

The Stanford Faculty Development Center

END-OF-LIFE CARE CURRICULUM FOR
MEDICAL TEACHERS

End-of-Life Care Teacher's Guide (September 2003)
Stanford Faculty Development Center
Stanford University School of Medicine
Palo Alto, CA 94304

Written by James Hallenbeck, MD, Sara Katz, PhD, and Georgette Stratos, PhD

Assistance with Curriculum Development:

Jon Fuller, MD (Module 6 - Venues & Systems of Care)
Richard Meyer, MD (Module 2 – Pain Management)
Stephen Pantilat, MD (Module 4 – Making Difficult Decisions)
Michael Rabow, MD (Module 3 – Communicating with Patients & Families)
Brad Stuart, MD (Module 7 – Psychiatric Issues & Spirituality)

Curriculum Advisory Board:

Susan Block, MD
Brad Stuart, MD
Charles von Gunten, MD
David Weissman, MD

Outside Review:

Robert Brody, MD
Christina Pulchalski, MD
Brad Stuart, MD

Conversion of the curriculum for Internet use:

Growth House, Inc.
<http://www.growthhouse.org>
With signal appreciation to Les Morgan

Grateful Dedication to the ELC Teachers – the Pioneers:

Jeffrey Alderman MD, Denis Bouvier DO, Richard Christie MD, Sheira Freedman MD, John Fromson MD, Annette Geisler MD, Carol Griffin MD, Jennifer Hughes MD, Dennis Johnson MD, Gary Lee MD, William Minier MD, Cynthia Pan MD, Gary Reisfield MD, Emese Somogyi-Zalud MD, A. Reed Thompson MD, Roberta Turner MD, Mary Wisely MD.

Special thanks to:

Kelley Skeff, MD (inspiration), Jane Mount (ELC literature database, research assistance, and editing), Merlynn Bergen, PhD (research), and the rest of the Stanford Faculty Development Center staff – Charmaine Agard, Katherine Blood, Christine Harms, Oma Morey, PhD, and Kelly Thijssen – (generous assistance in countless ways.)

The Stanford Faculty Development Program for End-of-Life Care was made possible by a grant from the Robert Wood Johnson Foundation, to whom we give unending thanks.

END-OF-LIFE CARE CURRICULUM FOR MEDICAL TEACHERS
Teacher's Handbook

TABLE OF CONTENTS

Introduction	1
How to use this Curriculum	2
Instructional Methods: Read This Before You Teach!	5
Teaching End-of-Life Care: Special Issues	10
Tools for Teaching Module 1: Overview and Death & Dying in the U.S.A.	13
Tools for Teaching Module 2: Pain Management	30
Tools for Teaching Module 3: Communicating with Patients & Families	52
Tools for Teaching Module 4: Making Difficult Decisions	64
Tools for Teaching Module 5: Non-Pain Symptom Management	84
Tools for Teaching Module 6: Venues & Systems of Care	95
Tools for Teaching Module 7: Psychiatric Issues & Spirituality	111
Tools for Teaching Module 8: Instituting Change	122
Comprehensive Bibliography	133
List of Relevant Websites	139
How to Access the End-of-Life Care Literature Database	140
Companion Book: Palliative Care Perspectives	142
Table of Contents for the PowerPoint Slides with Teacher's Notes: Module 1	144
Table of Contents for the PowerPoint Slides with Teacher's Notes: Module 2	145
Table of Contents for the PowerPoint Slides with Teacher's Notes: Module 3	147
Table of Contents for the PowerPoint Slides with Teacher's Notes: Module 4	148
Table of Contents for the PowerPoint Slides with Teacher's Notes: Module 5	149
Table of Contents for the PowerPoint Slides with Teacher's Notes: Module 6	150
Table of Contents for the PowerPoint Slides with Teacher's Notes: Module 7	151
Table of Contents for the PowerPoint Slides with Teacher's Notes: Module 8	152

INTRODUCTION

Welcome to the SFDC ELC Curriculum for Medical Teachers

Why a curriculum is needed

Until recently, end-of-life care has been neglected in physician training. A number of studies show serious deficiencies in end-of-life care (ELC), both in the U.S. and in other countries. This has resulted in bad dying experiences for patients, their families, physicians and other health care workers. With support from the Robert Wood Johnson Foundation, the Stanford Faculty Development Center (SFDC) developed a 16-hour faculty development course incorporating basic material designed to be used by physicians in any area of expertise. **This web-based curriculum is an adaptation of materials developed for that course.**

The overall goals are to enhance physician skills in ELC, foster a commitment to improving care for the dying, improve the dying experience for patients, families, and health care providers, and improve teaching related to ELC.

Originally each of the following topics was designed to be covered in a two-hour interactive and didactic seminar. You may wish to teach no more than a portion of a seminar or to use parts of the material in different combinations. Please familiarize yourself with the section “How to use this curriculum” and the Teaching Tips to help you make the most of the instructional methods for potential challenges in teaching that particular segment of the material.

- Overview: Death & Dying in the U.S.A.
- Pain Management
- Communicating with Patients & Families
- Making Difficult Decisions
- Non-Pain Symptom Management
- Venues & Systems of Care
- Psychiatric Issues & Spirituality
- Instituting Change

The End-of-Life Care curriculum contains:

Teacher’s Handbook

Background on the development of this curriculum and the Stanford Faculty Development Center

Commentary on education in end-of-life care

Instructional methods: Read this before you teach!

Teaching end-of-life care

How to use these slides and notes

Tools for teaching the modules, including teaching tips and supplementary instructional materials

Comprehensive bibliography & relevant websites

Companion book, “Palliative Care Perspectives,” by James Hallenbeck, MD

SFDC ELC literature database

Self-Rating exercise for use when teaching the entire series

Eight Modules:

PowerPoint Teaching Guides: Slides and Teacher’s notes

HOW TO USE THIS CURRICULUM

Before using the slides, please read the relevant Teaching Tips and Instructional Material!

The modules were designed for small groups of trainees or more senior clinicians. In our experience, a seminar with 6-8 learners can be ideal. In adapting this material to larger groups, some alteration will be necessary, with special attention to facilitating the interactive activities such as role plays or brainstorm exercises.

Given the interdisciplinary nature of our work in palliative care, most of the material would be very applicable for clinicians from other disciplines with minimal, if any adaptation.

- Modify the curriculum according to your learners' needs, group size, and time available
- Consult the Handbook prior to using the PowerPoint teaching guides
- The effectiveness of this interactive, experiential curriculum depends upon learners engaging and participating
- Use your own experience as a teaching tool
- Keep current with self-directed learning
- If you alter these materials, please attribute the source, and make it clear that you have made changes to what is provided here

Options

A number of options are open to users, including teaching from the scripts as written for delivery as 2-hour seminars, using selected modular segments in a variety of teaching contexts (small group, lectures, one-on-one), and blending sections of different modules together to create new modules. Because it is difficult to find two continuous hours for training, the modules may be broken into smaller sections. We think the coherence of individual modules is worthy of consideration, and that sacrifices may be made in breaking out sections. However, experience has also taught us that many sections stand quite well alone. Some such sections may be used in 15-20 minute sessions. Alternately, users may wish to expand certain sections, incorporating this material into a larger work. For example, sections in the first module on demographics or the last 48 hours can each easily be expanded into 1-hour sessions.

Your Experience with End-of-Life Care

The faculty members who attended the Stanford training were not expected to be experts in palliative care or education, although the majority had some experience with both. We believe teachers who are relatively inexperienced in palliative care can successfully teach this curriculum. However, it is worth noting that special challenges may occur at both ends of the experience spectrum. Less experienced clinicians will struggle with how to teach material where their content base is weak. They must learn in effect how to use their 'ignorance' as a teaching tool. Experience in palliative care and teaching is a real asset, however, experienced clinicians and teachers may be handicapped by their own biases and habits. They may seek out material that is similar in content or style to their own, rejecting something that takes a different approach. During the SFDC training some Facilitators with a background in conducting interactive sessions wanted to skip over more factual material such as the demographic information in the first module, because they found this material "boring." Some were surprised to find that certain learners really wanted such facts. Others were attracted to facts and were very uncomfortable facilitating interactions such as role plays, initially stating, "I don't believe in (or *do*) role plays." While

it is very important for more expert clinicians and teachers to use their experience, they may need to question their own assumptions, and experiment with broadening their repertoire of teaching tools.

Make it Your Own

In using this material, it is critical that teachers make the material their own. This can be the most difficult challenge of using someone else's material. In training teachers who struggled with this apparent paradox, we tried to encourage them to be thoughtful and even careful if they decided to stray far from the script. We suggested an exercise where they must provide a clear explanation of the educational purpose of the original material and their rationale for changing it. If they could convince themselves of the educational advantage of the modification, we encouraged them to experiment with it.

We also observed the opposite tendency. Teachers can so rigidly follow the script that the presentation becomes wooden. Intent on "getting it right," teachers overlook opportunities to share from their personal experiences and to adjust the curriculum to the needs of learners. Thus, teachers who use curricular material developed by others are constantly striving for a difficult balance – how to stay true to the overall structure and intent of that curriculum while being true to themselves and their personal teaching styles. With many teachers, practice in teaching the material can ease the tension as they seek this balance.

Creating Your Own ELC Curriculum

For experienced teachers interested in curriculum development in palliative care, this material may serve a very different purpose. It is indeed possible that some new trick or approach to teaching a particular issue may be found. Beyond this, consideration can be given to how effectively certain problematic topics were approached. How does one incorporate some training on spirituality? How does one address physician assisted suicide without getting bogged down in never-ending ethical debates? How are methods used to address certain topics adapted to different teaching venues? An overview session given as a plenary session for a large group, as frequently happens in EPEC training, may differ in interesting ways from an overview for a small group, for which this course was designed.

Educators working to design curricula in this area must wrestle with the fact that there is never enough time to do justice to all relevant topics. It is tempting to try to solve this problem by simply crowding more content into a given session, a temptation we were not entirely successful in avoiding. However, little is gained and much lost through such an approach. Thus, critics of palliative care curricula should attend to the very difficult choices made in including or excluding certain topics and the relative weight they receive. The underlying curricular challenges faced by developers of well-known curricula such as EPEC or the Program in Palliative Care Education and Practice at Harvard are also faced by thousands of others who struggle to develop their own material.

We invite you to change the material in the SFDC ELC Curriculum to suit the needs of your learners and to keep it current. However, if you alter any of these materials, please attribute the source, and make it clear that you have made changes to what is provided here.

An Interactive Curriculum

Learners seeking to improve their palliative care knowledge and skills by directly reviewing this material will likely be disappointed. Many of the slides stand alone rather poorly. We intended them to be integrated into instruction and discussion in the small group setting. The curriculum emphasizes the acquisition of attitudes and skills over knowledge. The power of the material is greatest when it manifests in real-time interactions among learners and teacher. For example, helping trainees realize that end-of-life care is a 'big deal,' worthy of considerable attention (an attitude objective) can be accomplished most effectively through an interactive exercise such as the 'ideal' death in the first module. Participating in these discussions can be a very powerful experience. Simply reading the PowerPoint module notes on how to conduct these exercises misses this experiential quality.

Using the Tools for Teaching the Modules

Although it may be tempting to save time by downloading the PowerPoint teaching guides and using them as they are, we strongly encourage you to read relevant sections of the Teacher's Handbook before teaching from this resource. In the Handbook you will find an in-depth treatment of each module with essential background information for the teacher: Teaching Tips, and supplemental instructional materials (handouts and references). The Tips contain the accumulated wisdom of numerous educators' experience in delivering this curriculum. Please read this before using the slides. If you open the PowerPoint presentations with Internet Explorer, only the slides will be displayed. In order to view the Teacher's Notes and Outline of the PowerPoint slides, open the presentation, go to the Edit Menu and pull down 'Edit Slides.' From there, you may view Slides, Notes, or Outline views. If you download the file, it will automatically open in the Outline view.

Supplemental Materials

Knowledge acquisition is also important. While certain facts are presented, ideally the course would be supplemented by outside reading of articles or other texts. ELC Facilitators did such supplemental reading during their month of training here and were provided with a list of suggested readings that might complement the course. All Facilitators were given a copy of *Palliative Care Notes*, an independent manuscript designed in part to parallel this course. Over time this manuscript was also significantly revised and edited. It has been formally published as *Palliative Care Perspectives* by Oxford University Press in 2003 (<http://www.growthhouse.org/stanford>). Learners who wish to consult a book for background reading may find this useful.

INSTRUCTIONAL METHODS: READ THIS BEFORE YOU TEACH!

This section provides background information on the general educational principles that guided the development of this curriculum, as well as specific teaching tips designed to help with facilitating portions of the seminars. But first a caveat! We originally intended that this curriculum would be delivered by facilitators who had participated in a month-long course during which they received over 40 hours of training in teaching skills. This included exposure to an intensive 16-hour teaching improvement course taught by Drs. Kelley Skeff and Georgette Stratos, directors of the SFDC. Trainees practiced teaching under supervision and were given extensive feedback. General educational principles and particular challenges in palliative care education were explored at length. In turn, the facilitator-trainees taught us about what worked and did not work for them, helping us modify the material over the years. Through this teaching commentary and the teaching guides for each of the modules we will attempt to share some of what we learned in training facilitators. Simply reading these notes and using the material cannot substitute for a very intense, month long experience. Rather, we hope that educators view this material as a toolbox from which they may pick up some useful items.

Educational Principles underlying the Curriculum

The small group instructional methods selected for use in the ELC curriculum are based on principles of effective teaching from the education and psychology literature, synthesized by Drs. Skeff and Stratos into an educational framework for clinical teaching. The seven critical success factors of the framework are provided below. This provides an analytical tool for evaluating teaching effectiveness. It also guided our decisions in selecting effective instructional methods.

Analytical Framework: Critical Success Factors for Teaching

LEARNING CLIMATE (LC):

The tone or atmosphere of the clinical teaching setting including whether it is stimulating and whether learners can comfortably identify and address their limitations.

CONTROL OF SESSION (CS):

The manner in which the teaching interaction is focused and paced as influenced by the teacher's leadership style.

COMMUNICATION OF GOALS (CG):

The establishment and explicit expression of a teacher's and/or learners' expectations for the learners.

PROMOTING UNDERSTANDING AND RETENTION (UR):

This category deals with the approaches the teacher can use (1) to explain the content being taught and (2) to have the learner meaningfully interact with that content, thus, assisting the learner to understand and retain it. Retention is the process of remembering facts or concepts. Understanding is the ability to correctly analyze, synthesize, and apply facts and concepts. Explaining is the process by which the teacher presents material to promote understanding and retention.

EVALUATION (EV):

The process by which the teacher assesses the learners' knowledge, skills, and attitudes, based on educational goals.

FEEDBACK (FB):

The process by which the teacher provides learners with information about their performance for the purpose of improving their performance.

PROMOTING SELF-DIRECTED LEARNING (SDL):

Self-directed learning is the form of learning initiated by the individual learner's needs, interest, and goals. This category deals with approaches the teacher can use to influence motivation and use of resources, thereby fostering self-directed learning. Copyright 1999, Stanford Faculty Development Center, Stanford University School of Medicine

Background and Teaching Tips on Instructional Methods Used

The seminars use a variety of active learning methods including (1) icebreakers, (2) interactive mini-lectures, (3) brainstorm exercises, (4) small group discussion (*e.g.*, case discussions, review of videotapes of patient care encounters and an EPEC plenary), (5) role play exercises reproducing challenging teaching and practice situations, and (6) opportunities for participants to identify both personal goals for improving their practice/teaching of ELC and goals for improving ELC education at their institution.

General background information on each of the key instructional methods adopted and specific tips for teachers are offered here as a companion resource to the teaching guides. Categories from the educational framework associated with the educational purposes and teaching tips for each method are noted in parentheses.

(1) Icebreaker – Definition: Something done to relax an unduly formal atmosphere or situation; a beginning or start.

Educational Purposes:

- foster participation from all participants (LC)
- increase comfort (LC)
- show respect for opinions (LC)
- learn about learners (EV)
- establish relevance of the topic (UR)

Teaching Tips:

- ask open-ended questions (LC)
- use wait time (EV)
- listen (LC)
- paraphrase their comments (LC)
 - insure that everyone participates (Options: go around the room, ask for volunteers, solicit comments from individuals) (LC)

(2) Interactive Mini-lectures – Definition: An exposition of a given topic delivered before an audience, for the purpose of instruction. These mini-lectures are intended to last 15 minutes or less, delivered interactively, interspersed with questions to participants (*e.g.*, requests for examples or application of concepts to other contexts).

Educational Purposes:

- increase understanding and retention
- increase self-directed learning

Teaching Tips:

- use handouts (UR)
- provide transitions between sections (UR)
- provide (and ask for) examples (UR)
- summarize (UR)
- stimulate active learning with questions (UR) (Reminder: be aware of potential threat in questions)
- stimulate active learning by asking participants to paraphrase (UR)
- refer to controversy (SDL)
- refer to resources for further learning (SDL)

(3) Brainstorming – Definition: Using an organized group process to try and solve a problem by thinking intensely about it. Can involve 2-phase process. Phase 1 is unrestricted brainstorming. This is

sometimes followed by Phase 2, a critical evaluation/analysis of ideas. It is important to distinguish the brainstorming phase from the evaluation phase in terms of teaching techniques.

Educational Purposes of Brainstorming:

- foster generation of multiple, possibly divergent, ideas (each of which might trigger additional ideas) (LC)
- involve learners (LC)
- stimulate further interest in the topic (LC, SDL)

Teaching Tips:

- encourage participation welcome all ideas, encourage them not to prejudge the worth of an idea (since its value may be simply to spark another idea) (LC)
- during brainstorm phase, use neutral responses, avoid judgments (Note: corrective feedback is not appropriate; positive feedback, if used, should be consistent to all participants) (FB)
- be generous with wait time after asking questions (EV)
- ask clarification questions if necessary (EV)
- record comments (*e.g.*, on whiteboard, flip chart, paper) using telegraphic verbatim transcription (aids memory for further discussion, conveys respect for opinions) (LC)
- avoid paraphrase (when paraphrasing is used, check on accuracy of interpretation) (LC)

(4) Case Discussion – Definition: Group discussion of a case that illustrates the content

Educational Purposes:

- give participants an opportunity for practical application of content (UR)
- promotes retention (memorable) (UR)
- check on understanding of content (EV)

Teaching Tips:

- stimulate active learning with questions (UR)
- encourage participation (LC)
- give feedback (both positive and corrective) (FB)
- paraphrase to generate discussion (LC)
- admit your own limitations (LC)

(5) Role Play Exercises – Definition: Group problem-solving method through

- initial enactment of proposals (taking on roles),
- participant reactions to enactments (discussion),
- observer reactions to enactments (discussion),
- exploration of alternatives (discussion/further enactments),
- drawing conclusions/generalizations, leading to higher level decision making

Assumptions:

- individuals can grow in capacity to deal with problems intelligently, if permitted to make own decisions and learn from own mistakes
- enactments are neither good nor bad, merely actor's best available
- behavior changes with insight through a 3-step change process of (1) unfreezing automatic behaviors, (2) changing, and (3) refreezing new behaviors

Applications:

- Skills training
- Therapy
- Improving interpersonal relations
- Improving understanding of social problems
- Training awareness of others' feelings
- Problem solving

Optional Methods for Role Play Exercises:

- single-group or 'fish-bowl': 1 dyad or small group as players, others observe; debrief in large group
- multiple-group: several dyads role play independently (or triads w/observer), options for serial or independent debriefing
- demonstration: with teacher in role
- re-enactment with players in same roles vs. role reversal

Guidelines for Facilitating ELC Role Plays:

(a) Set up:

- Set tone: Non-threatening environment to practice behaviors related to the topic
- State goals: Skills practice, increase awareness of own behaviors and their effects, increase versatility
- Set time limit: Role play runs for 3 minutes, at which time teacher will stop it
- Describe context/purpose of role play: "This scene takes place in XX setting and there are roles for XX#'s of people including, *e.g.*, physician/patient or attending/resident. The goal is to practice XX." Note: Remind them to refer to relevant handouts.
- Assign roles: Options: (1) ask for volunteers, (2) assign randomly by turning role instruction sheets upside down and distributing
Note: Can ask OBSERVERS to think about consequences of behaviors demonstrated and alternative approaches.

(b) Enactment:

Goal: Portray scenario as authentically and spontaneously as possible

Note: It can help the teacher to take notes on relevant behaviors

(c) Debriefing:

- Ask General Questions to blow off steam re: any discomfort
Options: How did it feel to be in the role play?
 How did it feel to play the physician?
 How did it feel to play the patient?
- Ask role players to share role instructions with group: ALWAYS START WITH 'PHYSICIAN' to allow the most vulnerable player to explain basis for behaviors
- Establish criteria for debriefing: Related to seminar content (*i.e.*, knowledge, skills, attitudes specific to the module)
Note: Remind them again to have relevant handouts in front of them.
- Ask specific questions:
Purpose: To explore the various behaviors relevant to the role play topic (*i.e.*, expression of knowledge, attitudes, skills) and generate alternative approaches.
SUGGESTED CYCLE of questions that can be asked about each behavior of the 'physician' under focus before moving on to discuss another behavior:
 What was your goal?
 What did you do?
 Was it effective?
 What else could you try?

NOTE: Teacher can refer to notes or memory of specific behaviors from the role play relevant to the role play focus. In anticipation of the question series, the teacher can remind role players, when you said "XX"...

(d) Action Plan:

- Bring closure: summarize comments or ask key player to summarize
- Ask 'Physician' what he/she would do differently if given chance to repeat role play

(6) Setting Personal Goals for Clinical Practice and Teaching – Definition: Participants formulate and share personal goals for behavior change related to content.

Educational Purposes:

- help participants identify specific plans (CG) (increases likelihood of implementation)
- sharing goals generates more ideas from colleagues (LC, UR)
- allows teacher to assess impact of the training (EV)

Teaching Tips:

- ask how they will do it (“how would an observer know you did it?”) (CG, EV)
- can ask why they chose this goal (CG, EV)
- can ask how difficult this change will be for them (CG)
- can ask follow-up question at subsequent session in seminar series: “What happened when you tried to implement your goals?” (EV)

TEACHING END-OF-LIFE CARE: SPECIAL ISSUES

The reality of death confronts each of us ultimately with what it means to be human. As an area of medical education, the end of life is exceptional in its application to us all, and in the fundamental responses death and dying evokes in each of us. End-of-life care (ELC) is challenging both to learn and to teach. Any end-of-life curriculum must compartmentalize and intellectualize something that basically is not teachable through the medium of written lectures. Developers of these curricula struggle with how to teach the empathy, presence, and wisdom the subject matter requires, along with imparting knowledge and offering training in specific skills. Integrated professional development in palliative care comes through role modeling and clinical experience.

While the Stanford Faculty Development Center's (SFDC) ELC curriculum encourages the teacher to model a goal-oriented, patient-centered attitude, it is not able to provide learners with what they need most: experience in the field. Ideally, practice will occur in real life under appropriate supervision as for other medical skills. If a curriculum can equip learners with a frame of reference that raises their sensitivity to the issues involved in ELC, and helps them avoid gross errors, this is probably the best we can hope for. This section addresses a number of particular challenges that have arisen as we learned more about medical teaching when the topic is death and dying.

Self Exposure of Learners

Because of the experiential, interactive nature of the curriculum, learners are asked at times to disclose personal experiences that may raise issues of vulnerability. For that reason it is essential to establish **ground rules of safety** at the outset of the group's work together, and to insure that these are honored throughout the seminar(s). We ask learners to agree to the following:

- The stories we share stay in this room. Information about a person belongs to that person, and is not discussed among others without his/her permission.
- There is no such thing as a 'stupid' question. It is difficult to process information when one is wondering about a point that wasn't clear. If a question occurs to one member of the group, he or she is probably not the only person wondering about it. It would do the group a favor to bring the question out into the open.
- To the learner: Honor your own comfort level. When working with very personal material, give yourself permission to abstain.

The content of the ELC curriculum raises several issues that are highly personal. We found that as topics for teaching, strong opinion, self reflection, and spirituality in particular are more personal and potentially more risky to address than many content areas of medical education. Although we make use of small-group discussion, role play, and other interactive, experiential forms of learning, we believe it is not fair to impose certain activities on learners. In ELC education, whether the learners are self-selected or required to attend, they need a safety zone regarding volunteering personal material.

To address this issue, we added the concept of a 'cushion.' When a learner exposes him or herself in the expression of personal material, the teacher can 'cushion' this exposure and keep the learning climate safe by focusing on the larger perspective the story illustrates, and commenting that, whatever this learner's experience, he or she is not alone.

Self Disclosure by the Teacher in the Service of Learning

Throughout this curriculum the teacher is encouraged to draw on his or her own experience as a teaching tool. This serves several functions. In teaching people who have varying levels of knowledge of and/or experience with ELC, you can set a positive learning climate by avoiding being seen as the 'expert.'

Through admission of one's own limitations, a teacher can encourage non-defensiveness in the group, whether the learners are relatively inexperienced or seasoned clinicians. By definition we cannot know what we do not know. The teacher who relates his or her own past insensitivity to an issue may encourage learners to consider their own knowledge or skill deficits with compassion and curiosity. Acknowledging one's own current shortcomings about a given topic models humility and the reality that there is always more to learn.

A word of caution about teacher self disclosure is in order, however. In relating a personal experience or opinion, it is crucial that the teacher be aware of his or her motivation and intention in doing so. What is the teaching goal in sharing this opinion or story? If unable to articulate this clearly and convincingly, one runs the risk of unwittingly undermining intended teaching goals by using the forum of the seminar to process one's own unresolved issues. If the goal is to facilitate the learners' relationship to the content, telling your story could be an opening for them to reflect upon theirs.

Encountering Strong Opinions

Strong opinions frequently arise in EOL care discussions. Teaching ELC brings up some educational considerations related to strong opinions. On the one hand they can be energizing, and on the other they can block new learning. Strong opinions can be socially divisive in a group, or they can be a source of cohesion – which may lead to in-group/out-group behavior. When strong opinions come up in the seminars, it can be very helpful to invite learners to express their opinions and state respect for divergent opinions.

Use of Humor in ELC Teaching

Humor is a powerful potential de-stressor, but it must be used with great care when dealing with sensitive matters. Physicians have historically resorted to 'gallows humor' as a coping response when faced with anxiety-producing realities in medical training and practice. You may notice, when teaching topics such as pronouncing death, that learners may make insensitive humorous remarks. An understanding tolerance, coupled with calm direction into the reality of the topic, will serve the teacher well in such situation.

Take care when using humor as a teaching tool, due to the potential for misunderstanding and hurt feelings when discussing life and death issues. If you find yourself with your foot in your mouth, it will probably always help to non-defensively inquire as to the unintended impact of your remark, and to explain that was not what you intended.

Cultural Sensitivity

Culture is a dynamic process, involving much more than ethnicity and 'cook-book' lists. Skills can be developed to help the clinician deal with a variety of cross-cultural issues. In general, EOL communication requires sensitivity and skill. The level of complexity increases when we consider differing backgrounds of the stakeholders. These are some of the challenges in teaching this subject:

- Dying patients and families often depend upon assistance from others of different backgrounds
- Language differences present enormous challenges to communication
- There is prejudice and mistrust based on history

Starting with learners' experiences makes discussion of these issues immediate and real.

Planning to Teach End-of-Life Care

As you plan to teach one or more of these seminars, take a few moments to consider your educational goals, and the potential obstacles that might arise, relative to your intended group of learners. These may be quite different depending upon whether you plan to teach residents or faculty. In reviewing the

curriculum prior to teaching, it may be helpful to focus on the specific attitude, knowledge and skills objectives you have for the learners in any given section of the material. Clinicians with ELC experience may benefit from attention to strategies for teaching material that they may already have mastered.

A Brief Teaching Point on the Use of Slides

Learning is more likely if participants struggle in some way with what is on the slides. Especially when there are more than 3-4 points on a slide, you need to find ways to quickly highlight what might be unfamiliar or challenging to the learners, such as:

- “How might you give an advance alert?”
- “What do you think a dying person might hope for?”
- “What on this list is surprising to you?”
- “Which of these strategies do you tend not to use?”

Teacher’s Self-Debriefing

Self reflection following a teaching session can provide you with useful learning and help you target your teaching objectives in the future.

- What were your goals for yourself and the learners, and how well do you think they were met?
- Is there anything you would want to do differently?

The Rewards of Teaching End-of-Life Care

Those of you who have already taught ELC are most likely aware of how rewarding this can be. The cultural taboo against discussing death, even (or particularly) in the medical world, has required considerable personal and collective energy to maintain. When this most basic reality of existence is brought to light, professionals and laypeople alike often feel a tremendous sense of release, relief, and reconnection to what is most important to them. Physicians enter the practice of medicine with a powerful desire to help their fellow human beings. There is probably no greater satisfaction than the basic and profound ability to help another person have a more peaceful death – a time when it might have been thought there was nothing more to be done. In teaching end-of-life care, you are participating in one of the great movements of the 21st century, addressing and improving the experience of dying, for us all.

End-of-Life Care Curriculum for Medical Teachers

TOOLS FOR TEACHING

MODULE 1: OVERVIEW and DEATH & DYING IN THE U.S.A.

Companion to Module 1 PowerPoint Presentation

James Hallenbeck, MD

Sara Katz, PhD

Georgette Stratos, PhD

END-OF-LIFE CARE CURRICULUM
Module 1: Overview and Death & Dying in the U.S.A.
Table of Contents

Title and credits

Teaching tips

- Overview to the ELC Course
- Icebreaker
- Self-Rating Exercise
- Introduction to Module 1
- Attitude Objectives
- Knowledge Objectives
- Skill Objectives
- Module Walk-Through

Handouts

- 1.1 Module Content and Self-Rating Exercise
- 1.2 Outline
- 1.3 Significant Events of the Last 48 Hours
- 1.4 Bibliography
(Provide 3x5 Cards for Goals)

TEACHING TIPS

Overview of the Entire End-of-Life Care Curriculum

James Hallenbeck, MD, Sara Katz, PhD, Georgette Stratos, PhD

The Overview provides an introductory frame to the entire Stanford End-of-Life Care (ELC) curriculum, as well as the introduction to Module I. These Teaching Tips will be of use to you whether you plan to teach the entire series, one module, or a smaller segment of the curriculum. If you are teaching a stand-alone seminar, you may wish to omit the Self-Rating Exercise, which is used at the beginning of the curriculum and again at the end. The Overview should take about five minutes to run through. The objective is to establish a positive learning climate where participants will be stimulated, encouraged to participate, respected, and comfortable admitting their limitations. Learners quickly come to understand that their active involvement is essential. While they become acquainted with the curriculum and the teacher, the teacher learns something about their current knowledge base, skills and attitudes. The Overview begins with introductions and proceeds to a question about how the learners think medical educators are doing in the provision of ELC. Modules 2-7 follow the general format of introducing the topic with a brief ‘icebreaker.’ This gets learners involved with the material, and ‘hooks’ their attention.

Icebreaker:

How are we doing in providing care at the end of life? Why start the entire series with a question? An obvious bias underlying the creation of this curriculum is that we believe we are *not* doing a very good job at the end of life. However, this is *our* bias as the developers. Do the learners share in this assessment? To the extent they agree and can testify to deficiencies, we have **buy-in** for learning. Is there someone in the group who thinks there is no problem in end-of-life care, or who communicates no interest in taking the class? Given the growing number of mandates requiring such training, do some participants feel they are there under duress? If so, their resentment will inevitably bubble to the surface. It is better for the teacher to learn these things early on. Demonstrating respect for opinions and feelings, even if they differ from the bias guiding the curriculum, can help create a positive learning climate. For example, if a learner said, “Frankly, this has nothing to do with my job. I am just here because my chairman told me I had to attend,” one could express sympathy for having to attend a seminar in which he or she has no interest. We can appreciate their willingness to share a different opinion, and use this as a model in which differences of opinion are welcome. We can tell the ‘reluctant learner’ we will want to check in during the seminar(s) to see how he or she is doing and if any changes occur. When treated with collegial respect, the vocal skeptic can play an important role in the group process, giving voice to questions others may share, and contributing to the **impetus for learning** in a positive way.

Self-Rating Exercise:

A self-rating exercise follows in which learners assess their current level of competence (knowledge, skills, and attitudes) and confidence to teach the topics of the curriculum. When teaching the entire series, administer this exercise at the beginning of the first module and the end of the last one. The goal of this exercise is not research, but self-assessment and buy-in.

When participants have completed their self-ratings on the handout, take a quick poll by asking for the numbers they have given themselves in each of the module content areas. Record these in some way. If you are using overheads, have the overhead in a transparent protector so you can tally directly on it with a felt-tip marker. If using slides, you can project the slide onto a whiteboard and fill in the blanks with a

marker. In addition, write the tally on one of the Self-Rating handouts, and record the date. Save these ratings for review in the final module.

Review with the group any trends that emerge in the self-ratings of the group. Note that participants' confidence to teach the material is usually lower than their ratings of their knowledge, skills, and attitudes. Even with a group of committed people, there may be considerable discrepancies in experience and confidence to teach various ELC topics.

MODULE 1

James Hallenbeck, MD, Sara Katz, PhD, Georgette Stratos, PhD

Introduction:

Continuing from the Overview into Module 1, the teacher begins to identify learners who enjoy active participation, those who may tend to dominate discussions, and quieter learners who will benefit from being encouraged to contribute to the group. To whom is one attracted as an ally? Do any learners seem to present special challenges? Given the highly interactive nature of the course, getting to know one another and establishing a positive learning climate is a central goal here.

The introduction to the topic of end-of-life care begins by presenting ‘macroscopic’ and ‘microscopic’ views of death and dying. It can be challenging for the teacher to change focus from a high altitude perspective, addressing historic changes in how we die, and nationwide demographics and economics, to very intimate considerations of dying in the individual. This approach is intentional, and serves a number of purposes. We believe that the end of life cannot seriously be addressed without some appreciation for the scope of the issues involved at societal levels. Evidence shows massive problems in our health care system related to the care of the dying. As we come to understand this, a very basic question arises, which underlies the entire course: Why are we doing such a poor job providing care at the end-of-life?

Can it be that death and dying are unavoidably horrible? In our opinion death and dying are very sad and involve some degree of inherent difficulty and suffering, but we prefer a more optimistic answer. We believe that care for the dying has been lacking, not so much because of something inherently dreadful about death, but because the health care system has poorly adapted to the needs of the dying. It may be tempting to blame clinicians, especially doctors, for the problem. Again, we take the optimistic position that in fact most clinicians (including doctors) went into medicine with the straightforward and honorable goal of helping people. That is, we believe clinicians *want* to provide good care, but that for a whole host of reasons, this has become difficult to do.

In this module and throughout this course, we wish to encourage the development of an **impetus for learning**. Encouraging motivation for further knowledge and skill development in the field is a key attitude objective for the course. However, it might be easy for a learner who is beginning to acknowledge the magnitude of the problem, to take the news as personal criticism. Should this happen, quite contrary to the teacher’s intent, the learner will be ‘de-motivated,’ perceiving new information only as further evidence of being a bad clinician. While we are frank in this course in identifying deficiencies in care, we also believe it is most important to ‘appeal to the good’ in the learner. That is, our intention is not to induce personal guilt about the current state of affairs, but to help learners connect more deeply with their natural caring and compassion, that part of themselves that inspired them to become healers in the first place.

Palliative care educators have developed a technique to address this dilemma. To help nail home the point that the problem is the system of care (including the educational system), and not in the individual, many palliative care teachers pepper their presentations and sessions with concrete examples of self disclosure. The introductory plenary tape for the EPEC course (Educating Physicians about End-of-life Care – <http://www.epec.net>) is a series of confessions by clinicians, many of whom are EPEC faculty leaders. These clinicians make the point that in the past they were ignorant of how best to provide good care, because of deficiencies in training: “We just did not know any better.” This message, which must come from the heart, stresses that training is required in ELC, not to make up for some personal deficiency in the learner, but because none of us was adequately trained in the past. We require

remedial work.

While discussing demographics and economics is important in getting a sense of the ‘big picture,’ this is fairly dry stuff for many learners. People vary dramatically in how they respond to the demographic data. While many will find this ‘background information’ somewhat boring, some will become very excited by it. In part to balance this, the module subsequently zooms right in, making death very personal. In fact an exercise is done in which learners are encouraged to share their fantasies about how they would like to die. The end of the module brings the focus back to that which is most important – care of the dying person and that person’s family in a section on care of the actively dying patient.

Beyond providing an overview, this first module tries to set the stage for the modules that follow. A foundation is established upon which subsequent modules will build. The teacher should look for opportunities to highlight a topic that will be discussed in greater depth in a later module. For example, the importance of good symptom management and effective communication are demonstrated in the discussion of the last 48 hours. The goal is to whet learners’ appetites for what will follow.

Attitude Objectives:

The objectives below are not written in the stylized manner that has become a tradition in many presentations. “By the end of this session the learner will be able to...” These stylized objectives (which appear in the modules themselves) are useful to learners in helping them organize what they are supposed to learn in a session. Here we will discuss objectives more freely. This approach has advantages, in allowing us to discuss both *overt* objectives (which are communicated to learners) and *covert* objectives (underlying objectives that we wish to address more in the process of the session). The stylized approach is also limited in that it usually addresses only what is to be accomplished *in that session*. Some of the most important objectives relate to stimulating self-directed learning outside of the session. Quite often, it would be fairer to state, “By the end of this seminar, you may not yet be able to do X, Y or Z competently, but you may be stimulated to think more, read more or practice these skills later on your own.”

Knowledge and skills objectives for the modules are relatively straightforward. In the Teaching Tips we invite the teacher to consider the special challenges associated with attitude objectives. Many attitude objectives, in this and other modules, are implicit. By definition, attitude objectives start with the hypothesis that certain assumptions in learners need to be shifted or changed. Thus, attitude objectives in these Teaching Tips contain two parts: an assessment of the problem with the current attitude and a desired outcome. This level of understanding is important background for the teacher.

One objective is for learners to develop attitudes that will result in their paying more attention to a topic and to improving their knowledge and skills in this area in the future. In listing presumed and desired attitudes, we do not assume that all learners have the undesirable attitude. However, in designing this curriculum it was assumed that such attitudes were widespread and important enough to be addressed. In the process of evaluating learners during a session, the teacher may get an idea as to the extent and prevalence of presumed attitudes. Also, learners can be encouraged to think of potential attitude barriers in the people they might teach.

In this first module, the attitude objectives listed below serve in part as global attitude objectives for the entire course.

PRESUMED ATTITUDE	DESIRED ATTITUDE
Dying and care for the dying is a minor concern in health care.	Death and dying are universal experiences affecting everyone, with profound personal and societal impact.
I have cared for a number of dying patients over the years. So, I have achieved reasonable competence in this area.	While experience is invaluable, it is usually inadequate in developing needed competencies. Given the historic neglect of training in this area, remedial training is required.
Care for the dying is not a particularly important part of my job as a clinician.	Care for the dying has strongly influenced my work as a clinician and will likely affect my work in the future.
Dying represents an unfortunate failure of our medical system to provide cure.	How we die has changed radically in the last 100 years. Successes in health care have <i>created</i> new ways of dying, to which we must adapt.
Dying is sad, but just happens when there is nothing else that we can do.	Dying is a dynamic process. While sad, there is a great deal clinicians can do to <i>improve</i> care.
What is most important in caring for the dying is being a sensitive clinician.	While sensitivity is important, specific competencies in terms of knowledge and skills must also be acquired and utilized.
Dying is something that happens to other people.	Dying is very personal and will happen for us all.
Dying is something that people undergo passively.	For most people, dying is an active process of engaging with other people and the world. Individuals have their own styles of dying, and goals they would like to accomplish in dying, which must be considered in providing care.

Knowledge Objectives:

Knowledge of:

- Changes in how people die in modern times
- Demographics and economics associated with end-of-life care
- Dying trajectories and basics of prognostication
- Physical and psychological changes of active dying

Skill Objectives:

Skill in:

- Coaching of family during active dying
- Adjusting care (using a physician ‘check-list’) when a patient enters the active dying phase

Module Walk-Through:

After the icebreaker in the Overview, learning objectives and the agenda for Module 1 are introduced. These should be displayed and read with a minimum of commentary. A common mistake is to begin teaching from these slides, when their sole purpose is to orient people to what is to come. You will note that the objectives listed on the slide are far more basic than the more detailed attitude, knowledge and skill objectives outlined above.

Who Dies Where, and How

After these orienting slides, the module proper begins with a ‘mini-didactic’ (*i.e.* lecture), which outlines changes in how we die in terms of cause and final venue of death. This information helps learners understand that radical changes have occurred in how we die. One of the reasons we are doing a poor job at end-of-life care is because the very nature of dying has changed and our systems of care are having trouble catching up with such change.

Basic demographic and economic information is then presented. The intent in this should be obvious; many people die each year (and everybody dies eventually). The economic and social impact of dying on our society and on individuals is huge. I think one of the most important ‘facts’ presented in the entire course is the statement that approximately 30% of Americans are impoverished through dying.

Most of us have trouble relating to millions of deaths or billions of dollars. A challenge for the teacher is to engage the learner with this information and make it more personal. One might involve learners by asking how it might be that 30% of Americans are impoverished? While some of the reasons are listed on slides (increased out-of-pocket expenses, time away from work for the dying person and family), one could ask learners for other reasons. Alternately, one might highlight this fact by asking something like, “Do you think most Americans know they have a 1 in 3 chance of becoming impoverished through the death of a family member? No? Do you think they would be surprised? Are *you* surprised? Do you think there would be more interest in improving end-of-life care in our society if people were aware of this?”

It is often a good idea to balance the presentation of ‘dry’ material like statistics by inviting learners to consider the personal implications of this data for themselves. Sometimes this can be done directly by asking learners how they think the information might relate to their lives or practice. The teacher might model this personal relationship, for example, “When I first read this statistic I was horrified both for me and my family, but also for our society. If something else (like a crash in the stock market) risked this kind of disaster, it would be front-page news. I wondered, why nobody seems to know or care about this?”

Dying Trajectories and Prognosis

The module goes on to a discussion of dying trajectories and prognosis. We have found the concept of dying trajectories is a useful way of organizing a number of complex issues in end-of-life care. While we obviously want to make sure learners know that people die in very different ways, perhaps more important for educational purposes is getting learners to consider the implications of these trajectories. Indeed, introducing the concept becomes a useful and efficient means of ‘advertising’ many of the topics discussed in subsequent modules. Thus, having diagrammed the trajectories, the group is asked to brainstorm the implications of different ones.

Major implications are listed in the module notes. Others are implied, but not so clearly stated.

Prognosis is listed as our “ability to predict who (and when) someone is going to die.” The potential

implications of uncertainty in prognostication are only implied. How does this affect communication and planning for the future? While reimbursement systems are listed, one could do an entire lecture (or series of lectures) on the implications of these trajectories on health care economics. How are grief, hope and suffering related to these trajectories? While dying trajectories demonstrate progressive decline, is growth possible during this time? What opportunities as well as challenges do these trajectories suggest? These and other questions are addressed elsewhere in the course. Here, we mean only to hint at their importance and suggest that this may be a useful way of organizing one's thinking.

Fantasy Death Exercise

Until this point, death and dying have been discussed at a relatively cerebral level – statistics, graphs and concepts. It is time to bring the curriculum closer to home. We do this using an exercise called the 'Fantasy Death.' This exercise asks learners to consider what might be important to themselves when dying. Where is fear and hope? What goals might they have? Where would they like to be, doing what and with whom? Making this a 'fantasy' death provides a safe space to explore these questions. While the question, "How do you want to die?" would be more direct, paradoxically, it might frighten learners into abstraction. They might then speak only of principles such as, "I would like to be comfortable or die with dignity." Within the safe space of a fantasy death, one can push for details. Who would be with you? What do you look like? One can even laugh at the creative scenarios people invent, trying to foil the intrinsic sadness of dying. (For example, a newlywed doctor wanted to die a sudden death, but realized that this would be most painful for her spouse. She 'trumped' this problem by having both of them die in a plane crash, while returning from a wonderful vacation in Hawaii.)

This exercise obviously addresses the attitude objective of acknowledging one's own mortality. Learners quickly see this objective coming. What often surprises them, at the end of the exercise, is when they realize that no one's 'fantasies' included clinicians in their clinical roles. To date, none of these ideal death scenarios has involved a doctor, a nurse, a hospital, a nursing home, or a hospice. The teacher might suggest that this is also true for many patients and families facing real death. The teacher can encourage them to ponder this conundrum. "What does it mean that, like most of my patients, I want nothing to do with the medical system when I die? What does this mean given the fact that this is where most people die – and where I work?" Implied is a common interest between clinicians and the dying. In making a transition out of the fantasy, the teacher can point out that we clinicians are here and involved with real patients dying not because they want us to be a part of their experience, but because most people do not get to die their ideal deaths. People need our help as clinicians, as we will need the help of clinicians in the future. This gives us a certain responsibility to help people move toward their own wishes for how to die. The exercise should also be humbling. It should become clear that, contrary to the way we might like to think of ourselves, we doctors are not the 'stars of the show.' The stars are the patient and significant others in their personal network of relations. At best we are a supporting cast, or perhaps more accurately, stage hands, helping set up the scene so that the real stars can do their work.

Self-Disclosure Exercises

A word about self-disclosure exercises. Palliative care educators have come to understand that self reflection is an incredibly powerful tool for education, particularly relative to attitude objectives. If we can really get in touch with what is or would be important for us as individuals, our ability to empathize and our motivation to change will increase substantially. However, a word of caution is in order. Even at a fantasy level, talking about one's death can be a scary business. At a minimum, it is very, very personal. Some learners will not be able or willing to share this information. Self reflection in these seminars is not psychotherapy, but should have a clear educational objective.

We have created a 'rule' regarding self disclosure: it should always be voluntary. While this should be

obvious, it is easy to be coercive in encouraging self disclosure without even knowing it. If the teacher goes from one individual to the next, the clear expectation is that each learner must take a ‘turn.’ I make a point to say that sharing is entirely voluntary. I never go down a line of learners, implying, ‘Who is next.’ I state that it would be helpful to have a few illustrative examples, of fantasy deaths. While I have no reservations about calling on individuals for participation in other educational activities, I make a distinction when it comes to very personal exposure. Relationships between learners in the group may also be an issue. People may genuinely wish to keep some personal thoughts private. These wishes must be respected. Doing so will enhance the learning climate for the session.

Experiences with the Dying

The Fantasy Death exercise transitions into a discussion of clinicians’ professional and personal experiences in caring for the dying. This too is a ‘self-disclosure’ exercise, so the rule respecting privacy should be followed. Here the teacher makes a transition from the fantasy world of the physician to the real world.

A *great* word of caution here – this topic, while educationally very powerful, is loaded with dynamite. Many clinicians are just bursting to tell a story about dying. While some stories can be inspiring, many clinicians for years have been carrying stories about events that resulted in significant trauma for them personally. Clinicians may believe they made some horrible mistake, perhaps resulting in a death. They may have felt abused by a patient, a family member or another clinician. Control of Session (spending only 15 minutes on this segment) can be difficult. The purpose of the exercise is educational, *not* therapeutic.

If difficult issues emerge, rather than probing deeper, the teacher might generalize to a broader educational point. For example, if a learner stated that he or she felt terrible about some aspect of care delivered, the teacher should be empathetic. The teacher might then raise the broader point that many clinicians have regrets about what they have done in ELC (as elsewhere), perhaps suggesting that we need to establish better support structures for clinicians. In contrast, if learners stay at a cerebral level (as is more common), describing only the ‘facts’ of a case, it is appropriate to probe gently for positive or negative affect associated with this experience. It is reasonable and appropriate to encourage statements such as, “I felt awful, because I had no idea what to do,” or “it was great being able to help someone. That was one of the most important days in my training.”

In most cases, this potentially volatile exercise does not ‘blow up.’ Learners seem very eager to share their experiences. Such sharing enhances bonding in the group and helps set the tone of the seminars. At the end of this exercise, learners are asked to create a list of positive and negative themes to their stories. Drawing these themes from learners’ stories is a powerful way to address the last attitude objective listed above; dying affects clinicians greatly in their roles of clinicians. When patients suffer and die, we too can suffer. When patients do well in their dying and when we can be of help, we can take great satisfaction in our work.

The Last 48 Hours of Life

The final section of the module is on the last 48 hours of life. Here we focus directly on the active dying process. It may seem strange to talk about active dying in the first module of the series, but we hope such a frank discussion grounds the earlier work in the module, which dealt with demographics, fantasies and personal experiences. This provides an opportunity to suggest some skill training. Having built some **impetus for learning**, hopefully, now we can suggest some practical things the clinician can do to assist in the dying process.

The section begins with a discussion of signs of active dying. An implied subtext to this discussion is the question, “Can we really know if a patient has ‘taken a turn’ and is now actively dying?” We cannot always know, but there are learnable skills that can improve one’s ability to predict death over a period of hours to days. Being able to recognize entry into this phase is critical if families are to be notified of the change and effective coaching is to occur.

Data from the now famous SUPPORT study is briefly presented to make the point that available evidence suggests that many people receive poor care, at least in acute care hospitals during this final phase of dying. In contrast a study from a hospice unit is presented, demonstrating that 91.5% of deaths in that setting were judged to be peaceful. Thus, dying need not be terrible. This same study is used to present a list of prevalence rates of common symptoms at the end of life. This list is a convenient way of organizing problems that may arise in the final phase of life. Some people have criticized the criteria for symptoms, as it is not clear how ‘confusion’ (prevalence of 8%) differs or overlaps with ‘restlessness and agitation’ (prevalence of 42%). Other studies report higher rates of confusion or delirium in the last 48 hours of life, and could be substituted for this one.

Educationally, the purpose of this list is to highlight certain key findings that might surprise the learner, such as the high prevalence rate of urinary retention, and the apparent dissociation between noisy, moist breathing (retained respiratory secretions) and dyspnea.

The discussion shifts to common changes in the senses and desires of dying patients in the last days and hours. Here, the module moves beyond a more traditional way of thinking about illness – signs and symptoms – to a model of dying as a dynamic process, one very foreign to the experience of most modern people. We teach that patients tend to lose senses and desires in an orderly fashion. This creates the framework for an important organizing concept; good care in active dying largely involves *coaching* the family and significant others. With the exception of childbirth, coaching is a foreign concept for most medical care. As with birth, most of the time what is happening in active dying is very ‘natural.’ Most patients are doing just fine during this time. Because the experience is unfamiliar to family members, otherwise normal processes can be very scary. Great sadness and grief are often also present and normal. However, families and others often project their distress into the normal changes of dying, which magnifies their worry and distress. Normalizing and advising as to how to respond to these changes helps them stay involved in the process.

Loss of desires and the senses in the dying person tends to be paralleled by an acute grief reaction by the family. When a person can no longer speak, the family experiences a loss of two-way communication. Coaching both instructs families regarding what is normal (or not normal) in active dying, and helps families adapt to the loss. If two-way communication is not possible, one can still speak lovingly to the dying person. If the person is no longer eating or drinking, one can still moisten the lips. While hard evidence is lacking as to the effectiveness of these techniques, our impression is that they provide solace to family members and may facilitate an easier transition from anticipatory grief to bereavement.

Often in the process of this discussion, the group can experience some of the great depth of emotion and spirit found in active dying. This can get rather intense for some learners. Partly as an antidote to this a ‘checklist’ for clinicians is then presented. When things get heavy, a useful coping response is to fall back on discrete tasks. This list is also useful because it is very easy to overlook the obvious, when someone is actively dying. As this course was originally developed for physicians, this is called a ‘physician checklist,’ although the points should be useful for other clinicians as well.

In reality, there is usually a natural transition from care of the actively dying patient into the next phase,

which is the death pronouncement. We have chosen to separate these topics in this course, and put death pronouncement in the module on communication. However, one powerful way to adapt this material is to combine this section on the last 48 hours with teaching about death pronouncement. One could also build in a more detailed discussion of the treatment of some of the symptoms, such as treatment of respiratory secretions, which we placed in the non-pain symptom module. This makes a nice, coherent one-hour session.

Personal Goal Setting

As will become familiar to learners during the course, at the end of the module a few minutes are taken to do ‘goal cards.’ Initially, there may be resistance to doing such cards. When goals are initially written out, often they are rather vague, *e.g.*, “Do a better job caring for dying patients.” Working with learners in the use of goal cards is a distinct educational art. For example, in hearing a goal such as “doing better,” the teacher might praise this intent, but push for a more concrete behavior or action the learner will take. “That’s great! Can you think of something specific you might try to accomplish that?” “Well, I might try coaching the family about the loss of the senses.” The more specific, concrete and behavioral the goal, the greater the chance the learner might actually do it.

Goal cards also are an excellent opportunity to evaluate what learners are getting out of the course, or not. The quiet learner you thought was half asleep may actually have been deep in thought and may come up with the most amazing goal. Another learner may report, “I am going to read up some more on what you talked about, because I have no idea what you meant.” Goal cards provide teachers with great feedback about what is working or not in their teaching.

END-OF-LIFE CARE CURRICULUM

Overview.

Module Content and Self-Rating Exercise

1. Death & Dying in the U.S.A.

Who dies where, how and when
 Patterns of dying and related issues of prognosis
 Implications for physicians
 The last 48 hours – physical and mental changes
 Physician tasks in caring for patients and families

2. Pain Management

Demographics - Pain in the dying
 Barriers to effective pain care
 Assessment of pain
 Non-pharmacological approaches
 Total Pain
 Pharmacological strategies for alleviating pain
 Pain Medications
 Neuropathic pain
 Nociceptive pain
 Non-steroidal anti-inflammatory drugs
 Combination drugs
 Opioids
 Using opioid conversion tables

3. Communicating with Patients & Families

Challenges to EOL communication
 Techniques critical to EOL communication skills
 Communication skills
 Sharing bad news
 Death pronouncement
 Death notification by telephone

4. Making Difficult Decisions

Difficult decisions at the end of life
 Preferences and decision-making
 When conflict arises
 Difficult decisions regarding hastening death
 Strategies for responding to requests to hasten death

5. Non-Pain Symptom Management

Symptom Definition
 Symptom analysis - the patient's perspective
 Nausea and vomiting
 Dyspnea
 Terminal syndrome characterized by retained secretions
 Cachexia/anorexia/asthenia

6. Venues & Systems of Care

Venues for ELC
 Enlisting Resources
 Strategies for system change
 Assessment of home institution
 Examples of local change

7. Psychiatric Issues & Spirituality

Psychiatric aspects of EOL Care
 Depression
 Anxiety
 Delirium: Terminal confusion very close to death
 Grief and bereavement
 Spiritual aspects of care
 Spiritual assessment tool

KNOWLEDGE, SKILLS & ATTITUDES

	1	2	3	4	5
1. Death & Dying in the U.S.A.					
2. Pain Management					
3. Communicating w/ Pts & Families					
4. Making Difficult Decisions					
5. Non-Pain Symptoms					
6. Venues & Systems of Care					
7. Psychiatric Issues/Spirituality					

CONFIDENCE TO TEACH

	1	2	3	4	5

(Self-Rating Scale: 1 = Low to 5 = High)

END-OF-LIFE CARE CURRICULUM

Module 1: Death & Dying in the U.S.A.

Outline

Learning objectives

- Describe where, when and how people die today
- Identify patterns of dying and related issues of prognosis
- Identify characteristics of what a 'good' death might be for different populations and yourself
- Increase your understanding of the events of the last 48 hours of life
- Incorporate this seminar content into your clinical teaching

Who dies: where, when and how

Causes of death 100 years ago vs. today

Epidemiology

Economics

Patterns of dying and related issues of prognosis

The dying trajectory

Steady decline

Sudden death

Other forms of dying

Fantasy death exercise

Themes for a 'good' death

Common scenarios

Social tasks of dying

Implications for physicians

BREAK

Experiences with dying

Stories from the group

Attributes of dying well and problematic dying

The last 48 hours

Trajectory concept review

Signs that suggest active dying

Objectives in discussing the last 48 hours

Background

Physician knowledge deficits

Events of the last 48 hours

Terminal syndrome characterized by retained secretions

Physician checklist

Summary and goals

END-OF-LIFE CARE CURRICULUM
Module 1: Death & Dying in the U.S.A.
Significant Events of the Last 48 Hours

Orderly Loss of the Senses and Desires

Hunger

Basic points:

- Families tend to want to nurture
- A basic way to nurture is to feed
- Families may be distressed if patient doesn't eat
- Distress arises from
 - Inability to nurture
 - Fear that patient is “starving” (suffering)

Coaching:

- Suggest ways to nurture other than through feeding high volume food
 - Tastes of favorite foods (if enjoyed)
 - Puddings, popsicles, etc. may be better tolerated
- The patient who is not hungry is not starving or suffering

Thirst

Basic point:

Dry mouth is misinterpreted as thirst

Coaching:

- Teach that while patients may say they are thirsty, usually they really mean a dry mouth
- If patient is swallowing only a little, this is usually not due to lack of strength, but need to ‘wet the whistle’
- Suggest that families help keep patient’s mouth moist with ice chips or swabs

Speech

Basic points:

- Loss of two-way verbal exchange is a challenge
- Families may really realize that patient is dying at this point
- Difficulty with communication brings up many questions:
 - “Is he in pain?”
 - “Can he hear me?”
 - “How do we know what she is experiencing?”

Coaching:

- Teach that while patient may not be able to speak, there is a good chance that hearing is intact
- Suggest that if family has something to say, to say it
- Verbal reassurance may help patient (thus elicit involvement of patient)

Vision

Basic point:

Patient may appear to stare off in space, as if looking through people (this can be disturbing to family)

Coaching:

- Normalize this for family
- Patient may be seeing people, especially deceased relatives or friends; this is rarely troubling
- Such visions are common (25%) and normal

Hearing and Touch

Basic point:

These appear to be the last senses to go

Knowing this allows families to be involved far into the dying process

Coaching:

Encourage families to speak to and gently touch the patient

Say what needs to be said

The “tasks of dying”: Forgive me, I forgive you, thank you, I love you, goodbye

Terminal Syndrome Characterized by Retained Secretions

The most common end pathway

- Lack of cough
- Multi-system shutdown
- Not always associated with dyspnea
- Vigorous hydration may flood lungs
- Deep suctioning generally ineffective
- Role of IVs and antibiotics is controversial

It differs from pneumonia

Physician Checklist

Treatment

Switch essential medications to non-oral route

Stop unnecessary medications, procedures and monitoring (*e.g.*, “We’ll simplify things a bit and focus just on your Mom.”)

Evaluate for new symptoms

Pain

Dyspnea

Troublesome respiratory secretions

Urinary retention

Agitation

Family

Contact

Engage

Educate – needs help with the changes the patient is going through

Facilitate relationship with dying patient

Console

Patient

Usually doing a very competent job of dying

Yourself

Bear witness: your calming presence is powerful medicine

END-OF-LIFE CARE CURRICULUM

Module 1: Death & Dying in the U.S.A.

Bibliography

- Brim OG, Friedman HE, Levine S & Scotch NA, eds. (1970). *The dying patient*. New York: Russell Sage Foundation. Cited in Institute of Medicine (US) Committee on Care at the End of Life. *Approaching death: Improving care at the end of life*. Washington, D.C. National Academy Press, 1997.
- Chaffee, S. Pediatric palliative care. *Primary Care* 2001; 28:365-90.
- Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *BMJ* 2000; 320:469-73.
- Covinsky KE, Goldman L, Cook EF, et al. The impact of serious illness on patients' families. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *JAMA* 1994; 272:1839-44.
- Cohen LM, Carlson BW, Potter DEB. Health care expenditures in the last 6 months of life. *Health Policy Review*. American Statistical Association Section on Health Policy 1995; 1:13 pages.
- Field MJ, Cassel CK, Institute of Medicine (U.S.). Committee on Care at the End of Life. *Approaching death: improving care at the end of life*. Washington, D.C.: National Academy Press, 1997:xvii, 437.
- Gornick ME, Warren JL, Eggers PW, et al. Thirty years of Medicare: impact on the covered population. *Health Care Financing Review* 1996; 18:179-237.
- Hallenbeck JL, Bergen MR. A medical resident inpatient hospice rotation: experiences with dying and subsequent changes in attitudes and knowledge. *Journal of Palliative Medicine* 1999; 2:197-208.
- Kearney M. Palliative medicine - just another specialty? *Palliative Medicine* 1992; 92:39-46.
- Lichter I, Hunt E. The last 48 hours of life. *Journal of Palliative Care* 1990; 6:7-15.
- Minino, A.M. & Smith, Betty, L. Deaths: Preliminary data for 2000. *National Vital Statistics Report* October 9, 2001; 49:1-40.
- Pan CX, Morrison RS, Meier DE, et al. How prevalent are hospital-based palliative care programs? Status report and future directions. *Journal of Palliative Medicine* 2001; 4:315-24.
- Rosenberg HM, Ventura AM, Maurer JD, L. HR, Freedman MA. Births and deaths: United States, 1995. *Monthly Vital Statistics Report* 1996; 45:1-40.
- SUPPORT. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators [see comments] [published erratum appears in *JAMA* 1996 Apr 24;275(16):1232]. *JAMA* 1995; 274:1591-8.
- Teno JM, Weitzen S, Fennell ML, Mor V. Dying trajectory in the last year of life: does cancer trajectory fit other diseases? *Journal of Palliative Medicine* 2001; 4:457-64.

End-of-Life Care Curriculum for Medical Teachers

TEACHING TIPS

MODULE 2: PAIN MANAGEMENT

Companion to Module 2 PowerPoint Presentation

James Hallenbeck, MD

Sara Katz, PhD

Georgette Stratos, PhD

END-OF-LIFE CARE CURRICULUM

Module 2: Pain Management

Table of Contents

Title and credits

Teaching tips

- Introduction
- Attitude Objectives
- Knowledge Objectives
- Skill Objectives
- Module Walk-Through

Handouts

- 2.1 Case of Mrs. Dolores Long
- 2.2 Outline
- 2.3 Definitions of Addiction, etc.
- 2.4 We are 'Color Blind' to Chronic Pain
- 2.5 NOPQRST
- 2.6 Opioid Conversion
- 2.7 Pain Problem Set
- 2.8 Bibliography
- 2.9 Pain Problem Answer Sheet for Teacher
(Provide 3x5 Cards for Goals)

TEACHING TIPS

Module 2: Pain Management

James Hallenbeck MD, Sara Katz PhD, Georgette Stratos PhD

Introduction:

In one sense this is the most straightforward of the modules. Learners know what pain is and few will debate the importance of pain management. Often, the most overt **impetus for learning** in palliative and end-of-life care relates to pain management. However, it is precisely this straightforwardness that makes this module tricky. Many learners want to fast-forward to technical details, such as how to choose among opioids or use conversion tables. Important as such knowledge and skills are, an overly mechanistic approach risks turning pain into a disease separate from the person. Conversely, teachers may err on the other side, strongly addressing attitude and knowledge objectives, while ignoring practical skill training. It is challenging to balance these objectives in this module. Time management, a challenge for all modules, seems to be particularly difficult here. Some time pressure arises from teacher and learner expectations. Because pain management seems familiar as a topic, people may expect that a two-hour session would be comprehensive. Teachers may try to cram too much into too short a period of time. Learners may push to learn too many facts and techniques. Indeed, a key attitude objective is that pain management is an immense area that cannot simply be mastered in one or two sessions.

Module Objectives:

The learning objectives below are not written in the stylized manner that has become a tradition in many presentations: “By the end of this session the learner will be able to...” We use these in the module to help learners organize what they are supposed to learn in a session. Here, we discuss objectives more freely. This approach allows us to discuss both *overt* and *covert* objectives. The stylized approach is also limited since it usually addresses only what is to be accomplished *in that session*. Some of the most important objectives relate to stimulating self-directed learning outside of the session. Quite often, it would be fairer to state, “By the end of this seminar, you may not be able to do X, Y or Z competently, but you might be stimulated to think and read more or practice certain skills later on your own.”

Many attitude objectives, in this and other modules, are covert. By definition, attitude objectives start with the hypothesis that certain assumptions in learners need to be shifted or changed. More bluntly, we may think some learners have incorrect or even bad attitudes. Thus, attitude objectives usually contain two parts: an assessment of the problem with the current attitude and a suggested change.

For example, in the Pain Module the objective, “Recognize and address barriers to effective end-of-life (EOL) pain care” is in fact based on a combination of barriers external to the individual (such as system barriers) and more covert barriers that might be present in the learners themselves. In listing presumed and desired attitudes, the teacher cannot assume that all learners have the undesirable attitude. Many learners will not. However, in designing this curriculum it was assumed that such attitudes were prevalent and important enough to be addressed. In the process of evaluating learners during a session, the teacher may get some idea as to the extent and prevalence of presumed attitudes.

Attitude Objectives:

Presumed attitude	Desired attitude
Pain management is a relatively insignificant aspect of the practice of medicine.	Greater attention to pain management, manifested in patient assessment and care, and self-directed learning of knowledge and skills.
Reluctance to treat pain, due to its subjective nature, addiction, drug overdose, patient ingratitude and regulatory scrutiny.	Skilled pain management can be one of the most rewarding things one can do as a clinician. We have very effective therapies for the majority of problems we encounter.
Pain management is simple. Most pain management just requires knowing the right drug and dose.	While we do have effective treatments, there is nothing simple about pain. Pain is linked in complicated ways to suffering. Pain management is less a <i>task</i> than a <i>process</i> of engagement with patients and families, utilizing a variety of pharmacologic and non-pharmacologic approaches.

Knowledge Objectives:

Knowledge of:

- The prevalence and extent of under-treated pain in a variety of settings and populations.
- Truth and falsehood in certain common barriers to pain management. For example, regulatory guidelines are true bureaucratic hurdles. The *perception* that opioids used in the treatment of pain are addicting is a major barrier. However, the concern about addiction in pain management is based on a false extrapolation from addicts to pain patients. (Note how meeting this knowledge objective in turn helps with the attitude objective about pain management being problematic.)
- A taxonomy of pain – acute and chronic, nociceptive and neuropathic.
- Basic facts about common pain medications, and core principles for use, following rules of thumb such as ‘pattern matching.’

Skill Objectives:

- Pain assessment, using the NOPQRST acronym and the ‘pattern matching’ concept
- Choice among common pain medications
- Adjustment and change of common medications, especially opioids

Module Walk-Through:

Icebreaker

After introductory remarks, the case of Dolores Long (note pun: dolor means pain in Spanish) is presented as an icebreaker. Having learners read the case and highlight concerns is a way of quickly involving them in the session. The case reveals common problems, from technical points to issues of human relations. Teachers can return to this case during the session to emphasize how topics might

relate to a real-life situation. Thus, many teachers refer to the case throughout the seminar.

By identifying and highlighting the complex issues in an otherwise straightforward case, learners buy into the attitude objective stressing the complexity of good pain management. Learners' attitudes are more likely to shift if *they* make the case for an attitude objective than if the teacher does.

Care must be taken to manage time here. Problems should be identified, but not discussed in any length. This helps build **impetus for learning**. This case is as an *icebreaker*. The learners have not yet been introduced to the objectives and agenda for the session.

Another common error is to begin to teach directly from the learning objectives or agenda. The course begins with background information on pain in the dying. Studies in acute, nursing home, outpatient and pediatric settings demonstrate that poor pain management is endemic in the health care system. The rhetorical question at the end of this segment aims to help learners understand that they have a personal stake in better pain management, for themselves and their families.

Barriers to Care

The next section presents six barriers to care. It begins with a brief brainstorm, which offers another opportunity to evaluate learner's knowledge and perceptions. Based on this evaluation, later material may be modified – emphasizing or de-emphasizing certain points. The organization of the six barriers presented in didactic form provides an opportunity for conveying more basic knowledge. For example, discussing the addiction barrier allows the teacher to define commonly confused terms such as addiction, dependence and tolerance. Note that there is some controversy about the definition of addiction. The definition provided (drug-seeking behavior despite adverse consequences) seems to be generally accepted in the world of palliative care. In going through these barriers the teacher must be sensitive to feedback from learners, both verbal and non-verbal. Do they really buy the argument that addiction is not a major problem in treating pain? Is someone scowling? Does someone ask what the evidence base is for this? One study cited answers this question.

Note that most of the barriers are stated as problems external to the learner, such as regulatory barriers. However, others hint at attitude objectives for the learner. The lack of attention to pain and other end-of-life issues in major medical textbooks, for example, is no fault of the learner. However, we have an *obligation* to compensate for these deficiencies through dedicated training and self-study.

In addressing these attitude objectives it is important not to make learners feel guilty; it is not their fault that their education was deficient. It is often effective to use self disclosure to demonstrate that the teacher's training was similarly deficient. The important thing is to encourage a sense of obligation to compensate for educational barriers. The teacher can similarly model this by talking about how he or she had to work to develop competencies. This helps to establish an alliance with the learners.

Types of Pain

The next section provides some basic vocabulary about pain, *e.g.*, the mistaken tendency to extrapolate from acute to chronic pain. The text creates a metaphor – “we are color-blind to pain.” This metaphor suggests we simply are not “wired” to see chronic pain, and we need to compensate for this disability through the use of pain assessment tools. We believe this is important because there appears to be significant resistance among clinicians to regularly using pain scores and other assessment tools, perhaps on the mistaken belief that they ought to be able to *see* if a patient is in pain.

Pain Assessment

This discussion provides a natural transition to a pain assessment tool. This tool is relatively straightforward. The challenge is creating an opportunity for learners to use it in skill practice. This could be done by briefly discussing how one might interview Dolores Long. It could also be assigned as homework – the learner is to use the acronym in assessing pain in a patient prior to the next session. While the acronym is useful for remembering assessment elements, in practice one must move freely from one ‘letter’ to another, following the patient’s lead. A real conversation might be something like this:

Clinician: On a scale of 0 to 10, how bad is your pain? (**S**=severity)

Patient: About a 5.

Clinician: Do you have more than one pain? (**N**=Number)

Patient: No, it’s just in my back.

Clinician: What helps with the pain? What makes it worse? (**P**=Potentiates/Palliates)

Patient: A warm bath helps. It is really bad at night. (**T** = Timing/Trend) Sometimes I can’t stand it.

Clinician: It sounds like you are having a hard time. How has your life been affected by this pain? (**S**=suffering)

Etc.

Non-Pharmacologic Interventions

The section on non-pharmacologic interventions suggests that there is considerably more to pain management than prescribing medications. Unfortunately, due to time limitations an in-depth discussion of these approaches is not possible.

General Principles for Medicating End-of-Life Pain

As this course was initially tailored for physicians, the second hour focuses on pharmacologic management. First, we provide general principles in selecting appropriate agents. The concept of pattern matching is introduced, to help practitioners in their choice of agents and dosing patterns. A simple rule of thumb is suggested. To the extent serum drug levels overlap the patient’s temporal pain pattern, pain efficacy is maximized and certain side effects minimized. This rule of thumb is particularly applicable to the use of opioids, although it does not apply for many medications used for neuropathic pain.

Case Application

At the end of this section learners apply this new knowledge and skill to the case of Mrs. Long in hypothesizing why her pain might be worse at night. A more subtle point is being made: differential diagnosis is possible for symptoms such as pain. As discussed further in the Non-Pain Symptom Management module, symptoms have traditionally been understood as *clues* to something more important, which is the *disease*. Applying more general differential diagnosis skills to understanding and treating a symptom, as a problem, in and of itself, may be a new concept for some learners.

The remainder of the session focuses on medications for pain. The discussions of neuropathic pain medications and NSAIDs are brief, serving only to highlight key points. The focus in this module is on the use of opioids. Initially, combination medications such as acetaminophen and codeine are discussed, as these are the agents with which learners are most familiar. We also begin with them because their use forms a barrier of sorts, which we call *the combo wall*. Escalation in drug dose is limited by the non-opioid ingredient, acetaminophen or aspirin. While certain of these agents have lower DEA regulatory control, this does not make them safer. A key teaching point is that the combo wall is a barrier only in the mind of the clinician. It is quite easy to prescribe opioids without the acetaminophen or aspirin,

although some states still require triplicate prescriptions.

In discussing stand-alone opioids, many teachers either chose 2-4 representative opioids commonly used in their facility, or ask learners which opioids they wish to consider. Going through all listed opioids can be a bit tedious and overwhelming. The teacher should be prepared with a brief *script* for each opioid, summarizing clear advantages and disadvantages.

Opioid Conversion

The session moves on to a discussion of opioid conversion and adjustment of opioid doses. The key organizing principle in discussing opioid conversion is that it is a *process*, not a *task*. If learners think that the issue is simply finding the ‘right’ equivalent dose on a conversion chart, they are mistaken. While conversion tables may be helpful in giving some rough idea of equivalence, many other factors need to be taken into consideration such as the residual drug dose in the patient, time to peak effect, patient pharmacokinetics and the total drug dose being converted – with special caution when converting high opioid doses to methadone.

Problem Sets

The session ends with handing out problem sets, to encourage learners to practice the skills presented in this module. Teachers may discuss or critique these problem sets outside the course or, at least, briefly discuss them at the beginning of the next module. If modifying this curriculum, it is extremely useful to schedule an additional hour to work through problems together. This enables the teacher to evaluate learner skills and provide feedback.

Personal Goal Setting

It should be very easy for learners to come up with concrete goals for this module. These might include: trying a different drug, working on an opioid conversion, or using the NOPQRST assessment tool. Given the importance of skill practice, the teacher may urge learners to practice skills that have been demonstrated (but not adequately practiced) in this module.

END-OF-LIFE CARE CURRICULUM
Module 2: Pain Management
Case of Mrs. Dolores Long

Mrs. Dolores Long is a 70-year-old widowed African American female who was recently diagnosed with lung carcinoma and metastasis to bone. She is being admitted to the hospital for a round of chemotherapy.

A medical resident performs the admission H&P. Mrs. Long denies symptoms. Physical examination is unremarkable. Mental status exam is significant for flat affect and poor eye contact.

The resident finishes the exam and leaves the room. Mrs. Long's daughter steps outside with the resident and explains that her mother has complained of severe pain and has become sedentary and withdrawn. She has refused the acetaminophen with codeine that was prescribed because she doesn't want to "get hooked" and the pills don't help anyway.

The resident is surprised, as Mrs. Long did not appear to be in pain. He explains that "nothing more can be done" for the pain as strong narcotics, like morphine, might cause her to stop breathing and NSAIDs, like Ibuprofen, could cause GI bleeding; however, psychiatry will be consulted to evaluate her depression.

END-OF-LIFE CARE CURRICULUM

Module 2: Pain Management

Outline

Learning objectives:

- Recognize barriers to effective EOL pain care
- Develop a better understanding of attitudes and beliefs about treating pain
- Improve your knowledge and skills in assessing and treating pain
- Incorporate this seminar content into your clinical teaching

Background – pain in dying

Barriers to effective EOL pain care

Assessment of pain

Key dimensions

Mechanism

Nociceptive

Neuropathic

Timeline

Acute

Chronic

A Tool to Help Assess Pain

NOPQRST

Non-pharmacologic approaches to pain

Total pain

Options

BREAK

Pharmacologic strategies

General principles

Pattern matching

Acute pain

Chronic pain

Pain escalating at night

Pain medications

Neuropathic pain

Nociceptive pain

NSAIDs

Combination drugs

Opioids

Opioid conversion: 24-hour equivalencies

Application exercise and conclusion

Summary and goals

END-OF-LIFE CARE CURRICULUM

Module 2: Pain Management

Definitions

Addiction: Psychological dependence on a drug

Drug-seeking behavior despite adverse consequences.

Tolerance and physical dependence may or may not be present and do not prove psychological dependence

Physical dependence: Development of physical withdrawal reaction upon discontinuation or antagonism of a drug

Tolerance: Need to increase amount of drug to obtain the same effect

Pseudoaddiction: Behavior suggestive of addiction occurring as a result of under-treated pain

END-OF-LIFE CARE CURRICULUM
 Module 2: Pain Management
We are all ‘Color Blind’ to Chronic Pain

	0-2 Little or no pain	3-6 Moderate pain	7-10 Severe pain
Patients’ assessments correlated with those of:			
Nurse	82%	51%	7%
House Officer	66%	26%	21%
Oncology Fellow	70%	29%	27%
Caregiver	79%	37%	13%

END-OF-LIFE CARE CURRICULUM
Module 2: Pain Management
NOPQRST: A Tool to Help Assess Pain

Number of pains

Origin or causes of pain, including patient's view of cause & meaning

Neuropathic: Nerve damage
Nociceptive: Tissue damage

Palliates or Potentiates

What makes the pain better or worse?

Neuropathic: Set off by unusual stimuli – light touch, wind on skin, shaving (trigeminal neuralgia)

Nociceptive: Worse with stress, pressure – responds better to opioids, NSAIDs

Consider psychological, spiritual & cultural factors which may either exacerbate or relieve pain

Quality of the pain

Neuropathic: Electric, burning, tingling, light touch, pins & needles, shooting
Nociceptive: Sharp, dull, stabbing, pressure, ache, throbbing

Radiation pattern

Neuropathic: Radiation in nerve-related pattern
Nociceptive: Occasionally radiates, but no obvious nerve distribution

Severity & Suffering

- Severity does not help differentiate between neuropathic & nociceptive, but is critical in understanding impact on patient
- Important to use a consistent way of recording
- There are many different scales
- 0-10 Visual Analogue Scale use is recommended
- Studies have demonstrated reliability
- Most people communicate through a pain scale at least what they would like us to do:
 - 1-3 tolerable
 - 4-6 change therapy soon
 - 7-10 emergency - change therapy now
- Where is pain relief on the scale?
- There may be considerable variation between individuals
- Important to ask if pain relief is adequate or not
- Suffering often results from pain, but they are not the same
- Suffering = “A state of severe distress associated with events that threaten the intactness of the person” (Cassell, 1982)
- Blends past experiences and anticipation of future
- How does the pain affect the person?
- Changes in activities, sleep, movement
- Changes in mood and thoughts

Timing and Trend

Timing: When the pain occurs during the day, during certain activities

Trend: Whether a pain is getting better or worse over time

END-OF-LIFE CARE CURRICULUM

Module 2: Pain Management

Opioid Conversion

Opioid	Comments	Advantages relative to other opioids	Disadvantages relative to other opioids
Morphine	<ul style="list-style-type: none"> • Formulation: Long-acting 'wax matrix', short-acting liquid tab • Don't try to crush wax-matrix tab: becomes short-acting & very potent • After getting idea of 24-hour dose go to long-acting • Or start with 15 mg q12h MSContin, Oramorph 	<ul style="list-style-type: none"> • Inexpensive (except for long-acting: MSContin, Oramorph) • Route: PO, PR IV, SC, lingual • Emphasize SC as often more rational than IV • Physicians have most experience with morphine 	<ul style="list-style-type: none"> • Side effects, toxicity in high dose/renal failure (may not be true with other opioids) • Strong first pass effect: 1st dose more potent; levels off over time • Psychological allergy'-True allergy is incredibly rare: Allergy is often confused with expected side effects (Explore this when someone says they're allergic to morphine)
Oxycodone		<ul style="list-style-type: none"> • Good alternative to morphine (although more expensive) • Available PO long-acting (q8-12) or short-acting (q4) • Less CNS alteration than morphine • Useful alternative for patients with "psychological allergy" to morphine 	<ul style="list-style-type: none"> • More expensive than morphine • No parenteral form available in U.S.
Hydromorphone		<ul style="list-style-type: none"> • Available PO, IV, SC • Good alternative to morphine for parenteral use (<i>e.g.</i>, in renal failure or where using high opioid doses subcutaneously) • Mg for mg significantly more potent than morphine [1/5 the oral dose of morphine] • No known toxic metabolites 	<ul style="list-style-type: none"> • Parenteral and long acting forms more expensive

Fentanyl Patch		<ul style="list-style-type: none"> • Nonenteral administration • Change q72h • Steady blood levels 	<ul style="list-style-type: none"> • Local skin problems • Temperature variation: • Absorption relates to skin temperature • Delayed onset and offset (approximately 12-16h) • Poor choice for unstable pain • Cumbersome to titrate (only q72h) • 20% of people need it changed q48h • Expensive
Opioid	Comments	Advantages relative to other opioids	Disadvantages relative to other opioids
Meperidine			<ul style="list-style-type: none"> • Toxic metabolites, especially in renal failure • Neurotoxicity: Seizures • Cannot be given subcutaneously • Not for chronic use or with renal failure
Tramadol	<ul style="list-style-type: none"> • Weak mu receptor binding 	<ul style="list-style-type: none"> • Inhibits re-uptake of serotonin, norepinephrine (its own co-analgesic) 	<ul style="list-style-type: none"> • Expensive • Currently only available in short-acting formulation
Dextropropoxyphene	<ul style="list-style-type: none"> • Methadone derivative • Long half-life 15h • Peak steady state 3-4 days when given q6-8 h 	<ul style="list-style-type: none"> • No obvious advantage in pain management 	<ul style="list-style-type: none"> • Increased toxicity due to metabolite norpropoxyphene

General Principles

- No opioid has a ceiling effect
- Dose to pain relief without side effects
- Give orally when possible
- Subcutaneous administration is basically equivalent to intravenous (and preferable).
- Treat constipation prophylactically
- In converting to new drug use low basal doses and use short-acting doses liberally

END-OF-LIFE CARE CURRICULUM

Module 2: Pain Management

Opioid Pain Problems

1. George is admitted to hospice with bony metastases. He is on acetaminophen with codeine; two tablets every four hours, and DSS 250 mg BID. He has taken occasional ibuprofen, but this has been stopped because of heartburn, although it did help with the pain. He was started on cimetidine for his heartburn. His pain is reported as 8/10. He has been constipated, with his last bowel movement 4 days ago. What suggestions do you have for changing his pain medications and for his constipation?
2. Ms. Smith has been doing well on sustained-release oral morphine 90 mg BID with acetaminophen with oxycodone for breakthrough pain, but now complains of increasing pain. Previously, she was at 4/10 on a pain scale, which was acceptable, but is now at 8/10, despite receiving her acetaminophen with oxycodone. How do you evaluate the patient and what might you change?
3. Sally was previously cheerful with her pain well controlled on controlled-release oxycontin 10 mg BID, but today she tells you to “go away,” when you visit her. She is curled in a ball, facing the wall. Why might she be exhibiting this unusual behavior?
4. Mr. Johnson has been slowly having his opioids increased. Currently, he is on 240 mg of sustained release oral morphine BID and morphine soluble tablets 10 mg q4h PRN pain. The patient has a particularly hard time when his painful wound is being dressed. What change(s) would you recommend?
5. Dan, who has gastric cancer, has a PEG tube in place. He cannot take medication by mouth. His pain has been reasonably controlled with oral morphine 30 mg q4h. You want to start him on a long-acting opioid. What might you choose and at what dose? Why?
6. Mr. Westen, who has done well for several weeks on sustained-release morphine 30 mg BID, began getting confused and sleepy last night. He has been eating very little and is bed ridden. A distant daughter flies in from Outastate, Montana and demands that you stop the morphine, which she thinks is obviously causing the problem. How would you evaluate the patient’s change in status and address the daughter’s concerns?
7. Jeannie is on *sustained*-release morphine 150 mg BID and short-acting morphine 20-40 mg q4h PRN pain with her pain well controlled. Unfortunately, she can no longer swallow the pills. What non-oral drugs would you suggest and in what doses?
8. Mr. Martinez is on a subcutaneous hydromorphone infusion with a basal rate of 10 mg per hour and a PCA of 2 mg per 30 minutes. In the last 12 hours he has used 12 PCA doses, but still has 8/10 pain. The pain has been responsive to hydromorphone in the past:
 - A) When is a subcutaneous pump generally indicated?
 - B) What advantages/disadvantages does a pump have over a fentanyl patch?
 - C) In this case what change in hydromorphone dosing would you suggest?
9. Tim has been taking acetaminophen with oxycodone for pain with some relief, but it is no longer working. You wish to recommend a long-acting agent, such as sustained-release morphine or oxycodone. The patient has heard bad things about morphine and last time he took it after surgery, he

vomited. He also doesn't want to be knocked out. Based on this:

- A) How would you address his fears?
- B) If he could swallow, but couldn't take pills, could you crush the sustained-release morphine or oxycodone and put them in applesauce in order to give him a long-acting agent?
- C) What effects and side effects of morphine or oxycodone relate to a change in dose as compared to effects related to steady state blood levels?

10. If two acetaminophen with codeine #3 tablets equal an analgesic strength of 100 (100%), using a conversion table, how much stronger is (are):

- A) Two tablets of acetaminophen with oxycodone?
- B) 10 mg of oral morphine?
- C) 4 mg of SC morphine?

11. How do 2 tablets of acetaminophen with oxycodone compare to sustained-release oxycodone 10 mg BID in strength in terms of milligrams per hour?

END-OF-LIFE CARE CURRICULUM

Module 2: Pain Management

Bibliography

Anderson R, Saiers JH, Abram S, Schlicht C. Accuracy in equianalgesic dosing: Conversion dilemmas. *Journal of Pain & Symptom Management* 2001; 21:397-406.

Bernabei R, Gambassi G, Lapane K, et al. Management of pain in elderly patients with cancer. SAGE Study Group. Systematic Assessment of Geriatric Drug Use via Epidemiology [see comments] [published erratum appears in *JAMA* 1999 Jan 13; 281(2):136]. *JAMA* 1998; 279:1877-82.

Cassell EJ. The nature of suffering and the goals of medicine. *NEJM* 1982; 306:639-45.

Cleeland CS, Gonin R, Baez L, Loehrer P, Pandya KJ. Pain and treatment of pain in minority patients with cancer. The Eastern Cooperative Oncology Group Minority Outpatient Pain Study. *Annals of Internal Medicine* 1997; 127:813-6.

Ferrell B, Virani R, Grant M, Borneman T. Analysis of content regarding death and bereavement in nursing texts. *Psychooncology* 1999; 8:500-10.

Gray, J. A pain in the neck – and shoulder. *Pain Topics* 1(6) 1977. Cited in Twycross, R. *Pain Relief in Advanced Cancer*. 1994, London: Churchill Livingstone, p111.

Grossman SA, Sheidler VR, Swedeen K, Mucenski J, Piantadosi S. Correlation of patient and caregiver ratings of cancer pain. *Journal of Pain & Symptom Management* 1991; 6:53-7.

Joranson DE, Ryan KM, Gilson AM, Dahl JL. Trends in medical use and abuse of opioid analgesics. *JAMA* 2000; 283:1710-4.

Levy MH. Pharmacologic treatment of cancer pain [see comments]. *NEJM* 1996; 335:1124-32.

McDowell I, Newell C. Pain Measurements. *Measuring health: A guide to rating scales and questionnaires*. Chapter 8. New York: Oxford University Press, 1996:335-46.

Miller KE, Miller MM, Jolley MR. Challenges in pain management at the end of life. *American Family Physician* 2001; 64:1227-34.

Pereira J, Lawlor P, Vigano A, Dorgan M, Bruera E. Equianalgesic dose ratios for opioids: A critical review and proposals for long-term dosing. *Journal of Pain & Symptom Management* 2001; 22:672-87.

Porter J, Jick H. Addiction rare in patients treated with narcotics [letter]. *New England Journal of Medicine* 1980; 302:123.

Rabow MW, Hardie GE, Fair JM, McPhee SJ. End-of-life care content in 50 textbooks from multiple specialties. *JAMA* 2000; 283:771-8.

Ripamonti C, De Conno F, Groff L, et al. Equianalgesic dose/ratio between methadone and other opioid agonists in cancer pain: comparison of two clinical experiences. *Annals of Oncology* 1998; 9:79-83.

Ripamonti C, Groff L, Brunelli C, Polastri D, Stavrakis A, De Conno F. Switching from morphine to oral methadone in treating cancer pain: what is the equianalgesic dose ratio? *Journal of Clinical Oncology* 1998; 16:3216-21.

Saunders CM. The philosophy of terminal care. In: Saunders CM, ed. *The Management of terminal disease*. London: Arnold, 1978:193-202.

SUPPORT. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators [see comments] [published erratum appears in *JAMA* 1996 Apr 24; 275(16):1232]. *JAMA* 1995; 274:1591-8.

Wolfe J, Grier HE, Klar N, et al. Symptoms and suffering at the end of life in children with cancer [see comments]. *New England Journal of Medicine* 2000; 342:326-33.

END-OF-LIFE CARE
Module 2: Pain Management
Opioid Pain Problems Answer Sheet

1. George is admitted to hospice with bony metastases. He is on acetaminophen with codeine; two tablets every four hours, and DSS 250 mg BID. He has taken occasional ibuprofen, but this has been stopped because of heartburn, although it did help with the pain. He was started on cimetidine for his heartburn. His pain is reported as 8/10. He has been constipated, with his last bowel movement 4 days ago. What suggestions do you have for changing his pain medications and for his constipation?

A number of small points to be made here:

- The patient should be on a long-acting opioid, NOT just acetaminophen with codeine. You might start with sustained-release morphine 15-30 mg BID or sustained-release oxycodone 10-20 mg BID.
- Acetaminophen with codeine is often a poor choice for a short-acting drug, as the efficacy varies among patients. If a short-acting agent is needed, acetaminophen with hydrocodone or oxycodone; hydromorphone, morphine or oxycodone are usually better choices.
- Patients with bony metastases often respond well to NSAIDs. Most patients should be on an NSAID. Occasional heartburn is not an adequate reason to stop. Rather, heartburn should be treated with H2 blocker, misoprostol or a pump inhibitor, such as omeprazole. Many patients have an easier time complying with a BID NSAID, like naproxen, as compared to ibuprofen.
- Re: constipation: Check rectum for hard stool, clear existing stool first, then start on senna.

2. Ms. Smith has been doing well on sustained-release oral morphine 90 mg BID with acetaminophen with oxycodone for breakthrough pain, but now complains of increasing pain. Previously, she was at 4/10 on a pain scale, which was acceptable, but is now at 8/10, despite receiving her acetaminophen with oxycodone. How do you evaluate the patient and what might you change?

- Evaluation: Don't assume this is the *same* pain as before. Perhaps her new pain arises from constipation. It wouldn't be appropriate to treat this type of pain with additional opioids. So you need to evaluate to determine if this is a new or old pain. If new, is the pain suggestive of nociceptive or neuropathic pain? Suggest treatment accordingly.
- If the same nociceptive pain but worse, you may recommend increasing the long-acting morphine by at least 25%. So you might recommend increasing the dose to 120 mg BID.
- Acetaminophen with oxycodone provides inadequate analgesia for someone on such a high dose of basal morphine. For chronic pain, the total potential 24h short-acting/breakthrough dose of opioid should equal approximately the 24-hour total basal dose. To calculate correct breakthrough dose:
- Total basal morphine dose: $120 \times 2 = 240$. Short-acting morphine is given q4h or six times per day, so divide this by 6. $240/6 = 40$ mg.
- An appropriate breakthrough dose would be 40 mg PO short-acting morphine (pill or liquid) q4h as needed. (Note this is 3-4X the equivalent dose of acetaminophen with oxycodone. If this much Acetaminophen with oxycodone had been given, acetaminophen toxicity would have occurred.)

3. Sally was previously cheerful with her pain well controlled on controlled-release oxycontin 10 mg BID, but today she tells you to "go away," when you visit her. She is curled in a ball, facing the wall. Why might she be exhibiting this unusual behavior?

Key point: This patient's chronic pain may have increased, which often presents as withdrawal. However other possibilities include depression and even 'normal dying.' These may all overlap. For chronic pain, you need to ask if the person is in pain and if so how bad it is on a visual analogue scale (from 1-10). Depression often overlaps with chronic pain. Depression in dying is not normal. To identify depression *look for 'less'* – are they hopeless, feeling worthless, is their life perceived as being purposeless?

Sometimes patients who are not in pain or depressed may present as she does. Some patients appear to withdraw from everyday life as they die. However, such patients will deny pain and do not show evidence of depression.

4. Mr. Johnson has been slowly having his opioids increased. Currently, he is on 240 mg of sustained-release oral morphine BID and morphine soluble tablets 10 mg q4h PRN pain. The patient has a particularly hard time when his painful wound is being dressed. What change(s) would you recommend?

Again, the short-acting morphine dose is too low relative to the basal dose. See problem 2 above. A minimum correct dose would be 40 mg PO q4h PRN. He may need more than this during an especially painful procedure. (? 60 mg PO). If so, the extra dose should be given approximately 1 hour before undertaking the procedure, for maximum effect.

You might also consider if there is a less painful way to change his wound dressing. For example, alginate dressings need to be changed less often than Wet to Dry NS dressings and are less painful when changed.

5. Dan, who has gastric cancer, has a PEG tube in place. He cannot take medication by mouth. His pain has been reasonably controlled with oral morphine 30 mg q4h. You want to start him on a long-acting opioid. What might you choose and at what dose? Why?

Choices include:

Methadone may be given as a liquid via tube.

Advantage: cheap, liquid. Disadvantage: Long half-life means cannot use in unstable pain. *Good rule of thumb – don't adjust methadone any more rapidly than every three days, to avoid drug dose stacking.*

Calculation for converting to methadone:

- Calculate 24h current drug dose: Morphine 30 X 6 = 180 mg oral morphine
- Use conversion chart to calculate methadone equivalent dose:
- (Old 24h drug) x ratio of (New drug equivalent dose) divided by old drug equivalent dose 180 mg used X 40 mg methadone equivalent divided by 180 mg morphine equivalent = 40 mg.
- The new 24-hour methadone dose is 40 mg. As often given as a BID drug, could order 20 mg BID. (Note this is a somewhat low estimate. If a high conversion value were to be used, say, 180 mg morphine = 60 mg of methadone, the final dose would be 30 mg BID.)

Fentanyl patch: You may also use a fentanyl patch. As per the conversion table, an approximate equianalgesic dose is a 100 mcg/h patch. Advantages: good for stable pain, possibly less associated constipation, avoids use of enteral route entirely (useful if vomiting). Disadvantage: relatively expensive. Drug takes at least 16 hours to kick in and 16 hours to wear off. The dose may fluctuate with patient temperature. *Use only in stable pain situations.*

6. Mr. Westen, who has done well for several weeks on sustained-release morphine 30 mg BID, began getting confused and sleepy last night. He has been eating very little and is bed ridden. A distant daughter flies in from Outastate, Montana and demands that you stop the morphine, which she thinks is obviously causing the problem. How would you evaluate the patient's change in status and address the daughter's concerns?

Two rules of thumb:

- Sometimes it's the morphine.
- Most of the time it's not the morphine.

While opioids can cause confusion and sedation, these side effects occur most commonly with rapid increases in the dose of the drug. Confusion is more common in higher dose ranges (less common at 30 mg BID sustained-release morphine, as in this case). True drug overdose is *rare*. Hints to true overdose are:

- The patient denies any pain.

- The patient acts drunk, not just sleepy
- May be associated with slow breathing and bradycardia.

That Mr. Westin was stable on this dose before makes this unlikely. (Rare causes of overdose on previously stable dose: a) pain otherwise "fixed" as when radiation therapy "cures" a bony metastatic pain, and b) progressive renal failure resulting in drug accumulation due to a prolonged half-life.)

While drug side effects should be evaluated, so should other causes. The most likely cause is progressive disease. Has the patient developed pneumonia or another infection? If a patient deteriorates suddenly when previously well and if not immunocompromised, it is wise to consider correctable causes, such as hypoglycemia or hypercalcemia.

For the daughter – she may be shocked with the change in her Dad. Her demand may arise from this feeling of shock. She likely feels the need to do "something." Often patient explanation and recognition of how hard it must be for her will go a long way. "*It must be hard to see your father like this*". In this case the presentation with a bedridden status, eating less suggests normal dying.

7. Jeannie is on sustained-release morphine 150 mg BID and short-acting morphine 20-40 mg q4h PRN pain with her pain well controlled. Unfortunately, she can no longer swallow the pills. What non-oral drugs would you suggest and in what doses?

The patient described has stable, chronic pain at a moderate opioid dose. A fentanyl patch might work very well here. If started, be sure to "cover" the patient for at least 12 hours, while the fentanyl patch kicks in. Equivalent fentanyl dose: approximately 150 mcg.

Rule of thumb: the fentanyl patch strength in micrograms/h can be estimated to half of the 24h oral morphine dose or equivalent. Thus, if a patient on 150 mg sustained-release morphine BID (total 300 mg) the equivalent fentanyl patch would be 150 mcg/h.

The patient may be able to take morphine elixir, even if unable take pills for breakthrough and pending the fentanyl patch taking effect. In an emergency, sustained-release morphine tablets can be given rectally with approximately 80% absorption. If the pain was unstable or the patient was at a very high dose level, the patient should probably be started on a subcutaneous (or IV if access available) infusion.

8. Mr. Martinez is on a subcutaneous hydromorphone infusion with a basal rate of 10 mg per hour and a PCA of 2 mg per 30 minutes. In the last 12 hours he has used 12 PCA doses, but still has 8/10 pain. The pain has been responsive to hydromorphone in the past.

A) When is a subcutaneous pump generally indicated?

A pump would be indicated for patients unable to use the oral route, where high doses are required and where pain is unstable.

B) What advantages/disadvantages does a pump have over a fentanyl patch?

A pump can be titrated more rapidly up and down as compared to a patch. For patients who are really on high doses a pump would probably work better and might be less expensive. Disadvantage to the pump: a bit of nuisance to set up and "invasive" in that skin is punctured

C) In this case what change in hydromorphone dosing would you suggest? (Assuming it is not a new pain and this pain thought to be hydromorphone responsive)

First, calculate how much you would go up if all PCAs given were basal. Here, as patient got an average of 2 mg PCA q 1 hour, your *minimum* increase would be by 2 mg to 12 mg/h. However, if you did this and didn't use any PCAs, he would still have 8/10 pain, so you should increase a minimum of 25% on top of this. An increase to 15 mg/h would be more appropriate. PCA dose should also be proportionately increased to 7-8 mg q 30 minutes. (Note: while going from 10-15 mg/h hydromorphone may not seem like a big deal, if this were morphine it would be roughly the equivalent of going from 70 mg/h to 105 mg/h IV morphine. While completely appropriate, this would scare many clinicians.)

9. Tim has been taking acetaminophen with oxycodone for pain with some relief, but it is no longer working. You wish to recommend a long-acting agent, such as sustained-release morphine or oxycodone. The patient has heard bad things about morphine and last time he took it after surgery, he vomited. He also doesn't want to be knocked out. Based on this:

A) How would you address his fears?

Fears: tell him these drugs are not particularly sedating or nauseating if given chronically. (Mild sedation/nausea may occur over first couple of days.) If very afraid of morphine, may wish to use sustained-release oxycodone for "psychological allergy."

B) If he could swallow, but couldn't take pills, could you crush the sustained-release morphine or oxycodone and put them in applesauce in order to give him a long-acting agent?

You *could*, but you shouldn't. Crushing sustained-release morphine or oxycodone releases pure, short-acting morphine or oxycodone.

C) What effects and side effects of morphine or oxycodone relate to a change in dose as compared to effects related to steady state blood levels?

Related to change in dose: sedation, nausea, respiratory depression.

Related to steady state level: pain, constipation.

10. If two acetaminophen with codeine #3 tablets equal an analgesic strength of 100 (100%), using a conversion table, how much stronger is (are):

A) Two acetaminophen with oxycodone

Acetaminophen with oxycodone – **about 66% percent stronger** (however, note that 10% of population may not get good response to acetaminophen with codeine #3, due to difficulty converting drug in the liver.)

B) 10 mg of oral morphine?

10 mg oral morphine-**about 11% stronger** if given chronically. If given once, morphine 10 mg PO is actually weaker, due to a strong first-pass effect in the liver (liver lessens availability of morphine when first given).

C) 4 mg of SC morphine?

4 mg SC morphine: **Approximately 33% stronger** than acetaminophen with codeine #3.

Note: 10-15 percent means very little in palliative care. Thus writing orders like, "Give acetaminophen with codeine for mild pain, acetaminophen with oxycodone for severe pain," is illogical.

11. How do 2 tablets of acetaminophen with oxycodone compare to sustained-release oxycodone 10 mg BID in strength in terms of milligrams per hour?

Two tablets of acetaminophen with oxycodone (5 mg oxycodone each tab) contain the same amount of oxycodone as one 10mg sustained-release oxycodone (10 mg). The difference is that the combination form (in addition to having 325 mg of acetaminophen per tablet) releases the oxycodone all at once and the dose lasts approximately four hours, as compared to sustained-release oxycodone, which lasts 12 hours. Thus, per unit time 2 tablets of acetaminophen with oxycodone are 3 times as potent as one 10 mg sustained-release oxycodone pill. It's very hard to overdose someone on 10 mg of sustained-release oxycodone. The acetaminophen with oxycodone is also more likely to cause side effects due to fluctuating opioid levels. The acetaminophen may be a useful co-analgesic. However, as an antipyretic, it may also keep a patient from mounting a fever, which may not be desirable. For patients with chronic pain, if therapy with two tablets of acetaminophen with oxycodone provides inadequate analgesia, there may be a risk of acetaminophen toxicity, if patients take more pills.

End-of-Life Care Curriculum for Medical Teachers

TEACHING TIPS

MODULE 3: COMMUNICATING WITH PATIENTS & FAMILIES

Companion to Module 3 PowerPoint Presentation

James Hallenbeck, MD

Sara Katz, PhD

Georgette Stratos, PhD

END-OF-LIFE CARE CURRICULUM
Module 3: Communicating with Patients & Families
Table of Contents

Title and credits

Teaching tips

- Introduction
- Attitude Objectives
- Knowledge Objectives
- Skill Objectives
- Module Walk-Through

Handouts

- 3.1. Outline
- 3.2. Sharing Bad News Role Play
- 3.3. Death Pronouncement and Death Notification by Telephone
- 3.4. Bibliography

(Provide 3x5 Cards for Goals)

TEACHING TIPS

Module 3: Communication

Introduction:

This module and Module 4, Making Difficult Decisions, focus on communication. It is our strong bias that communication skills are the most important of all skill sets in end-of-life care. Without them it is impossible to effectively address any other concerns or needs that might arise. Effective communication skills also seem to be the most difficult to acquire. Comparatively speaking, it is easy to learn how to adjust pain medications. Developing the high-level communication skills needed in end-of-life care is so difficult that one could say it is the work of a lifetime.

Some learners will come to communication training with a high degree of impetus for learning. They may recognize, upon reflection, that their most demanding clinical challenges involved difficulties in communication in some way. Others may tend to under-appreciate the importance of such skills and/or over-appreciate their own intrinsic competence.

A number of challenges arise in teaching communication. Clinicians will readily admit that they do not know how to do a certain procedure, without previous training. However, because communication is central to our roles as clinicians and as people, some learners may not recognize that the communication skills needed in end-of-life care are in some ways special. The situations in which we must use these skills are very difficult. Often they are emotionally intense and relate to very difficult decisions, with high stakes involved. Patients, families and clinicians must communicate under adverse conditions of illness, sleep deprivation and severe time restraints. A second challenge is that communication skill training tends to be approached as a series of tasks. To some extent this is unavoidable; one must be able to crawl before one can walk or dance. Just as the one-two-three-four of dance instruction, focusing on foot placement, is not really dance, a proscriptive series of listening and speaking tasks is not real communication. The challenge seems to be first to master the basic steps, with the goal of transcending them, eventually finding a more expert and freer expression in actual practice.

Here, we encounter a strong cultural bias. Our biomedical culture tends to value technology and facts more than human relations. What matters most are the disease and the technologic solution for that disease. In highlighting the importance of communication, we should not be surprised to encounter resistance.

Finally, practicing communication skills (as in the role plays used in this module) requires us to reveal ourselves in very personal ways. Communication skills are intricately linked to one's individuality. If they are found wanting, it is easy to think that we have been revealed as inadequate. While the teacher needs to be sensitive to these concerns, he or she must not be daunted by them. It is true most people do not like role plays or other forms of being on display. We must recognize that egos may be exposed or bruised, but given the importance of the topic, we cannot afford not to practice these skills, any more than we could afford not to practice a difficult surgical procedure. This point is reinforced by asking learners to consider how important these skills will be when it is their turn to receive bad news, make a difficult decision or have their loved-one pronounced dead.

Attitude Objectives:

The objectives below are not written in the stylized manner that has become a tradition in many presentations: “By the end of this session the learner will be able to...” Although we do use those more formal statements in the module to help learners organize what they are supposed to learn in a session, here, we discuss objectives more freely. This approach allows us to discuss both overt and covert objectives. The stylized approach is also limited since it usually addresses only what is to be accomplished in that session. Some of the most important objectives relate to stimulating self-directed learning outside of the session. Quite often, it would be fairer to state, “By the end of this seminar, you may not be able to do X, Y or Z competently, but you might be stimulated to think and read more or practice certain skills later on your own.”

Many attitude objectives, in this and other modules, are covert. By definition, attitude objectives start with the hypothesis that certain assumptions in learners need to be shifted or changed. More bluntly, we may think some learners have incorrect or even inappropriate attitudes. Thus, attitude objectives usually contain two parts: an assessment of the problem with the current attitude and a suggested change.

One objective is for learners to develop attitudes that will result in their paying more attention to the topic and improving their knowledge and skills in this area. We do not assume that all learners have undesirable attitudes. However, in designing this curriculum it was assumed that such attitudes were widespread enough to address. In the process of evaluating learners during a session, the teacher may get some idea of the extent and prevalence of barriers to desired attitudes. We also encourage participants to anticipate potential attitude barriers in their learners.

Presumed attitude	Desired attitude
Communication skills are relatively unimportant in medicine.	Communication skills are important in reaching desirable health outcomes.
My current communication skills are sufficient for end-of-life care.	High-level communication skills are especially necessary in end-of-life care.
Practice is unnecessary.	Practice is essential to improving these skills.
My time and ideas are more important than the patient's.	Listening and paying attention to the patient's agenda are important.
The death pronouncement is simply a matter of documentation.	Pronouncing death is a significant event for physicians as well as family members.

Knowledge Objectives:

Relative to attitude and skill objectives, this module is light on hardcore facts.

Knowledge of:

- Facts regarding clinician dominance in communication
- Basic steps in sharing bad news and death pronouncement
- Basic concepts relating to culture and its importance in end-of-life care

Skill Objectives:

Skill in:

- Active listening
- Identifying and addressing cognitive and affective components of communication
- Sharing bad news
- Death pronouncement

Module Walk-Through:

The Importance of Good ELC Communication

After introductory remarks, the teacher is prompted to tell a story highlighting the importance of good communication. Most clinicians have no shortage of possible stories. Speaking from one's own experience is a powerful way to get a point across. However, some thought should go into story selection. Will the learners get the same punch-line that you intend?

Deficits

The identified deficit slide pulls no punches in summarizing studies demonstrating the extent of the problem in patient-physician communication. The guide prompts for yes/no responses. It is equally important to evaluate learners' non-verbal reactions to determine if any learners dispute these findings.

Basic Skills Training

After objective and agenda slides, we immediately launch into skill training. First is identifying and addressing cognitive and affective components of communication. Overtly, clinicians tend only to pay attention to cognitive components. While no discrete exercise is presented to practice distinguishing between cognitive and affective statements, this skill will be incorporated into later role plays and exercises.

It may be helpful in teaching these skills to instruct learners first not to change their methods of communication, but simply to observe what arises in the process of interaction. This is because they may rush too quickly into doing something different, when, in fact, the first step is awareness of what is happening. Thus, the first skill practice may simply be mindfulness. In this case, one can observe both the cognitive and affective components of a request for some therapy like IV fluids. One can observe the tendency to respond to the cognitive component first, while experiencing annoyance (as a personal affect) with a request that implies neglectful care.

The second skill is to clarify ambiguity. This is important in that ambiguity, on the part of clinicians, patients and families, clouds communication, making misunderstandings more likely. However, it is also important to respect ambiguity. Ambiguity may reflect fears, worries or dangers. Some ambiguity is culturally sanctioned and perfectly appropriate. We may use special wording to discuss taboo topics. Usually, the meaning of such culturally sanctioned ambiguity is clear, at least within the culture. For example, there is no lack of clarity in English to the expression, "He passed away." This is just a respectful way of saying that someone has died. The key point here is that if you really do not know what someone means by something, or you think someone does not understand you, you may need to clarify ambiguity.

The third skill is balancing listening with speaking. This skill is best first practiced with mindfulness. Later, one may set a goal of listening more and speaking less. This skill is practiced with a listening and

delay exercise, attending to ambiguity and affective and cognitive components of communication at the same time.

Sharing Bad News

The next skill exercise relates to sharing bad news. This seems to be the most commonly taught communication exercise in palliative and end-of-life care, and there is remarkable agreement among experts about the basic steps involved. Our suggestions differ only in minor ways. We utilize an excellent tape by Dr. David Weissman of the Medical College of Wisconsin in which he models less and more competent ways to share bad news. This raises an important point. Good videotapes are hard to make. Teachers should freely borrow from available curricular material (with proper acknowledgements) in adapting material into their own work. The power in using such trigger tapes is that learners can readily identify poor communication techniques. While it is easy to criticize poor techniques, most learners will not know how to organize steps in effective communication. This makes it much easier for them to accept the suggested steps.

Learners then practice these steps in role plays. The first role play is a fish bowl-style role play conducted by 2 learners in front of the rest of the group. This has the advantage of allowing everyone to see to what extent the steps were followed and whether they seemed effective. However, with this method only one learner actually gets to practice as the ‘physician.’ It also maximizes learner exposure and potential anxiety about doing role plays. An alternative approach is the dyad or triad role play (physician-patient or physician-patient-observer). These allow more learners to practice skills. Indeed, reversing roles in a dyad role play allows everyone to take a turn. This is generally less stressful. The downside is that it is harder to evaluate skill improvement, especially for the teacher, who cannot observe multiple, simultaneous role plays.

Death Pronouncement

The next skill training is the death pronouncement. This curriculum is unusual in including pronouncing death as a discrete skill set. The key point is: this is not so much a bureaucratic task or a matter of ‘diagnosing death,’ as it is a very important ritual acknowledging the end of a person’s life and providing consolation for the immediately bereaved.

Two possible demonstration role plays for practicing death pronouncement are included. The group or the teacher can choose whether or not to have family present at the death pronouncement. We have noticed a tendency for teachers to get creative with these role plays. Dolls, paper cut-outs, rolled up coats, and even people have been used in the role of the deceased. Often, there is a great deal of defensive humor around this role play, as learners connect with the seriousness of the topic at hand. A key to role plays is that while they are artificial in construct, the feelings and thoughts they evoke in participants are very real. Death pronouncement is one of the most serious, and for some, even sacred, duties a physician can perform. Getting in touch with associated feelings can be a heavy experience for learners.

Goal Cards

This module contains many behavioral skills that can be practiced. As always the teacher should work with learners to help them be as specific and behavioral as possible in writing goals. Better than, “I will try to communicate more effectively,” is a statement such as “I will practice listening more than I speak the next time I am in clinic.”

END-OF-LIFE CARE CURRICULUM
Module 3: Communicating with Patients & Families
Outline

Learning objectives

- Heighten your awareness of the importance of effective end-of-life communication
- Increase your end-of-life communication skills in:
 - Listening
 - Sharing bad news
 - Pronouncing death
- Incorporate this seminar content into your clinical teaching

Introduction

Some factors which physicians consider as challenges to general patient-physician communication
Some unique challenges to end-of-life communication

Three techniques critical to ELC communication

Distinguish between cognitive and affective elements of communication and respond appropriately
Clarify ambiguity
Listen in balance with speaking
Skills training

- Delay exercise

Sharing bad news training tape

BREAK

Skills practice sharing bad news

Role play

Death pronouncement

Steps in pronouncing death

Death notification by telephone

Summary and goals

END-OF-LIFE CARE CURRICULUM
Module 3: Communicating with Patients & Families
Sharing Bad News Role Play: Physician Role

An elderly patient presented to the Emergency Room having been found on the floor at home.

You have just diagnosed a new, massive stroke in this previously healthy 65-year-old patient. Your job is to share this bad news with the patient's family member, who was called to come in but does not know what has happened to his/her relative.

Step 1: Prepare

Prepare yourself:

- Get the facts
- Prepare yourself emotionally
- Decide which words and phrases to use
- Practice delivering the news

Prepare the recipients:

- Establish what patient/family already knows, and how much they want to know
- Plan with recipient how information will be conveyed

Prepare the environment:

- Comfortable, private
- Allow for uninterrupted time
- Who else would the recipient like to be present?
- Chairs for all, introduction
- Some physicians tape record the meeting

Step 2: Convey information

- Establish empathic connection
- Give an advance alert
- Convey realistic information in a clear manner
- Observe, respond to cognitive & affective reactions
- Clarify ambiguity
- Restore and catalyze hope

Step 3: Follow up (manage the consequences)

- Set concrete goals
- Connect patient &/or family with support systems
- Arrange follow-up meetings
- Convey commitment & nonabandonment
- Communicate with treatment team

END-OF-LIFE CARE CURRICULUM
Module 3: Communicating with Patients & Families
Sharing Bad News Role Play: Family Member Role

You have just arrived at the Emergency Room, having heard that your 65-year-old parent was found on the floor at home. You have no idea what the problem was. Your parent was previously in good health. You are somewhat anxious and concerned about his/her welfare.

Step 1: Prepare

Prepare yourself:

- Get the facts
- Prepare yourself emotionally
- Decide which words and phrases to use
- Practice delivering the news

Prepare the recipients:

- Establish what patient/family already knows, and how much they want to know
- Plan with recipient how information will be conveyed

Prepare the environment:

- Comfortable, private
- Allow for uninterrupted time
- Who else would the recipient like to be present?
- Chairs for all, introduction
- Some physicians tape record the meeting

Step 2: Convey information

- Establish empathic connection
- Give an advance alert
- Convey realistic information in a clear manner
- Observe, respond to cognitive & affective reactions
- Clarify ambiguity
- Restore and catalyze hope

Step 3: Follow up (manage the consequences)

- Set concrete goals
- Connect patient &/or family with support systems
- Arrange follow-up meetings
- Convey commitment & nonabandonment
- Communicate with treatment team

END-OF-LIFE CARE CURRICULUM
Module 3: Communicating with Patients & Families
Death Pronouncement and Death Notification by Telephone

Death pronouncement

Diagnosing death is relatively straightforward

Technically, you must ‘certify’ that recipient has died

- Feel pulse
- Watch for respirations
- Listen for heartbeat

These tasks are secondary to the role of bearing witness to the end of a human being’s life and consoling the bereaved

- This is one of the most important moments in the lives of survivors
- Physician’s social function is very meaningful here:
 - Acknowledge passing
 - Say goodbye

Suggestions for pronouncing death as a ritual

The concept of ‘ritual’

- A behavior that sustains people as a social function
- Done to satisfy a sense of fitness
- Not performed for technological purposes
 - Behavior can have both technological & ritual function

Find a calm & peaceful place within yourself before going to bedside

If you don’t know the recipient, inquire about:

- The circumstances of the death
- Was it expected? Unexpected? Traumatic? Peaceful?
- The status of family/loved ones

Are they present or not? Was death expected or not? Are they angry or at peace?

If family is present, assess their state of mind & respond accordingly

There are two possibilities, which may pose different skills challenges for the physician:

- ‘Waiting to exhale’ = the family is not yet grieving
 - Do the ritual of pronouncement in order to begin the process of bereavement
 - Then console
 - ‘Huddle’ = family actively grieving
 - Console (join the huddle)
 - Then model saying goodbye with the pronouncement ritual

Pronouncement ritual

- Avoid potentially disrespectful behavior such as examination of pupils or pain test
- Silence: ‘The Pause’
 - There will come a pause, at which point everyone acknowledges what has happened
 - There is value here in silence
 - People have a tendency to hurry past this moment
 - Slow them down: this is an important skill
 - Help them be in this moment
 - It will soon pass and be gone forever
 - Connect the bereaved to support systems
 - This is especially critical for:
 - Traumatic, unexpected, or violent death
 - Death of a child

Survivors are frail & isolated elderly or young children

Death notification by telephone

This is always difficult to do
Rehearsal will help you feel prepared

Suggestions:

- Preface notification with a gentle advance warning
- Allow time for immediate grief reaction
- Suggest they don't have to come in right away
 - Let the reality settle it
 - Take time (avoid accidents)
- Encourage them to be accompanied by a support person
- Provide clear instructions about coming to hospital
 - A contact person to guide them through the experience
- Follow up with a condolence call to the bereaved a few days later
 - This is highly valued by family member

END-OF-LIFE CARE CURRICULUM
Module 3: Communicating with Patients & Families
Bibliography

- Back AL, Curtis JR. Communicating bad news. *Western Journal of Medicine* 2002; 176:177-80.
- Braddock CH, 3rd, Edwards KA, Hasenberg NM, Laidley TL, Levinson W. Informed decision making in outpatient practice: Time to get back to basics [see comments]. *JAMA* 1999; 282:2313-20.
- Buckman R. Breaking bad news: Why is it still so difficult? *British Medical Journal (Clin Res Ed)* 1984; 288:1597-9.
- Buss MK, Marx ES, Sulmasy DP. The preparedness of students to discuss end-of-life issues with patients. *Academic Medicine* 1998; 73:418-22.
- Crawley L, Payne R, Bolden J, Payne T, Washington P, Williams S. Palliative and end-of-life care in the African American community. *JAMA* 2000; 284:2518-21.
- Ford S, Fallowfield L, Lewis S. Can oncologists detect distress in their out-patients and how satisfied are they with their performance during bad news consultations? *British Journal of Cancer* 1994; 70:767-70.
- Parle M, Maguire P, Heaven C. The development of a training model to improve health professionals' skills, self-efficacy and outcome expectancies when communicating with cancer patients. *Social Science & Medicine* 1997; 44:231-40.
- Rabow MW, McPhee SJ. Beyond breaking bad news: How to help patients who suffer. *Western Journal of Medicine* 1999; 171:260-3.
- Suchman AL, Markakis K, Beckman HB, Frankel R. A model of empathic communication in the medical interview [see comments]. *JAMA* 1997; 277:678-82.
- Tulsky JA, Fischer GS, Rose MR, Arnold RM. Opening the black box: How do physicians communicate about advance directives? *Annals of Internal Medicine* 1998; 129:441-9.
- Wear D, Nixon LL. The spirit catches you and you fall down: A Hmong child, her American doctors, and the collision of two cultures. *Academic Medicine* 2001; 76:620-1.

End-of-Life Care Curriculum for Medical Teachers

TEACHING TIPS

MODULE 4: MAKING DIFFICULT DECISIONS

Companion to Module 4 PowerPoint Presentation

James Hallenbeck, MD
Sara Katz, PhD
Georgette Stratos, PhD

END-OF-LIFE CARE CURRICULUM
Module 4: Making Difficult Decisions
Table of Contents

Title and credits

Teaching tips

Introduction
Attitude Objectives
Knowledge Objectives
Skill Objectives
Module Walk-Through

Handouts

4.1 Outline
4.2 It's GOOD to Discuss Patient Preferences
4.3 Role Plays
4.4 Conflict Resolution
4.5 PAS pro/con
4.6 Glossary
4.7 Bibliography
(Provide 3x5 Cards for Goals)

TEACHING TIPS

Module 4: Making Difficult Decisions

Introduction:

In many ways this module is an extension of Module 3 on communication. However, this module focuses on two particular topics – making difficult decisions and responding to requests for a hastened death or assisted suicide. The major attitude objective underlying this module is based on the observation that clinicians too often neglect to take into account patient and family wishes regarding goals of care. The desired attitude is for clinicians to acknowledge the importance of incorporating patient and family goals into care plans.

One difficult decision we faced in drafting this module was whether or not to include a formal section on medical ethics. In the end we decided not to do so, although we believe that the module has strong ethical underpinnings. A number of reasons went into this decision. First, ethics is the least neglected of subject matters in end-of-life care, as reviews of medical education have demonstrated (Billings, 1997). Excellent educational material on ethics is already available through such programs as EPEC (Educating Physicians about End-of-Life Care (<http://www.epec.net>)). Finally, we will admit to a certain bias. Historically, from the 1970s to the early 1990s the major driver for better end-of-life care was the field of medical ethics. However, the effectiveness of this approach has been questioned (Lynn, 2000). We believe the reason is that, too often, medical ethics have been taught in relative isolation from related fields such as communication and anthropology (Hallenbeck, 1999; Hallenbeck, 2001). As a case in point, Teno demonstrated that formal, written advance directives had an impact on the care of only a small number of patients in the now famous SUPPORT study (Teno, 1997). We believe that advance directives are important. However, as long as physicians fail to incorporate patient and family preferences into decision making, directives and other statements of preference will remain relatively insignificant in their impact. Thus, the focus of this module is on developing the attitudes and skills that will result in more clinicians involving patients and families in decision making. We believe this is as much a matter of communication (and culture) as of ethics.

Joanne Lynn in the article cited above asks the question, if not ethics, then what? Her response seems to be that system changes appear to be more important drivers of change in end-of-life care. We agree. If so, how does this module and the topic relate to system change? While certainly much could be done to improve availability of various forms, such as advance directives or do not resuscitate (DNR) forms for home use, we believe that larger system change related to the cultural phenomenon of clinician behavior is worthy of consideration. In this module, participants are encouraged to think about larger system changes.

For example, currently, medical culture and accrediting organizations agree that certain basic information needs to be included in a history and physical (H&P) on admission to an inpatient facility such as vital signs, allergy status, and heart examination. Similarly there is agreement, in principle if not always in practice, that if a patient or family elects a DNR status, appropriate documentation should be included in the medical record about the basis for such an order. However, it is still not a standard of care to include a brief statement of goals of care from the perspective of the patient and family on an admission note. If goals (or plans) are included, they are usually the goals of the clinician. If it were to become standard of care to include such a note and to check for these as a matter of quality assurance, *that* would be a major system change. We realize that such cultural change does not occur all at once. This is an example of the kinds of larger system changes that might get discussed in the module.

In this module, we believe it is important to ask clinicians to reflect on their personal standards. *When* exactly do they believe it is appropriate to discuss and document patient and family goals of care? Is it only when the clinician thinks such questions are warranted, as too often appears to be the current standard of practice? Is it only when certain conditions are met – for example some degree of terminality or serious illness? Or is this a routine inquiry, the depth of which is dictated by the nature of the encounter and circumstances? We hope this module will evoke such self reflection.

The topics of assisted suicide and other forms of hastening death have been much discussed from ethical and legal perspectives. It is safe to say that much controversy still remains. We do not attempt to resolve this debate here. Rather, we have chosen to focus on one aspect of the issue that respected leaders on both sides of the debate seem to agree upon – sensitivity and skill must be used in responding to requests and inquiries.

Attitude Objectives:

The attitude, knowledge and skill objectives below are not written in the stylized manner that has become a tradition in many presentations: “By the end of this session the learner will be able to...” These stylized objectives are useful to learners in helping them organize what they are supposed to learn in a session. Here, we discuss objectives more freely. This approach allows us to discuss both *overt* and *covert* objectives. The stylized approach is also limited since it usually addresses only what is to be accomplished *in that session*. Some of the most important objectives relate to stimulating self-directed learning outside of the session. Quite often, it would be fairer to state, “By the end of this seminar, you will *not* be able to do X, Y or Z competently, but you may be stimulated to think and read more or practice certain skills later on your own.”

Many attitude objectives, in this and other modules, are covert. By definition, attitude objectives start with the hypothesis that certain assumptions in learners need to be shifted or changed. More bluntly, we may think some learners have incorrect or even bad attitudes. Thus, attitude objectives usually contain two parts: an assessment of the problem with the current attitude and a suggested change.

One objective is for learners to develop attitudes that will result in their paying more attention to the topic and improving their knowledge and skills in this area. We do not assume that all learners have these presumed and undesirable attitudes. However, in designing this curriculum it was assumed that such attitudes were widespread enough to address. In the process of evaluating learners during a session, the teacher may get some idea of the extent and prevalence of barriers to desired attitudes. We also encourage participants to anticipate potential attitude barriers in their learners.

Presumed attitude	Desired attitude
Discussion and documentation of patient and family goals of care is not a routine clinician task.	Discussion and documentation of goals of care are a central task for clinicians.
The only important goal of care for patients at the end of life relates to their resuscitation status – FULL CODE or DNR.	Numerous important goal of care issues arise in end-of-life care. While some goals are very medical, <i>e.g.</i> , the use of certain therapies, many are less medical and more personal in nature.

Physician-assisted suicide (PAS) and other forms of hastened death are simply ethical and legal concerns.	Requests for a hastened death require skilled communication, regardless of one's personal stance or any legal stance.
As PAS is illegal in all but one state, clinicians do not need to be concerned with this topic.	Many patients and families facing an intolerable end-of-life situation will consider the possibility of a hastened death. Sensitivity and skill in responding to their concerns and inquiries are essential.

Knowledge Objectives:

Knowledge of:

- Steps in the GOOD acronym (Goals – Options – Opinions – Documentation)
- Definitions related to hastened death
- Common arguments for and against physician-assisted suicide (PAS)

Skill Objectives:

Skill in:

- Using the Good acronym to address patient and family goals of care
- The use of strategies to respond to conflict
- Responding to requests and inquiries about a possible hastened death

Module Walk-Through:

Case Examples

After introductory remarks, the teacher is prompted to use either of two offered scenarios (or a personal experience) that are intended to raise tension for learning about addressing goals of care and making difficult decisions. The first case of a woman with breast cancer represents a too common problem of focusing exclusively on the patient's resuscitation status, rather than more comprehensively addressing goals of care. The overt inconsistency between the patient refusing traditional aggressive oncologic therapy, and stating that she wants to be Full Code and return home, calls for further discussion and clarification. Despite the request to establish a code status (*i.e.*, convince her that a DNR would be more appropriate), her resuscitation status is a relatively minor issue, compared to the more complex issues such as where she would like to live and what are her broader goals of care. The second case overtly concerns an inquiry about assisted suicide. Here again, there may be more than meets the eye. While the patient seems to have made a clear decision about ventilator therapy and tube feeding, part of his concern may relate to his wife's role and what might happen when she is unable to care for him. This case also calls for further discussion.

These cases illustrate the narrow focus that clinicians may have. As always, when using a real or hypothetical case, the teacher must work very hard to keep the discussion brief for the sake of time. Thus, minimal comment is requested from learners at this point. The first case is more likely to be familiar than the second.

If one wanted to expand upon the second case, one could use the actual scene from the Bill Moyer's

series, *On Our Own Terms*, <http://www.pbs.org/wnet/onourown/terms/>, in which an ALS patient requests a physician's assistance with a hastened death. The physician's response can be critiqued.

Difficult Decisions at the End of Life

Following Objectives and Agenda slides, the session formally begins with a brainstorm, working to identify what difficult decisions may arise at the end of life. Most learners have no difficulty generating a long list, although what does *not* come up may be quite revealing. In our experience, it is easier for physicians to identify discrete medical interventions such as code status, ventilator withdrawal or the use of antibiotics, than more personal matters of choice such as where to live or overall goals of care. The key points in this exercise are: many potentially difficult decisions may arise, considerably more than resuscitation (code) status needs to be addressed, and some decisions are more personal (and less medical) than others. If learners have difficulty with this last point, one can prompt them to think about the difficult decisions that might arise in their own (real or imagined) death. In this self reflection they should come to understand that from the patient's perspective, non-medical issues such as where to live, what the finances might be, and how loved-ones might be affected are often dominant concerns. The discussion encourages clinicians to consider what is troubling or difficult about such decisions in their roles as clinicians. Clinicians, who tend to address cognitive aspects of communication, as discussed in Module 3, may respond very intellectually with abstract or overly concrete statements such as, "I do not have time to address these concerns," or "Well, you never know about these things. It is very difficult to know what the best course of action is." We encourage learners to recognize how these difficult decisions in their professional roles make them *feel*. Our point is that these decisions are not just difficult for patients and families, but are personally stressful for clinicians. We suggest that greater competence in dealing with such decisions might relieve some of this stress.

The GOOD Acronym

The GOOD acronym is then introduced. One point not stressed in the PowerPoint notes is that most difficult decisions present as a desired option by someone (the first O for option). A clinician may call for something to be started or stopped, or the request may come from a patient or family member. The most common mistake in our experience is to respond to (or initiate a discussion of) this option as a *position* to be argued for or against. Rather it is generally advisable to back up to the G (goals) step to gain a better understanding of how the desired option fits in, or does not fit in, to the broader goals of care for the patient.

An analogy often used for this, and used by many teachers in making this point, is to ask learners what they would do if someone called for directions for how to drive to the hospital. They would not respond, "You cannot get here from there." They would first ask *where* the person is in relation to the hospital and would only then discuss possible routes. In difficult clinical situations the related question is often, "Where do you *think* you are right now," or for other stakeholders such as clinicians and family members, "Where do you think the patient is in his or her illness right now?" Some variation of the question, "What is your understanding of..." begins the GOOD acronym, on the premise that goals only make sense in relation to one's perception of where one has been and where one presently is.

One additional point is to be made on the teaching of this tool. Many teachers start with a full head of steam discussing G (goals) and O (options), but then weaken in discussing the second O (opinions) and D (documentation). To some extent this arises from problems with time management. However, it is all too easy to simply say, "And of course, you should then give your opinion and document the discussion." The Opinions step contains the potential for much interesting discussion. Do clinicians really believe they should express their opinions on end-of-life matters? (In many hospitals, resuscitation status seems to be approached neutrally as a patient/family choice, much like one might

choose different entrées from a menu.) Some clinicians are actually quite unsure about whether they should offer an opinion about such decisions, especially when decisions seem very personal. Of course, clinicians usually do have opinions, which, if contrary to patient and family wishes, tend to leak out in indirect and often damaging ways.

Most clinicians are so tired of hearing, “Document! Document!” that they are unable to listen to the message in this context. The documentation step can be addressed in a variety of ways. Perhaps the bluntest way is to point out that many clinicians seem to document at such a poor level as to pose medico-legal risk. The most common case in point is the note that simply states, Full Code or DNR with absolutely no comment on how such a status was obtained.

Skills Practice

Following the introduction of the acronym, learners get a chance to role play. Dyads and triads are suggested. Given realistic time constraints, only half the group will get to play the physician. If expanded or if time allows, it is advisable to reverse physician and patient roles. The role play is designed to highlight the complexity of goals of care from a patient’s perspective, including where to receive care. Two possible scenarios are offered, so that it is not clear at the beginning of the role play what the patient’s position and goals are. Discussing goals of care means exactly that. Too often end-of-life decision-making is framed in a way that suggests our only interest is in getting patients and families to make the ‘right’ choice by choosing less aggressive care. Both scenarios make sense from the perspective of the patient. Thus, exploring goals is not about finding what appears to be the best or most rational goal, but trying to understand the context of the patient and family for whatever goals they have.

Requests to Hasten Death

Following the break is a discussion about requests or inquiries concerning a possible hastened death. After some initial definitions, a brainstorm is generated to identify why patients might consider a hastened death desirable. As the text points out, the educational purpose of the discussion is not to get into an ethical argument about whether PAS is right or wrong, but to understand why some patients might be interested in exploring the possibility of hastening death. Because this topic is so explosive, we suggest the teacher exercise rather rigorous control of session. The personal beliefs of the learners or teacher are *not* at issue. Should the discussion veer in too personal or uncomfortable a direction, the teacher needs to reinforce that the purpose is to practice communication skills. General ethical positions for and against PAS are then presented in as neutral a way as possible, with a strong warning against any discussion of personal beliefs. Following this skills practice, we discuss responses to a request for PAS. The GOOD acronym can be helpful in this regard, and serves as a review of this topic.

Personal Goal Setting

The session ends, as always, with goal cards. The more specific the learner’s goal, the higher the probability of success. For example, a vague goal, “I will try to communicate more effectively around difficult decisions,” is not likely to result in behavioral change. A more concrete statement, “I will try using the GOOD acronym in evaluating patient goals, at least once before the next session,” is more likely to be successful.

END-OF-LIFE CARE CURRICULUM
Module 4: Making Difficult Decisions
Outline

Learning objectives

- Apply a tool for assessing preferences and moving towards decisions
- Identify arguments regarding practices that may hasten death
- Increase your skills in responding to requests to hasten death
- Incorporate this seminar content into your clinical teaching

Difficult decisions at the end of life

Preferences and decision-making

Four steps:

Goals of care

Options

Opinions

Documentation

Skills practice

Dealing with conflict

BREAK

Difficult decisions regarding hastening death

Pros and cons of the hastening death debate

Why a patient would want to hasten death

Prominent arguments in favor and against

Case application

Strategies for responding to requests to hasten death

Reaction

Assessment

Apply the GOOD steps

Additional resources

Summary and goals

END-OF-LIFE CARE CURRICULUM
 Module 4: Making Difficult Decisions
It is GOOD to Discuss Patient Preferences

Steps	What you Might Say or Do	Background
GOALS 1. Identify stakeholders 2. Ascertain stakeholders' cognitive understanding 3. Assess stakeholders' values	"What is your understanding of...(your condition, your illness, why you are here)." "What have you been told about...(your condition, your illness, why you are here)."	<ul style="list-style-type: none"> • Goals for the future only make sense relative to what is important in life and makes it worth living, as well as current understanding • There may be a discrepancy between one's understanding and what one has been told • Understanding includes cultural background and assumptions
4. Elicit 'big picture' goals first 5. Internally clarify your own goals	"I'm trying to understand how you see the big picture. We'll get to the specific decisions we have to address in a moment. Do you have a major goal in your care? What is most important to you? "If you were to think about getting very sick, what worries you the most?" It's important for me to know you as a person, and what is important to you."	<ul style="list-style-type: none"> • Discussing specific interventions too soon can lead to serious misunderstandings • Discussing patient's reasons for a preference will allow you to extrapolate to other situations • Preferences may change over time • Self-awareness will help you set biases aside
OPTIONS 1. Identify available options	Rank order relevant options to consider "It seems to me the first decision we need to make is..." "What is the most important option for us to address today?"	<ul style="list-style-type: none"> • A natural hierarchy usually appears as options emerge from consideration of big picture goals • A clear decision on one major option will often resolve a subordinate option
2. Present benefits & burdens	"Let me lay out for you what we know about the pluses and minuses of this option..."	<ul style="list-style-type: none"> • Do your homework first • Benefits and burdens only make sense relative to goals • Present the "grey zone" of decision-making, not just extremely positive or negative scenarios
3. Present probability	"The chance of a similar patient surviving CPR is..." "The chance of survival with significant brain damage would be..." "How would you feel about trying this intervention if there were...very little chance of recovery (1%), intermediate probability, and 100% chance of success (e.g., would a 5% chance be enough? Would 10%?"	<ul style="list-style-type: none"> • For many decisions the probability of a particular outcome is important • Understanding probability helps many patients decide on a particular course of action • Avoid exclusive use of qualitative terms • Use percentages when possible <ul style="list-style-type: none"> – Insures you & patient are talking about the same thing – Frame both ways (90% chance of one outcome = 10% chance of the opposite)

Steps	What you Might Say or Do	Background
<p>OPINIONS</p> <p>1. Elicit patient/family preferences for specific options</p>	<p>“Now that we’ve identified the options, what do you wish to avoid, what do you fear or hope to accomplish?”</p> <p>“Some people have different beliefs about the importance of giving nutrition by any means, How do you feel about that?”</p> <p>“How important is it to you to be able to live at home?”</p> <p>“How important is it to be able to eat by mouth?”</p>	<ul style="list-style-type: none"> • Elicit values for specific options in a non-judgmental way • Carefully consider your own values relative to the question at hand • People may not understand an option the same way • They may have different hopes and fears about the outcomes of particular choices
<p>2. Offer your opinion</p>	<p>“Given what I know about you, it seems to me you would be best served by...”</p> <p>“Based on what you said earlier about wanting to die peacefully, I would recommend...”</p> <p>“You’ve told me that quality of life is the most important thing to you. There isn’t good evidence that a feeding tube will improve your quality of life. You’ve told me that eating gives you great pleasure. So in your case, I’d recommend against a feeding tube.”</p>	<ul style="list-style-type: none"> • Separate data from opinion • Provide a basis for your opinion, linking it to the previous discussion • Consider your own bottom line carefully <ul style="list-style-type: none"> – What you are willing and not willing to do • Use neutral language
<p>3. Verify decision & summarize</p>	<p>“Now let me make sure that we all understand the decision we’ve reached here.”</p>	
<p>Document Discussion</p> <p>1. Record the essence of the discussion</p> <p>2. List participants</p>	<p>“I discussed possible tube feeding with the patient and his daughter. Possible benefits and burdens identified. I recommended against tube feeding at this time, and patient and daughter agreed.”</p> <p>“At this time the patient would like to return home under the care of his wife and the hospice team. If his care proves burdensome to his family or he should require acute symptom management, then he requests that he be transferred to the inpatient hospice unit.”</p> <p>“Patient (or surrogate) requests DNR status” or “Patient states desire for a Full Code status at this time”</p>	<ul style="list-style-type: none"> • When discussing care planning/code status, pay attention to both what the patient wants now (current directive) as well as what the patient prefers if certain things happened (advance directive). • It is not enough to write “DNR” or “Full Code”

END-OF-LIFE CARE CURRICULUM
Module 4: Making Difficult Decisions

Role Play Scenario A

Physician Role:

You have been called to admit a 92-year-old patient. This patient is a ‘frequent flyer’, who has been admitted numerous times over the past few months with CHF exacerbations. He/she has been studied and restudied. His/her ejection fraction is 25%. He/she has inoperable coronary disease and the decision has been made for medical management. He/she has been variably compliant with his/her medical regimen. Usually, he/she tunes up reasonably well, but then bounces back often a few days later.

This time the patient looks pretty sick. You think there is a chance that he/she might be able to tune-up with aggressive diuresis, but there is a fair chance that intubation may be needed to keep the patient alive. You are also considering placing a Swan for more aggressive monitoring.

While the patient is dyspneic and somewhat anxious, he/she seems remarkably clear and does seem to be able to make decisions and communicate them.

YOUR ROLE IS TO ASSESS THIS PATIENT’S PREFERENCES: (DO GOOD!)

PLEASE DISCUSS MAJOR OPTIONS RELEVANT TO CARE SUCH AS HIS/HER CODE STATUS, ICU ADMISSION, INTUBATION AND SWAN-GANZ CATHETERIZATION.

Goals of Care

Identify the stakeholder
Ascertain stakeholders’ cognitive understanding
Assess stakeholders’ values
Elicit ‘big picture’ goals *first*
Internally clarify your own goals

Options

Identify available options
Present benefits and burdens
Present probability

Opinions

Incorporate patient/family preferences for specific options
Offer your opinion
Use neutral language
Summarize and verify the decision

Documentation

Record the essence of the discussion and who participated
Current and future preferences
It is not enough just to write ‘DNR’ or ‘Full Code’

END-OF-LIFE CARE CURRICULUM
Module 4: Making Difficult Decisions

Role Play Scenario A

Patient Role:

You are a 92-year-old patient with advanced CHF. You live alone and have been admitted several times over the past several months for CHF exacerbations. You have been finding it increasingly difficult to live on your own at home. You have great doctors, but they don't seem to understand how hard it is to make it on Social Security. Why, some of those fancy pills you simply can't afford. You take the water pill – it's cheap and helps your breathing. But that "something-statin" and zolapril or whatever – why, you couldn't afford to eat if you bought those.

You hate coming to the hospital. But when your breathing gets bad, what are you supposed to do? You can't drive and there is no one to call, except 911. You know that you are old and your time is short. All your family is dead. You've lived a good life and aren't the least bit depressed. But, when your time comes, you are ready. Your *only* interest is in getting comfortable – to be able to breathe better! If you die tonight, it's fine with you. You've taken care of business. If you don't die, that would be OK too – although you wonder if there isn't some place else for you to live, as it's getting to be too much for you to live alone in your apartment.

END-OF-LIFE CARE CURRICULUM
Module 4: Making Difficult Decisions

Role Play Scenario B

Physician Role:

You have been called to admit a 92-year-old patient. This patient is a "frequent flyer" who has been admitted numerous times over the past few months with CHF exacerbations. He/she has been studied and restudied. His/her ejection fraction is 25%. He/she has inoperable coronary disease and the decision has been made for medical management. He/she has been variably compliant with his/her medical regimen. Usually, he/she tunes up reasonably well, but then bounces back often a few days later.

This time the patient looks pretty sick. You think there is a chance that he/she might be able to tune-up with aggressive diuresis, but there is a fair chance that intubation may be needed to keep the patient alive. You are also considering placing a Swan for more aggressive monitoring.

While the patient is dyspneic and somewhat anxious, he/she seems remarkably clear and does seem to be able to make decisions and communicate them.

YOUR ROLE IS TO ASSESS THIS PATIENT'S PREFERENCES: (DO **GOOD!**)

PLEASE DISCUSS MAJOR OPTIONS RELEVANT TO HIM/HER CARE SUCH AS HIS/HER CODE STATUS, ICU ADMISSION, INTUBATION AND SWAN-GANZ CATHETERIZATION.

Goals of Care

Identify the stakeholder
Ascertain stakeholders' cognitive understanding
Assess stakeholders' values
Elicit 'big picture' goals *first*
Internally clarify your own goals

Options

Identify available options
Present benefits and burdens
Present probability

Opinions

Incorporate patient/family preferences for specific options
Offer your opinion
Use neutral language
Summarize and verify the decision

Documentation

Record the essence of the discussion and who participated
Current and future preferences
It is not enough just to write 'DNR' or 'Full Code'

END-OF-LIFE CARE CURRICULUM
Module 4: Making Difficult Decisions

Role Play Scenario B

Patient Role:

You are a 92-year-old patient with advanced CHF. You live alone and have been admitted several times over the past several months for CHF exacerbations. You have been finding it increasingly difficult to live on your own at home. You have great doctors, but they don't seem to understand how hard it is to make it on Social Security. Why, some of those fancy pills you simply can't afford! You take the water pill- it's cheap and helps your breathing. But that "something-statin" and zelapril or whatever – why, you couldn't afford to eat if you bought those.

It is December 8th and you'd really like to make it through the holidays if possible. Your granddaughter is about to have a baby and you'd love to see your first great grandchild before you die. So, you'd like to have the doctors try to keep you alive, if possible. However, you'd hate to be kept on machines. After all, you are old and the last time was miserable. You suppose it would be OK for the doctors to try all the fancy machines including the breathing machine if necessary. However, if it looked like you wouldn't get better or ever get off the machines, well, you are not crazy. You'd like them to take the tubes out and keep you comfortable.

You are also concerned that it is getting to be too much for you to make it at home. If you did pull through, perhaps the hospital could help you go to an old folks' home near your daughter's place, across the river.

END-OF-LIFE CARE CURRICULUM
Module 4: Making Difficult Decisions

Conflict

When conflict arises a win-lose mentality often sets in and it is impossible to negotiate a solution. The following steps may help:

1. Describe the conflict as a mutual problem.
2. Offer to negotiate differences. This does not have to mean compromise.
3. Brainstorm alternative solutions together.
4. Evaluate your solutions together and eliminate any that either of you do not agree with.
5. Decide on the best solution and plan how to implement it.

Negotiation does not always work. You cannot change personality or the whole relationship. In these circumstances:

- Decide what outcome you want and whether this is feasible.
- Tackle one problem at a time (for example, start with how you feel about someone's behavior rather than how everyone else feels).
- If they cannot change, can you change the way you respond to that person in order to unfreeze the situation and enable change to begin (take it less personally, become more assertive, learn to say no, etc)?

END-OF-LIFE CARE CURRICULUM
Module 4: Making Difficult Decisions
Glossary of Terms and Concepts

Advance Care Planning

Discussion, documentation and implementation of wishes

Living Will: An instructional directive to limit life-sustaining medical treatment in the face of a life-threatening illness

Durable Power-of-attorney for health care: Appointment of a health care agent or proxy to make decisions according to the incapacitated patient's preference

Other types of instructional directives: • Personal letter • Values history • Medical directive

Advance Directive

A written instruction that relates to the provision of health care when an individual is incapacitated. In California, these include a Durable Power of Attorney for Health Care, and a Declaration pursuant to the Natural Death Act. In an advance directive, a person states choices for medical treatment and/or designates who should make treatment choices if the person creating the advance directive should lose decision-making capacity. (California Consortium on Patient Self-Determination, 1991)

Agent

The individual ('attorney-in-fact') designated by a person ('principal'), pursuant to a Durable Power of Attorney for Health Care to act on his or her behalf in health matters in the event that the person loses decision-making capacity. (California Consortium on Patient Self-Determination, 1991)

Altruism

Derived from the Greek words meaning 'self-ruled.' A concern primarily with the well being of others rather than one's own self-interest. (Madigan, 1997)

Beneficence

Performing an act which is good or which brings about good effects. (Madigan, 1997)

Competence

A patient's capacity to make decisions about the provision of medical care for him or herself. Competence is also considered to be the *legal* capacity to make decisions in contrast to capacity/decision making capacity. (Madigan, 1997)

Confidentiality

Not divulging information, which another has revealed on condition of secrecy. (California Consortium on Patient Self-Determination, 1991)

Consent

A voluntary act by which one person agrees to allow another to do something. (California Consortium on Patient Self-Determination, 1991)

Conservator

The person appointed by a court with the legal power and duty of taking care of and managing the

property and/or personal affairs of another person (conservatee) who is considered incapable of administering his or her own affairs. (California Consortium on Patient Self-Determination, 1991)

Decision-Making Capacity

The ability to make choices that reflect an understanding and appreciation of the nature and consequence of one's actions. A person is presumed to have capacity to make health care decisions unless the attending physician, together with family members and/or close friends, determines that the person is incapacitated or a court rules that the person is incompetent. (California Consortium on Patient Self-Determination, 1991)

A patient's ability to make decisions about the provision of medical care for him or herself. This is a clinical determination which is specific to the decision at hand. As such, it may vary from time to time, or from decision to decision (see also Competence). (Madigan, 1997)

Double Effect

"...An outwardly identical action or omission, such as administering life-shortening palliative care, can be a case of either euthanasia, or of pain relief, depending on what it is that the agent intends to bring about as a consequence of her action or omission. Since intentions are internal states, this means that ultimately only the agent herself will be able to say what she intended to do when she did what she did." (Kuhse, 1997, p. 259)

Durable Power of Attorney for Health Care

An advance directive established in conformance with California statutory law by which an individual may name someone else (the 'agent' or 'attorney-in-fact') to make health care decisions in the event that the individual becomes unable to make such decisions herself or himself. (California Consortium on Patient Self-Determination, 1991)

Extraordinary Measures

Any means used to treat a sick or dying person that is out of the ordinary, or heroic. (California Consortium on Patient Self-Determination, 1991)

Incompetence

The state of being generally incapable or incompetent, or unable to make *any* decisions for oneself, medical or otherwise, occurs in situations of coma and profound mental disability. (California Consortium on Patient Self-Determination, 1991)

Incapacity

The condition of an adult whereby the capacity to make informed decisions regarding health care is either temporarily lost (*e.g.*, due to unconsciousness, the influence of mind-altering substances, or treatable mental disability), or is permanently lost (*e.g.*, due to irreversible coma, persistent vegetative state, or untreatable brain injury), or never existed (*e.g.*, due to profound mental retardation). Commonly, incapacity is less comprehensive than incompetence, and it is necessary to assess capacity for the specific decision at hand. Declarations of incompetence can be done by a formal, legal statement, but more usually are done by simply recording the evaluation of the primary physician or a psychiatrist in the medical record. Once incapacity is determined, physicians should use one of two criteria: determination that the treatment would not be in the *best interests* of the patient. Apply the proxy's *substituted judgment* to determine whether the patient would have wanted treatment withheld if he or she had been competent. Decision making that involves the application of advance directives uses this criterion. (California Consortium on Patient Self-Determination, 1991)

Informed Consent

The process in which a physician informs a patient of his or her diagnosis, prognosis and treatment alternatives including the nature of the recommended procedure, its risks, complications, and expected benefits as well as the risks and benefits of the alternatives and the patient then decides which treatment alternative to pursue. (California Consortium on Patient Self-Determination, 1991)

Usually a formal written consent that patients give to health care professionals allowing them to conduct tests, procedures, or experimentation on patients with their complete understanding and agreement. (Madigan, 1997)

Life-Sustaining Treatment

Any intervention that prolongs life and delays death. (California Consortium on Patient Self-Determination, 1991)

Living Will

Any advance directive that expresses treatment choices; the term usually refers to nonstatutory directives, which are considered advisory to patients' families and health care providers, but it also encompasses directives authorized by statute, such as a Declaration pursuant to the Natural Death Act. (California Consortium on Patient Self-Determination, 1991)

Medical Futility

Life-or-death situations in which proposed treatments will fail to prolong quality of life, achieve the patient's key goals for medical care, achieve a critical physiologic effect on the body, or result in a therapeutic benefit for the patient. (Schneiderman & Jecker, 1994)

Natural Death Act (CA H&SC)

A document in which a patient directs the attending physician to withhold or withdraw life-sustaining treatment in instances of terminal illness or permanent unconsciousness. (California Consortium on Patient Self-Determination, 1991)

Nonmaleficence

Not performing an action that would cause harm to a patient. "Above all, first do no harm." (Madigan, 1997)

Ordinary Measures

Distinguished from extraordinary or heroic means of medical treatment of patients: refers to the appropriate treatment that would not be unusual or beyond what should be done in routine situations. (Madigan, 1997)

Patient Self-Determination Act

A federal statute, enacted as part of the 1990 Omnibus Budget Reconciliation Act, which requires, among other things, that health care facilities provide information regarding the right to formulate advance directives concerning health care decisions.

Physician-Assisted Suicide

At the patient's request, a physician provides the necessary means or information to end his or her life. (Chochinov & Wilson, 1995) [EPEC adds "and the patient performs the act."]

Proxy Consent

Voluntary informed consent is given on behalf of another person who is unable, for some reason, to give it himself or herself. (Madigan, 1997)

Right to Die

Death is not as much a right as a destiny. The phrase “right-to-die” signifies the hard-won right to die *with some measure of control over the manner and timing of one’s death*. (Young, 1998)

Slippery Slope Argument

If X is allowed, Y will follow, and Y is ethically unacceptable. (AMA, 1999)

Surrogate Decision Maker

An individual who participates in health care decision making on behalf of an incapacitated patient. The surrogate decision maker may be formally appointed (*e.g.*, by the patient in a durable Power of Attorney for Health Care or by a court in a conservatorship proceeding) or, in the absence of a formal appointment, may be recognized by virtue of a relationship with the patient (*e.g.*, the patient’s next of kin or close friend). (California Consortium on Patient Self-Determination, 1991)

Terminal Condition

Defined for purposes of the Natural Death Act as an incurable and irreversible condition which in reasonable medical judgment would, without the application of life-sustaining treatment, produce death within a relatively short time. (California Consortium on Patient Self-Determination, 1991)

Terminal Sedation

Patient is sedated for otherwise unmanageable symptoms; not necessarily at the request of the patient. “An ambiguous term open to different interpretations.... defined as the *intention* of deliberately inducing and maintaining deep sleep, but *not* deliberately causing death in very specific circumstances.” These are:

1. For the relief of one or more intractable symptoms when all other possible interventions have failed and the patient is perceived to be close to death, or
 2. For the relief of profound anguish (possibly spiritual) that is not amenable to spiritual, psychological, or other interventions and the patient is perceived to be close to death.”
- (Chater, et al, 1998)

Voluntary Euthanasia

Positive act of commission, such as lethal injections, which are undertaken deliberately by physicians to end the lives of patients who have explicitly asked to die. (Chochinov & Wilson, 1995)

Voluntary Stopping of Eating and Drinking

Patient capable of taking nourishment decides to stop and dies. (EPEC, 1999)

Withholding or Withdrawing of Therapy

Therapies which may sustain life for a period of time may be available to patients with a poor quality of life, comatose patients, and those who will not recover from their illness to any extent, and where every day of life adds a day of suffering.

Under these circumstances, it may be wise to either withdraw futile therapy, or to make the decision not to offer futile therapy in the first instance. (Roy & MacDonald, 1998)

END-OF-LIFE CARE CURRICULUM

Module 4: Making Difficult Decisions

Bibliography

American Medical Association. Advance directives, surrogacy, competency, and Futility, in EPEC Project Participant Handbook (Education for Physicians on End-of-Life Care) 1999; www.epec.org.

Back AL, Starks H, Hsu C, Gordon JR, Bharucha A, Pearlman RA. Clinician-patient interactions about requests for physician-assisted suicide: a patient and family view. *Archives of Internal Medicine* 2002; 162:1257-65.

California Consortium on Patient Self-Determination (1991). PSDA Handbook.

Chater S, Viola R, Paterson J, et al. Sedation for intractable distress in the dying – a survey of experts. *Palliative Medicine* 1998; 12:255-269.

Chochinov, H.M. & Wilson, K.G. The euthanasia debate: attitudes, practices & psychiatric considerations. *Canadian Journal of Psychiatry* 1995, December; 40, 593-602.

Fins JJ, Miller FG. Clinical pragmatism, ethics consultation, and the elderly patient. *Clinics in Geriatric Medicine* 2000; 16:71-81, ix.

Fisher R, Ury W. *Getting to Yes: Negotiating agreement without giving in*. New York: Penguin, 1983.

Koenig BA. Cultural diversity in decision making at the end of life. In: Field MJ, Cassel CK, Institute of Medicine (U.S.). Committee on Care at the End of Life, Eds. *Approaching death: Improving care at the end of life*. Appendix E. Washington, D.C.: National Academy Press, 1997:363-82.

Kuhse, H. *Caring: Nurses, women, and ethics*. Oxford: Blackwell Publishers, 1997.

Madigan, T. Ethics Committee Core Curriculum. University of Buffalo Center for Clinical Ethics and Humanities in Health Care. 1997; <http://wings.buffalo.edu/bioethics/manle-e.html>.

Quill TE, Arnold RM, Platt F. "I wish things were different": Expressing wishes in response to loss, futility, and unrealistic hopes. *Annals of Internal Medicine* 2001; 135:551-5.

Roy, D. J. & MacDonald, N. Ethical issues in palliative care. In D. Doyle, G.W.C. Hanks & N. MacDonald (Eds.), *Oxford Textbook of Palliative Care* 2nd ed., Oxford: Oxford University Press, 1998.

Schneiderman L, & Jecker, N.S. Beyond futility to an ethic of care. *American Journal of Medicine*, 1994; 96:110-14. Cited by McGee, et al. The patient's response to medical futility (editorial). *Archives of Internal Medicine*, June 12, 2000;160, 1565-6.

Stone D, Patton B, & Heen S. *Difficult conversations: How to discuss what matters most*. New York: Penguin, 1999.

Tulsky JA, Chesney MA, Lo B. How do medical residents discuss resuscitation with patients? *Journal of General Internal Medicine* 1995; 10:436-42.

Young EWD. Ethical issues at the End of Life. *Stanford Law & Policy Review* 1998; 9:267-288.

End-of-Life Care Curriculum for Medical Teachers

TEACHING TIPS

MODULE 5: NON-PAIN SYMPTOM MANAGEMENT

Companion to Module 5 PowerPoint Presentation

James Hallenbeck, MD
Sara Katz, PhD
Georgette Stratos, PhD

END-OF-LIFE CARE CURRICULUM
Module 5: Non-Pain Symptom Management
Table of Contents

Title and credits

Teaching tips

Introduction
Attitude Objectives
Knowledge Objectives
Skill Objectives
Module Walk-Through

Handouts

5.1 Outline
5.2 Causes of Nausea and Vomiting
5.3 Symptom Analysis Checklist
5.4 Bibliography
(Provide 3x5 Cards for Goals)

TEACHING TIPS

Module 5: Non-Pain Symptom Management

Introduction:

This module is heavy on attitude and knowledge objectives and relatively light on skill training. Because of this bias, a major challenge for teachers is to stay connected to the learners, making sure they are engaged and can reasonably assimilate the material.

Module Objectives:

The learning objectives below are not written in the stylized manner that has become a tradition in many presentations: “By the end of this session the learner will be able to...” We use these in the module to help learners organize what they are supposed to learn in a session. Here, we discuss objectives more freely. This approach allows us to discuss both *overt* and *covert* objectives. The stylized approach is also limited since it usually addresses only what is to be accomplished *in that session*. Some of the most important objectives relate to stimulating self-directed learning outside of the session. Quite often, it would be fairer to state, “By the end of this seminar, you may not be able to do X, Y or Z competently, but you might be stimulated to think and read more or practice certain skills later on your own.”

Many attitude objectives, in this and other modules, are covert. By definition, attitude objectives start with the hypothesis that certain assumptions in learners need to be shifted or changed. More bluntly, we may think some learners have incorrect or even bad attitudes. Thus, attitude objectives usually contain two parts: an assessment of the problem with the current attitude and a suggested change.

We do not assume that all learners have the undesirable attitude. Many learners will not. However, in designing this curriculum it was assumed that such attitudes were prevalent and important enough to be addressed. In the process of evaluating learners during a session, the teacher may get some idea as to the extent and prevalence of presumed negative attitudes.

The title of the module reflects a commonly accepted way of lumping together a whole host of problems that may arise at the end of life. In fact, it is artificial to divide symptomatology into pain and non-pain. The key point of the module is to encourage a different way to think about symptoms overall – not just as clues to disease, but as experiences of suffering in illness. It is suggested that symptoms have their own physiology, which needs to be analyzed and understood, if effective therapies are to be employed. A method of breaking down the experience of illness into constituent parts is offered to aid in this analysis. This point differs radically from the traditional view of symptoms as having meaning only as *clues* to illness. We suggest that one reason symptoms have received so little attention in modern medicine is that most patients now have chronic illness. That is, the ‘mystery’ has already been solved. Most patients at the end of life suffer from symptoms that result from very well-known causes. A frame-shift is suggested for learners to deal with this problem. For many patients with chronic and terminal illnesses, the question is not so much what the symptom says about the underlying disease, but what the disease tells us about the experience of that symptom.

Attitude Objectives:

Presumed attitude	Desired attitude
Symptoms matter only as clues to an underlying problem	Symptoms reflect experiences of suffering and deserve to be addressed in their own right
Non-pain symptom therapy is simple. To the extent possible you just fix the underlying disease	A whole host of non-pain symptoms exist, each with complex physiologies. Understanding these physiologies helps the clinician rationally choose more effective therapies, whether the underlying disease is curable or not
Wasting syndromes at the very end of life reflect starvation	Most wasting syndromes differ significantly in their physiology from starvation

Knowledge Objectives:

Knowledge of:

- A general structure for analyzing the physiology of symptoms
- The underlying physiology of:
 - Nausea/vomiting
 - Dyspnea
 - Cachexia, anorexia and asthenia
 - Common approaches to the terminal syndrome with respiratory secretions
- Rules of thumb for using blood products at the end of life
- Pros and cons to artificial hydration and nutrition at the end of life

Skill Objectives:

Skill in:

- Using a checklist to analyze symptoms
- Using the VOMIT acronym to identify types of nausea and appropriate therapy
- Using standard palliative measures for the treatment of dyspnea
- Treating the terminal syndrome with respiratory secretions

Module Walk-Through:

After introductory remarks, the teacher is prompted to use a story as an icebreaker. The teacher may use one of his or her own or may use the case on the second slide to illustrate key points of this module. This may be a superb place to borrow a trigger tape from the EPEC curriculum. The non-pain symptom module contains one of the best trigger tapes in the set, featuring Charles von Gunten interviewing a patient. This tape superbly demonstrates how the patient's symptoms are far more than clues. They are a part of her experience in everyday life. This is also one of the best tapes we know demonstrating great communication skills on the part of Dr. von Gunten. (<http://www.epec.net>)

Symptoms

After Objective and Agenda slides, a discussion of the meaning of the word, 'symptom' begins the module. We suggest the frame-shift in thinking about symptoms, as discussed above. Few learners will be able to explain the physiologic mechanisms for nausea in a patient with cancer of the liver, so this should provide motivation for learning. This is a great place for the teacher to make a self-deprecating remark to the effect that prior to studying this material, he or she similarly had no real understanding of nausea. Most clinicians learn treatment of nausea through imitation of superiors, who are often equally ignorant. For example, "When I was an intern, I would ask my resident how to treat nausea. One resident said use a promethazine suppository. Another said use prochlorperazine. I assumed 'one size fit all' and that it didn't make much difference. I had no idea what I was doing." The point is that almost all of us were poorly taught.

Symptom Analysis

A framework for symptom analysis is presented, dividing the physiology into physical and mental factors. Because this is a very new concept for most learners, the teacher must slow down and evaluate their comprehension before proceeding. To help with this, learners are asked to analyze a patient with pain according to the checklist. (Using this case also illustrates that any division between pain and non-pain symptoms is artificial.)

This is the first introduction to spirituality. This will be addressed in more detail in Module 7. While not going into any depth on the subject here, the teacher should observe how learners respond to the concept of spirituality as a relevant dimension to consider. A more detailed discussion will be presented in Module 7.

The slide showing 64 symptoms from the Oxford Textbook of Palliative Medicine makes the case that it would be impossible to cover all relevant symptoms comprehensively in one short discussion. Showing the breadth of symptomatology that exists at the end of life also hints that this entire area has been severely neglected in training.

With this organizational base, two major symptoms are discussed in more detail, nausea/vomiting and dyspnea. These were chosen because of their prevalence and the degree of distress they cause. These discussions help learners gain some understanding of the underlying physiology of these symptoms and subsequently to treat them more rationally.

Nausea and Vomiting

One way to understand any physiology (whether of a symptom or a disease) is to create a story to make sense of it. Nausea is a superb example. We start by trying to understand *why* we experience nausea. The answer is, to protect us from various poisons. This storyline helps organize the complex physiology of nausea in a way that we hope is easier for learners to retain. We actually know quite a bit about the physiology of nausea. For example, which chemical messengers bind which receptor. We hope this will prompt learners to reflect on why they had not been taught this physiology, and why much therapy for nausea does not reflect this understanding. Learners are then introduced to the VOMIT acronym, a tool for remembering causes of nausea and identifying appropriate classes of therapeutics.

Dyspnea

While the discussion of nausea focuses primarily on physical aspects of symptomatology, the dyspnea discussion makes a different point. Our understanding of the mechanisms of dyspnea is quite primitive. Most learners were taught a story about the physiology of dyspnea that exaggerated the importance of blood gases and virtually ignored other physical and psychic components. Because dyspnea is tightly linked to psychological states, it is easy for learners to experience the importance of mental factors. The

approach used here is modeled after a presentation by Charles von Gunten, Chair of the American Board of Hospice and Palliative Medicine, in which he taught the physiology of dyspnea to a group of residents almost completely through the residents' own bodily experience. In part, this exercise compensates for the otherwise heady didactic approach of this module. Beyond this, we hope that experiencing dyspnea will encourage attitude change about the importance and physiology of dyspnea. Experiencing dyspnea through exercise, learners understand that one can be severely short of breath with a normal oxygen level. Participants also learn that symptoms and suffering, while linked, are not synonymous. A runner may be dyspneic and yet enjoy life, while a patient with lung disease with similar physical parameters of dyspnea may suffer greatly. Similarly, in holding one's breath one learns that the perception of air flow and one's psychological state (as in the experience of drowning) has a significant impact on the experience of dyspnea. If time is short, the module can be concluded at this point. The following segments on active dying, wasting syndromes and artificial hydration and nutrition are very brief. Any of these could be expanded into stand-alone sessions.

Treatment for Active Dying

Following this, is a brief discussion about treatment for active dying, "the terminal syndrome characterized by respiratory secretions." This section extends the discussion on active dying in Module 1. The section on dyspnea provided a clear understanding of why opioids and anxiolytics might be helpful for dyspneic patients who are actively dying. We regret the awkward wording for this 'syndrome,' but have yet to find a better one. Initially, we called it, 'terminal pneumonia,' but then had to explain that the 'death rattle,' rarely represents bacterial pneumonia. The module briefly addresses therapy for active dying, mentioning the use of anticholinergic agents for drying respiratory secretions. Teachers should be prepared to discuss these therapies in more detail, if desired.

We then present cachexia, anorexia and asthenia. In his critique of Western biomedicine, Kleinman has noted that this culture almost uniquely ignores suffering and does not contain a notion of a 'life force.' (Kleinman, 1995; Hallenbeck, 2002) Our language in discussing these issues is severely lacking. The key points of this section are that weakness (or in the vernacular the dwindles) is a major cause of death in chronic illness and that the physiology underlying this constellation of problems is complex and significantly different from starvation.

This flows into a brief discussion of artificial nutrition and hydration. The major attitude objective is to understand that physiologically, wasting syndromes differ significantly from starvation. Placing the learner in the position of the patient builds impetus for learning. In addition, research shows that patients, family members, and clinicians poorly understand relevant variables in IV insertion at the end of life.

In the discussion of the symptomatology of active dying and terminal wasting syndromes (anorexia, cachexia and asthenia) at the end of the module, some attention is paid to medical therapies. However, probably more important is to emphasize that most requests for artificial hydration at the end of life come from a desire to nurture and be nurtured. Responding only to the cognitive components of inquiries regarding hydration and nutrition will totally miss this affective component. The key point is that if a decision is made not to artificially feed or hydrate, clinicians must work with patients and families to identify means of nurturing that are appropriate and would be appreciated.

Personal Goals

The module concludes with learners writing out and discussing their goals. Again, teachers are prompted to encourage learners to be concrete. Learners often reflect a sense of being overwhelmed by this module. It contains a great deal of new content. This is partly intentional. A key attitude objective is for learners to understand that this is a huge topic area. The module can be an entrée to palliative care

for learners who are resistant to what they perceive as ‘soft’, or ‘touchy-feely’ topics like communication and psychological distress. There is plenty to satisfy learners’ appetite for hard-core pathophysiology in this module. Through this discussion, we hope clinicians are filled with excitement about learning new and effective means of alleviating suffering.

END-OF-LIFE CARE CURRICULUM
Module 5: Non-Pain Symptom Management
Outline

Learning objectives:

- Explain how physical and mental factors affect symptomatology
- Use this understanding in the treatment of patients suffering from:
 - Nausea and vomiting
 - Dyspnea
 - Cachexia, anorexia, asthenia
- Incorporate this seminar content into your clinical teaching

Overview

Symptom definition
Patient's perspective
Symptom analysis checklist

Nausea and vomiting

Protective mechanisms
Central final pathway
Causes of nausea and vomiting
Opioid-related nausea
5HT3 antagonists

BREAK

Dyspnea

Dyspnea in different situations
Treatment implications

Terminal pneumonia

Description
Treatment

Cachexia/anorexia/asthenia

Case exercise
Definitions
Background
Treatment

- Medical
- Psychological

Artificial hydration at the end of life is controversial

Summary and goals

END-OF-LIFE CARE CURRICULUM
Module 5: Non-Pain Symptom Management
Causes of Nausea and Vomiting

Vestibular apparatus

Nausea with head movement
Mediated by acetylcholine & histamine receptors
Most anticholinergic, antihistaminic drugs will help

Obstruction

Constipation = most common cause
External or internal obstruction
Mediated by mechano and/or chemoreceptors
Controversy re best drugs for true bowel obstruction
Anti-constipation medications for constipation

Mind

Memory, meaning, emotion can be very powerful
Manipulate taste and other senses

Dys**M**otility

Multiple causes of dysmotility
Upper intestinal dysmotility is very common

Infection & Irritation

Mediated through chemoreceptors
Gut and adjacent organ inflammation can trigger
Anticholinergic/antihistaminic medications help

Toxins

Most important source: medications
Various mechanisms of inducing nausea
Treatment depends on mechanism of action

END-OF-LIFE CARE CURRICULUM
 Module 5: Non-Pain Symptom Management
Symptom Analysis Checklist

Patient presentation:

- Physical signs
- Lab & other studies
- Verbal report
- Non-verbal communication
- Magnifying factors
- Minimizing factors

P H Y S I C A L	Local Physiology	
	Central Physiology	

M E N T A L	Emotional Factors	
	Cognitive Factors	
	Spiritual Factors	

END-OF-LIFE CARE CURRICULUM
Module 5: Non-Pain Symptom Management
Bibliography

- Oxford CD-ROM (Firm). The new shorter Oxford English dictionary. Oxford: Oxford University Press, 1996:1 computer optical disc.
- Oxford University Press. Electronic Publishing B.V. The new shorter Oxford English dictionary. Oxford: Oxford University Press and Electronic Pub. 1996:1 computer laser optical disc.
- Bruera E, MacDonald N. To hydrate or not to hydrate: how should it be? *Journal of Clinical Oncology* 2000; 18:1156-8.
- Doyle D, Hanks GWC, MacDonald N. Oxford textbook of palliative medicine. Oxford medical publications. Oxford ; New York: Oxford University Press, 1998:xxv, 1283.
- Dyspnea. Mechanisms, assessment, and management: a consensus statement. American Thoracic Society. *American Journal of Respiratory and Critical Care Medicine* 1999; 159:321-40.
- Hallenbeck JL, Bergen MR. A medical resident inpatient hospice rotation: Experiences with dying and subsequent changes in attitudes and knowledge. *Journal of Palliative Medicine* 1999; 2:197-208.
- Neuenschwander H, Bruera E. Pathophysiology of cancer asthenia. In: Portenoy RK, Bruera E, eds. *Topics in palliative care*. Vol. 2. New York: Oxford University Press, 1998:171-81.
- Peroutka SJ, Snyder SH. Antiemetics: Neurotransmitter receptor binding predicts therapeutic actions. *Lancet* 1982; 1:658-9.
- Reuben DB, Mor V. Nausea and vomiting in terminal cancer patients. *Archives of Internal Medicine* 1986; 146:2021-3.
- Reuben DB, Mor V. Dyspnea in terminally ill cancer patients. *Chest* 1986; 89:234-6.
- Rousseau P. Nonpain symptom management in terminal care. *Clinics in Geriatric Medicine* 1996; 12:313-27.
- Saunders CM. The philosophy of terminal care. In: Saunders CM, ed. *The Management of terminal disease*. London: Arnold, 1978:193-202.

End-of-Life Care Curriculum for Medical Teachers

TEACHING TIPS

MODULE 6: VENUES & SYSTEMS OF CARE

Companion to Module 6 PowerPoint Presentation

James Hallenbeck, MD

Sara Katz, PhD

Georgette Stratos, PhD

END-OF-LIFE CARE CURRICULUM
Module 6: Venues & Systems of Care
Table of Contents

Title and credits

Teaching tips

Introduction
Attitude Objectives
Knowledge Objectives
Skill Objectives
Module Walk-Through

Handouts

6.1 Work Rounds Script
6.2 Outline
6.3 Medicare Hospice Benefits
6.4 Extended Care Options
6.5 Questionnaire: Assessing the Institution
6.6 Examples of Local Change
6.7 Bibliography
(Provide 3x5 Cards for Goals)

TEACHING TIPS

Module 6: Venues & Systems of Care

Introduction:

This module contains basic information about hospice and palliative care, and makes the case that working the system is one of the most effective ways to improve care.

When our advisory group brainstormed what topics to address in our course, all the participants cited knowledge of hospice and palliative care (both philosophical and organizational issues) as high priority topics. Given the dominance of the Medicare Hospice Benefit in the United States, learners need to know certain basic facts about it to utilize it more effectively. However, details about what the benefit does and does not cover are rather dull. It is challenging to organize and present this material in a manner that holds the learner's attention.

The dominant concept underlying this module is that good health care outcomes for patients and families depend more on the ability of clinicians to work and change the system than most clinicians realize. At least for physicians, the dominant belief system seems to be, "If I just cram enough facts into my head and perform medical procedures with great technical skill, then I will be a good physician." While basic knowledge and skills are important, it is equally important to work the system for the good of current and future patients. This is particularly true in end-of-life care, where patients and families have multiple needs and frequently go between different venues of care. Even small changes in the system can result in better care for many patients.

At some level clinicians, especially physicians-in-training, know this. The resident who knows just who to contact in Radiology to get an x-ray done right away is respected for his skill in working the system. However, the *scope* of the system upon which clinicians work, often seems too narrow. The resident's skill may be limited to getting things done in the acute care hospital. He or she may know little, and do next to nothing, about improving access to needed services for a patient at home. There also seems to be a tendency to work (or work *around*) the system, rather than engage in an ongoing process of evaluation and change. The crafty resident works around bureaucratic obstacles rather than take on the system itself. There are, of course, many reasons for this. Working to change the system takes time and energy. Medicine is a conservative culture. Change agents may be labeled as troublemakers. From a personal perspective, it is certainly easiest just to go with the flow. However, if clinicians desire better outcomes for their patients, they have *no choice* but to work on the system.

The suggestion that clinicians widen the scope of the system they work in, and that they actively engage as change agents, may be met not so much with active resistance as frank exhaustion. It simply seems like too much to ask, given all that clinicians must do these days. This exhaustion often manifests itself in recognizing a need for change but feeling that the task is too large and they are too powerless. Someone else will have to do it. Such a response must be respected, but not accepted. A corollary for this module is that some ways of working or changing the system require minimal time or effort. Locating a support group for a patient and family struggling to cope with a new, devastating illness, might take only a couple of minutes but would make a great difference in their lives. We hope to foster attitudes in which searching for ways to work and change the system become *standard approaches to patient care*. Having such attitudes makes it easy to find any number of helpful methods or interventions, large or small.

Attitude Objectives:

The attitude, knowledge and skill objectives below are not written in the stylized manner that has become a tradition in many presentations: “By the end of this session the learner will be able to...” We use these in the module to help learners organize what they are supposed to learn in a session. Here, we discuss objectives more freely, discussing both *overt* and *covert* objectives. The stylized approach is also limited since it usually addresses only what is to be accomplished *in that session*. Some of the most important objectives relate to stimulating self-directed learning outside of the session. Quite often, it would be fairer to state, “By the end of this seminar, you may not be able to do X, Y or Z competently, but you might be stimulated to think and read more or practice certain skills later on your own.”

Many attitude objectives, in this and other modules, are covert. By definition, attitude objectives start with the hypothesis that certain assumptions in learners need to be shifted or changed. More bluntly, we may think some learners have incorrect or even bad attitudes. Thus, attitude objectives usually contain two parts: an assessment of the problem with the current attitude and a suggested change.

One objective is for learners to develop attitudes that will result in their paying more attention to the topic and improving their knowledge and skills in this area. We do not assume that all learners have undesirable attitudes. However, in designing this curriculum it was assumed that such attitudes were widespread enough to address. In the process of evaluating learners during a session, the teacher may get some idea of the extent and prevalence of barriers to desired attitudes. We also encourage participants to anticipate potential attitude barriers in their learners.

Presumed Attitude	Desired Attitude
Working and changing the system are not tasks central to the job of a competent clinician.	Working and changing the system are key responsibilities for clinicians seeking better health care outcomes for patients and families.
The job of working and changing the system is overwhelming. Someone else will have to do it.	Even small, very simple interventions may have a profound impact on outcomes. <i>Everybody</i> can find something to improve. Making even a small positive change increases one’s sense of empowerment to do more.
Social workers, discharge planners and others have responsibility for understanding and helping patients and families with these issues, which are largely social. It is not my job.	While social workers and others have important roles in this process, a rigid distinction between medical and social is artificial and not helpful. Physicians and other clinicians need a basic understanding of venues and systems of care for patients at the end of life.
The scope of the system with which the clinician needs to be familiar is restricted to the clinical venue in which the clinician works.	The relevant scope of the system, in which the clinician can work, is defined by patients, families and their needs, not solely by where the clinician works.

Knowledge objectives:

Knowledge of:

- The philosophies of hospice and palliative care
- Benefits and policies regulating the Medicare hospice benefit
- Advantages and disadvantages of differing venues and care models (home care vs. hospice care) for terminally ill patients
- Key steps in system change

Skill Objectives:

Skill in:

- Identifying system issues that might be addressed
- Gathering data supporting and evaluating action
- Working with allies in system change

Module Walk-Through:

After introductory remarks, the learners are asked to read/act out a short vignette in order to stimulate interest in the topic and foster motivation for learning. Hopefully, through enactment of an all too familiar scenario depicting the pressure to discharge a dying patient, clinicians are reminded that system issues arise daily in patient care and cannot be ignored.

We approach the topic of hospice care with a quick run-through of myths about hospice. Our sense is that most learners overall have a positive impression of hospice, but misunderstandings abound. The mechanics of hospice are quite mysterious to many of us. Separate from any personal experience, most learners' relationship to hospice will revolve around disposition of patients, usually from acute care. Because learners relate to hospice from the *outside*, as a matter of disposition, many will be very familiar with perceived problems regarding "getting people into hospice." These problems may vary, from patient and family resistance to the idea of hospice care, to the perception that hospice is defined more by what it does *not* provide than what it does. There is an obvious bias in this curriculum that the hospice system, while needing improvement, is a good idea. We want to allow learners to express the difficulties or problems they have experienced in referring to or working with hospices.

We have borrowed the Plenary 3: Cicely Saunders tape from the EPEC curriculum, available at: <http://www.epec.net/>. We could not possibly improve on her commentary on the history and philosophy of hospice. It is a judgment call whether to use just part of the tape or play it all and proportionately cut other topics in the session.

After a summary of basic information about hospice, learners brainstorm a list of problems or questions. (Positive remarks about hospice are welcome.) Too often the hospice option is presented as simply a good thing or the right thing to do at a certain point in the patient's illness. Often, this is taken as trying to talk someone into something, which can come across poorly. Hospice as a system of care has certain major advantages, about which many people are unaware. Here, we simply list them. As we have found in clinical practice, rather than argue that hospice is the right thing to do, it seems more effective (and proper) to compare different systems of care and then match these systems with patient and family goals. Resistant patients, families and clinicians often will agree that if the goals of care are to maintain

a patient at home to the extent possible toward the end of life, then whatever one thinks of the hospice philosophy, the hospice benefit offers the most comprehensive method of meeting such goals.

The next section presents basic information about hospice. It is important here to involve the learners and let them demonstrate how they are dealing with this new information. This is done by referring back to the introductory vignette. Hopefully, the learners will now have a clearer idea of relevant questions they might ask of the patient and family. *Why* does the family not want to take him home? Perhaps more importantly, what *do* the family and patient want? If they are considering home care, is the support structure at home adequate to meet medical needs? While a discharge planner or social worker very likely has a role in resolving these issues, the physician bears some of the responsibility to find these answers.

Next follows a transition pointing out that hospice might not be appropriate for a patient, for a variety of reasons. This enables the group to talk about the provision of end-of-life care in other venues. The majority of Americans die in institutions without the benefit of hospice care. This statistic seems unlikely to change in the near future. We do not wish to suggest that a referral to hospice alone can provide better end-of-life care. A great deal can be done in the acute care hospital and nursing home to improve care for the dying.

A brief discussion of *palliative care* then takes place, based on the *Precepts of Palliative Care* (Task Force on Palliative Care, 1998)). While palliative care may be distinguished from hospice care in many ways, one concept needs particular emphasis. It is not just the imminently dying who would like to have their suffering alleviated and to be made as comfortable as possible. A rigid dichotomy between traditional medical care and hospice care is not helpful. It is better to think of a continuum in which palliative care is a component of all health care, but grows in relative importance as one becomes more chronically and eventually terminally ill. In this context, it may be useful to examine alternatives to the standard phases, “withdrawal of support”, or “withdrawal of care.”

We then turn to the acute care venue, where the majority of Americans die, and where most trainees work. We point out that some hospitals now have dedicated acute bed programs for dying patients and many have or are developing palliative care consultation teams. While learners may not be able to bring about such large-scale ventures, we hope they will advocate for them. There is still much the individual clinician can do to improve the dying experience in an acute care hospital. We offer some concrete ideas. It is advisable to check in with learners about which, if any, of these ideas they have used, whether or not they believe these interventions are feasible at their site, or whether they have any additional suggestions for actions they could take. In many cases these interventions will take place during the last few days of a patient’s life. In Module 1, we discussed clinical care for patients who are actively dying. Here, we suggest a wider scope focusing on the system of care.

Dying in long-term or extended care facilities is the next topic. Many clinicians have been trained exclusively in acute care settings, and remain woefully uneducated about nursing homes and related facilities. Breaking down these venues into long-term, sub-acute, rehabilitation and other residential/assisted living care facilities may seem simplistic, however, many learners do not know about the system of long-term care, and do not understand the relative advantages and disadvantages of each type of facility. As enacted in the introductory vignette, the issue for clinicians often is not so much whether a rehabilitation facility would be *appropriate* for the patient, but whether the facility would *accept* the patient.

The module then addresses interventions an individual might make to work the system more broadly.

After the break, we discuss general system change and levels of change, from macro to micro. This is important, because one rationale people use for not engaging in system change is that only large changes are recognized and considered meaningful.

We then walk through a basic step of system analysis and change. First, we ask learners to reflect on the strengths and weaknesses of their institution. The dynamics of this discussion will vary, depending upon whether learners form a homogenous group or have come together from different institutions. Each type of group has its own advantages and disadvantages. In a homogenous group, it is easier to discuss concrete problems, as the group shares a common understanding of the institution. However, homogeneity may inhibit some from speaking freely in front of their peers or supervisors. Heterogenous groups allow more comparison. Learners may be surprised about the range of problems presented. The downside of a heterogenous group is that each learner struggles with unique circumstances in their home facility, so the group may lack a common context. Having identified strengths and weaknesses, the group moves on to brainstorm types of changes in end-of-life care they would like to see in their institution.

Then we frame choice among possible interventions in terms of balancing prioritization against feasibility. Often, these principles are in conflict. The most important thing to change may not be possible, and what is easy to do may be relatively unimportant. The discussion then moves on to tactics. Who are one's allies? How does one avoid insurmountable barriers? How does one advocate passionately without creating enemies? What simple data might be helpful? Data can be helpful as a needs assessment, as a way of making one's case, or as a means of measuring change once it has been initiated.

The information presented here is very basic, serving largely to awaken learners to the possibility of making change. This section could easily be expanded to one or more sessions. We recommend the website of the Center to Advance Palliative Care (CAPC) for readers who are interested in more detail on how to work the system to improve care for the dying (<http://www.capcmssm.org>). Another great resource is the book, *Improving Care for the End of Life* by Joanne Lynn and colleagues (Lynn et al., 2000; available through <http://www.medicaring.org>).

The last part of the module focuses on the individual learner. Any intervention that affects more than the patient one is currently caring for, is a form of system change. We discuss a handout listing potential changes well within the power of the individual to accomplish. Nowhere are goal cards more important than in this seminar. The module makes a strong case that everybody can be involved in system change to some degree. In writing out goals, learners have the opportunity to focus on one or two interventions that they might actually try. The teacher has a chance to evaluate the extent to which learners have accepted the content. He or she can offer feedback on specific goals, encouraging learners to make them concrete and feasible. It is therefore very important to make time for goal cards in this module.

END-OF-LIFE CARE CURRICULUM
Module 6: Venues & Systems of Care
Work Rounds Script

Scene: Work rounds outside the room of a terminally ill patient.

Players: Resident, intern and medical student.

Intern: (flipping open Vitals Sheet): “Mr. Young’s B/P is 110/70, pulse 90, temp 98.2, respirations: 20, 900 cc’s in and 450 cc’s out. O₂ Sat 93 on 2 Liters. No weight listed. He was in no acute distress this morning, sleepy, with clear lungs, regular rate and rhythm with bowel sounds present.”

Resident: “Yeah, great, great. What’s he still doing on our service? I’ve only got two days until change of service and we need to clear the board. He’s got no acute care needs. How’s placement going?”

Intern: “That’s the problem. I told him we’ve treated the pneumonia and he’s ready for discharge. But the family won’t take him home. They say they can’t take care of him. I tried to talk to him about a nursing home or a SNF or something, but he said there was no way in hell he’s going to a nursing home.” (Turning to medical student.) “Did you talk with that discharge planner yesterday, like we said? We need to get this guy packaged.”

Medical Student: “Uh, yeah. I talked with her. She said utilization review is breathing down her neck – we’ve got to get this guy out of here. She’s checking his eligibility and seeing what the options are. She wondered if maybe rehab or subacute might take him.”

Resident: “Good idea! Why don’t you get a consult to rehab and have the case manager check out sub-acute?”

Intern and student: “OK.”

Resident: “Let’s move on...”

END-OF-LIFE CARE CURRICULUM

Module 6: Venues & Systems of Care

Outline

Learning objectives

- Describe venues for ELC
- Navigate across care systems to meet needs of patient and family
- Utilize strategies for making system changes within your own institution
- Incorporate this seminar content into your clinical teaching

Venues for ELC

Hospice background

Myths and realities

Precepts

Hospice basics

Comparison to standard home care

Eligibility requirements

Financing

Not appropriate for every patient

Application exercise

Acute care

Options

What you can do

Subacute care

Options: strengths and weaknesses of subacute unit, nursing home/SNF, rehabilitation

Hope for the future: Inpatient hospice/palliative care wards

Application exercise

What you can do

Enlisting resources

Resources within your system

Community services

BREAK

Strategy for change

System change, large and small

Exercise: Assessment of home institution

Effecting system change

- Assess priority
- Assess feasibility
- Obtain buy-in

Measuring change

- Numerator/denominator
- Pre-post data
- Benchmarking against standards

Documentation and Appreciation

Application exercise

Summary and goals

Application

Examples of local change

Summary and goals

END-OF-LIFE CARE CURRICULUM

Module 6: Venues & Systems of Care

Medicare Hospice Benefits

Hospice services covered by Medicare Part A:

- Doctor services
- Nursing care
- Medical equipment (such as wheelchairs or walkers)
- Medical supplies (such as bandages and catheters)
- Drugs for symptom control and pain relief
- Short-term care in the hospital (including respite)
- Home health aid and homemaker services
- Physical and occupational services
- Speech therapy
- Social worker services
- Dietary counseling
- Counseling to help patient and family with grief and loss

Hospice services NOT covered by Medicare Part A:

- Treatment to cure terminal illness
- Care received from a different hospice that was not set up by the original hospice provider
- Care from another provider that is the same care provided by hospice

To qualify for hospice benefits:

Patient can receive hospice benefits through Medicare Part A as long as the physician and the hospice medical director certify that the following three conditions are met:

1. Patient's physician and hospice medical director certify that patient is terminally ill (life expectancy is 6 months or less)
2. Patient chooses to receive care from a hospice instead of standard Medicare benefits and signs a statement to that effect
3. Care is to be provided by a hospice program that is certified by Medicare

Length of hospice care:

- Hospice care is given in periods of care
- The physician must recertify the patient at the beginning of each period
- A patient may receive hospice care for two 90-day periods followed by an unlimited number of 60-day periods

Patient rights:

- Patient can elect to stop hospice benefits and return to their physician at any time (can restart hospice as long as meets the above qualifications)
- Patient can change hospice providers only once during each period of care

END-OF-LIFE CARE CURRICULUM
 Module 6: Venues & Systems of Care
Extended Care Options

	Strengths	Weaknesses
Subacute Unit	<ol style="list-style-type: none"> 1. Higher staffing ratio than nursing home or SNF 2. More complex care 3. Many people see ELC as subacute level 	<ol style="list-style-type: none"> 1. May not specialize in ELC 2. Your discharge planner may be unaware of a subacute unit specializing in ELC in your community
Nursing Home/ Skilled Nursing Facility	<ol style="list-style-type: none"> 1. Most Medicare will follow patient for 2 months after acute care admission 2. Hospice may follow patients in the nursing home 3. Recognized as appropriate for long term care 4. Some nursing homes specialize in ELC 	<ol style="list-style-type: none"> 1. Variation in quality of nursing 2. Nursing homes are required to have only one RN on duty 3. Lower staffing ratio 4. May not provide skilled ELC 5. Nursing homes are notoriously poor at medicating for pain and agitation (<i>e.g.</i>, 'chemical restraints') 6. May not be able to provide technologically complicated care
Rehabilitation	<ol style="list-style-type: none"> 1. Appropriate if there is a concrete rehabilitation goal 2. Increase independence & decrease skill need 	<ol style="list-style-type: none"> 1. If patient has no rehabilitation potential: failure, discouragement and loss of hope
Residential Care Facilities (Assisted Living)	<ol style="list-style-type: none"> 1. Excellent option if facility has experience and willingness 2. Number of facilities is growing rapidly 	<ol style="list-style-type: none"> 1. Requires hospice waiver 2. State laws may restrict availability of hospice in assisted living facility

Hope for the future: Inpatient hospice/palliative care wards: These are currently rare.

END-OF-LIFE CARE CURRICULUM
Module 6: Venues & Systems of Care
Questionnaire: Assessing the Institution

No matter how good your institution is in providing EOL care improvements can be made and you are a potential change agent. These questions are designed to help you understand where you might be of most help as a change agent.

1. My institution's greatest strength(s) in EOL care:

2. My institution's greatest weakness(es) in EOL care:

3. Name 2 or 3 changes you'd like to see in EOL care at your institution:

4. Self-assessment: I see myself as (check one):

_____ Having no ability to effect change in my institution

_____ A small ability to effect change in my institution

_____ A major change agent in my institution

END-OF-LIFE CARE CURRICULUM
Module 6: Venues & Systems of Care
Examples of Local Change

1. Educational system

- Develop formal & informal curriculum
- Use established curricula
- Create your own curricula
- Develop talks, handouts, laminated cards
- EPEC, Unipacs from AAHPM, other people's handouts
- Educational assessment
- Evaluate offered educational content for % and quality of EOL/palliative care issues
- Ask various rotation directors (also undergrad. medical schools) what handouts, papers, etc. address palliative care
- Sample educational forums listed below
- Textbooks in library, chief resident's office and clinic offices:
 - How many of these have quality palliative care content? (*e.g.*, what percentage of grand rounds overtly addressed a palliative care issue?)
- Feedback – collect information for important change agents: clinic chiefs, residency program directors, department chairs
- Incorporate EOL care issues into routine educational forums:
 - Residents Report, ICU Rounds, Morbidity and Mortality, Attending Rounds, Work Rounds, Journal Clubs, Clinic Teaching Sessions, Grand Rounds
- Hold 'in-services' for others involved in EOL care:
 - Nurses, Social workers, Pharmacists, Respiratory Therapists, Chaplains

2. Symptom management

- Review formulary related to commonly used palliative medications
- Assess local procedures to assess and record pain
- Institute pain as the fifth vital sign
- Assess how symptom management is included/or not on care plan by:
 - Physicians
 - Nurses
- Target a specific intervention:
 - Use of subcutaneous rather than IM shots of morphine
 - System of assessment/treatment of dyspnea
 - Increase use of a long-acting opioid for chronic pain
 - Address barriers to proper opioid use, such as local policies that actively discourage use, and frequent renewal policies
- Address common practices based on little if any data such as:
 - Chronic use of meperidine
 - Use of lorazepam as sole agent for nausea
 - Use of promethazine for opioid related nausea
 - Deep suctioning for patients with terminal pneumonia
- Access program to reduce waste of medications remaining after a patient's death

3. Decision making/communication

- Take a stand on assessment and documentation of patient preferences
- Set standards for yourself and those you supervise
- Include specific skills on a sanctioned procedure checklist for residents “observed,” “witnessed doing,” “performed independently”
 - Sharing bad news, addressing prognosis, pronouncing a patient & notifying family
- Model these skills to those you supervise
- Obtain and distribute brochures/documents (*e.g.*, DPAHC) in key areas, such as clinics
- Use a unique form of communication with patients, family (*i.e.*, email for forms of support)

4. Psychosocial

- Do an assessment of resources available for supporting patients and families in your community
 - Other agencies: disease-specific groups, ethnic support groups
 - Websites
 - Transportation
 - Bereavement support
 - Translation/cultural guide support
- Add a real social history to your H&P
- Check for documentation of psychological factors on admit notes (*e.g.*, documentation regarding possible depression, delirium)
- Not just what grandfather died of but patient’s hobbies and/or who were relevant people in the patient’s life
- Ask families of patients (especially in ICU) to bring in a photo of what the patient looked like when well, post in visible spot
- Add a profile of who the patient was to remind participants that the patient was more than pathologic tissue
 - Photo
 - Video
 - Statement
 - Poem
- Assess bereavement support in your facility, especially in areas with high-impact deaths, such as ER, transplant units, ICUs
- Work with allies to establish a policy that families of all patients dying in your facility receive a minimum of one bereavement follow-up call
- Work with your billing office to insure that once a patient dies, they are not then sent a bill

5. Spiritual

- Incorporate a spiritual assessment into your evaluation
- Identify resources for spiritual assistance for your patient population
- Provide telephone number, access list for clergy
- Reference books for patients/families who request

6. Venues

- Invite members of agencies with whom you work to come and teach you what they can offer or for educational material
- Identify key contact people within agencies with whom you work
- Set up listserv, email links between people at different venues to facilitate communication

- Visit a patient you know in one venue in a different venue

7. Awards

- Give awards to allies who are beginning to do something new
- ‘Special achievement’ awards from housestaff, ward team, clinic team, and residency program for the group/individual who made a special effort/achievement in something related to caring. (Note: it doesn’t take much effort to print an award for someone)
- Possible targets of awards: special caring nurses, social workers, case managers that made the most progress in incorporating EOL/palliative care into rotation

8. Research

- Model doing Medline searches for questions related to palliative care
- Add major palliative care websites to bookmark lists for resident room computers
- Review library holdings and request major palliative care textbooks and journals
- When hearing presentations on research, which could have important implications for palliative care, ask specific questions; *e.g.*, “How were the quality of life issues addressed in this study?” “How do researchers think this new finding might result in less suffering?”
- Do a small study or review of a palliative care issue

9. Spontaneous EOL care: making a difference in a moment

- Model treating a severe symptom, such as pain, as a medical emergency
- Model spending as much time with a dying patient as with a patient who has a ‘fascinating diagnosis’
- Sit down
- Model listening
- Ask a family member to bring in a photo and place it in a conspicuous place
- Speak up politely yet firmly when people say something (*i.e.*, “He’s just here for pain control, just an old guy dying, just here for placement,” or “The DNR in Room 37.”)
- Model good documentation in assessing patient preferences or pain assessments
- If there is no other way to obtain it, BUY a good textbook and donate it, conspicuously, in an area actually used by residents.
- Make a statement regarding YOUR priorities to those you supervise and also to your supervisors:
 - “Working to provide good care at the end of life is a priority for me.”
 - “I’m trying to carefully document patient preferences on all seriously ill patients”
 - “There are more important things than placement”
 - “Trying to provide excellent symptom management is as important to me as is getting the right diagnosis”
 - “I keep trying to see the person behind the patient behind the disease.”
- Encourage public awareness of ELC issues:
 - Write letters to the editors of newspapers publishing articles on EOL care
 - Volunteer to speak to community organizations about aspects of end-of-life care

END-OF-LIFE CARE CURRICULUM
Module 6: Venues & Systems of Care
Bibliography

- Berwick DM. From victim to leader: Physicians as agents of change, ACP-AIM Annual session. Keynote address to opening ceremony, New Orleans, LA, April 22, 1999.
- Hallenbeck JL, Bergen MR. A medical resident inpatient hospice rotation: experiences with dying and subsequent changes in attitudes and knowledge. *Journal of Palliative Medicine* 1999; 2:197-208.
- Hallenbeck J. Building or expanding palliative care in the department of Veterans Affairs Healthcare System, Planning a hospital-based palliative care program: A primer for institutional leaders, Alexandria, VA, March 12, 2001.
- Levinsky NG, Yu W, Ash A, et al. Influence of age on Medicare expenditures and medical care in the last year of life. *JAMA* 2001; 286:1349-55.
- Lynn JA, Wilkinson AM. Quality end-of-life care: The case for a MediCaring demonstration. *Hospital Journal* 1998; 13:151-63
- Muir JC, von Gunten CF. The Palliative Care unit as a Focus for Professional Education. In: Portenoy RK, Bruera E, eds. *Topics in Palliative Care*. Vol. 4. New York: Oxford University Press, 1998; 131-46.
- Naierman N. Debunking the myths of hospice. *Choices: The newsletter of choice in dying* 1998; 7:1,4.
- Perron V, Schonwetter R. Hospice and palliative care programs. *Primary Care* 2001; 28:427-40.
- Robinson BE, Pham H. Cost-effectiveness of hospice care. *Clinics in Geriatric Medicine* 1996; 12:417-28.
- Standards and Accreditation Committee Medical Guidelines Task Force. Medical guidelines for determining prognosis in selected non-cancer diseases. Arlington, VA: The National Hospice Organization, 1996:6-26.
- Task Force on Palliative Care. Precepts of palliative care (National Policy Statements in End-of-Life Care). *Journal of Palliative Care* 1998; 1:109-12.
- VanGeest JB. Process evaluation of an educational intervention to improve end-of-life care: The Education for Physicians on End-of-Life Care (EPEC) program. *American Journal of Hospice & Palliative Care* 2001; 18:233-8.
- von Gunten CF, Ferris FD, Kirschner C, Emanuel LL. Coding and reimbursement mechanisms for physician services in hospice and palliative care. *Journal of Palliative Medicine* 2000; 3:157-64.

End-of-Life Care Curriculum for Medical Teachers

TEACHING TIPS

MODULE 7: PSYCHIATRIC ISSUES & SPIRITUALITY

Companion to Module 7 PowerPoint Presentation

James Hallenbeck, MD
Sara Katz, PhD
Georgette Stratos, PhD

END-OF-LIFE CARE CURRICULUM
Module 7: Psychiatric Issues & Spirituality
Table of Contents

Title and credits

Teaching tips

Introduction
Attitude Objectives
Knowledge Objectives
Skill Objectives
Module Walk-Through
Self-Rating Exercise

Handouts

7.1 Outline
7.2 Pharmacotherapy Anxiety and Depression
7.3 Self-Rating
Bibliography
(Provide 3x5 Cards for Goals)

TEACHING TIPS

Module 7: Psychiatric Issues & Spirituality

Introduction:

This final module addresses psychiatric and spiritual aspects of end-of-life care (ELC). Originally, the title for the module was Psychosocial and Spiritual Issues. Some trainees objected to this title for a variety of reasons, such as a relative lack of focus on ‘social’ issues. The use of the term ‘psychiatric’ is still problematic. It may imply a focus on psychopathology, whereas some of the material addressed here, (*i.e.*, grief) is perfectly normal. It also suggests a more medical focus to psychic aspects of end-of-life care. The inclusion of spirituality as a domain was similarly controversial.

Some have argued that spirituality does not belong in a course for physicians. Others, including members of our Curriculum Advisory Board, believe this is *the* most important content area to address. The discussion of delirium in the module is controversial, suggesting a differentiation between ‘terminal’ delirium and (by default) ‘non-terminal’ delirium. When such distinctions are made in the literature, there is considerable disagreement about their usefulness. Experts disagree on approaches to altered states of consciousness at the end of life. It was tempting to omit this entire topic area, except that our impression is that the greatest suffering experienced in dying relates primarily to psychic distress, whatever that might be. This domain does offer rich potential for growth at the end of life. If there is such a thing as a ‘good’ death, it is to be found here, not simply through the absence of physical pain and suffering.

Given the strong opinions these topics evoke, we have found it essential in this module to focus on what is important to the patient and family. Nowhere is this clearer than in the discussion of spirituality. In our experience, teachers and learners tend to veer off into their own belief systems, whether these beliefs reflect strong religious or spiritual values, atheistic beliefs, or a (common) belief that science and the practice of medicine should be assiduously separated from religion and spirituality. This is entirely natural. Whatever this realm is called, it is here that we hold our core beliefs and values most dearly. Often, we had to remind participants, “This is not about you. It is about what is important to the patient and the family.”

We also discuss such phenomena as pre-death visions, in which patients see deceased relatives or angels. As with the discussion of spirituality, we attempt to maintain a neutral stance about whether something is real or true. We are not suggesting that people should be any more or less ‘spiritual’ than they already are, and we do not comment on whether angels or deceased relatives are actually in the patient’s room. We hope this curriculum applies to anyone. Because such experiences and beliefs are very real to patients and families, we need to deal with them in a respectful manner. In doing so, we hope to minimize suffering and increase the chances the patient and family will experience a ‘good’ death, whatever that means to them. We have no choice but to deal with these topics, as they are central to the experiences of our patients and families.

Attitude Objectives:

Presumed Attitude	Desired Attitude
Psychological and spiritual aspects of end-of-life care are outside the scope of physicians' practice	Psychological and spiritual aspects of end-of-life care are integral to physicians' scope of practice in end-of-life care
The only way to treat delirium is to remove or withhold possibly offending agents and re-orient the patient, if possible	Not all delirium is effectively treated in this manner. Terminal delirium is often irreversible and may require some degree of sedation
Depression is inevitable and a normal part of dying	Depression is not inevitable in dying and is highly treatable

Knowledge Objectives:

Knowledge of:

- Prevalence and special characteristics of depression, anxiety and delirium at the end of life
- General therapeutic approaches for the above
- Characteristics of grief – anticipatory and complicated grief, bereavement, and the physician's role in addressing all these
- Patient's interest in discussing spiritual concerns with physicians

Skill Objectives:

Skill in:

- Distinguishing between grief and depression
- Choosing among common agents in the treatment of depression and anxiety
- Distinguishing between terminal and non-terminal delirium
- Using the FICA acronym to do a spiritual assessment

Module Walk-Through:

Negative Fantasy Death

After introductory remarks, the icebreaker is another 'fantasy' death exercise. However, unlike the exercise in Module 1, this is a 'negative fantasy death' in which participants can express concerns about dying. Even without any possible physical discomfort, it is not hard for learners to imagine a very undesirable death. They tend to describe places and situations they would like to avoid, such as dying in an ICU, in a nursing home, or being alone, isolated or confused. The key point in this exercise is to help learners understand that what they (and most dying people) fear is not just physical discomfort. Matters of the mind, such as loss of control, isolation and loss of self, are in many ways the most frightening things about dying. Through this exercise, we hope that learners will expand their empathy for patients and families who are struggling with dying, and will understand better the importance of emotional or mental aspects of suffering at the end of life.

Case Example

After Objective and Agenda slides, the module begins with a case, which may feel safer to learners than the 'negative fantasy death.' Learners consider the differential diagnosis for a patient facing away from

them in bed. This behavior could point to a variety of problems, many of which we will cover in this module. Is the patient depressed, anxious, delirious, grieving, experiencing spiritual distress, or just very tired as a component of normal dying? The teacher can refer to this case as new topics come up. This brief case also eases learners back from their fantasy roles as dying people to more comfortable roles as clinicians. Empathy for patients in psychic distress is vital.

Depression

The first major topic is depression. The point of this section is: depression, while common at the end of life, is not inevitable and is highly treatable. Many learners have heard of Kubler-Ross's 'five steps' in dying – denial, depression, anger, bargaining and acceptance. While very helpful historically, this implies that depression is inevitable and only a stage that the patient goes through on the way to acceptance. More recent literature shows that depression is not inevitable at the end of life, and often responds to treatment. Most important, in dying patients who are depressed, therapy is often a race against time. If the onset of action of an antidepressant is 2 weeks and that is the patient's life expectancy, the medication will do little good. The other key point (equally applicable to the topic of anxiety) is to ask *why* the patient might be feeling this way. Special concerns come up at the end of life, resulting in situational depression (or anxiety), for which the best therapy may be changing the situation, if that is possible. For example, a patient may be depressed because he or she did not have time to meet and reconcile with a long-lost family member. If a meeting is desired, facilitating it may be the most effective means of treating the depression. We give some suggestions for diagnosing depression and differentiating it from commonly overlapping grief reactions. Unfortunately, there is not yet a validated instrument for diagnosing depression in dying patients.

Anxiety

The discussion of anxiety is brief. Again, the key point to stress is *why* the patient is anxious or fearful. While anxiety may be part of a more general anxiety disorder, many special concerns arise at the end of life that can best be addressed by educating the patient and family. For example, we have found that many patients who have achieved some degree of acceptance (using Kubler-Ross's terminology) are very concerned or anxious about *how* they will die. Discussing this concern often has a calming effect. Reassuring the patient and family that most deaths are peaceful, and that symptoms are usually quite manageable, often alleviates fears of uncontrollable pain, dyspnea or agitation.

Altered States of Consciousness at the End of Life

The section on delirium addresses altered states of consciousness at the end of life. This topic is challenging, as there is a lack of agreement on proper terminology. The word 'delirium' clearly suggests a negative state of consciousness. Some altered states at the end of life seem quite pleasant. Many patients who report visits by deceased loved-ones find such visitations reassuring. We suggest a distinction between *terminal delirium* and *non-terminal delirium*. Others have used expressions such as *terminal distress*. Whatever the language used, the main points here are:

- Distressing altered states of consciousness (delirium) are common at the end of life.
- Treat reversible forms of delirium. However, as death approaches, delirium becomes less reversible.
- Standard treatment, (*e.g.*, withholding offending drugs and correcting metabolic abnormalities) may not work in terminal delirium and may cause real harm (*e.g.*, by withholding needed opioids).
- If re-orientation is not possible and if a patient close to death is distressed, then it is reasonable to consider some degree of sedation for patients.

Grief and Bereavement

Next we address the topic of grief, going through a list of ‘myths’ and then discussing anticipatory grief and bereavement. The major attitude objective here is helping learners understand that grief is present in many medical encounters. A basic understanding of grief processes is essential for good clinical care. In addressing bereavement grief, a more specific objective is helping learners understand that their work as clinicians does not necessarily end with the death of the patient. Bereavement grief, especially complicated bereavement, is a major health risk. While psychologists and others may offer formal counseling for bereaved individuals, physicians have special roles in caring for the bereaved, *i.e.*, explaining the results of an autopsy, or helping a grieving family member re-think a sequence of care decisions that were made. This is followed by a brief discussion of physician losses, both professional and personal. The obvious point is that it is not just patients and families who grieve. We all grieve.

Spiritual Aspects of Care

After the break, we address spiritual aspects of care. We have attempted to take a matter-of-fact approach to this difficult topic. Evidence is presented that spirituality in some form is important to many patients, who wish they could discuss this with their physicians. However, few physicians attend to this level of patient experience. We also suggest that clinicians have to address spirituality in some way, because questions such as, “Why did God do this to me” are inevitable.

As mentioned earlier, it is very important in this section to remain neutral about the value of spirituality *per se*. We are not trying to convince people to be any different than they are. While teacher or learner spirituality may assist them in their clinical care and to appreciate the importance of spirituality, again, it is not about you. It is about what is important to the patient and family. We repeat this as, even having made this point, we have observed teachers make comments like, “You are all spiritual people”. While this person has every right to this opinion, we discourage such comments as, frankly, not everybody agrees about this. Such a remark, well-intended though it undoubtedly was, might offend some learners, resulting in their rejecting the skill training that follows.

Spiritual Assessment and Skills Practice

We then introduce a simple tool for conducting a spiritual assessment. In dealing with a controversial topic that tends to float off into abstractions, we found it useful for beginners to be very concrete. The point is that spirituality is important to many people, especially toward the end of life. Therefore you have an obligation to assess this to see how you might help.

As with any acronym, there is a certain artificiality about FICA. The point is to give beginners some sort of tool. All patients toward the end of life should undergo some spiritual assessment. Equally important is developing a set of *scripts* to fall back on, when a patient or family member raises an issue of spirituality in the context of everyday care. For example, a patient might express her faith that she is going to a better place when she dies. The clinician might respond with a modified FICA saying, “It sounds like your faith is very important to you. Are you part of a faith community?”

FICA is then practiced in dyadic role plays. The module gives learners the choice of who they would like to portray. This gives them permission *not* to discuss personal beliefs, if they prefer. In practice, most learners choose to be themselves. In the debrief session, most ‘clinicians’ will note on how easy the exercise was, and most ‘patients’ will say how nice it was to talk about what was really important to them.

If providing a ‘demo’ role play, it can be fun to do with someone who takes an atheistic stance. While questions of community and assistance rarely come up, it can be amazing to see how easy it is to adapt FICA to any stance. Most relevant to the dying person is how to make sense of one’s own dying. If

approached respectfully, most people very much appreciate clinicians' attempts to understand how they view the world. This understanding is at the core of people's being and sense of self. There are few better ways to make a connection with people.

Self-Rating Exercise

After the summary and goal cards comes a review of the entire course. This could be done in many different ways. We have chosen to ask learners to assess their own abilities after taking the course, as compared to when it began. We compare their initial assessment scores to new self-rating scores. This is not for formal research but for participants to reflect on the complex process of learning. A conundrum for all learners is, "We don't know what we don't know." In learning new content during the course, it is a common experience for learners to realize how little they actually know.

This is not a comprehensive course, teaching learners "everything they wanted to know" about death and dying. Our hope is to facilitate development of some basic competencies. More importantly, we hope participants will incorporate these domains into their self-directed learning, over a lifetime of professional practice. Some spark will help learners to see the person behind the patient behind the disease.

END-OF-LIFE CARE CURRICULUM
Module 7: Psychiatric Issues & Spirituality
Outline

Learning objectives

- Identify and treat depression, anxiety, delirium, & grief at the EOL
- Demonstrate the ability to take a spiritual history
- Define possible physician roles in the spiritual life of the patient
- Incorporate this seminar content into your clinical teaching

Psychosocial aspects of care at the end of life

- End-of-Life Depression
Assessment and differential diagnosis
Depression screen
 - “Do you find yourself depressed most of the time?”
 - “As compared to other people in your situation, do you feel that you are depressed?”
 - “Inside yourself, how do you feel about yourself?”Risk factors
Interventions
- Anxiety
Assessment
 - “What is worrying you?”
 - “Do you know what you are anxious about?”
 - “Are there particular things you’re worried about?”
 - “Are you scared of what may happen to you?”
 - “Is there something you’re worried that we might do?”
 - “Are there important things we need to know to do or not to do?”Interventions
- Delirium: Terminal confusion very close to death
‘Terminal delirium’
Assessment
Interventions
Confusion without distress
- Grief
Myths and realities
Preparatory grief
Bereavement
Physician loss

BREAK

Spiritual aspects of care

Definition
Spiritual Assessment Tool: FICA
Application exercise

Summary and goals

END-OF-LIFE CARE CURRICULUM
 Module 7: Psychiatric Issues & Spirituality
Pharmacotherapy Anxiety and Depression

Antidepressants

General tips:

- Choose by time to effect
- Start low & go slow

1. Tricyclics/Atypicals

- Advantage:
Documented co-analgesic effect, especially in neuropathic pain
- Disadvantages:
Time to onset
Side effects

	Desipramine	Nortriptyline	Amitriptyline	Trazodone	BupropionSR
Sedation	low	mild	high	high	low
ACH	low	mild	high	none	none

2. Serotonin-specific reuptake inhibitors (SSRIs)

- Advantages:
Speed of onset is a major advantage of SSRIs over TCIs
Well tolerated
- Disadvantages:
Less clear that they have a co-analgesic effect
Less effective against neuropathic pain

	Fluoxetine	Sertraline	Paroxetine
Sedation	low	low	low
ACH	none	none	low

3. Psychostimulants: Methylphenidate, dextroamphetamine, pemoline

- Advantages:
Quite safe
Cardiotoxicity is uncommon with low doses
Rapid onset of action – within 24 hours
Stimulates appetite (gives energy to eat)
- Disadvantage: Contraindicated in depression associated with anxiety or delirium

Anxiolytics

1. Benzodiazepines

May worsen delirium in people prone to it

2. Buspirone

Good anxiolytic in delirium-prone
5-10 days to effectiveness

END-OF-LIFE CARE CURRICULUM
End of Seminar Series
Module Content and Self-Rating Exercise

1. Death & Dying in the U.S.A.

Who dies where, how and when
Patterns of dying and related issues of prognosis
Implications for physicians
The last 48 hours - physical and mental changes
Physician tasks in caring for patients and families

2. Pain Management

Demographics - Pain in the dying
Barriers to effective pain care
Assessment of pain
Non-pharmacological approaches
Total Pain
Pharmacological strategies for alleviating pain
 Pain Medications
 Neuropathic pain
 Nociceptive pain
 Non-steroidal anti-inflammatory drugs
 Combination drugs
 Opioids
Using opioid conversion tables

3. Communicating with Patients & Families

Challenges to EOL communication
Techniques critical to EOL communication skills
Communication skills
 Sharing bad news
 Death pronouncement
 Death notification by telephone

4. Making Difficult Decisions

Difficult decisions at the end-of-life
Preferences and decision-making
When conflict arises
Difficult decisions regarding hastening death
Strategies for responding to requests to hasten death

5. Non-Pain Symptom Management

Symptom Definition
Symptom analysis - the patient's perspective
Nausea and vomiting
Dyspnea
Terminal syndrome characterized by retained secretions
Cachexia/anorexia/asthenia

6. Venues & Systems of Care

Venues for ELC
Enlisting Resources
Strategies for system change
Assessment of home institution
Examples of local change

7. Psychiatric Issues & Spirituality

Psychiatric aspects of EOL Care
 Depression
 Anxiety
 Delirium: Terminal confusion very close to death
Grief and bereavement
Spiritual aspects of care
 Spiritual assessment tool

(Self-Rating Scale: 1 = Low to 5 = High)

KNOWLEDGE, SKILLS & ATTITUDES

	1	2	3	4	5
1. Death & Dying in the U.S.A.					
2. Pain Management					
3. Communicating w/ Pts & Families					
4. Making Difficult Decisions					
5. Non-Pain Symptoms					
6. Venues & Systems of Care					
7. Psychiatric Issues/Spirituality					

CONFIDENCE TO TEACH

1	2	3	4	5

END-OF-LIFE CARE CURRICULUM
Module 7: Psychiatric Issues & Spirituality
Bibliography

- Block SD. Assessing and managing depression in the terminally ill patient. ACP-ASIM End-of-Life Care Consensus Panel. American College of Physicians - American Society of Internal Medicine. *Annals of Internal Medicine* 2000; 132:209-18.
- Doka K. Shattering eight myths about grief. Hospice Foundation of America. 2003; <http://www.hospicefoundation.org>.
- Fainsinger RL. Treatment of Delirium at the End of Life: Medical and Ethical Issues. In: Portenoy RK, Bruera E, eds. *Topics in Palliative Care*. Vol. 4. New York: Oxford University Press, 1998:261-77.
- Prigerson HG, Jacobs SC. Perspectives on care at the close of life. Caring for bereaved patients: "All the doctors just suddenly go". *JAMA* 2001; 286:1369-76.
- Puchalski CM. Spirituality and end-of-life care: A time for listening and caring. *Journal of Palliative Medicine* 2002; 5:289-94.
- Puchalski CM, Larson DB. Developing curricula in spirituality and medicine [published erratum appears in *Academic Medicine* 1998 Oct;73(10):1038]. *Academic Medicine* 1998; 73:970-4.
- Random House (Firm). *Random House Webster's college dictionary*. New York: Random House, 1999:xxviii, 1571.
- Waring N. Physician loss, grief, and healing. *HIPPOCRATES* 2000; 14.

End-of-Life Care Curriculum for Medical Teachers

TEACHING TIPS

MODULE 8: INSTITUTING CHANGE

Companion to Module 8 PowerPoint Presentation

James Hallenbeck, MD

Sara Katz, PhD

Georgette Stratos, PhD

END-OF-LIFE CARE CURRICULUM

Module 8: Instituting Change

Table of Contents

Title and credits

Teaching tips

Introduction

Attitude Objectives

Knowledge Objectives

Skill Objectives

Module Walk-Through

Self-Rating Exercise

Handouts

8.1 Outline

8.2 Samples of 8th Seminar Reports

8.3 Bibliography

(Provide 3x 5 Cards for Action Plans)

TEACHING TIPS

Module 8: Instituting Change

James Hallenbeck, MD, Sara Katz, PhD, Georgette Stratos, PhD

Introduction:

In the systems change half of Module 6: Venues & Systems of Care, we lead an exercise in which learners assess their home institution's ELC practices and target areas for change in improving how ELC is delivered and taught. The 8th module provides a more specific strategy to bring these concepts home and into action at your institution: the participative problem-solving approach to educational change.

This final session provides a forum in which participants generate key recommendations for changing the institutional ELC environment, identify individuals responsible for implementing these recommendations, and follow up with an action plan. Participants also discuss strategies for monitoring the success of these implementation strategies. Our experience with these sessions has shown that they can be a powerful catalyst for organizational change (Stratos et al, 1997).

This module feeds back the institutional goals participants have generated at the end of each of the other modules, as a basis for making concrete changes at the local level. If you are teaching the entire series, be sure to collect copies of the personal goal cards generated at the end of each seminar. From these, compile a list of the all the institutional goals your participants generated throughout the series. Bring this list to the 8th seminar, to use as a basis for brainstorming institutional recommendations. If you wish to use Module 8 without having taught the entire series, begin the process with the handout of examples generated by groups in various institutions. In any event, it will be useful to review the Tips for Module 6 before conducting Module 8.

Attitude Objectives:

Presumed Attitude	Desired Attitude
The greatest effect I can have on my patients' health is through the exercise of my medical knowledge and skills.	Good health care outcomes for patients and families also depend on me and my colleagues to change the system.
I do not have the skills, energy, or power to solve problems in the way in which ELC is delivered.	Especially in concert with allies, I can make a difference in the way ELC is taught and/or practiced.

Knowledge Objectives:

Knowledge of:

- Key steps in implementing system change

Skill Objectives:

Skill in:

- Identifying systems issues that might be addressed
- Strategic planning for systems change

Module Walk-Through:

Brainstorming Phase

The process starts with a brainstorming phase. Beginning with a list of the institutional goals members had set at the end of each seminar (if they participated in the whole series) and/or the handout providing examples of strategic planning from other ELC seminar groups at a variety of institutions, learners are asked to come up with anything they can think of that would improve ELC at their institution – without censoring any ideas, including their wildest dreams for perfect end-of-life care practice and education. The teacher writes these goals verbatim on the whiteboard or pages of an easel board, giving the group time to spark each other's ideas.

Evaluation Phase

The teacher then facilitates an evaluation phase during which the group assesses the importance and feasibility of each of the goals mentioned. Different methods can be used to achieve consensus regarding the top three to five recommendations for Instituting change.

During the evaluation phase, the participants may choose to refine the list by establishing broad sorting groups to help them structure the rating process to come (*e.g.*, education, administration, volunteers, etc). Once the list is organized, the group can assess both the importance and the feasibility of each idea. Those recommendations that meet the importance and feasibility criteria can then be rated and ranked to identify the top three to five.

Reaching Consensus

“Consensus means coming to an agreement. Creating consensus in a team setting means finding a proposal acceptable enough that all team members can support it, with no member opposing it. Consensus includes polling opinions, listening effectively, discussing ideas and differences, not getting what you want, and coming to an agreement that everyone ‘can live with.’ Consensus is not a unanimous vote, majority or minority rule, one-person rule, or bargaining.” (Workforce Performance, April 1999)

The multi-voting method of reaching consensus involves giving each learner a number of votes (no more than 1/2 or 1/3 of the total items listed) to be cast for the goals they would most like to see realized. Members use colored dots, highlighters, or pens to vote for the items they perceive as best on the list. Traditionally, members may cast only one vote per item. Items receiving votes from half or more of the group are circled. The process repeats, with members casting limited votes for the best of the remaining circled items. The team continues multi-voting until it reduces the list to three to five items. In a variation of this technique, people are free to cast multiple votes for a single idea if they wish. Multi-voting reduces a list containing a large number of items to a manageable few.

Strategic Planning

Once the top recommendations have been identified, the group discusses strategies for implementing

them. The discussion explores potential allies or key players in helping to realize these goals; barriers to their implementation; and realistic time frames to accomplish them. Short- and long-term planning is also valuable (*e.g.*, 3-month, 6-month, and 12-month plans). Other key questions include:

- How could we obtain buy-in here to make this happen?
- How can we build on existing strengths?
- What steps or tasks need to be undertaken?
- Who here would be willing to be on the work group for this goal?
- Who in this work group will take responsibility to make sure it happens?

Backwards Planning

Backwards planning is a time management strategy designed to maximize the success of a project. It can be useful in strategic planning for the group to imagine that a particular goal has been accomplished and, starting from there, work back to the present. Make a list of tasks that must be completed to achieve the goal. Start with the last task to accomplish before the goal is met. Give it an appropriate date, and then consider its components. If there are component tasks which need to be completed, work backwards with them, and setting realistic time frames, proceed with the next to the next-to-last task to be completed, and so on. Decide who will take responsibility for the steps of each goal. For instance, if 3 participants take on a task, one of them agrees to report back to the teacher on the results.

Measuring Change

The next phase of the session is to identify monitoring strategies to evaluate progress toward achieving the goals. How will the group know they've been successful? Small work groups, each with a monitor, can be formed. Make a plan to meet again or to communicate with the group in 3, 6, and 12 months about what has been accomplished on each of the key goals. The group may decide to collect evaluation data (*e.g.*, numerator/denominator statistics, pre/post data, measure benchmarks against standards), while recognizing that much important change may not be obvious (*e.g.*, gradual shifts in attitude). A simple numerator/denominator statistic can convey important information; however, the group should be aware of the danger of setting impossible goals with this tool, and setting themselves up for failure. Pre/post data demonstrate the relative power of an intervention. Finally, it often helps people understand their own system if local data are compared to either published standards or 'standard of care' statistics.

Measuring change can be a powerful tool in effecting change itself. It allows people to see what has been accomplished, creates tension to promote buy-in, and can facilitate adjustment required to improve results.

Conclusion: Promoting the Cycle of Change

The session concludes with a discussion of methods for reinforcing recommended changes. How will we sustain these changes? In-house newsletter announcements, achievement awards, newspaper article, research reports in journal articles are possibilities. To promote the cycle of change, the group will need to insure that positive efforts are recognized and rewarded.

Participants in the ELC seminars have been able to accomplish many changes in their institutions. Many report that their early efforts, although modest, have led to other improvements, such as development of publications, multidisciplinary teams, multi-site interventions, and more ambitious research projects. Small successes can cycle into further advancements. Failures can raise awareness of obstacles, and foster reformulation of goals and strategies.

The “8th session” is designed to assist participants in taking ownership of the process of Instituting change. Different groups do it in different ways. This module provides the ‘payoff’ for the SFDC ELC Curriculum and for any efforts to improve end-of-life care in a given setting. As Les Morgan, of Growth House, Inc. (<http://www.growthhouse.org>) signs off on his e-mails: "You must be the change you want to see in the world"

-- Mohandas K. Gandhi

END-OF-LIFE CARE CURRICULUM

Module 8: Instituting Change

Outline

Learning objectives

- Apply a consensus model to generating realistic goals for improving end-of-life care at your institution
- Plan for realistic changes in the way end-of-life care at your institution
- Understand strategies for promoting the cycle of change

Brainstorming improvements

Evaluating goals

Reaching consensus

Measuring change

Conclusion: Promoting the cycle of change

END-OF-LIFE CARE CURRICULUM

Module 8: Instituting Change

Samples of 8th Seminar Reports

From an Inner-City County Medical Center

Desired Changes:

- Help nurses to provide environmental changes at EOL
- Make rooms more comfortable and homelike for families and patients at EOL
- Increase recognition of dying patient and increase acceptability of palliative care
- Teach housestaff and colleagues to recognize futility of further treatment and need for comfort
- Get institutional commitment to assess and control pain in a competent and rational way
- Get S.Q. MS and dilaudid drips and 15 mg MS Contin here
- Privacy
- Training session for more MDs and housestaff
- Formalize educational process around death pronouncement
- Ask for time (long visits) and location to talk to patients and family about durable power of attorney and patient wishes
- Support ELC development among med center faculty in general
- Track assisted suicide controversy and federal legal changes
- Promote institutional mindfulness of goal setting and personalizing care in accord with patients' wishes and values
- Consultation service to assist with difficult decisions at EOL
- Documentation leads to billing for time for family discussion
- Clarify need for IV access in terminal hospitalized patients
- Get fans
- Support efforts to establish ELC consult service
- Designated area beds
- Discuss with housestaff how to approach EOL discussions
- More social workers as a conduit
- Support groups for staff
- Review available bereavement services
- Hospice-Hospital collaboration

Targeted Goals:

- Palliative Care Consult Service
 - Start with assessment questionnaire of inpatient caregivers
- ELC noon conferences
- Intern Introduction Series to include ELC
- Train pharmacy students on medicine service
- Laminated ELC cards for house officers
- Advocate for institutional goals and policy change to support improved ELC:
 - Pharmacy
 - Admissions
 - UR
 - Nursing administration
 - Create quiet space for talking with families

From a Community Hospital

I began by passing out a list of the institutional goals that had been recorded on the goal cards during each of the seminars. The goals were reproduced verbatim. I also included the list of opportunities for change that had been generated during the brainstorming session of Module 6, Venues & Systems of Care. First, we grouped goals into common themes:

Education

Communication

Interdisciplinary (primary care/oncology, nursing/MDs)

Consult service for palliative care

Support

Under educational goals, we identified both educational venues and the topics that would best fit in each venue. These included noon conferences, morning reports, Grand Rounds, nursing inservices, and patient/family education. A special subset of noon conferences is the Emergency Medicine Series, which is delivered to the new housestaff in July each year. In addition, each house officer is issued a handheld computer. We felt that topics such as pain, non-pain symptoms, and venues of care could be taught in a larger group setting, whereas topics such as communication and cross-cultural awareness were better taught in settings with fewer attendees. The handhelds could have an opiate conversion table and acronyms (*i.e.*, GOOD for discussing goals of care, VOMMIT for causes of nausea) installed on them.

We lumped the communication and interdisciplinary goals into one group. Communication, or lack of communication, between primary care and oncology was a common theme during our seminars. Many of us identified communication of prognosis and determining the goals of care as areas in need of improvement. We decided to begin this process by networking with an oncologist who had an interest in EOL and had taken the EPEC course. Another idea was to have some sort of primary care or palliative care representation at tumor board.

We are in the fortunate position of working at an institution where many of our colleagues are interested in ELC. Work is already being done to establish a palliative care service here. The goals of this service would be to facilitate communication between patients, family, and medical staff, to educate the staff in palliative care, and to assist in providing palliative care to patients and family.

We discussed the need for improved grief and bereavement support for physicians, staff, and family. There have been a few grand rounds related to this area in the past year – one on physician burn-out, another on stress during residency. One set of goals related to establishing a forum for physicians to discuss psychological and emotional issues, such as a regular lunch with a psychologist. We questioned, though, whether this would be feasible given the time constraints on all our schedules. We also debated how to avoid stigmatizing such a forum. One suggestion was to find out what kinds of support programs work and are in place in other residency programs (family practice, psychiatry).

We did not formally reduce the list to a top 10 or top 5 list, but we did spend a portion of our time determining which goals were both important and feasible, and we assigned a champion to implement and monitor the goals.

Education – Dr. R. will work on creating a monthly noon conference series in ELC. We identified at least 11 faculty members in the department who have either some training or interest (or both) in the field, so if each of us gave one conference each year, the schedule would be filled. We believe there is an opening for a new noon conference series. Dr. R. will also investigate the results of a recent attempt to incorporate palliative care sensitivity into morning report. Dr. L will work on having an opioid equivalence table installed on the handheld devices issued to the housestaff at the beginning of the year.

Communication – The primary care division's monthly educational meeting would be an excellent forum for discussing ways to improve inter-specialty communication, advance planning, and palliative care. Dr. O, who organizes these meetings, will make these arrangements, and will talk with Dr. H about having a palliative care representative at tumor board. Many questions, including whether

the institutional culture is ready for a palliative care voice on tumor board, need to be answered before this particular goal could be implemented.

Palliative Care Consult Service – The Dept. of Medicine/Division of Primary care has hired one of our graduating residents. One half-day of her time will be dedicated to developing palliative care services. We were therefore hesitant to set specific goals in this area without first determining what is already being planned. Dr. G agreed to contact Dr. H to discuss her goals and how this group could help with achieving those goals.

Support – Dr. G agreed to take on the implementation of this goal as well. The specific tasks assigned to her were:

- 1) to assess the need for loss and bereavement support among residents, primary care/internal medicine faculty, and the rest of the medical staff (in that order)
- 2) to contact the chief resident who has an interest in resident stress
- 3) to determine if other programs have any sort of curriculum for psychological support
- 4) to see if any funds are available in the division or department to pay for either a psychologist or food (*i.e.*, a support group dinner).

We made no specific plans to meet again, but I intend to meet either as a group or individually with each participant in about six months to see what progress has been made.

From a VA Medical Center

Targeted Goals:

- Revise and improve Palliative Care Team meeting report
 - Discipline-specific focus group to discuss what are needs of each discipline and of the larger group
- Hire social worker for Supportive Care Unit and palliative care patients
 - Explore foundation grants
- Nursing CEU program
 - Symptom assessment, communication issues
 - Several group members will be asked to serve as speakers
- Support groups for Nursing Home Unit
 - To address staff burnout
- Bereavement program
 - Send out packet (need updating from GRECC) – use SW intern
 - Memorial service 2xyr
 - Support group for families
 - Conquer transportation problems
- Other items:
 - More palliative care time for Dr. X
 - Clinic palliative care assessments
 - Send this list to VAMC Director

END-OF-LIFE CARE CURRICULUM

Module 8: Instituting Change

Bibliography

Adelson R, Hepburn K, Vanloy W. Performance Change in an organizational setting: A conceptual model. *Journal of Continuing Education in the Health Professions* 1997; 17:69-79.

Delbecq AI, Van de Ven A, Gustafson D. Group decision-making in modern organizations. In: *Group Techniques for program planning*. Glenview IL: Scott, Foresman and Company, 1975: 1-15.

Lazarus J, Marden RM. The innovative process in medical education. *Medical Teacher* 1985; 7 (3/4):333-42.

Mennin SP, Kaufman A. The change process and medical education. *Medical Teacher* 1989; 11(1):9-16.

Stratos G, Bergen M, Albright C, et al. Use of faculty development to improve ambulatory-care education. *Medical Teacher* 1997; 19(4):285-92.

Workforce Performance Newsletter Reprint. Effective teams strive for consensus.
<http://www.opm.gov/perform/articles/1999/apr99-5.htm>.

END-OF-LIFE CARE CURRICULUM Comprehensive Bibliography

Module 1: Death & Dying in the U.S.A.

- Brim OG, Friedman HE, Levine S & Scotch NA, eds. (1970). The dying patient. New York: Russell Sage Foundation. Cited in Institute of Medicine (US) Committee on Care at the End of Life. Approaching death: Improving care at the end of life. Washington, D.C. National Academy Press, 1997.
- Chaffee, S. Pediatric palliative care. Primary Care 2001; 28:365-90.
- Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. BMJ 2000; 320:469-73. Covinsky KE, Goldman L, Cook EF, et al. The impact of serious illness on patients' families. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. JAMA 1994; 272:1839-44.
- Cohen LM, Carlson BW, Potter DEB. Health care expenditures in the last 6 months of life. Health Policy Review. American Statistical Association Section on Health Policy 1995; 1:13 pages.
- Field MJ, Cassel CK, Institute of Medicine (U.S.). Committee on Care at the End of Life. Approaching death: improving care at the end of life. Washington, D.C.: National Academy Press, 1997:xvii, 437.
- Gornick ME, Warren JL, Eggers PW, et al. Thirty years of Medicare: impact on the covered population. Health Care Financing Review 1996; 18:179-237.
- Hallenbeck JL, Bergen MR. A medical resident inpatient hospice rotation: experiences with dying and subsequent changes in attitudes and knowledge. Journal of Palliative Medicine 1999; 2:197-208.
- Kearney M. Palliative medicine - just another specialty? Palliative Medicine 1992; 92:39-46.
- Lichter I, Hunt E. The last 48 hours of life. Journal of Palliative Care 1990; 6:7-15.
- Minino, A.M. & Smith, Betty, L. Deaths: Preliminary data for 2000. National Vital Statistics Report October 9, 2001; 49:1-40.
- Pan CX, Morrison RS, Meier DE, et al. How prevalent are hospital-based palliative care programs? Status report and future directions. Journal of Palliative Medicine 2001; 4:315-24.
- Rosenberg HM, Ventura AM, Maurer JD, L. HR, Freedman MA. Births and deaths: United States, 1995. Monthly Vital Statistics Report 1996; 45:1-40.
- SUPPORT. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators [see comments] [published erratum appears in JAMA 1996 Apr 24; 275(16):1232]. JAMA 1995; 274:1591-8.
- Teno JM, Weitzen S, Fennell ML, Mor V. Dying trajectory in the last year of life: does cancer trajectory fit other diseases? Journal of Palliative Medicine 2001; 4:457-64.

Module 2: Pain Management

- Anderson R, Saiers JH, Abram S, Schlicht C. Accuracy in equianalgesic dosing: Conversion dilemmas. Journal of Pain & Symptom & Management 2001; 21:397-406.

Bernabei R, Gambassi G, Lapane K, et al. Management of pain in elderly patients with cancer. SAGE Study Group. Systematic Assessment of Geriatric Drug Use via Epidemiology [see comments] [published erratum appears in JAMA 1999 Jan 13; 281(2):136]. JAMA 1998; 279:1877-82.

Cassell EJ. The nature of suffering and the goals of medicine. NEJM 1982; 306:639-45.

Cleeland CS, Gonin R, Baez L, Loehrer P, Pandya KJ. Pain and treatment of pain in minority patients with cancer. The Eastern Cooperative Oncology Group Minority Outpatient Pain Study. Annals of Internal Medicine 1997; 127:813-6.

Ferrell B, Virani R, Grant M, Borneman T. Analysis of content regarding death and bereavement in nursing texts. Psychooncology 1999; 8:500-10.

Gray, J. A pain in the neck – and shoulder. Pain Topics 1(6) 1977. Cited in Twycross, R., Pain Relief in Advanced Cancer. 1994, London: Churchill Livingstone, p111.

Grossman SA, Sheidler VR, Swedeen K, Mucenski J, Piantadosi S. Correlation of patient and caregiver ratings of cancer pain. Journal of Pain & Symptom Management 1991; 6:53-7.

Joranson DE, Ryan KM, Gilson AM, Dahl JL. Trends in medical use and abuse of opioid analgesics. JAMA 2000; 283:1710-4.

Levy MH. Pharmacologic treatment of cancer pain [see comments]. NEJM 1996; 335:1124-32.

McDowell I, Newell C. Pain Measurements. Measuring health: A guide to rating scales and questionnaires. Vol. Chapter 8. New York: Oxford University Press, 1996:335-346.

Miller KE, Miller MM, Jolley MR. Challenges in pain management at the end of life. American Family Physician 2001; 64:1227-34.

Pereira J, Lawlor P, Vigano A, Dorgan M, Bruera E. Equianalgesic dose ratios for opioids: A critical review and proposals for long-term dosing. Journal of Pain & Symptom Management 2001; 22:672-87.

Porter J, Jick H. Addiction rare in patients treated with narcotics [letter]. New England Journal of Medicine 1980; 302:123.

Rabow MW, Hardie GE, Fair JM, McPhee SJ. End-of-life care content in 50 textbooks from multiple specialties. JAMA 2000; 283:771-8.

Ripamonti C, De Conno F, Groff L, et al. Equianalgesic dose/ratio between methadone and other opioid agonists in cancer pain: comparison of two clinical experiences. Annals of Oncology 1998; 9:79-83.

Ripamonti C, Groff L, Brunelli C, Polastri D, Stavrakis A, De Conno F. Switching from morphine to oral methadone in treating cancer pain: what is the equianalgesic dose ratio? Journal of Clinical Oncology 1998; 16:3216-21.

Saunders CM. The philosophy of terminal care. In: Saunders CM, ed. The Management of terminal disease. London: Arnold, 1978:193-202.

SUPPORT. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators [see comments] [published erratum appears in JAMA 1996 Apr 24;275(16):1232]. JAMA 1995; 274:1591-8.

Wolfe J, Grier HE, Klar N, et al. Symptoms and suffering at the end of life in children with cancer [see comments]. New England Journal of Medicine 2000; 342:326-33.

Module 3: Communicating with Patients & Families

- Back AL, Curtis JR. Communicating bad news. *Western Journal of Medicine* 2002; 176:177-80.
- Braddock CH, 3rd, Edwards KA, Hasenberg NM, Laidley TL, Levinson W. Informed decision making in outpatient practice: Time to get back to basics [see comments]. *JAMA* 1999; 282:2313-20.
- Buckman R. Breaking bad news: Why is it still so difficult? *British Medical Journal (Clin Res Ed)* 1984; 288:1597-9.
- Buss MK, Marx ES, Sulmasy DP. The preparedness of students to discuss end-of-life issues with patients. *Academic Medicine* 1998; 73:418-22.
- Crawley L, Payne R, Bolden J, Payne T, Washington P, Williams S. Palliative and end-of-life care in the African American community. *JAMA* 2000; 284:2518-21.
- Ford S, Fallowfield L, Lewis S. Can oncologists detect distress in their out-patients and how satisfied are they with their performance during bad news consultations? *British Journal of Cancer* 1994; 70:767-70.
- Parle M, Maguire P, Heaven C. The development of a training model to improve health professionals' skills, self-efficacy and outcome expectancies when communicating with cancer patients. *Social Science & Medicine* 1997; 44:231-40.
- Rabow MW, McPhee SJ. Beyond breaking bad news: How to help patients who suffer. *Western Journal of Medicine* 1999; 171:260-3.
- Suchman AL, Markakis K, Beckman HB, Frankel R. A model of empathic communication in the medical interview [see comments]. *JAMA* 1997; 277:678-82.
- Tulsky JA, Fischer GS, Rose MR, Arnold RM. Opening the black box: How do physicians communicate about advance directives? *Annals of Internal Medicine* 1998; 129:441-9.
- Wear D, Nixon LL. The spirit catches you and you fall down: A Hmong child, her American doctors, and the collision of two cultures. *Academic Medicine* 2001; 76:620-1.

Module 4: Making Difficult Decisions

- American Medical Association. Advance directives, surrogacy, competency, and Futility, in EPEC Project Participant Handbook (Education for Physicians on End-of-Life Care) 1999; www.epec.net.
- Back AL, Starks H, Hsu C, Gordon JR, Bharucha A, Pearlman RA. Clinician-patient interactions about requests for physician-assisted suicide: a patient and family view. *Archives of Internal Medicine* 2002; 162:1257-65.
- California Consortium on Patient Self-Determination (1991). PSDA Handbook.
- Chater S, Viola R, Paterson J, et al. Sedation for intractable distress in the dying – a survey of experts. *Palliative Medicine* 1998; 12:255-269.
- Chochinov, H.M. & Wilson, K.G. The euthanasia debate: attitudes, practices & psychiatric considerations. *Canadian Journal of Psychiatry* 1995, December; 40, 593-602.
- Fins JJ, Miller FG. Clinical pragmatism, ethics consultation, and the elderly patient. *Clinics in Geriatric Medicine* 2000; 16:71-81, ix.
- Koenig BA. Cultural diversity in decision making at the end of life. In: Field MJ, Cassel CK, Institute of

- Medicine (U.S.). Committee on Care at the End of Life, Eds. *Approaching death: Improving care at the end of life*. Appendix E. Washington, D.C.: National Academy Press, 1997:363-382.
- Kuhse, H. *Caring: Nurses, women, and ethics*. Oxford: Blackwell Publishers, 1997.
- Madigan, T. *Ethics Committee Core Curriculum*. University of Buffalo Center for Clinical Ethics and Humanities in Health Care. 1997; [Http://wings.buffalo.edu/bioethics/manle-e.html](http://wings.buffalo.edu/bioethics/manle-e.html).
- Quill TE, Arnold RM, Platt F. "I wish things were different": Expressing wishes in response to loss, futility, and unrealistic hopes. *Annals of Internal Medicine* 2001; 135:551-5.
- Roy, D. J. & MacDonald, N. Ethical issues in palliative care. In D. Doyle, G.W.C. Hanks & N. MacDonald (Eds.), *Oxford Textbook of Palliative Care* 2nd ed., Oxford: Oxford University Press, 1998.
- Schneiderman, L.J. & Jecker, N.S. Beyond futility to an ethic of care. *American Journal of Medicine*, 1994; 96:110-114. Cited by McGee, et al. The patient's response to medical futility (editorial). *Archives of Internal Medicine*, June 12, 2000;160, 1565-6.
- Tulsky JA, Chesney MA, Lo B. How do medical residents discuss resuscitation with patients? *Journal of General Internal Medicine* 1995; 10:436-42.
- Young EWD. Ethical issues at the End of Life. *Stanford Law & Policy Review* 1998; 9:267-288.

Module 5: Non-Pain Symptom Management

- Oxford CD-ROM (Firm). *The new shorter Oxford English dictionary*. Oxford: Oxford University Press, 1996:1 computer optical disc.
- Oxford University Press. Electronic Publishing B.V. *The new shorter Oxford English dictionary*. Oxford: Oxford University Press and Electronic Pub. 1996:1 computer laser optical disc.
- Bruera E, MacDonald N. To hydrate or not to hydrate: how should it be? *Journal of Clinical Oncology* 2000; 18:1156-8.
- Doyle D, Hanks GWC, MacDonald N. *Oxford textbook of palliative medicine*. Oxford medical publications. Oxford ; New York: Oxford University Press, 1998:xxv, 1283.
- Dyspnea. Mechanisms, assessment, and management: a consensus statement. American Thoracic Society. *American Journal of Respiratory and Critical Care Medicine* 1999; 159:321-40.
- Hallenbeck JL, Bergen MR. A medical resident inpatient hospice rotation: Experiences with dying and subsequent changes in attitudes and knowledge. *Journal of Palliative Medicine* 1999; 2:197-208.
- Neuenschwander H, Bruera E. Pathophysiology of cancer asthenia. In: Portenoy RK, Bruera E, eds. *Topics in palliative care*. Vol. 2. New York: Oxford University Press, 1998:171-81.
- Peroutka SJ, Snyder SH. Antiemetics: Neurotransmitter receptor binding predicts therapeutic actions. *Lancet* 1982; 1:658-9.
- Reuben DB, Mor V. Nausea and vomiting in terminal cancer patients. *Archives of Internal Medicine* 1986; 146:2021-3.
- Reuben DB, Mor V. Dyspnea in terminally ill cancer patients. *Chest* 1986; 89:234-6.
- Rousseau P. Nonpain symptom management in terminal care. *Clinics in Geriatric Medicine* 1996; 12:313-27.
- Saunders CM. The philosophy of terminal care. In: Saunders CM, ed. *The Management of terminal*

disease. London: Arnold, 1978:193-202.

Module 6: Venues & Systems of Care

Berwick DM. From victim to leader: Physicians as agents of change, ACP-AIM Annual session. Keynote address to opening ceremony, New Orleans, LA, April 22, 1999.

Hallenbeck JL, Bergen MR. A medical resident inpatient hospice rotation: experiences with dying and subsequent changes in attitudes and knowledge. *Journal of Palliative Medicine* 1999; 2:197-208.

Hallenbeck J. Building or expanding palliative care in the department of Veterans Affairs Healthcare System, Planning a hospital-based palliative care program: A primer for institutional leaders, Alexandria, VA, March 12, 2001.

Levinsky NG, Yu W, Ash A, et al. Influence of age on Medicare expenditures and medical care in the last year of life. *JAMA* 2001; 286:1349-55.

Lynn JA, Wilkinson AM. Quality end-of-life care: The case for a MediCaring demonstration. *Hospital Journal* 1998; 13:151-63

Muir JC, von Gunten CF. The Palliative Care unit as a Focus for Professional Education. In: Portenoy RK, Bruera E, eds. *Topics in Palliative Care*. Vol. 4. New York: Oxford University Press, 1998; 131-46.

Naierman N. Debunking the myths of hospice. *Choices: The newsletter of choice in dying* 1998; 7:1,4.

Perron V, Schonwetter R. Hospice and palliative care programs. *Primary Care* 2001; 28:427-40.

Robinson BE, Pham H. Cost-effectiveness of hospice care. *Clinics in Geriatric Medicine* 1996; 12:417-28.

Standards and Accreditation Committee Medical Guidelines Task Force. Medical guidelines for determining prognosis in selected non-cancer diseases. Arlington, VA: The National Hospice Organization, 1996:6-26.

Task Force on Palliative Care. Precepts of palliative care (National Policy Statements in End-of-Life Care). *Journal of Palliative Care* 1998; 1:109-12.

VanGeest JB. Process evaluation of an educational intervention to improve end-of-life care: The Education for Physicians on End-of-Life Care (EPEC) program. *American Journal of Hospice & Palliative Care* 2001; 18:233-8.

von Gunten CF, Ferris FD, Kirschner C, Emanuel LL. Coding and reimbursement mechanisms for physician services in hospice and palliative care. *Journal of Palliative Medicine* 2000; 3:157-64.

Module 7: Psychiatric Issues & Spirituality

Block SD. Assessing and managing depression in the terminally ill patient. ACP- ASIM End-of-Life Care Consensus Panel. American College of Physicians - American Society of Internal Medicine. *Annals of Internal Medicine* 2000; 132:209-18.

Doka K. Shattering eight myths about grief. Hospice Foundation of America 2003; <http://www.hospicefoundation.org> 2003.

Fainsinger RL. Treatment of Delirium at the End of Life: Medical and Ethical Issues. In: Portenoy RK, Bruera E, eds. *Topics in Palliative Care*. Vol. 4. New York: Oxford University Press, 1998:261-277.

Prigerson HG, Jacobs SC. Perspectives on care at the close of life. Caring for bereaved patients: "All the doctors just suddenly go". JAMA 2001; 286:1369-76.

Puchalski CM. Spirituality and end-of-life care: A time for listening and caring. Journal of Palliative Medicine 2002; 5:289-94.

Puchalski CM, Larson DB. Developing curricula in spirituality and medicine [published erratum appears in Academic Medicine 1998 Oct; 73(10):1038]. Academic Medicine 1998; 73:970-4.

Random House (Firm). Random House Webster's college dictionary. New York: Random House, 1999:xxviii, 1571.

Waring N. Physician loss, grief, and healing. HIPPOCRATES 2000; 14.

Module 8: Instituting Change

Adelson R, Hepburn K, Vanloy W. Performance Change in an organizational setting: A conceptual model. Journal of Continuing Education in the Health Professions 1997; 17:69-79.

Delbecq AI, Van de Ven A, Gustafson D. Group decision-making in modern organizations. In: Group Techniques for program planning. Glenview IL: Scott, Foresman and Company, 1975: 1-15.

Lazarus J, Marden RM. The innovative process in medical education. Medical Teacher 1985; 7 (3/4):333-42.

Mennin SP, Kaufman A. The change process and medical education. Medical Teacher 1989; 11(1):9-16.

Stratos G, Bergen M, Albright C, et al. Use of faculty development to improve ambulatory-care education. Medical Teacher 1997; 19(4):285-92.

Workforce Performance Newsletter Reprint. Effective teams strive for consensus.
<http://www.opm.gov/perform/articles/1999/apr99-5.htm>.

END-OF-LIFE CARE CURRICULUM

List of Relevant Websites

American Academy of Hospice and Palliative Medicine

<http://www.aahpm.org>

ABCD – Americans for Better Care of the Dying

<http://www.abcd-caring.org>

American Society for the Advancement of Palliative Care

<http://www.asap-care.com>

CAPC – Center to Advance Palliative Care

<http://www.capc.org>

CPCS –The Washington Home Center for Palliative Care Studies

Formerly known as the Center to Improve Care of the Dying (CICD)

<http://www.medicaring.org>

Dying Well

<http://www.dyingwell.com>

The EPEC™ Project – The Education for Physicians on End-of-Life Care (EPEC) Project

<http://www.epec.net/>

EPERC – End of Life / Palliative Education Resource Center

<http://www.eperc.mcw.edu>

Growth House, Inc.

<http://www.growthhouse.org>

Last Acts

<http://www.lastacts.org>

Partnership for Caring (This replaces Choice in Dying)

<http://www.partnershipforcaring.org>

END-OF-LIFE CARE CURRICULUM
How to Access the End-of-Life Care Literature Database
Jane Mount BA (OXON)

The End-of-Life Care program literature, relating to the topics covered by the ELC curriculum and collected over the grant period (1998-2003), is organized in a bibliographic database managed by EndNote. It presently includes nearly 1800 articles downloaded where possible through remote databases including MEDLINE.

The database has been regularly updated with articles selected through e-mail Table of Contents alerts (e-tocs) set up for major and palliative medicine journals, specific MEDLINE searches, and through major websites including EPERC, Growth House, and Last Acts (see list above).

The major journals in this field are: Journal of Palliative Medicine; Palliative Medicine; Journal of Pain & Symptom Management; Pain; Clinical Journal of Pain; Death Studies; Journal of Palliative Care; Journal of Clinical Oncology; Oncology; American Journal of Hospice & Palliative Care.

You may download the SFDC ELC literature database for yourself through our website: <http://sfdc.stanford.edu>. Then select SFDC LITERATURE DATABASES in the left-hand column.

Due to copyright rules, only citations and abstracts are entered. You can add the full text/pdfs of the articles to your personal library database if you have online access through your own or your institution's subscriptions, and a copy of EndNote.

The references in the SFDC ELC curriculum are marked by an asterisk beside the author's name in the database. These articles may be displayed by a 'search' under the References pull-down menu on the toolbar. Select 'notes' and enter 'In ELC Bibliography' or just * in the 'author' field.

This database is current only through Fall 2003. Please use it as a resource and a personal database that you are free to add to anytime in the future to keep abreast of the literature.

If you simply wish to access the database in read-only mode, you may download the free demo/viewer from the EndNote website.

To search the database you can simply type the first letter of the author or pull down the 'References' menu on the toolbar and select 'Search'. A 'Search' dialog box opens which allows you to search different fields e.g., Author; Title; Label; Journal; Year; Keyword; Pages; Volume, etc. To display an article the best way is usually a combination of these. Below is a list of the ELC literature categories – to search by category, insert the numeric category into the 'Label' field of EndNote's dialog box.

1. Overview and Death & Dying in the U.S.A. (epidemiology and demographics of death in U.S., patterns of dying and related prognosis issues, the last 48 hours)
2. Pain Management (pain assessment, pharmacological and non-pharmacological pain alleviation, opioid conversion tables)
3. Communicating with Patients & Families (EOL communication skills, sharing bad news, death pronouncement, diversity, physician self-care strategies)
4. Making Difficult Decisions (clinical, ethical and legal aspects of EOL decision making)
5. Non-Pain Symptom Management (identification and treatment of non-pain symptoms at EOL)

6. Venues & Systems of Care (ELC venues, system change to improve palliative care)
7. Psychiatric Issues and Spirituality (assessment and treatment of depression, anxiety, delirium, etc. at EOL; grief and bereavement; spiritual aspects of medical care)
8. Diversity (culturally-laden, death-related issues)
9. Patient Education (general patient and family EOL education)
10. Teaching End-of-Life Care (didactic and content issues in ELC education)
11. Pediatrics (general pediatric palliative care)

Palliative Care Perspectives

James L. Hallenbeck, M.D.
Oxford University Press, 2003

Synopsis

Drawing from his extensive clinical experience and many years of teaching, Dr. Hallenbeck presents a guide to palliative care for clinicians. Topics addressed range from an overview of death and dying to specific approaches to symptom management. As an introduction to both the art and science of palliative care, this book reflects the perspectives of one physician who has dedicated his career to this rapidly evolving field. The book links real stories of illness with practical advice, thereby delineating clinical practice in a way that reflects the daily concerns of clinicians.

About This Book

This book is intended for clinicians relatively new to palliative care who want to learn more about core topics in the field. Practical suggestions for approaching certain care issues are presented. Beyond this, I also hope the text will help readers piece together from overtly disparate topics a more coherent picture of palliative care as it is currently evolving. This book evolved out of talks and presentations given to medical students, residents, and fellows trying to learn palliative care fundamentals with me over the past nine years. As such, the text is probably most appropriate for trainees in similar circumstances. I hope that others, both physicians and non-physicians, may also find something of use. The text was originally designed to parallel a course given by the **Stanford Faculty Development Center** in end-of-life care [<http://sfdc.stanford.edu>]. This course presents seven discrete modules:

1. an overview of death and dying in America,
2. pain management,
3. nonpain symptom management,
4. communication,
5. difficult decisions,
6. psychosocial and spiritual aspects of care, and
7. issues relating to venues of care.

The last module also addresses how the clinician can work as an agent of change to improve the quality of palliative care in his or her health care system. Not all topics addressed in the course are covered in this book, and certain topics are covered here that are not covered in the course.

Over the past several years many fine texts and other educational tools have emerged that deal with palliative care. Why another book? Learners have different styles and may be drawn to different formats. Some may do best with classic textbooks. Some may prefer interactive multimedia presentations or problem-based learning. In this book I attempt to be clear but not comprehensive; this is not a textbook, nor is it a simple "how-to" manual. Excellent examples of these types of texts exist, and I do not wish to write another one. I am striving to make some sense of palliative care as I have come to understand it – via **stories**. While I sometimes highlight issues with stories of people, most of these stories attempt to make sense of certain aspects of palliative care. Many stories emerge from core questions about the nature of what we do, such as **why** are we doing such a poor job caring for very sick and dying people and **what** is the relation of hospice to palliative care. While some stories address "big-picture" issues such as these, others are quite practical in their implications. It is often helpful in learning how to treat certain symptoms to make stories about some otherwise complicated pathophysiology and

then devise related strategies for treatment. The complex mechanisms of nausea, for example, can best be understood if we first think about **why** we experience nausea and vomiting, which leads to a discussion of the pathophysiology of nausea and finally suggestions for treatment. I combine big-picture issues and nitty-gritty aspects of palliative care in this text because, frankly, both are necessary for good practice. Simple how-to manuals risk reducing the practice of palliative care to recipes, when, in fact, all of us, patients, families, and clinicians, are struggling with big-picture questions when encountering suffering and death. On the other hand, philosophy divorced from practice is a weak brew. Suffering manifests itself concretely in specific pains and agonies that must be addressed in very practical ways. Thus, certain how-to skills will also be discussed within the contexts of particular stories.

Throughout the text I highlight certain points as palliative care notes. Focusing on certain points to the exclusion of others reflects personal biases on my part and even a certain arrogance in directing the reader toward these rules of thumb. For this I ask forgiveness. My hope is that these points will be useful to the reader and serve as guiding principles and, occasionally, as morals to my stories.

We are not so different from our ancestors, who used to sit around campfires telling and hearing stories. People live, learn, and remember through storytelling. The stories presented here reflect my current level of understanding and my efforts to transmit this understanding. While I attempt to provide what evidence I can to support this understanding, for better or worse this text emerges from the thinking and the practice of one palliative care physician. The reader is advised not to accept my writing uncritically. Please do the much needed work for expansion of the evidence base underlying such stories. Test these stories through your practice and your study, and then defeat this level of understanding. In this process I hope you will create new stories to share with others.

For my daughter, Mika
J. L. H., Palo Alto, California

Reference

1. Hallenbeck, J. L. and M. R. Bergen. A medical resident inpatient hospice rotation: Experiences with dying and subsequent changes in attitudes and knowledge. *Journal of Palliative Medicine* 1999; 2(2):197-208.

This book may be purchased through: <http://growthhouse.org/stanford>

The online version of this book is used with permission of the publisher and author on websites affiliated with the Inter-Institutional Collaborating Network on End-of-life Care (IICN), sponsored by Growth House, Inc.

END-OF-LIFE CARE CURRICULUM
Titles of PowerPoint Slides with Teacher's Notes

Module 1: Overview and Death & Dying in the U.S.A.

1. ELC Curriculum for Medical Teachers
2. Introductions
3. Brief Overview of ELC
4. Why a course in ELC is Needed
5. Self-Rating Exercise
6. Self-Assessed Knowledge Study
7. Overall Goals of the Course
8. End-of-Life Care: Module 1
9. Learning Objectives
10. Top Five Causes of Death
11. Where We Die
12. Dying in the U.S.A.: Epidemiology and Economics
13. Dying is Largely Publicly Funded in U.S.
14. Economic Impact on Family of a Death in the Family
15. The Facts of Life About Dying
16. Trajectory of Steady Decline
17. Other Dying Trajectories
18. Brainstorm
19. Different Dying Trajectories Affect...
20. Fantasy Death Exercise
21. Discussion
22. Themes for a 'Good' Death
23. Common Ideal Death Scenarios
24. Dying Involves a Lot of People
25. Discussion
26. Experiences with Dying
27. Discussion of Cases
28. The Last 48 Hours
29. Signs that Suggest Active Dying
30. SUPPORT Study
31. Most Hospice Deaths Judged Peaceful
32. Symptoms & Signs in the Last 48 Hours
33. Events of the Last 48 Hours
34. Loss of Hunger
35. Loss of Thirst
36. Loss of Speech
37. Loss of Vision
38. Loss of Hearing & Touch
39. Terminal Syndrome Characterized by Retained Secretions
40. Physician Checklist
41. Learning Objectives

END-OF-LIFE CARE CURRICULUM
Titles of PowerPoint Slides with Teacher's Notes

Module 2: Pain Management

1. End-of-Life Care
2. Case of Mrs. Dolores Long
3. Learning Objectives
4. Outline of Module
5. Pain in the Hospitalized Seriously Ill
6. Pain in Nursing Home Patients
7. Pain in Outpatients
8. Pain in 103 Children who Died of Cancer or its Complications
9. Brainstorm
10. Six Major Barriers to Adequate Pain Care
11. Definitions
12. Barrier #1: The Myth of Addiction
13. Barrier #2: Regulatory and Legal Concerns
14. #3: System Barriers
15. Barrier #4: Deficits in Knowledge and Education
16. Barrier #5: Bad Side Effects of Opioids – Key Points
17. Barrier #6: Assessment Challenges
18. Assessment of Pain: Key Dimensions
19. We are 'Color-blind' to Chronic Pain
20. A Tool to Help Assess Pain
21. Neuropathic Pain
22. Nociceptive Pain
23. Visual Analogue Scale
24. Suffering
25. Back to the Mnemonic
26. Total Pain
27. Discussion
28. Non-Pharmacological Approaches to Pain
29. General Principles for Alleviating Pain
30. Pattern Matching
31. How Would You Treat the Acute Pain Pattern?
32. What Would a Chronic Pain Pattern Look Like?
33. Treating Chronic Pain
34. Case Discussion
35. Brainstorm
36. Neuropathic Pain Medications
37. NSAIDs
38. Combination Drugs
39. Acetaminophen with Codeine
40. Acetaminophen with Oxycodone, Hydrocodone
41. Case Discussion
42. Opioids

43. Principles of Opioid Use
44. Morphine
45. Standard Starting Dose
46. Oxycodone
47. Hydromorphone
48. Transdermal Fentanyl
49. Question
50. Case Discussion
51. Case Discussion, Continued
52. Opioid Conversion
53. Using Opioid Conversion Tables
54. Application
55. Warnings
56. Opioids May Differ
57. Two Principles
58. Conclusion
59. Learning Objectives

END-OF-LIFE CARE CURRICULUM
Titles of PowerPoint Slides with Teacher's Notes

Module 3: Communicating with Patients & Families

1. End-of-Life Care
2. Identified Deficits in Physician Communication Skills
3. Learning Objectives
4. Outline of Module
5. General Challenges to Patient-Physician Communication
6. Unique Challenges in Communication at the End of Life
7. Three Techniques Critical to ELC Communication
8. Two Elements to Keep in Mind
9. Cognitive Response
10. Affective Response
11. Clarify Ambiguity
12. Listen in Balance with Speaking
13. Delay Exercise
14. Debrief
15. Sharing Bad News
16. Step 1: Prepare
17. Step 2: Convey Information
18. Step 3: Follow Up
19. Training Tape
20. Discussion
21. Discussion, Continued
22. Skills Practice
23. Debrief
24. Action Plan
25. Death Pronouncement
26. Steps in Pronouncing Death
27. Role Play #1
28. Role Play #2
29. Debrief
30. Summary
31. Death Notification by Telephone
32. Learning Objectives

END-OF-LIFE CARE CURRICULUM
Titles of PowerPoint Slides with Teacher's Notes

Module 4: Making Difficult Decisions

1. End-of-Life Care
2. Vignette #1
3. Vignette #2
4. Learning Objectives
5. Outline of Module
6. Brainstorm
7. Discussion
8. Summary
9. It is GOOD to Discuss Preferences
10. Goals of Care
11. What You Might Say...
12. Brainstorm
13. Some Questions to Elicit Values
14. Internally Clarify Your Own Goals
15. Options
16. Present Benefits and Burdens
17. Discussion
18. Present Probability
19. Discuss Probabilities
20. Opinions
21. What You Might Say...
22. Summarize and Verify the Decision
23. Documentation
24. What You Might Write...
25. Role Play
26. Debrief
27. Dealing with Conflict
28. Summary
29. Difficult Decisions Regarding Requests for Hastening Death
30. What is Physician-Assisted Suicide?
31. Brainstorm
32. Arguments For and Against PAS
33. Discussion
34. Summary
35. Strategies for Response to Requests to Hasten Death
36. Reaction
37. Assessment
38. Adapt the GOOD Steps: Goals
39. Options
40. Opinions
41. Additional Resources
42. Conclusion
43. Learning Objectives

END-OF-LIFE CARE CURRICULUM
Titles of PowerPoint Slides with Teacher's Notes

Module 5: Non-Pain Symptom Management

1. End-of-Life Care
2. Case
3. Learning Objectives
4. Outline of Module
5. Symptoms as Clues
6. Disease as a Clue to the Symptom
7. From the Patient's Perspective
8. Symptom Analysis Checklist
9. Skills Practice: Patient with Pain Symptoms Due to Metastatic Bone Cancer
10. Non-Pain Symptoms at the EOL
11. Nausea & Vomiting
12. Nausea & Vomiting as Protective Mechanisms
13. A Central Final Pathway for Nausea
14. Receptor Affinity Common Antiemetics
15. Causes of Nausea & Vomiting
16. V: Vestibular Apparatus
17. O: Obstruction/Opioids
18. M: Mind
19. M: DysMotility
20. I: Infection/Irritation
21. T: Toxins
22. Opioid-Related Nausea
23. 5HT3 Antagonists
24. Symptom Analysis Checklist
25. Exercise 1: The Runner
26. Exercise 2: Being Held Under Water
27. Exercise 3: Lung Cancer
28. Treating Dyspnea
29. Dyspnea in the Dying
30. 'Terminal Syndrome Characterized by Retained Secretions'
31. Treatment of the Terminal Syndrome
32. Case Exercise
33. Definitions
34. Physiological Mechanisms
35. Cachexia/Anorexia/Asthenia
36. Medical Interventions
37. Psychological Interventions
38. Artificial Hydration at the End of Life is Controversial
39. Brainstorm
40. Some Arguments...
41. Medical Issues Aside...
42. Learning Objectives

END-OF-LIFE CARE CURRICULUM
Titles of PowerPoint Slides with Teacher's Notes

Module 6: Venues & Systems of Care

1. End-of-Life Care
2. Work Rounds Vignette
3. Learning Objectives
4. Outline of Module
5. What Exactly is Hospice?
6. Myths of Hospice
7. Realities of Hospice
8. Realities of Hospice
9. Realities of Hospice
10. Realities of Hospice
11. The Modern Hospice Movement
12. Hospice is...
13. Brainstorm
14. Comparing Hospice and Standard Home Care
15. Medicare Hospice Eligibility Requirements
16. Brainstorm
17. Medicare Hospice Financing
18. Steps to Making a Hospice Referral
19. Hospice in Not Appropriate for Every Patient
20. Precepts of Palliative Care
21. Options for Dying in Acute Care
22. What You Can Do if Patient is Imminently Dying
23. Extended Care Options
24. Subacute Unit
25. Nursing Home or Skilled Nursing Facility
26. Rehabilitation
27. Residential Care Facilities (Assisted Living)
28. Inpatient Hospice/Palliative Care Wards
29. Brainstorm
30. What You Can Do
31. Enlisting Resources
32. Continuum of System Change
33. Quality of ELC at the Local System Level
34. A Strategy for Change
35. Key Ways to Obtain Buy-in
36. Measuring Change...a Powerful Tool in Effecting Change Itself
37. Three Ways to Measure Change
38. Promoting the Cycle of Change
39. In Your Institution, Where Can You Make a Difference in ELC?
40. Learning Objectives

END-OF-LIFE CARE CURRICULUM
Titles of PowerPoint Slides with Teacher's Notes

Module 7: Psychiatric Issues & Spirituality

1. End-of-Life Care Curriculum
2. Orientation
3. Distress in Dying Comes in Many Forms
4. Learning Objectives
5. Outline of Module
6. Case Example
7. Depression at the End of Life
8. Evaluation of EOL Depression
9. Quick Depression Screen
10. Risk Factors for Clinical Depression at the End of Life
11. Depression Medications: Advantages & Disadvantages
12. Non-pharmacological Interventions
13. Depression Overlaps with Grief and Normal Dying
14. What is Unique About Anxiety at the End of Life?
15. Assessment
16. Types of Treatment for Anxiety
17. Delirium Very Close to Death
18. Differentiating Delirium from Dementia
19. What is 'Terminal' Delirium?
20. Assessment
21. Treating Delirium Close to Death
22. Special Interventions for Terminal Delirium
23. Medications for Terminal Delirium
24. 'Confusion' without Distress
25. GRIEF
26. Eight Myths about Grief
27. Myths, continued
28. Myths
29. Grief and Loss: Temporal Element
30. Preparatory or Anticipatory Grief
31. Patient Losses
32. Family Losses
33. Bereavement
34. What You Need to Do
35. Discussion: Physician Loss
36. Spirituality
37. Patients' Spiritual Concerns that will Require Your Response
38. Concerns Physicians Have About Addressing Spirituality
39. 1997 Gallup Poll
40. Spiritual Assessment
41. Application Exercise
42. Debrief
43. Interventions
44. Learning Objectives

END-OF-LIFE CARE CURRICULUM
Titles of PowerPoint Slides with Teacher's Notes

Module 8: Instituting Change

1. Module 8: Instituting Change
2. Examples from Other Institutions
3. Brainstorm
4. Categories of Change
5. Screen for Importance and Feasibility
6. Sorting
7. Reaching Consensus
8. Discussion
9. Timeline
10. Discussion
11. How Will We Know the Goals Have Been Accomplished?
12. How Will We Reinforce These Changes?
13. New Directions
14. Conclusion: Mission Possible