how to make a bed but not have any idea of how to do this when someone is in the bed. A health care provider can demonstrate and request that the caregiver assist in changing the bed next time. If the caregiver is not able to be present when the health care provider is present, a video or web site that shows someone performing the task that might be helpful.

[www.webofcare.com](http://www.webofcare.com) - This site posts helpful videos showing how to perform certain tasks, such as caring for a bed-bound patient and feeding a patient. A caregiver can choose animation (with or without sound) or the printed version. This site will allow the caregiver to model behaviors.
Verbal persuasion
The goal here is to persuade the caregiver that an action will work and that they are able to perform the task. This will influence the caregiver's confidence in their capabilities. If you as the expert think and tell the caregiver that she/he is doing a good job, then it must be so. Give the caregiver positive feedback and good reasons as to why their actions will be effective.

www.Extendedcare.com: This site allows users to talk free of charge with a geriatrician.

Reducing aversive physiological signs and symptoms
People often gauge their confidence by the emotional state experienced as they contemplate an action. Excessive physical and psychological fatigue or stress can negatively impact a caregiver’s willingness to perform a task. Sometimes a caregiver needs permission to care for him/herself. The health care provider can inform a caregiver of the difficulties that arise when the caregiver is depressed and not healthy. They want to be in this for the duration and need to be able to maintain their energy. This can be done by offering a companion or volunteer for a few hours so that the caregiver can go out for a walk. It could be as simple as reducing the amount of time that visitors stay. In short, encourage good health habits among caregivers.

www.Caregiverzone.com - Offers a variety of caregiver sites, helpful hints. It offers information on caregiving and how to stay healthy.

8.2 Key item - the basics about promoting self efficacy

It is important to know what to expect, how you can help, and what help you can expect.
~Bereaved family member

Promoting self-efficacy can break down barriers to effective caregiving by increasing confidence and decreasing fear of making serious mistakes. Health care workers play a key role in this process. They can provide the informational tools and practice opportunities to educate caregivers, rather than allowing the caregiver to learn by trial and error.

Following Bandura’s model, let’s review the basic steps for effectively promoting self-efficacy:
1. **Skills mastery** → Ask caregivers what they know about the topic; provide information and education about the skill.

2. **Modeling** → Demonstrate skills and watch caregivers perform the skills.

3. **Verbal persuasion** → Give constructive feedback and complement caregivers on their successes.

4. **Reduce aversive physiological signs and symptoms** → Promote caregiver’s health, and encourage him/her to call for help when needed.

To apply these steps, health care providers need to determine **WHAT** a caregiver needs to know (i.e., **content**) and **WHEN** he/she needs to know it (i.e., **timing**).

**Content needs**

To meet the needs of individual caregivers, information and education are needed in a variety of areas. Caregivers need to know what to expect, what to do in specific situations, and when to call for help.

**INFORMATION AND CORRESPONDING EDUCATIONAL NEEDS OF FAMILY CAREGIVERS**

<table>
<thead>
<tr>
<th>INFORMATION</th>
<th>EDUCATIONAL NEED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient’s diagnosis</td>
<td>What is it, how it will progress</td>
</tr>
<tr>
<td>Symptoms (particularly pain)</td>
<td>What to expect. What to do.</td>
</tr>
<tr>
<td></td>
<td>When to call, provide a resource guide</td>
</tr>
<tr>
<td>Likely prognosis</td>
<td>What to look for- improvement or how the patient may be</td>
</tr>
<tr>
<td></td>
<td>approaching death</td>
</tr>
<tr>
<td>Change in functional abilities</td>
<td>How to provide care. Provide tools that make simple steps</td>
</tr>
<tr>
<td></td>
<td>for a complicated task.</td>
</tr>
<tr>
<td>Sudden changes in patient's</td>
<td>How to access emergency services. Provide written</td>
</tr>
<tr>
<td>condition</td>
<td>resources</td>
</tr>
<tr>
<td>Patient’s and caregiver’s</td>
<td>How to offer psychosocial &amp; spiritual support, Provide</td>
</tr>
<tr>
<td>emotions</td>
<td>options</td>
</tr>
<tr>
<td>Community support agencies</td>
<td>How to access these services</td>
</tr>
</tbody>
</table>

~Adapted from Joishy (1999)
Timing: different needs at different stages

For caregivers of someone with a life threatening-illness, different needs arise at different stages of a patient's illness. Caregivers need information about the illness and its management at three basic stages:
- diagnosis and prognosis
- each new crisis
- when death is imminent

- **Diagnosis and prognosis**
  - Some people might seek a non-intrusive strategy as opposed to a one on one session or multiple support sessions.
  - An educational program can give a caregiver the opening to seek out sources of support as she/he comes to know what is available.

- **Each new crisis**
  When a crisis occurs, the focus is still on the patient, but caregiver involvement also increases. The caregiver might now need to drive the patient to medical appointments, watch for side effects of a new treatment, or listen to the patient talk about how she/he thinks that life is coming to an end because the pain is getting worse. At this point, caregivers may need:
  - an ongoing educational program on pain management and symptom management;
  - review of the disease process and a person's social supports;
  - literature about the disease process; and
  - information about the availability of a palliative care consultant.

- **When death is imminent**
  When death is imminent, the information and educational needs focus primarily on the caregiver. Caregivers can benefit from:
  - literature about what it is like to be with someone who is dying;
  - web sites that provide instruction for different aspects of care step by step;
  - a 24-hour hospice service; and
  - literature on non-invasive comfort measures.

**Note:**

At one oncology clinic, an educational program is part of their protocol. A palliative care nurse practitioner meets with the patient and family after the diagnosis to present all the available support options, including the educational classes that are offered on symptom management, the disease process, pain management, and care for a person who is dying. The community agencies that can be of support are discussed, including the option of hospice.
More about Gloria and Mary…

About a week later, Gloria is no longer able to feed herself. The hospice nurse and nurse's aide review with Mary some techniques for safely and comfortably feeding her mother. They ask Mary to observe them feeding Gloria and then to give it a try herself. They are very supportive and never criticize Mary when she doesn’t get it right the first time.

At about the same time, Gloria loses the ability to get out of bed. She clearly is getting weaker. The nurse and nurse’s aide again review the process of changing the bed and applying a brief for incontinence, having Mary assist and then eventually try it alone. In addition to in-person instruction, Mary likes to search for information and review effective techniques for providing care on her computer. The hospice nurse suggests a web site that is interactive and can offer extra helpful tips. During each subsequent visit, the nurse reviews the care skills and is always sure to point out the positive aspects of the care Mary provides.

Mary is beginning to feel confident that she is capable of providing her mother's care. She is both surprised and grateful that, while offering help for her mother, the hospice staff members are concerned about her health as well. Hospice House sends volunteers who stay with Gloria so that Mary can go to the gym two times a week to swim. For Mary, swimming is the best way to relieve stress. In addition, the social worker and chaplain who visit Gloria also listen to Mary’s concerns. Mary begins to realize that maintaining her own physical and emotional health is essential for being able to care for her mother.

In addition to areas related to the patient’s illness, caregivers often need to be reminded that they must also take care of themselves.

**10 Messages that Caregivers Need to Hear**
~Adapted from Schmall and Stiehl (1987)

1. Take care of yourself.
2. Maintain contact with friends and involvement in outside activities.
3. Caregiving to adults is more stressful than childrearing.
4. It is okay not to love (or like) the older person who needs care.
5. Asking for help is not a sign of weakness, inadequacy, or failure.
6. You have a right to set limits and to say "no".
7. Begin taking regular breaks early in caregiving - it is not selfish.
8. Make caregiving decisions based on the needs of everyone involved.
9. Moving a family member to a care facility can be the most loving step.
10. Focus on what you have done well - and forgive yourself.
Tips for Promoting Self-efficacy

- Focus on the needs of each particular situation. For example, it may appear to a health care provider that the focus should be on the symptoms of pain and the decrease in bodily functions, but the caregiver may not be able to move beyond the stress and anticipatory grief.

- Provide easy to read literature; write out key points on a small card.

- Determine if community support groups and resources have been helpful to others who have used them. If so, inform caregivers of these resources.

- Build on caregiver strengths by encouraging her/him to seek resources.

Returning to Gloria and Mary...

Despite trying to maintain her health, Mary is exhausted. She has not gotten much sleep the past few nights because Gloria's confusion is increasing and she often is awake during the night. Mary's brothers come by frequently, but they are uncomfortable with providing hands-on care for their mother.

Talking with an old friend, Mary worries aloud: "There are times when I wish this would be over for Mom...then I feel so guilty for even thinking that way." Her friend asks if Mary has considered placing Gloria in a nursing home. "Oh, I promised Mom I would try to take care of her at home. I want to try, but I suppose I should think about other options in case I can't continue to do it." Again, Mary calls the nurse at Hospice House.

When the hospice nurse arrives for her visit, Mary talks with her about the options for more help at home as well as about residential nursing facilities. Mary is feeling very conflicted – on one hand wanting to honor her promise to her mother and yet on the other hand feeling the burden as Gloria's care becomes increasingly demanding. They decide to have the hospice social worker plan a family meeting to discuss caregiving options with Gloria and her children.

During the family meeting, Mary's brothers agree to pool their resources to hire private help to give Mary a break three nights per week so she can go out with friends, do errands, and attend church services. Mary appreciates the opportunity to raise her brother's awareness about her needs. As a family, they make a contingency plan for Hospice House inpatient services just in case the combination of hospice home services, private help, and volunteer assistance is not sufficient.
8.2.1 Defining an overall goal for promoting self-efficacy

Take a look at the audit results concerning the domain of promoting self-efficacy. 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 the 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 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).”

8.5 Key item - the kinds of interventions that are appropriate and measurable for promoting self-efficacy

Returning to Bandura’s theory, recall the four main ways to promote self-efficacy among family caregivers for patients at the end of life.

♦ Inform and educate the caregiver about each skill.

♦ Model the particular task as appropriate for each stage.

♦ Support and persuade the caregiver of his/her effectiveness.

♦ Emphasize the importance of the caregiver’s health, and encourage him/her to call for help when needed.
Based on this theory, below are some ideas for developing interventions that will promote self-efficacy, with the end goal of decreasing caregiver stress and increasing overall satisfaction.

**Develop a packet of educational fact sheets, informational booklets, or pamphlets** that are easily available to caregivers. Potential topics include pain and symptom management, what to expect when death is imminent, and what to do at the time of death. Be sure to personalize the available resources to reflect your facility. For ideas, check out the web site [www.stoppain.org](http://www.stoppain.org).

**Give caregivers information about end of life services.** Tell them about the structure and staff of the service. Be sure to include contact and when. Brochures, leaflets and family conferences are useful methods for disseminating such information.

**Make tools accessible to caregivers and staff.** Encourage the use of step-by-step pictures on educational fact sheets, teaching videocassettes, and even web sites. Have these readily available for the staff to obtain, and offer a lending library so that they are readily accessible to family caregivers.

**Provide training sessions.** A structured education intervention will provide the opportunity for staff members to model particular tasks and for caregivers to observe that others are able to perform the tasks. The program could include skills training as well as communication strategies that will prepare caregivers to provide their best care for a patient. One-on-one sessions can be a powerful influence on the caregiver's self-efficacy and confidence.

**Focus on pain management and comfort measures.** Two areas in which caregivers often need to build confidence are administering the appropriate dose of *morphine* to avoid negative side effects (e.g., addiction, respiratory depression or drug tolerance) and being creative with *non-pharmacological* ways of providing comfort. Offer training sessions that inform caregivers about the appropriate use of morphine to manage pain and model non-pharmacological ways of providing comfort.

**Offer a round-the-clock resource.** A 24-hour phone service or home care service can offer essential information, seven days a week. This will enable a family caregiver to feel safe enough to try to give the care. A caregiver's anxiety is always present and at times s/he is frightened. Having the support of others is important.
Many caregivers can access the internet from home.

More ideas for promoting self-efficacy

Provide online information. The Wall Street Journal reports that there are 21 million Americans who are caregivers to aged and ailing family members, and many are looking online for information. Caregivers are often isolated from other caregivers and cannot go out to a support group to attend an educational session.

- Refer caregivers to a chat room or message board aimed specifically to address issues of caring for a person at the end of life.
- Refer caregivers to online sites that specialize in information on how to handle medical care and related topics. These are appealing especially if the caregiver is pressed for time.
- Offer a resource list of sites that may be helpful. The National Alliance for Caregiving offers a clearinghouse of web sites that rates the best sites and resources (www.caregiving.org).

Offer to facilitate family conferences. Decisions about care affect not only the caregiver but also other family members. Sometimes the family members who are not actively involved in caregiving perceive that they are being left out of decisions regarding their loved one. A family conference gives everyone an opportunity to know the plan and even to vent their feelings, decreasing the potential for dissention to occur.

Provide support groups for caregivers. Caregiver may experience a variety of feelings, including grief, frustration, anger, inadequacy, resentment, or guilt. The support group can validate these feelings and support the caregiver. Knowing that others have the same feelings often lifts the burden.
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Chapter 8 • Appendix A

*Signs and Symptoms of Approaching Death*

The hospice staff realizes that this particular period of time is one of the most difficult times you and your family will have to endure. Our approach in all matters affecting you during this time is to be as honest and straightforward as possible. In this way, the hospice team members can establish a trusting and open communication relationship with your family member who is very ill and the members of your family who are concerned about the possibility of impending death. Our philosophy of care is that the “fear of the unknown” is always greater than the “fear of the known”.

**Why do I need to know this information?**

We offer you this information to help you prepare and anticipate symptoms, which are indicative of approaching death. We want you to know what to expect and ways to respond. Your hospice nurse, volunteer and physician are your best resources to help you clarify your concerns about this information. Not all these symptoms will appear at the same time and may never appear. It is important to remember that the signs and symptoms of approaching death vary with each individual and with the type of illness. We want to relate each possible symptom to you in order to decrease your fear if one should appear suddenly. All the symptoms described are indicative of how the body prepares itself for the final stage of life.

**What will we see in the final days of life?**

1. The arms and legs of the body become cool to the touch and you may notice the underside of the body becoming much darker in color. These symptoms are the result of blood circulation slowing down.

2. The Hospice patient will gradually spend more and more time sleeping during the day and at times will be difficult to arouse. This symptom is a result of a change in the body’s metabolism.

3. Your family member may become increasingly confused about time, place and identity of close and familiar people. Again, this is a result of body metabolism changes.

4. Incontinence (loss of control) of urine and bowel movements is often not a problem until death becomes imminent. Your hospice nurse can help you prepare the bed linens to provide comfort to the individual.

5. If your loved one has a catheter in place, you will notice that the amount of urine will decrease as death comes closer.

6. Oral secretions may become more profuse and collect in the back of the throat. You may have heard friends refer to a “death rattle”. This symptom is a result of a decrease in the body’s intake of fluids and inability to cough up normal saliva production.
7. Hearing and vision may decrease slightly.

8. You may notice your loved one becoming restless, pulling at bed linen and having visions of people or things which do not exist. These symptoms are a result of the decrease in oxygen circulation to the brain and a change in the body’s metabolism.

9. Your family member will have decreased need for food and drink because the body will naturally begin to conserve energy which is expended on these tasks.

10. During sleep, at first, you will notice breathing patterns in your loved one change to an irregular pace and where there may be 10-30 second periods of no breathing. Your doctor and nurse refer to this as period of “apnea”. This symptom is very common and indicative of a decrease in circulation and build up in body waste products.

What can I do about these symptoms?

1. Keep warm blankets, but not electric, on the family member’s body to prevent him/her from feeling overly cold.

2. Plan your time with your family member for those occasions when he/she seems most alert. We encourage you spend time talking, sharing and touching your loved one. It is equally as important to remember to take breaks (e.g. maybe getting outside for a brisk walk; sharing with friends; etc.)

3. Remind your family member frequently what day it is, what time it is and who is in the room talking to him/her.

4. Consult your hospice nurse for pads to place under the incontinent patient and for hygiene techniques for cleanliness.

5. Keeps light on in the room when vision decreases and never assume the patient cannot hear you. Hearing is the last of the five sense to be lost.

6. Talk calmly and assuredly with the confused person so as not to startle or frighten him further.

7. Giving your loved one small amounts of ice chips and using swabs dipped in water, ginger ale or club soda will help relieve the feeling of dehydration. Wiping the person’s face with a cool moist wash cloth also helps to provide comfort. If your loved one’s lips are dry, applying chapstick is helpful.

8. Elevating the head of the bed often relieves the person who has irregular breathing patterns.

9. Consult with your hospice nurse as the urine output decreases, for there is a possible need to irrigate the catheter to prevent blockage.

10. If the person is not communicating, using a blink system may be helpful (e.g. one blink of the yes for “yes” and two blinks for “no”).
How will I know that death has occurred?

1. No breathing
2. No heartbeat
3. Loss of control of bowel and bladder
4. No response to shaking or shouting
5. Eyelids slightly open
6. Eyes fixed on a certain spot
7. Jaw relaxed and mouth slightly open

What do I do at the time of death?

Your hospice nurse will help you confirm that death has occurred and handle calls to the mortuary and your doctor. A call to the police or 911 is not necessary. Please know that although this information may sound frightening, the Hospice team’s first goal is to help prepare you for what to expect. Your physical and emotional well being is as important to us as the dying person is. It is important not to expect that all of these symptoms of approaching death will occur. The focus of this paper is to help you prepare for when or if they do occur. Remember that a member of the hospice nursing team is always available to help you.
Chapter 8 • Appendix B

Hospice: Comforting the Dying Patient

While traditional medicine seeks to cure the patient and prolong death, the intent of hospice is to treat the symptoms of disease to allow the terminally ill patient to die with as much comfort as possible. The primary goal of the hospice team is to minimize the patient's pain and maximize the patient's comfort level while death approaches. "Comfort" is more than just pain reduction; the patient will need spiritual and emotional comfort as well. The hospice team attempts to achieve "comfort" in a number of ways.

Physical Comfort

Minimizing the physical pain experienced by many terminally ill patients is a major goal of the hospice team. Acute pain is pain of a relatively short duration. Chronic pain, experienced by patients with degenerative joint disease, chronic obstructive pulmonary disease, emphysema, cancer and other conditions, is experienced constantly and over an indefinite period of time. Terminal patients frequently require treatment for chronic pain.

Both narcotic (usually morphine) and non-narcotic (aspirin, acetaminophen) analgesics are used to control pain symptoms. When used properly, analgesics provide tremendous, much-needed relief to the terminal patient.

Unfortunately, many health care providers are not knowledgeable about pain control. Often, patients are under medicated because "it's not time yet" for their next dosage. The patient is then forced to endure pain until the next scheduled dosage, by which time it will take even longer for the drug to take effect because of the increased severity of the pain. Other symptoms can arise out of this unnecessary pain such as increased anxiety which in turn can lead to nausea and a decrease/loss of appetite. These secondary symptoms then need to be addressed as well.

Sometimes drugs are administered only when a patient requests them. The patient may suffer needlessly if he or she is unwilling to speak up, or if he or she feels that the pain medication should only be requested if the pain is extreme.

The key to appropriate pain management lies in thoroughly assessing and monitoring the patient's pain. The hospice worker and the patient work together so that a record of the patient's pain can be maintained. This record should include pain rating, duration of pain, the drug used to alleviate the pain, side effects, and the duration of the drug's effect. The record allows the physician or nurse to evaluate the effect of the medications and to change the drug and/or dosage schedule as necessary, providing optimal pain relief for the patient.

Physical agents offer effective, non-drug methods that can be used to control pain. Physical agents are often used in conjunction with medication. Massage benefits the patient by increasing circulation, restoring homeostasis, and reducing pain via counter-irritation. One study showed that men with cancer who received ten minutes of massage experienced a significant decrease in pain. Massage also provides soothing effects that can help a patient relax both physically and mentally. Superficial heating and cooling of tissues can help decrease muscle spasm, pain, and resolve local infections. TENS can be used for pain relief associated with decreased mobility secondary to poor posturing.

Appropriate positioning and movement of inactive patients can help alleviate pain. Patients are often unable to make the little adjustments in posture and position that healthy, mobile people do without even thinking. These patients need to rely on their health professionals or caregivers for relief. Proper positioning can provide relief and decrease the complications
associated with prolonged bed rest such as pressure sores and contractures. Static posturing, ischemia, and contractures can cause pain; AROM and PROM can decrease the pain by benefiting the muscles, joint surfaces, connective tissues, vasculature, and nerves.

Pain is not the only physical symptom that needs to be addressed. Anorexia is a symptom that accompanies many major illnesses and is also caused by various treatments. Appetite can sometimes be improved with nutritional supplements and feeding tubes. Patients should not be pressured into eating more than they can tolerate. Dehydration can actually have a palliative effect by decreasing anxiety and pain. Weakness can be treated by various means such as physical therapy or changes in medication and fluid intake. Dyspnea is a frequently experienced symptom. Because oxygen and pleural effusion and rarely effective treatments for dyspnea in the terminally ill patient, morphine is often administered to decrease anxiety and respiratory drive. Dry mouth can be treated via oral care and by sipping liquid. A catheter can be put in place for the incontinent patient.

When a patient has any sort of infection, the "natural" response is to treat it. However, initiating treatments such as antibiotics should be discussed with the patient's family ahead of time, for sometimes an incurred infection can lead to a more comfortable death than the underlying disease would allow. A comfortable death, after all, is the point of hospice care.

Patients often suffer from sensory and motor dysfunction and accommodations should be made for these deficits. For example, if a patient has poor vision, good lighting should be provided and eye wear should be kept clean. If a patient has painful joints, he or she should be handled gently and minimally. If a patient tends to react and respond slowly, then ample time should be set aside for that patient's visit. These compensations for the patient's deficits helps to make the patient more comfortable in his or her surroundings and with other people.

Spiritual Comfort

It is important that the patient's spiritual needs be met with hospice care. Zerwekh describes four areas of Spiritual Caring: Recognizing Spiritual Issues, Dialogues about Spiritual Issues, Fostering Reconciliation, and Sharing Nearing Death Experiences. Recognizing Spiritual Issues deals not only with overt religious beliefs but with the more subtle issues of meaning, purpose, forgiveness, and transcendence. Unresolved issues can lead to agitation and further the patient's suffering. An appropriately trained hospice worker can help a patient to work through these spiritual issues.

Dialogues about Spiritual Issues involves being able to facilitate sharing between the hospice worker and the patient. Patients often want to explore questions such as "Why is this happening to me?" and about the meaning of life. The hospice worker can also help facilitate spiritual sharing between the patient and patient's family.

Fostering Reconciliation is about resolving relationships. Life review is encouraged in an attempt to integrate life experiences so that meaning and forgiveness can be found.

When Sharing Nearing Death experiences, patients often describe seeing a beautiful place or sensing the presence of benevolent beings. These experiences appear to bring great comfort to the dying patient. Sharing these experiences often brings comfort to the patient's loved ones.

Emotional Support

Counseling is a method by which emotional comfort can help be attained; hospice care would not be complete without it. The patient needs help coping with his or her impending death and the separation that death will bring. The counselor attempts to create an atmosphere in which the patient will feel comfortable enough to talk about his or her concerns. The counselor should be a skilled listener that is able to draw the patient out. The patient should not
be bombarded with questions, nor should a counselor moralize or preach to the patient, for this would contradict the concept of emotional support.

Hospice does not end with the death of the patient. The patient's family receives help during the patient's decline and after the patient's death. The hospice team can help the family by assisting with daily chores that have become cumbersome, such as grocery shopping, cooking, and cleaning. Counseling while the patient is dying involves facilitating communication between the family and the patient. The counselor also helps the family deal with anticipatory grief that accompanies the impending death of a loved one. Grief, either anticipatory or after the patient's death, can lead to divorce, separation, drug and alcohol abuse, and a decline in health. The hospice attempts to help the family avoid these unfortunate "side-effects" of death. Families are periodically visited and assessed in their time of need. Risk factors, such as family discord or an inability to express feelings, are assessed during the initial visit and are addressed in subsequent visits. The families are not quickly forgotten; follow-up visits sometimes take place up to several years after the death of the patient.

Conclusion

The hospice treats the patient as a whole person who needs comfort and support in a variety of areas in his or her life. The dying patient needs love and needs to know that someone will be there at any given moment. A properly trained hospice staff can meet the needs of the patient and family while making the transition into the unknown much more bearable for everyone involved.

References

Chapter 8 • Appendix C

The Care Givers’ Guide: An Instructional Booklet for Home Care

This booklet is published by Home & Hospice Care of Rhode Island and can be viewed by clicking here.
Chapter 9:  

Attending to Family Members’  
Emotional & Spiritual Needs

STEP I – CONDUCT AN AUDIT

Key Item -- the questions the TOOLKIT After-death Bereaved Family Member Interview asks about family members’ emotional & spiritual needs

1. (In [PATIENT’S] last week/ While [PATIENT] was under care of the hospital/hospice/nursing home), did someone talk with you about your religious or spiritual beliefs?
   [ ] YES  [ ] NO
   a. [If yes] Was this done in a sensitive manner?
      [ ] YES  [ ] NO
   b. Did you have as much contact of that kind as you wanted (in [PATIENT’S] last week/ while [PATIENT] was under care of hospital/hospice/nursing home)?
      [ ] YES  [ ] NO

2. (In [PATIENT’S] last week/ While [PATIENT] was under care of the hospital/hospice/nursing home), how much support in dealing with your feelings about [PATIENT’S] death did the doctors, nurses, and other professional staff taking care of (him/her) provide you - less support than was needed or about the right amount?
   [ ] LESS THAN WAS NEEDED  [ ] RIGHT AMOUNT

3. (In [PATIENT’S] last week/ While [PATIENT] was under care of the hospital/hospice/nursing home), did a doctor, nurse, or other professional staff taking care of [PATIENT] talk about how you might feel after [PATIENT’S] death?

   | [ ] YES | → | Was it done in a sensitive manner? |
   | [ ] YES |
   | [ ] NO | → | Would you have wanted them to? |
   | [ ] YES |
   | [ ] NO |

4. (In [PATIENT’S] last week/ While [PATIENT] was under care of the hospital/hospice/nursing home), did a doctor, nurse, or other professional staff taking care of [PATIENT] suggest someone you could turn to for help if you were feeling stressed?
   [ ] YES  [ ] NO
5. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of
the hospital/hospice/nursing home), how well did those taking care of
[PATIENT] do at providing emotional support for you and [PATIENT'S]
family and friends?

[ 0    1    2    3    4    5    6    7    8    9    10  ]

STEP II – ENGAGE STAKEHOLDERS & DEFINE A GOAL

9.1 Key item – the importance of focusing on family members’
emotional and spiritual needs

The World Health Organization defines goals of palliative care as providing
the best possible quality of life for the patient and family. Inherent in the
WHO definition is that dying impacts both the patient and those who live on.
We must strive to focus on the patient, but we must also remember the
important needs of the family through emotional support both prior to and
after the patient's death and through attending to their spiritual needs in a
sensitive manner.

One group of loved ones who often have particularly pressing needs are
family caregivers. The importance of supporting family caregivers is
underscored by these findings:

- Heavy-duty caregivers, especially spousal caregivers, do not get
  consistent help from other family members. One study has shown that as
  many as three fourths of these caregivers are “going it alone” (National
  Family Caregivers Association).

- Elderly caregivers with a history of chronic illness themselves who are
  experiencing caregiver related stress have a 63% higher mortality rate
  than their non-caregiving peers (Schulz & Beach 1999).

- Sixty-one percent of “intense” family caregivers (those providing at least
  21 hours of care a week) have suffered from depression (National Family
  Caregivers Association).

More research is needed to fully explore the impact of caring for a loved one
through the course of a serious, life-limiting illness. An important question is
how systems can respond to assure quality interventions that address family
caregivers’ emotional and spiritual needs before and after their loved one’s
death.

A 1997 national Gallup Poll found that most Americans long for spiritual
support at the end of life, yet few would choose their clergy members to
provide it. In fact, the poll suggests that most people would look to their family
and friends when it comes to good care at the end of life. Physicians and
nurses scored even lower as sources of support. Only 30% of respondents
said they would look to their doctors for comfort, while 21% said they would
rely on a nurse.
What can we learn from this information?

What improvements can we consider that will increase patients’ confidence that their health care providers are interested in and concerned about their spiritual and emotional needs?

What changes need to be made in our systems to respond to the stated desire for more family involvement? Do we have systems in place that can support an increased role?

What do health care providers need to do to increase their own level of comfort and confidence with emotional and spiritual issues?

How can Quality Improvement efforts impact patient and caregiver satisfaction with the emotional and spiritual support provided by their health care team, including clergy?

If we are to improve the quality of supportive care provided to family members, we must come to identify, validate and appreciate their needs both prior to and after the death of their loved one. A family members’ bereavement experience can be complicated by many factors, some of which may be related to events or unresolved emotional and spiritual concerns that were present before the patient died. Even the sudden absence of care giving responsibilities can deepen the void already felt by the patient’s death.

9.2 Key Item – expert advice about attending to emotional and spiritual needs

A society needs more than anything else to care.
~Whitney M. Young, Jr. 1921-1971, Social worker, educator and Director of the National Urban league

With whom should we consult to gain insight into methods of improving how our health care system attends to the emotional and spiritual needs of the family? The logical answer would seem to be that family members themselves are the experts. While this is true, it is important to bear in mind that family members may feel uneasy about revealing their emotional and spiritual concerns, even to the most caring of professionals.

As a result, any intervention in this domain will need to take into account the family’s willingness or ability to share intimate and personal thoughts about grief, loss, and spiritual meaning. Recognizing the need to attend to family’s emotional support, many professional and consumer organizations have guidelines that should be considered as your Quality Improvement Team begins its work in this domain.
Last Acts Precepts of Palliative Care

“Palliative care: …

- provides physical, psychological, **social and spiritual** support to help the patient and **family** adapt to the anticipated decline associated with advanced, progressive, incurable disease.

- extends support beyond the life span of the patient to assist the **family in their bereavement**.

- appreciates the substantial physical, emotional and economic demands placed on families caring for someone at home, as they attempt to fulfill care giving responsibilities and meet their own **personal needs**.

- anticipates that some family caregivers may be at **high risk** for fatigue, physical illness and **emotional distress**, and considers the special needs of these caregivers in planning and delivering services…”

National Hospice & Palliative Care Organization (NHPCO): A Pathway for Patients and Families Facing Terminal Illness

As part of the goal of self-determined life closure, safe and comfortable dying, and effective grieving, the NHPCO makes several statements about the **family**.

- “…**Treat** problems associated with coping and grieving, such as **anxiety and depression**.

- **Assist** family members’ emotional adjustment to **changing role** in relation to patient and within family system.

- **Educate** caregivers in preparation for eventual loss.

- Assess family members for risk factors that may contribute to **complicated grieving**; refer to bereavement service prior to death if necessary.

- **Promote opportunities** for growth, reconciliation, sense of completion, expression of self in relation to dying person, sense of involvement and accomplishment in dying person’s life, sense of preparedness for death, higher sense of connectedness, integrated concept of life and memories. …”
Institute of Medicine’s Approaching Death: Improving Care at the End of Life

- “…The psychological dimension of end-of-life care, which encompasses both cognitive function and emotional health, calls for openness and sensitivity to the feelings and emotional needs of both the patient and the family.

- Psychological caring involves recognizing and managing emotional barriers to accepting incurable illness and preparing for death.

- Emotional care extends beyond a patient’s death to concern for grieving families and friends.

- Spiritual—like emotional—caring embraces those close to the patient and extends beyond the patient’s death. …”

National Family Caregivers Association 10 Tips for Family Caregivers:

- Choose to take charge of your life, and don’t let your loved one’s illness or disability always take center stage.

- Remember to be good to yourself. Love, honor and value yourself. You’re doing a very hard job and you deserve some quality time, just for you.

- Watch out for signs of depression, and don’t delay in getting professional help when you need it.

- When people offer to help, accept the offer and suggest specific things that they can do.

- Educate yourself about your loved one’s condition. Information is empowering.

- There’s a difference between caring and doing. Be open to technologies and ideas that promote your loved one’s independence.

- Trust your instincts. Most of the time they’ll lead you in the right direction.

- Grieve for your losses, and then allow yourself to dream new dreams.

- Stand up for your rights as a caregiver and a citizen.

- Seek support from other caregivers. There is great strength in knowing you are not alone.
Canadian Palliative Care Association

The Canadian Palliative Care Association’s Model Guideline for Palliative Care Standards of Practice includes goals and objectives for care that relate specifically to family members.

- "... Goal: Psychological, social and spiritual support meets the expectations and needs of patients and families. 

  Objective 1: The patient and family are satisfied with the individualized psychological, social & spiritual support.

- Goal: Loss, grief, death planning and bereavement support meets the expectations and needs of patients, families, caregivers and service providers.

  Objective 2: The family is satisfied with the loss, grief, death planning and bereavement support. …"

9.3 Key Item - the basics of attending to emotional & spiritual needs

To keep a lamp burning, 
we have to keep putting oil into it.
~Mother Teresa

Family issues are often neglected as part of the patient assessment process. Health care systems generally are designed to identify and treat physical problems. Often, a patient’s psychological, emotional and spiritual concerns are given a low priority in these designs.

With that in mind, it is not too surprising that a loved one’s emotional and spiritual needs may go unattended. Yet, in order to develop strategies and interventions that promote coping and problem solving, relieve anxiety, and support an understanding of the changing nature of hope in the face of serious and life-limiting illnesses, the psychological vulnerabilities and spiritual frameworks of families must be identified (Anderson 1989).

9.3a Emotional assessment- including family and loved ones in the plan of care

“ I was not prepared for how it actually went. 
I was not prepared for my emotions.”
~Focus group participant talking about the death of a loved one

It is important to appreciate the balance between patient autonomy and inclusion of family/loved ones into the patient’s plan of care. The patient must have input, to the extent possible, into the role that loved ones will play in his/her care. Begin early in your relationship with a patient to explore the wishes, values and beliefs that may influence how much or how little he/she wants loved ones involved.
Professional caregivers need to encourage family members and loved ones to express their concerns. Since most encounters with families will be in the context of the patient’s care, you should include questions in your admission and ongoing assessments that stimulate exploration of family members’ distress or anxiety.

For example, a palliative care consultant asked this question of a 79-year old woman caring alone for her 80-year-old husband with end-stage multi-system organ failure: “Can you tell me how you feel when you wake up each day?” The woman answered:

“Some days I’m just not sure I can keep going, I’m not sure I can do all that I need to do.”

The woman’s answer provided an opening for the clinician to explore the emotional and psychological stress associated with her daily responsibilities. This example illustrates the importance of asking questions that help you appreciate a caregiver’s perception of the patient’s illness and its impact on his/her life (Ramirez et al. 1998).

**Important Messages to Remember about Emotional Assessment**

✓ Once you have established a comfortable rapport with the family/loved one, you can begin to further assess the severity of their emotional and spiritual needs.

✓ _Be patient_. Family members need guidance through the emotional maze that accompanies the anticipation of and actual loss of a loved one.

✓ Living with the uncertainty of a life-limiting illness provokes anxiety, fears and a range of intense emotions--even in the most well supported families. Remember, _be patient_.

✓ When appropriate, seek the involvement of other disciplines, such as social workers, psychological counselors, chaplains and trained volunteers.

✓ Your assessment should include an inventory of resources available within your organization and in the family member’s community that can assist with emotional and spiritual support.

✓ Also, don’t underestimate the social fabric of the loved one. A caregiver may be connected to a garden group, a reading club, or even a card group that might be a good source of stability and emotional normalcy.
9.3b Spiritual assessment- going beyond “What is your religion?”

When a loved one is dying, relationships with the patient and others may experience profound changes. In the face of serious illness, it is not uncommon for patients and families to reconsider their spiritual selves, their God, and their place within the universal scheme. It is important to provide the atmosphere and the resources to allow family members to pursue their spiritual questions as part of the patient’s overall plan of care.

The Spiritual History - Christina M. Puchalski, M.D., M.S.

Spirituality can be defined as whomever or whatever gives one a transcendent meaning in life. This is often expressed as religion or relationship with God, but it can also refer to other things: nature, energy force, and belief in the good of all, belief in the importance of family and community. So a spiritual history is a beliefs or values history.

The spirit is the essence of the person---what makes them unique. The spiritual part of each person can bring wholeness to the emotional, the physical, and the intellectual parts of life.

Spiritual questions of life which come up especially during illness are:
1. What gives my life meaning?  2. Why is this thing happening to me? 3. How will I survive this loss?  4. What will happen to me when life ends?

It is not our job to provide answers to these questions, but we can support and encourage people as they search for these answers. We can use people's religious faith, other spiritual beliefs or values as resources. Referral to chaplains or other spiritual directors is key, if desired by the family member.

Usually the meaning of illness or wellness relates directly to a person's perception of the purpose of his or her life. Each person's thoughts or perceptions of what is the meaning of life influences how they think about their own illness. One may have assigned certain behaviors as wrong or violating one's sense of purpose. An illness may be perceived as a form of punishment. Some patients view a return to health as a means to reaching ultimate goals in their lives. One's beliefs and values can profoundly affect how a person copes with illness and with the treatment of illness.

Spirituality is important during all phases of one's health and illness, but spiritual and religious factors play an especially prominent role in patients' experience with terminal illness, the dying process, and death. For example, a Hindu patient may see elimination of pain and suffering as a primary life goal. He believes his spirit will be passed to another life through reincarnation. Therefore, he may emphasize comfort measures at the end of life and refused heroic life-supportive measures. Discussion of beliefs is also a good lead into discussing other issues of end of life care, such as a living will. This should be done long before the person is imminently dying; therefore, when one is obtaining the spiritual history, one can then ask about preferences in end of life care.
FICA is an acronym that can help providers remember what to ask in a spiritual history.

- Faith or beliefs
- Importance and influence
- Community
- Address

There also are some specific questions providers can use to discuss these FICA issues.

**F**: What is your faith or belief? Do you consider yourself spiritual or religious? What things do you believe in that give meaning to your life?

**I**: Is faith or spiritual belief important in your life? What influence does it have on how you take care of yourself? How have your beliefs influenced your behavior during this illness? What role do your beliefs play in regaining health?

**C**: Are you part of a spiritual or religious community? Is this of support to you and how? Is there a person or group of people you really love or who are really important to you?

**A**: How would you like me, as your healthcare provider, to address these issues in your care?

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**Important Messages to Remember about Spiritual Assessment**

- A spiritual history is nothing more than talking with your patient or their caregivers about his or her beliefs and what is important to him or her. So in getting a spiritual history, you are simply listening to that person’s story.

- During a history or admission assessment, you can ask about beliefs during the social history section.

- One can get basic spiritual history at the first visit and then follow-up in subsequent visits as appropriate.

- Consider spirituality as a potentially important component of every person’s physical well-being and mental health.

- Address spirituality at each complete physical exam and continue addressing it at follow-up visits, if appropriate. Spirituality is an on-going issue.
✓ Respect a person’s privacy regarding spiritual beliefs; don’t impose your beliefs on others.

✓ Make referrals to chaplains, spiritual directors, or community resources as appropriate.

✓ Be aware that your own spiritual beliefs will help you personally and will overflow in your encounters with those for whom you care to make the doctor-patient encounter a more humanistic one.

9.3c Bereavement - One Journey’s End…

...Another’s Beginning

I carry your heart in my heart
I carry your heart in mine
~e. e. cummings

Serious illness involves multiple losses for everyone involved. The death of someone close often begins one of the most painful times of a person’s life. Yet, many people don’t understand that their bereavement journey may begin long before their loved one dies. It is not unusual for a family member to experience some of these feelings during the period of anticipatory grief.

Sadness. People may experience an intense sadness knowing that someone they love is dying and that some of their plans will go unfulfilled.

Frustration. One day a person may be in denial. The next, they may be hopeful their loved one will beat the illness. This ambivalence can be very frustrating.

Guilt. A family member or close friend may have said or done things that make them feel guilty.

Anger. A person may display anger toward the doctors and other health care providers, the one who is dying, or God.

Loneliness. Some people feel extreme loneliness because the dying person is no longer part of their everyday life.

Fear. Loved ones are entering unknown territory and may be afraid of how the disease will run its course or what life will be like after the person dies.

Hope. Some people find a great well of inner strength; some may call it faith. This strength may come from spirituality, friends & family, or life experience.
Following the death of a loved one, people may experience many of these same feelings. Grief is the combination of sorrow, strong emotion, and the resulting confusion that comes from losing someone important. They mourn not only the loss of that person but also others they have lost in the past.

The journey through grief is as individual as the journey through life. Yet, there are opportunities to use the intensity of bereavement as a time for personal growth and understanding about relationships, meaning and transcendence. Some family members may benefit from a support group or individual counseling to assist in their bereavement journey, before or after the death of the loved one.

9.4 Defining an overall goal for addressing family members’ emotional and spiritual needs

Take a look at your audit results concerning support for family members’ emotional and spiritual needs. 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).”

9.5 Key Item - the kinds of interventions that are appropriate and measurable for attending to emotional and spiritual needs of family members

Raise awareness about the importance of rituals. Conduct a PDCA cycle to raise cultural sensitivity about the importance of various rituals at the end of life. Involve clergy, medical interpreters, and others that might share an interest in promoting greater cultural awareness. For some patients and families emotional and spiritual support is closely linked to certain cultural, religious or spiritual rituals. It is important to honor these rituals, to the extent
possible, within your care setting. Don’t underestimate the significance of rituals – without them some family members will have a very difficult time achieving closure. In fact, interference with rituals can leave a family member feeling guilty or worried that their loved one will not achieve an eternal peace.

**Build emotional and spiritual needs of family members into the admission and discharge processes.** For example, add questions corresponding with FICA to your admission form. Consider adding a question about special needs, such as religious or spiritual sacraments or ceremonies, to your initial assessment. It may be helpful to with discharge planners, many of whom are nurses as well as social workers, about family support needs they struggle with when planning for the patient’s transition from one care setting to another.

**Develop a Palliative Care Kit** (Lynn et al. 2000). One health care institution developed Palliative Care Kits that included:

- prayer book with a variety of readings, including poems and scripture;
- oils for rituals and blessings;
- music therapy with CDs and tapes;
- potpourri/sachets for aroma therapy;
- lotions for massage therapy.

Other items you might want to consider for your patient’s family members include coloring books for children, disposable cameras to capture family moments, and journals for writing.

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 addressing emotional and spiritual needs of family members

Form an interdisciplinary team. Improving how your organization attends to the emotional and spiritual needs of patients and family members requires careful consideration of your resources. Clinicians may feel uncomfortable with these issues or may lack confidence in their ability to do a good job. Seek guidance from social workers, chaplains, physical therapists, and volunteers within your institution. Consider ways to bring these resources together to support mutually beneficial collaborations. For example, consider developing a model for interdisciplinary rounds that can meet with sufficient regularity to be meaningful to your patient population.

Utilize resources outside your institution. Hospice is a framework that considers the patient and his/her loved ones as the unit of care. The hospice framework also uses an interdisciplinary team model to assess and manage patients' and family members' changing needs. Since hospice programs routinely incorporate psychological, spiritual, and emotional assessments in their plans of care, consider inviting a local hospice team to a brainstorming session on methods to improve how your staff assesses patients using an interdisciplinary approach. Other resources outside your facility to consider are community clergy groups, parish nurses, community wellness centers, bereavement professionals, school guidance counselors, mental health professionals, and various support group networks.

Develop or expand family support groups. Assess the family members of the population that you serve for unmet emotional and spiritual support needs, and consider developing a support group to address those needs. Think about potential bereavement support groups that are in keeping with the population your organization serves. For example, an extended care facility that specializes in Alzheimer’s disease and other forms of dementia might offer a support group for grieving spouses. It may be helpful to look to other disciplines within your organization for assistance. In addition, look for ways to collaborate with outside groups, such as the Alzheimer’s Association and your local hospice.

Explore non-pharmacological therapies. There are numerous resources available--including relaxation exercises, yoga, aromatherapy, and expressive therapies--that could offer a new dimension of support. Seek input from wellness specialists on ways to incorporate some techniques into your practice or opportunities for complementary therapies to be offered to patients and their families in your institution. Music, art, movement and other methods of expression can provide a valuable outlet for emotional and spiritual suffering.
Institute bereavement follow-up. Consider ways that you can follow-up with families and staff after the death of a patient. Whatever you choose to do, make it a routine practice that becomes part of your care plan.

- Send a sympathy card from unit staff immediately following the death and at the one year anniversary.
- Develop a packet of information for family members regarding internal and external support groups, counseling, and other bereavement resources.
- Encourage family caregivers to schedule a visit with their physician for a routine check up to support their own wellness.
- Consider establishing a memorial program that is appropriate to your setting to remember patients who have died. This might be annual or more frequent, depending on need. Invite family members and staff to participate.
- Support your staff's bereavement needs by providing opportunities to discuss difficult cases and losses. This will strengthen their abilities to be present to family members who are grieving.
Reference List


National Family Caregivers Association/Fortis Long Term Care. Caregiving Across the Life Cycle. 1998

